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WOMEN WITH BREAST CANCER IN MALAYSIA: SOCIAL WORK PERSPECTIVES ON THE CHALLENGES AND SOCIAL SUPPORT

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ABSTRACT

It has been reported that breast cancer is the most common type of cancer affecting women in Malaysia. A diagnosis of breast cancer will usually bring upon a set of issues and challenges affecting the well-being of these women. The aim of this paper is to provide a literature review regarding the biopsychosocial issues, challenges, social support and adaptation process experienced by women with breast cancer, with an application to the Malaysian setting focusing on the Malaysian socio-cultural backgrounds. The discussion of this paper focuses on the importance of social support in adaptation process such as from immediate family members, support group and the medical team following the challenges faced by the patients such as ones stemming from their cultural background, their biological issues and their refusal to seek treatments. The overall review of the literature is aligned with the social work values in addressing human wellbeing including the recognition of the psychosocial and sociocultural backgrounds as powerful components of health in practice and policies. Finally, this paper will provide insights for the helping profession in the country such as medical social workers in providing social work assessments and interventions suitable for Asian women with breast cancer.

Keywords: Breast cancer, issues and challenges, social support, women

INTRODUCTION

Cancer is one of the most prevalent diseases globally, including in Malaysia. According to the World Health Organization (2021), cancer was one of the

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leading causes of death in 2020, accounting for 10 million deaths. Additionally, out of all the recorded types of cancer, breast cancer was recorded to be a most persistent type. In Malaysia, the Malaysia National Cancer Registry reported in 2002 that breast cancer was the most common type of cancer affecting women. This trend persisted in 2020, where breast cancer remains as one of the most prevalent cancers in women in Malaysia (Azizah et al., 2019; World Health Organization, 2021). Even so, while breast cancer is prevalent among women, their individual experiences may vary according to their demographic backgrounds.

One demographic factor that may have a substantial impact on the experience of having breast cancer is ethnicity (Beyers, 2017). Ethnicity affects two aspects of breast cancer rates in Malaysia: prevalence and mortality. In Malaysia, the population comprises three main ethnicities, including Malay, Chinese and Indian. Between 2012 to 2016, breast cancer was most prevalent among Chinese women, but Malay women showed the highest mortality rates (Azizah et al., 2019). One common explanation for this difference between prevalence and mortality rates is that most Malay Malaysian women will only visit their doctor once they have already reached an advanced stage of cancer. According to Hisham & Yip (2003), almost 50% to 60% of patients seeking treatment in hospital had reached either stage III or IV of the illness. Elucidating the reason for this phenomenon requires an understanding of the socio-cultural features of these ethnic groups that contribute to these women's decisions in relation to dealing with their suspicions of breast cancer and later diagnosis.

Malay women recorded the lowest survival rate compared with other ethnicities due to several factors, including obtaining treatment at an advanced illness stage, a large tumour size, and a large number of infected lymph nodes (Ibrahim et al., 2012). Additionally, overall, the survival rate for women with breast cancer in Malaysia is low compared with women in the West (Leong et al., 2010). However, these differences between Asian and Western women are mostly evaluated from the perspective of their genetic and biological differences rather than social differences (Bhoo-Pathy et al., 2013; Yap et al., 2019). Therefore, findings often recommend several similar treatments options according to the extent of spread of cancer cells, the cancer stage, and the analysis made by the doctor. These treatments include surgery, radiotherapy, chemotherapy, hormone therapy, or a combination of these treatments (Abdul Khalid & Mohd Yusoff, 2005).

While the discussion of the medical aspects (i.e., genetic profiles, epidemiological outcomes) is important, the objective of this paper is to provide an overview of the social features of women in Malaysia who are diagnosed with breast cancer. Attempting to further understand these social aspects echoes with

the recommendations of various parties such as social workers to adopt a more biopsychosocial-spiritual perspective of diseases (Lehman et al., 2017).

The biopsychosocial-spiritual model of diseases provides insights on the unique experiences and challenges facing women with breast cancer, compared to other types of cancer. For example, one unique experience of women with breast cancer is related to the fact that they may be more likely to be concerned about their appearance and body image than men (Quittkat et al., 2019). Alongside this, women are more vulnerable and exposed to gender stereotypes from the media, which have a strong influence on the perceived ideal shape and size of a woman (Rodgers, 2017). In addition, self-objectification theory suggests that society tends to view women's bodies as an objects (Fredrickson & Roberts, 1997). Therefore, women may be more sensitive to their appearance, which may, in turn, increase their distress when something negative happens to their bodies. Breast cancer affects the breast, and the breast is a symbol of femininity for women. As a result, when they are diagnosed with breast cancer, the negative effects on this symbol may detriment the woman's biopsychosocial well-being. Indeed, in response to physical changes to their bodies, woman may feel that they no longer match the stereotypes created by the society and, thus, begin to think that their bodies are no longer perfect (Moorey, 2007). As a result, some studies have documented that women who perceived their bodies to be different experienced a lower level of self-esteem (Fitch, 2000).

Despite of several psychosocial issues that women have to face after their breast cancer diagnosis, there still are many women who can remain healthy and optimistic about their lives. The strength to accept and adapt to the illness can allow women to overcome the situation or be resilient in fighting the illness. Therefore, using the perspectives offered by the previous literature, the purpose of this paper is to provide an overview of the experiences of Malaysian women following a diagnosis with breast cancer, with a special focus on the challenges faced by these women and how social support plays an important role in helping the women to face their diagnosis. While social sciences have contributed to understanding the biopsychosocial aspects of Malaysian women diagnosed with cancer, this paper focuses specifically on the social work perspective considering the significant roles that social workers can play in supporting breast cancer patients (Lilliehorn et al., 2019). Some of these roles are related to enhancing their clients' strengths and resources for coping with the situation that they are experiencing, especially in terms of dealing with interpersonal and environmental problems. Furthermore, social workers are trained in assessing their patients from a biopsychosocial-spiritual perspective (National Association of Social Work [NASW], 2016). However, as will be outlined below, social workers also confront several issues in the process of supporting clients with a diagnosis of breast cancer.

CHALLENGES RELATED TO BIOPSYCHOSOCIAL-SPIRITUAL DIMENSIONS

In the social work profession, illnesses are often viewed from a biopsychosocial perspective. According to the NASW standards for social work practice in healthcare, a biopsychosocial perspective is important for emphasising the overall care of the individual and accounting for the physical health of the client, as well as their emotional and psychological level, and socioeconomic, socio-cultural, and socio-political status (NASW, 2016). This is a powerful perspective because it allows for a more comprehensive understanding of individuals, compared to the traditional medical approach that is often employed by health practitioners. Therefore, social workers working in healthcare often consider the biological, psychological, and social aspects of an individual in order to recognise the complexities of their lives and ensure a more holistic recovery process.

The Biological Challenges

Firstly, based on a biopsychosocial-spiritual model, we also discuss the biological issues experienced by Malaysian women with breast cancer, which appear to be similar to the experiences of women in the West. However, these biological issues do not have independent impacts on their lives of these women. Instead, they often interact with other psychosocial challenges, thus make each woman's experience unique and personal. For example, one of the most reported biological difficulties experienced by women with breast cancer is the side effects from treatment (Husain et al., 2019; Nies et al., 2018), such as hair loss, nausea, and erosion of breasts, and these side effects affect almost every woman undergoing treatment.

However, the impacts of these side effects may be exacerbated by the psychological and social aspects of these women, which means that different women respond differently to these biological issues. Additionally, in relation to the focus of this paper, different women may also experience resilience differently. For example, while findings in the Western contexts demonstrated that women desire to return to their normal routines, which may accelerate the process of beginning and adjusting to treatment (Asbury et al., 2014), Malaysian women take a longer time to getting adjusted (Norsa'adah et al., 2012).

The Spiritual and Psychological Dimension

Recently, there has also been a trend, even in the West, to consider the spiritual aspect of the clients in healthcare as an important factor in recovery. Additionally, religious principles, such as remembrance of God, can be utilised to gain strength and build hope to cope with a diagnosis, thus extending the

aforementioned biopsychosocial model into a biopsychosocial-spiritual model. The extension of this model has also been supported by studies showing that religion and spirituality can contribute to strong inner resilience in recovery (Nordin & Mohamed Hussin, 2023; Ahmadi et al., 2019). For example, the findings of Aziz and Hamjah (2017) supported the importance of spirituality in healthcare, as they reported that religion helps to provide inner happiness and peace for women with cancer to enable them to conduct their daily lives. Furthermore, a biopsychosocial model of health recognizes the importance of strengthening spirituality in order to equip the patients with the tool to face the breast cancer diagnosis (Perez et al., 2021). This positive inner experience enhances coping mechanisms and contributes to higher resilience, which increases the chances of survival.

Additionally, one of the most important considerations for women with breast cancer may be the unique experiences of Eastern women, including Malaysian women, as their spiritual and religious identities play a significant role in their management of cancer. This has implications for social work practice. A previous study carried out in a Malaysian setting showed that the Malaysian women's belief in the supernatural appears to influence their options for treatment (Mohd Mujar et al., 2017). As mentioned above, instead of opting for both the alternatives and conventional treatments for cancer, Malaysian women prioritise alternative medicine due to several factors, such as obedience to shamans and witch doctors. This phenomenon represents a dilemma for social workers in healthcare in relation to values and ethics in the field. Although the goal of social workers is to increase the quality of life and well-being of their clients, they must also adhere to several ethical concepts, such as self-determination, when assessing whether a patient requires a particular intervention.

Challenges in the System

While breast cancer affects women in an individual way, it also influences the dynamics of the systems around them. In turn, these effects provide their own sets of issues and challenges. Among people with cancer, both two-way communications and transaction processes between the individuals and their social environment are crucial in helping them to employ healthy coping strategies for their diagnosis (Smit et al., 2021). However, a breast cancer diagnosis may cause certain conflicts to arise in the women's relationships with others. Unsolved interpersonal conflicts may become a significant problem for women with breast cancer as they can become uncertain about how to plan and prioritise the issues that they should focus on first. Indeed, this is especially pertinent for women who carry out multiple roles in their lives.

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In terms of the concept of multiple roles, women with breast cancer may experience challenges in balancing different aspects of their lives, resulting in feelings of burden that may disrupt their psychosocial functioning. To meet their daily needs, some women with breast cancer continue to work. This can exacerbate their negative feelings due to difficulties coping with the multiple roles that they have to fulfil because they have to work even with poor health (Ghazali et al., 2009). In Malaysia, the percentage of households with two earners in the family, where both the husband and the wife work, is increasing (Bakar & Abdullah, 2013). Women with breast cancer who are also primary earners in a family may have difficulties because their treatment will affect their work and, thus, the family's financial situation. This highlights the influence of socio-economic status in the biopsychosocial-spiritual aspects of these women.

A second reason is that women in Malaysia, especially Malay Malaysian women and their families, with strong religious identities may try alternative medicine first before opting for mainstream treatments, which may cause symptoms deteriorations (Mohd Mujar et al., 2017). These religious identities are also stronger among women who live in rural areas than their urban counterparts. These preferences for alternative medicines seem to be influenced by the belief of Malaysian women and their family's in the supernatural, which dominate medical decision-making. For example, instead of undergoing treatment to remove their breast, some women prefer to use alternative medicine because they believe it is less painful and they will recover faster. However, delays in beginning treatment due to prioritising alternative medicine based on supernatural beliefs may contribute to a poorer cancer prognosis (Mohd Mujar et al., 2017). At later stages of the disease, there are not many treatment options that can be used because, in stage III or IV, the cancer cells have already metastasized to other parts of the body (Noor, 2008). At the final stage, the treatment given is intended to reduce the suffering of the patients, and it does not provide a cure for breast cancer (Abdul Khalid & Mohd Yusoff, 2005). If the patient meets with a doctor in the early stage of cancer when cancer cells have still not spread or are in metastasis, the chance to recover from the cancer is high (Muhammad, 2013).

Social Dimension

The model also emphasizes that while having diseases is an individual experience, the social dimension of this experience cannot be ignored. One of the most important aspects of a patient's social dimension is their cultural background, as this alters certain experiences in relation to their diagnosis (Dein, 2005). It is helpful to understand the role of culture by looking into one aspect of healthcare – medical decision-making. A study by Alden et al. (2018) demonstrated that, in terms of medical decision making, there is a difference between Eastern and Western families, where Eastern families usually prefer a

medical decision-making process that involves a wider network which is characterized by interdependence while Western families prefer the contrary. However, the preference for independent or interdependent decision making does not seem to be influenced by merely cultures. Some other factors like age and level of disease severity may also affect preferences among individuals which causes within-culture variability as well.

Regarding socio-economic status as an element in the biopsychosocial-spiritual model, one notable difference between the Malaysian healthcare and the healthcare in many other countries is that, in Malaysia, the medical institutions operate based on a social approach from taxation policies. This approach results in cheap costs of medical consultations and treatments for individuals. Therefore, this raises the question as to why many women in Malaysia refuse to seek treatments in public hospitals, especially Malay Malaysian women, despite the treatments being affordable. One of the ways this refusal is calculated is through the rates of breast cancer patients in stage III and stage IV (Azizah et al., 2019; Hisham & Yip, 2003). For example, a report showed that, out of 13,000 recorded cases of breast cancer, almost 50% were classified as those in stage III and IV. Studies have offered several explanations on this phenomenon. Firstly, women in Malaysia in certain locations where information is not easily accessible (e.g., rural areas) may lack of knowledge about breast cancer (Mohamad & Kok, 2019). Further to this lack of information, rural women may also be more affected by their gender roles and stereotypes (Bettencourt et al., 2007).

The Family System

Another challenge faced by these women is related to their families. In the life of Malaysian women with breast cancer, family is one of the most important systems that helps with the recovery process. However, the family system also contains its own sets of challenges. Some women with breast cancer experience distress relating to how to tell their family members about their illness, especially their husbands and children. While we are not aware of any studies specifically focusing on Malaysian families, some studies with Asian families have revealed that women prefer to receive the news of their diagnosis alongside their family members (Wong et al., 2021). This format may be beneficial for promoting healthier coping mechanisms, but it also has its own issues. For example, women revealing their cancer diagnosis may experience unsupportive responses from their partners. Some reports indicate that spouses may express unsupportive thoughts, such as that people who are ill should be independent and should not let the disease interfere with their responsibilities (Keitel & Kopala, 2000). Additionally, there are times when the husbands may experience difficulties in coping with their emotions, especially when their wives feel depressed. Commonly, they are not able to provide the social support that their wife desires

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(Sawin, 2010; Zahlis & Shands, 1991). Importantly, miscommunication between women with breast cancer and their partners can complicate the adaptation process. Family members also face dilemmas when they have to deal with tense situations that arise from uncertainties surrounding the diagnosis, such as worrying they might lose a family member.

Issues with family can also be observed in the support process for women with breast cancer. In this regard, the literature has reported notable differences between perceived social support and actual social support (McDowell & Serovich, 2007). For example, a study among Malaysian breast cancer patients in Malaysia by Ng et al. (2015), showed that perceived social support for certain groups of social environments may be different based on the individual stage of cancer. According to the authors, some women with breast cancer perceived low levels of social support from family and friends at advanced stages of cancer, which could be due to several factors, such as expectations of family and friends and discomfort. Although these expectations may be viewed by family members as a form of social support, it may be perceived by the women as burdensome. Indeed, their role in supporting breast cancer patient is relatively unclear.

It is inevitable that women with breast cancer experience some of these issues and challenges, especially for women in Malaysia. Some of the most important aspects in the lives of these women are the various types of social support they receive following their diagnosis. The next section of this paper provides an overview of the role of social support in supporting women to manage their cancer diagnosis. The discussion will also examine the role of culture in the perception of social support of these women.

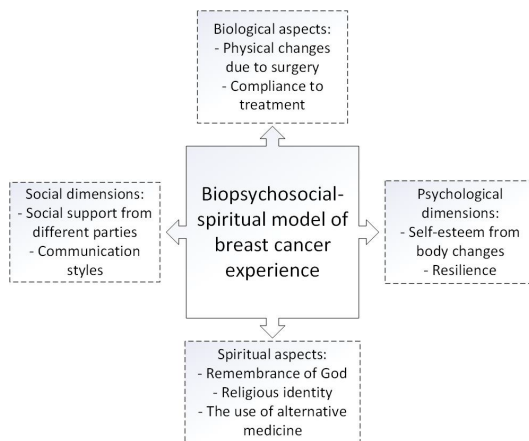


Figure 1

THE DYNAMICS OF SOCIAL SUPPORT IN ADAPTATION PROCESS

As can be determined from the discussion above, social support is an important tool for the women with breast cancer, including Malaysian women, to enable them to cope with their breast cancer diagnosis. However, social support is not just a tool for recovery as demonstrated by multiple previous studies, it can also present a type of challenge for these women. Significantly, social support is one of the most common areas of exploration in social scientific research in relation to cancer. According to Bayarne and Sebastian (1994), social support is helpful in problem-solving, decision making and the ability of the patient to spend time with other individuals. In the context of women with breast cancer, the various benefits of social support are well-documented. The result of studies both globally and in Malaysia (e.g., Coughlin, 2019; Nurasyikin et al., 2018; Ozdemir & Tas Arslan, 2018) indicate that cancer patients who receive social support from friends, family, and their spouses have a longer life expectancy. Helpful attitudes from family members for managing the daily lives of patients can reduce the stress they experience. However, the opposite occurs if the family members also feel depressed and are unable to accept the changes the patient undergoes.

Each individual requires different types of social support. Specifically, for some women with breast cancer, their partner is the most important person that encourages and supports their adaptation to the situation. Emotional support from the husbands can help women with breast cancer to manage their coping strategies (Baider et al., 2003; Kadmon et al., 2004). Husbands can help their wives in three ways, including “expressing sympathy, cheer and comfort, affection or reassurance; giving advice or problem solving; and passive listening” (Barker & Lemle, 1984, as cited in Muhamad et al. 2011). Additionally, social support from family members can also reduce levels of anxiety and depression in women with breast cancer, help them to adapt better, promote patient autonomy, improve mental well-being, and enhance their coping skills (Hann et al. 2002; Ommen et al., 2008). Furthermore, social support from a husband and family members is important for promoting resilience in women with breast cancer. Positive attitudes in their environment may reduce adjustment problems and lower psychological distress in women with breast cancer (Baider et al., 2003). This suggestion is also supported by past literature (Firouzbakht et al., 2020; Waxler-Morrison, 1991), where women receiving some form of social support from friends, family, general socializing, or partners may live longer and be better able to cope better with their illness.

The importance of social support in the adaptation process is especially clear in relation to the ability of women with breast cancer to adapt to their situation. After receiving the news of their diagnosis, the process of adaptation may be

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quite challenging for some individuals – this is where social support reveals to be a crucial element in these women’s experience. Consistent with the adaptation theory applied on women with breast cancer, adaptation to the new situation, capability to manage the situation, and understanding meaning in their lives can motivate them to continue their lives (Taylor, 1983). However, the ability to be optimistic about their life conditions does not only depend on internal factors. Instead, strong social support, which can be either formal or informal, has a key role in helping women with breast cancer to build their confidence and strength to continue with their lives. Furthermore, the factors of inner strength, social support, and resilience are all interrelated in supporting these women to cope with the difficulties they have to confront.

The above discussions clarify that social support is beneficial for recovery and resilience in women with breast cancer, including Malaysian women. However, it is important to determine the personal differences in relation to social support in women with breast cancer. This is important because while social support is beneficial, it may pose as a challenge for women and their supporters. Indeed, the influence of personal characteristics on social support is demonstrated by the women’s preferences for different types of individuals in their social environment. Although families are often found to represent one of the most important types of social support, including in Malaysia (Othman et al., 2019), intra-family preferences also exist, which may impact social work interventions. For example, in general, older male adults often expect social support from their spouses whereas older female adults expect social support more from their children (Mohd et al., 2020). Similar findings have also been found specifically in the context of cancer, as men tend to have fewer sources of social support, and obtain support predominantly from their wives, whereas women are more willing to find support from both inside and outside the family system (Ali, 2017).

Based on the above findings, the family plays an important role as a source of support for women with breast cancer. However, this may be more nuanced especially for Asian women, as cultures also represent an important personal characteristic for these women with breast cancer. For example, one study concluded that, in cultures where support can be obtained from various sources in the social environment, it may be difficult to define who the “primary” caregivers are should be (Andruske & O’Connor, 2020). In Malaysian cultures, identities are often intertwined with religion and caring for family members may be perceived as a religious duty, thus making it easier for these women with breast cancer to obtain support and care from their family members (Ibrahim et al., 2018).

In addition, it is also essential to examine the type of social support offered by these family members. Reports have shown that different individuals provide social support to address different needs, which may correspond to various needs

of the individuals with cancer (Kelly et al., 2019). For example, fellow cancer patients can provide informational support. In contrast, it has been shown that family members have the capacity to provide all types of social support, which can also include emotional support and praise. For family members with stronger religious values, their desire to provide social support may be driven by their beliefs, which has been shown to have an overall positive effect for both the caregivers and the patients (Kristanti et al., 2019). Therefore, due to the importance of spirituality in social support, it has been suggested that family members should also encourage the individuals with cancer to strengthen their spiritual well-being as a strategy to overcome and cope with cancer (Fehling et al., 1997; Kristanti et al., 2019). In general, during the recovery period, resilience is developed over time, and resilient individuals are able to use positive emotions to overcome the negative emotions. Regardless of various psychosocial problems, more resilient individuals have effective coping skills to adapt even during times when their motivation is low (McMurray et al., 2008). Indeed, stable emotions may help women with breast cancer to consider, decide, and plan the best courses of action for them.

Family members are not the only important type of social support for women with breast cancer. Support from outside the family system has also been shown to be beneficial for these women. One instance of such support comes from support groups. Support groups play an important role in supporting the women in various ways, such as overcoming anxiousness and providing emotional support to encourage the women during their treatment. Studies have shown that women with breast cancer showed more positive adaptation when they were involved in support groups because the groups consisted of individuals with similar experiences (Moon et al., 2017; Spiegel, 1993). The benefits of support groups are well accepted, but cultural effects have to be considered when implementing support groups with Asian women with breast cancer. According to Chou et al., (2016), it is rare for Asian people to freely express and share their feelings and thoughts, especially in relation to their illness. Indeed, stigma may exist around having breast cancer, and it may be appropriate to discuss physical changes, especially in relation to sensitive areas such as breast, in Asian cultures. This is where the role of another party – the medical team, could supplement the challenges for these Asian women to freely express in support group. The relationship between women and their medical team is important for various reasons. One of the most important reasons is complementary to the role of support group, as the medical team is able to facilitate planning for treatment and provide essential information about their breast cancer diagnosis (Martinez et al., 2016).

Taken together, social support provides important benefits for women with breast cancer, but further investigation is warranted regarding the preferences for

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different forms of social support in women of different cultures. For example, Lam et al. (2011), in their study, showed that women from Eastern cultures prefer social support in the form of provision of information regarding their disease and treatment, which is an opposite to their Western counterparts, who prefer physical and psychological support. Similar studies have not been conducted in Malaysian settings, but the study provides insights into how cultures affect the preferences for different forms of social support. In turn, this insight is important for the optimization of social work interventions for these women.

CONCLUSION

This paper provides an overview of the experiences of Malaysian women with breast cancer, in relation to the issues and challenges experienced by these women and the influence of social support in ameliorating the impacts of these difficulties. According to the past literature, various issues faced by these women like the biological, cultural and personal issues, as well as the cultural nuances, are integrated into the complexity of these women's experience as breast cancer patients. Furthermore, past literature also demonstrates the dynamics of social support in helping the women with breast cancer to undergo their adaptation process. Indeed, we have extended the question to examine the specific elements of social support related to the concept of culture that should be considered by social workers in their assessments and interventions. One of the main conclusions this paper highlights is that social work services with women with breast cancer in certain demographic groups should not be entirely dependent on scientific findings from the Western contexts. One of the clearest examples of this is the propensity of Malaysian women to rely on supernatural and alternatives beliefs in understanding their cancer diagnosis.

Additionally, the discussion presented in this paper indicates new avenues for future research. Firstly, further investigation should be conducted to better understand why the mortality rate among the three main ethnicities in Malaysia does not match their affliction rates from a social scientific perspective. In Malaysia, although Chinese women are recorded to be the ethnicity with the highest rate of breast cancer, Malay women have the highest mortality rate. While some suggestions have been proposed to explain this ethnicity disparity, no direct cause has been established to understand the socio-cultural factors underpinning this phenomenon. Secondly, medical policy in Malaysia has been designed to financially facilitate Malaysian women with breast cancer to access treatment. However, high levels of treatment refusal still exist, meaning some of these women are unable to manage their diagnosis in a timely manner. While the statistics are clear regarding the concerning rates of women with breast cancer who are in stage III and IV, the reasons why these women delay their treatment require further investigations.

All in all, practitioners such as social workers in a health setting should consider these psychosocial characteristics in helping these women adapt to their diagnosis in a holistic manner. Because of the complexity of these women's experience, cooperation from various parties, including the immediate social environment such as the family members and also the larger agents such as the medical team is pivotal in promoting resilience among women who are diagnosed with a breast cancer. In Malaysia particularly, these different parties should take into consideration the sociocultural and religious identity that may also be useful in their helping process.

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