ORIGINAL ARTICLE

An Exploration of Family Members' Roles in the Context of Breast Cancer: A Narrative Study in Malaysia

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ABSTRACT

Introduction: Breast cancer is a significant health problem that affects patients and their family members. Family members are often key to supporting the patient. However, there is an inadequate understanding of the role of female breast cancer patients' family members in Malaysia. This study aimed to explore the roles of family members of female breast cancer patients from symptom appraisal until the patient treatment commences. **Methods:** Snowball sampling was applied and 14 participants were recruited through the nomination of the female breast cancer patients. The participants took part in in-depth, face-to-face, and audio-recorded one-time interviews. All of the interviews were subsequently transcribed verbatim and analysed using narrative analysis. **Results:** Five themes were identified with regard to the roles of family members: 1) confirming breast changes; 2) managing personal emotions; 3) seeking the information; 4) seeking alternative forms of treatment; and 5) advocating for conventional treatment. **Conclusion:** This study discovered that family members play an important role in the journey of women with breast cancer from the time an abnormality is discovered to the time the patient receives treatment. During this time, many of them suppressed their emotions in order to focus on the women suffering from breast cancer. Healthcare professionals working with breast cancer should recognise and support the key role of family members in supporting women to get treatment. It is important to take a proactive approach in recognising the early signs of stress for family members and, when appropriate, offering them additional sources of support.

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INTRODUCTION

Agrowing number of patients with breast cancer results in a significant burden on the health systems and economies across countries. Worldwide, breast cancer is the most common cancer among women, with an estimated 2.3 million cases diagnosed in 2020 (1). In Malaysia, the National Cancer Registry Report 2012–2016 revealed that breast cancer is the most common cancer among women from all three major ethnic groups (Malay, Chinese, and Indian), accounting for a total of 34.1% of all cancers with an overall lifetime risk of 1 in 27 (2). The incidence of breast cancer is increasing every year (2) and has become the second leading cause of death after lung cancer among the Malaysian population (3). For the Asian region, the 5-year relative survival among female breast cancer patients in Malaysia is higher (4)

as compared to Thailand and India, but lower than in Singapore, China, Korea, and Japan (5).

There is already much known about the role of family including assistance in activities of daily living (6), symptom management (7), decision making (8), managing finance, and providing emotional support (7-8). A previous study in Malaysia showed that female patients' family members, such as their husbands and siblings, had inadequate knowledge of breast cancer (9). They did, however, play an important role in treatment decisions (9–11), assisting in the household, looking for information, and providing motivational, emotional, and spiritual support (11).

Even though family members have an impact on women's decisions and actions throughout their breast cancer journey, the majority of studies examined did not incorporate the perspectives of the women's family members into their design. Family members provide daily support to a person with cancer, although the decision-making research has rarely sought to include

their involvement (12). There have also been limited international studies that recruited family members as participants, although most of the findings revealed that the participants' family members had influenced the women's decisions (13-14). As a result, this study examined family members' roles, as their involvement is regarded as essential in Malaysian culture.

MATERIALS AND METHODS

Study design and sampling

This study used a narrative approach, which is known as having the potential to give a voice to people and may reveal a deeper understanding of the tellers' own lives through the ability to bring out hidden and marginalised stories (15). A narrative is created within a broader socio-cultural context and the resulting socio-cultural template provides a store of meaning for people to live by and to explain their experience (16). Thus, the narrative is a viable method for comprehending the role of family members of women diagnosed with breast cancer.

Snowball sampling was used to recruit participants through nominations from the patients. Inclusion criteria for the participants are: i) men or women; ii) having personal experience dealing with female breast cancer patients; iii) being able to speak Malay or English; and iv) being 18 years old and above. This paper reports findings that are part of a larger study that also included female breast cancer patients as participants.

Ethical considerations

Study participation was voluntary, and participants were assured of the right to withdraw at any point during the study with no consequences. Written consent was obtained from each participant prior to data collection. The interviews were recorded with the participants' permission, and they were guaranteed confidentiality and anonymity of their data. The study was approved by the Faculty of Health Sciences, University of Southampton, and the Research Ethics Committee, Malaysia Ministry of Health Research and Ethics Committee (NMRR-16-1319-31877).

Procedures

The researcher conducted narrative interviews and asked a broad question, such as "May I ask you to share with me your story about when your (wife/daughter/sister) told you she had a problem with her breast?" Additional questions and clarifications were requested based on the responses of the participants. The interviews were informal, unstructured, one-on-one, and conversational in nature. The majority of interviews took place in the participants' homes, at their request. The interview lasted an average of 32 minutes. Sample size was determined by data saturation and interviews were stopped when there was no new information contributed during the interview and no new codes could be produced (17). All interviews were audio-recorded and transcribed

in the language used by the participants during the interviews. After completing the transcription process, the transcripts were read and re-read several times to familiarise the researcher with the participants' stories. The second stage was data analysis using the narrative analysis process described by Riessman (18). Data analysis began with the structure of each narrative in order to examine the sequence of the events that had taken place. This process continued with a content analysis of the narrative. Finally, in the interpretation stage, the narrative devices such as language, causality, temporality, and contextual aspects were examined (18). These included the use of imagery, metaphors, idioms, and the repetition of words or phrases within their stories that provided clues for understanding how the participants perceived their experiences. After the individual analysis was completed, a search for commonalities across narratives was undertaken to look for patterns across the participants' experiences with regard to their roles.

RESULTS

Throughout the period of data collection, 14 family members agreed to participate and completed their interviews. The background of the participants is summarised in Table I.

Through narrative analysis, five themes were identified regarding the roles of family members: 1) confirming breast changes; 2) managing personal emotions; 3) seeking the information; 4) seeking alternative forms of treatment; and 5) advocating for conventional treatment.

Theme 1: Confirming breast changes

In this study, the family members were influential in confirming the women's concerns regarding the symptoms, either by observing, feeling, or recognising the vulnerability of contracting breast cancer due to family history. They were also involved in making the decision to seek immediate medical opinion. This is illustrated in the following quotes:

When my mother told me about that (lump), I felt it first. I thought it was excess milk. There were people that had had excess milk. When they were getting older, they started to have it. So, I thought it was nothing. But I was still not satisfied, I wanted to see it. Then I said, "Mum, I would like to see it." When I saw the nipple already inverted, then immediately I asked my mother to go to a clinic. (Participant 3)

One day, my wife told me that she had a lump in her breast. I felt her breast. I felt a lump, it was like a thumb size, like that. So, then we went to the clinic. (Participant 9)

When my wife told me that she had found a lump in her breast, I was worried, because her mother had

Table I: Demographic characteristics of the participants.

Participants (n=14)		
Age (year)	28 – 59 (mean: 43.9)	
Ethnicity	Malay Chinese Indian	9 3 2
Occupation	Government worker Private sector worker Self-employment Housewife Retired	2 4 4 2 2
Relationship with the patient	Husband Mother Sister Daughter/Son Niece	9 1 1 2 1

previously had breast cancer. But I always prayed that she would not have the same disease. After that, I asked her to see a doctor immediately, to check. (Participant 7)

The decision to seek a doctor's input in the first instance indicates that family members wanted a qualified person to examine the abnormal symptom in the breast. This is closely related to their understanding and belief that only the doctor could examine the breast lump properly to make sense of what was happening to the patient. Thus, they assumed that the doctor was an expert and gatekeeper of knowledge regarding health problems, perhaps drawing on a reasonable expectation or sociocultural view of the medical profession. This is evident in the following quotes:

Last year, my wife told me that she had a lump in her breast. I thought it was nothing. I told her, "InshaAllah (God willing), it's nothing." But we went to the clinic to check. I took her to the clinic because the doctor knows about this thing (lump). It was the doctor's job. (Participant 2)

My wife told me that she had found a lump when she took a shower. I immediately took her to see a doctor at the clinic. So, for me, I didn't have any experience of dealing with this. So, I asked her to see the doctor first, because only the doctor could confirm it. For me, I didn't know, I'm not sure. But, there was a lump. (Participant 1)

Theme 2: Managing personal emotions

In this study, the family members realised that their behaviour and emotional reactions could have an impact on the patient. They tried to avoid facing their inner feelings by minimising their emotional reactions to the diagnosis of breast cancer because they did not want to burden patient. As can be seen, the family members took care to maintain some semblance of personal coherence in order to remain strong for the patient. This is illustrated in the following quotes:

When she knew that she had that thing (breast cancer), I saw her cry. I felt so sad. I just told her, "I will always be with you no matter what happens", I didn't want to

see her cry ... From my experience, when dealing with someone who needs support, you must have positive energy when you're around that person. Because they often depend on our positive energy to be happy. So, I am always positive in front of her. And never say that you understand what they are going through because you never will. As a husband, I have, actually I also felt the same things, but as a husband, I have to be strong because I have to help her. (Participant 6)

When the result was confirmed, I just thought about death. I afraid I will lost my mum like my aunty, to the same cancer. I like to think about bad things first to happen. My brother already died, and then my father (died). All of them died within a short interval. So I think about bad things first. Even I felt sad, but in front of my mum, I gave support, so that she is not afraid. (Participant 3)

Theme 3: Seeking the information

Several family members discussed their efforts to learn more about breast cancer once they became aware of it. Access to information about breast cancer was a personal responsibility for them. They accessed data via online resources such as the Internet. This is illustrated in the following quotes:

When the diagnosis was confirmed, I kept reading all the information about breast cancer. (Participant 3)

Then, my mum told me that the doctor suggested undergoing chemotherapy. Then, I searched everything for my mum. I searched for information through the Internet. (Participant 10)

Theme 4: Seeking alternative forms of treatment

Several husbands sought traditional treatment for their wives as a possible treatment option for breast cancer. Their narratives describe how the husbands concentrated their efforts on pursuing additional treatment options, believing that doing so would increase their wives' chances of recovery from breast cancer. This is illustrated in the following quotes:

I bought her a supplement, tried traditional treatment, found the remedies that the traditional healer asked for ... We just tried it. Allah Almighty heal. For me, it's fine to try, who knows if it is suitable, she will recover. As long as it is not contrary to religion, I just tried it. (Participant 4)

We made a second option before undergoing mastectomy. We had a second alternative. We went to, followed whatever people said about the treatment. I had spent a lot of money at that time, but it was fine, for her. At least, when she looked at my effort, she got more enthusiastic ... We tried a lot of things. We met this Islamic practitioner, that traditional healer, we tried as an attempt to treat her disease. (Participant 8)

Theme 5: Advocating for conventional treatment

The majority of healthcare professionals recommend conventional or hospital-based treatment for cancer, such as surgery, chemotherapy, or radiotherapy. The following excerpts demonstrate how family members backed the women's choices and offered physical and emotional support.

At first, it was quite hard for me to persuade my wife. I knew she was sad. I just told her that surgery was the best treatment if she wanted to treat her breast cancer. Every day, I tried to persuade her to undergo the treatment. I asked her, "What will happen if you don't undergo the treatment, and just let it be like that?" At first, she refused, but I stressed to her, "If you don't undergo treatment, your condition will get worse. You must be strong to accept this entire test, think about your family and children." I told her like that. I told her about the effect if she did not remove her breast cancer. The doctor had already told me. I always advised her. Finally, she agreed to undergo treatment, which had taken nearly three months for her to agree. That made me really happy. (Participant 1)

She asked me, "Is it okay, dear, if I'm not perfect as your wife?" I said, "It's fine, I accept you as who you are." I said to her, "Whatever you look like, that is you, you will be my wife forever." That is what I told her. "It's fine if you want to remove (the breast)." I said "I don't care as long as you are healthy. Our children, me, we still need you." (Participant 8)

DISCUSSION

All the family members in this study encouraged the women to check their breast changes immediately with a doctor the moment they knew about them. At the same time, they observed and checked the symptoms. They were concerned and sensitive to the possible implications of breast symptoms for the women's health, which prompted an early consultation. According to Donkor et al. (19), symptoms may be considered serious depending on the individual's preconceived ideas about the nature of breast cancer. In previous studies, the husbands believed that the lump was clotted milk (9) or a normal symptom (11), whereby women were discouraged from seeking medical attention. Therefore, this study portray that family members had more awareness and prompt immediate actions regarding the breast changes as compared to previous studies.

According to the family members' narratives, they were distressed by the women's breast cancer diagnosis but refrained from expressing their feelings in order to spare the women additional distress. This finding may be related to the social-cultural view of men as being strong and emotionless when confronted with difficult situations. Similarly, another study discovered that some husbands concealed their true feelings from cancer patients in order to spare them distress (20). As

a result, family members in this study were aware of the emotional needs of women with breast cancer and frequently struggled with their own emotions, which they did not openly share with the patients. Husbands made a concerted effort to be sensitive to their wives while maintaining a positive attitude toward their wives' health (21). Encouragement and support from family members, such as a husband or son, helped the women feel strong when faced with the challenge of fighting breast cancer (22).

When family members learned of the patient's diagnosis, they began looking for additional information. They became more proactive in their search for information about the symptoms and treatment of breast cancer. As a result of technological advancements, many people now prefer to obtain information about breast cancer via the Internet. According to a report published by the Malaysian Communications and Multimedia Commission (23), 77.2 percent of Internet users in Malaysia searched online for health-related information and 82.7 percent trusted the information they found regardless of its source. Individuals experiencing health problems frequently turn to the Internet for relevant health information due to its ease of access (24). Thus, family members showed enthusiasm to understand about breast cancer by searching the information through internet after they knew about it.

Globally, alternative treatments have grown in popularity among cancer patients in the hope of discovering a cure (25). This study demonstrated that family members were supportive of the women's use of alternative treatment by accompanying them to traditional treatment, purchasing supplements, and searching for remedies in the hope that they would recover from breast cancer, although research has shown that using alternative therapies as the primary form of treatment for breast cancer sped up the disease's progression and increased the risk of rectal cancer (26). Similarly, another study discovered that family members supported the use of alternative medicine in cancer patients when accompanied by the expectation of a cure and improved survival (27). Numerous factors, including traditional culture, religious beliefs, and the high cost of conventional treatment, may contribute to the higher prevalence of alternative treatment use in Asian countries (25).

One of the new findings that can be highlighted in this paper is the role of the husband. According to previous research, some Malaysian women reported that their husbands refused to allow them to seek medical treatment (28), and instead advised them to try alternative treatments (9). As a result, there is a sense of "blaming" the husbands for any worsening of the women's situation as a result of their decision. However, this research shows that husbands were strongly supportive of medical intervention. None of them were opposed to conventional treatment, and they were influential in and

supportive of the women's decisions.

The importance of family members in the disease processes of patients was recognised in this study. It did, however, acknowledge some challenges, such as the potential psychological burden on family members when they learn of a breast cancer diagnosis and attempt to support patients' emotions. Future research should focus on developing and establishing a systematic assessment of family members' needs in order to provide them with information and support. This qualitative study provides a starting point for understanding family roles and involvement in breast cancer, but more research (i.e., investigating different settings, using different research paradigms and methods) is needed to gain a deeper understanding of this complex phenomenon.

This study was conducted in an urban area of Malaysia, so further research should be conducted among women with breast cancer from rural areas. Malaysia is a very diverse nation. Their roles may differ in other states, particularly along the Malaysian Peninsula's East Coast and in East Malaysia, where family members are thought to be more dominant than the patient (29). Moreover, different roles may also be obtained from family members from other cultures or who live in different geographical locations and contexts.

This study provides a basis for future research to gain other people's perspectives that are directly or indirectly involved in the process of decision-making about breast cancer; for example, to gain further understanding of the contribution of healthcare professionals such as doctors and nurses, traditional healers and Islamic practitioners in breast cancer decision-making experiences. Information captured from a variety of such sources could work synergistically to improve the quality of life of women with breast cancer.

The limitations of this study include that this study focuses on family members of patients who sought medical help, but it does not portray the experience of family members of patients who did not seek medical help. In addition, family members were recruited in an urban setting on Peninsular Malaysia's west coast.

According to this study, family members were frequently the ones who sought help, making them ideal candidates to be targeted and engaged in breast cancer health promotion. Malaysia, like other Southeast Asian countries with a strong extended kinship system, can rely on family members to provide necessary support to patients.

Patients and their families should receive educational interventions to improve their knowledge and awareness. Structured education and support group-based programmes play an important role in providing information and support about the illness, treatment,

and prognosis (30). Depending on the needs of patients and their families, different intervention programmes should be developed.

Family members were also found to have encouraged the women to take supplements and traditional remedies recommended by some traditional healers. In some studies, patients with cancer have been reported to use herbal products to slow the progression of their disease and relieve their symptoms (31). Despite the fact that the participants did not discuss the effectiveness of the supplement and traditional remedies with the patients, healthcare professionals should provide health education about the products' effects and safety because the participants may be unaware of the side effects.

Many of the family members in this study used the internet to learn more about breast cancer. The Internet has made it easier to access health information online, but it has also increased the risk of users encountering misleading or unreliable health information, which could have a negative impact on their health-related decisions (32). Healthcare professionals should be able to assist patients in selecting appropriate online health information in a secure internet world to avoid these issues. Patients' ability to assess health information obtained via the internet could be improved by developing an appropriate education plan and evaluation tools.

This study also revealed that a diagnosis of breast cancer can affect the emotions of family members. Thus, healthcare professionals need to be aware of the likelihood of stress among the family members of breast cancer patients and be able to identify early symptoms of depression (33). Therefore, continued coping strategies such as support from healthcare professionals are needed to minimise the stress and improve the adaptation of family caregivers (34). It is also beneficial to provide caregivers with respite care and to improve caregiver engagement by healthcare professionals (35).

CONCLUSION

From the discovery of an abnormality to coping with the diagnosis, seeking information, and the point at which the patient undergoes conventional treatment, this study contributes to a better understanding of how family members play significant roles and involvement in breast cancer. Different types of support are needed to help patients accept and adapt to their breast cancer journey. Patients will be able to become more emotionally resilient, improve their coping strategies, improve their prognosis, and improve their quality of life as a result of this.

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