

ORIGINAL RESEARCH

Women and Family Members' Views Regarding Early Decisions about Breast Cancer Treatment: A Qualitative Study



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Abstract

Background: Conventional or hospital treatment such as surgery, chemotherapy, or radiotherapy is widely recommended by health care providers for treating breast cancer. Early decision in conventional treatment is a complex phenomenon that requires careful consideration of the medical condition, available information, potential risk, financial, job, and involvement of family members. However, there is an inadequate understanding of early decisions about conventional treatment in Malaysia.

Purpose: This study aimed to explore the early decisions about breast cancer treatment among women and their family members.

Methods: This study employed a qualitative, narrative approach. Purposive and snowball sampling were applied, and 28 participants were recruited for this study. The participants took part in in-depth, face-to-face, and audio-recorded one-time interviews. All interviews were subsequently transcribed verbatim and analysed using narrative analysis.

Results: This study identified two themes regarding early decisions about breast cancer treatment: (1) women and family members who accepted immediate conventional treatment, and (2) women and family members who refused immediate conventional treatment. This study discovered that some women and family members agreed to undergo conventional treatment immediately due to following doctors' advice, influence by other patients with breast cancer, personal attitude, and appropriate knowledge concerning breast cancer. Meanwhile, other women refused it due to fear, not ready to undergo treatment, influenced by other people and socio-culture template. The unique finding in this study is the presence of specific socio-cultural templates related to breast cancer.

Conclusion: This study highlights that health care providers can assist women who decline breast cancer treatment by offering education about conventional treatment options. This can be achieved by providing accurate information about the treatment, addressing treatment-related fears, providing emotional support, and encouraging open communication regarding the reasons for refusing conventional treatment.

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1. Introduction

Breast cancer is the most common cancer in women, accounting for 2.3 million diagnosed cases and 685,000 deaths worldwide (WHO, 2021). In Malaysia, breast cancer affects 34.1% of all women living in Malaysia based on the National Cancer Registry Report 2012–2016, and 1 in 27 women is likely to develop breast cancer during their lifetime (Azizah et al., 2019). According to the same report, 17.5%, 34.5%, 25.1%, and 22.8% of breast cancer cases were diagnosed at stages I, II, III, and IV, respectively.

Patients with breast cancer need to make early treatment decisions. In this study, early decision in the context of breast cancer treatment refers to the practice of making treatment choices after a patient is diagnosed with breast cancer, including the decision of whether to accept or refuse the treatment. The primary treatments for breast cancer are radical mastectomy, breast

conservation surgery, chemotherapy, or radiotherapy, depending on the size and pathological characteristics of the cancer (Joseph et al., 2012). The refusal of cancer treatment is a serious concern in Malaysia, in which the proportion of non-adherence to surgery, chemotherapy, radiotherapy, and hormonal therapy was 14%, 30.1%, 33.3%, and 36.3%, respectively (Taib et al., 2017). The concern is that the effect of the refusal of cancer treatment has increased mortality across surgical, systemic treatment, and radiotherapy for certain cancers, including breast cancer (Hanna et al., 2020).

Several individual preference factors contribute to the acceptance of conventional treatment for breast cancer, such as treatment efficacy, physical, emotional, and cognitive side effects of treatment, financial implications, the salience of cutting-edge treatment options, either clinical trial or newly approved medication, treatment logistics, personal and family responsibilities, treatment impact on daily activities, participation in self-defining endeavours, attending important events, and pursuing important goals (Rocque et al., 2019). Positive attitudes and family priorities also influenced the women agreeing to accept conventional treatment (Yusuf et al., 2013). The opinion of family members was also found to be important in treatment decision-making for women with breast cancer (Teh et al., 2014; Yusuf et al., 2013).

In contrast, some women refused conventional treatment because of fear of the consequences of cancer, such as pain, death, side effects of chemotherapy, physical disability resulting from surgery (Norsa'adah et al., 2012; Taib et al., 2014), poor physical condition, poor family support (Chang et al., 2021), negative experiences with oncologists, and belief in the efficacy of alternative therapies (Citrin et al., 2012). Even some patients felt that the treatment would worsen their condition (Chang et al., 2021). Moreover, some had prior knowledge of patients with breast cancer who had died after undergoing conventional treatment and this influenced the women's decisions to refuse conventional treatment (Norsa'adah et al., 2012). However, the study to understand early treatment decisions among Malaysian women and their family members is limited. In this study, the Malaysian women and their family members live within a multicultural community and so they might have the same or different views regarding conventional treatment for breast cancer. Their early decision about conventional treatment is important because it will influence their survival time. Therefore, this study was conducted to explore early decisions regarding conventional treatment among Malaysian women with breast cancer and their family members.

2. Methods

2.1 Research design

This study used a qualitative, narrative approach. The narrative is more appropriate for this research because it allows for a rich description of the experiences and an exploration of the meanings that the participants derive from their experiences (Wang & Geale, 2015).

2.2 Setting and participants

Purposive sampling was applied to recruit participants from two hospitals located in urban areas in Malaysia. Both hospitals provide comprehensive services in the field of cancer care. These hospitals were selected due to their location in a highly populated, multi-ethnic, and religiously diverse part of Malaysia, thereby increasing the likelihood of accessing participants from various socio-economic backgrounds and all three main ethnic groups. The hospital staff approached eligible participants, introduced the research, and gave them a recruitment pack that consisted of an invitation letter, patient information sheet, and consent form. The inclusion criteria for the participants were women diagnosed with primary breast cancer, 18 years old and above, and able to speak Malay or English. Snowball sampling was used to recruit family members through nominations from women with breast cancer. Meanwhile, the inclusion criteria for the family members were men or women, having personal experience dealing with female breast cancer patients, being able to speak Malay or English, and 18 years old and above.

In qualitative research, there are no rules for sample size, and it should be based on the information needed or the research aims set (Polit & Beck 2008). The sample size used in previous qualitative studies on breast cancer in Western countries that employed a narrative method ranged from 8 to 12 participants (Sadati et al., 2015; Thomas-MacLean, 2004). The sample size was determined by data saturation, and interviews were stopped when no new information was contributed during the interview, and no new codes could be produced (Guest et al., 2006). In

this study, after 13 interviews, the data reached saturation. Other interviews were conducted to confirm the data saturation. Finally, this study was able to get 28 participants, with 14 participants from each hospital.

2.3 Data collection

Data were collected through face-to-face, informal, and unstructured interviews by the first author. Most of the interviews took place in the participants' homes of their own choice. Only four interviews were conducted at the participants' workplace. Before starting the interview, the researchers took time to build rapport with the participants. Each interview lasted between 20 and 90 minutes (an average length of 32 minutes). Sixteen interviews were conducted in Malay language and others were conducted in mixed English and Malay language. Since the researcher is fluent in both languages, there was no problem understanding the conversation with the participants. The researcher conducted narrative interviews. The narrative interview "envisages a setting that encourages and stimulates an interviewee or informant to tell a story about some significant event in their life and social context" (Jovchelovitch & Bauer, 2000, p.2). The researcher started each interview with the same narrative script that had been developed with the help of the expert team members and already tested during the pilot study. For the patient, a broad question such as "May I ask you to share with me your story since you first thought that you may have a problem with your breast?" was asked. As for the family member, the interview started with "May I ask you to share 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.

2.4 Data analysis

Data processing started with verbatim transcription. All of the interviews were transcribed verbatim in the language used by the participants during the interviews. After completing the transcription process, the transcripts were read and re-read several times by three researchers for the purpose of familiarisation and gaining a basic understanding of the participants' stories before applying the narrative analysis to identify the main themes. Then, data were analysed using the narrative analysis process described by Riessman (1990). Riessman (1990) did not provide any clear-cut or specific steps for conducting data analysis. Applying Riessman's approach to the analysis, interpretation, and presentation of the data was based on understanding and discussion with the team members regarding her assumptions of narrative research, recommendations, and the way she conducted her analysis. Riessman (1993) recommended beginning the analysis with the structure of the narrative to avoid the tendency of reading a narrative simply for content. Thus, 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 analysis of the content of the narrative. Riessman (1990) stated that the content informs what each narrative is about. At this stage, the team members considered the following aspects: What has the participant said? What is the participant's story when s/he talks about decision-making related to treatment for breast cancer? What is the decision? Who made the decision? What are the turning points, key features, people, and events that influenced the decisions? All three researchers independently coded at least two transcripts to identify the initial coding. Finally, the stage of interpretation, in which the narrative devices such as language, causality, temporality, and contextual aspects were examined (Riessman, 1990). After the individual analysis was completed, a search for commonalities across narratives was undertaken to look for patterns across the experiences of participants regarding early decision-making about the treatment. This was followed by a discussion with the other two researchers until a consensus on the common emerging themes was reached. Any discrepancy among the researchers would be referred back to the participants' interview transcripts, audio recordings, reflective diary, and field notes. Finally, the selected quotes were translated into English for the purpose of publication.

2.5 Trustworthiness

Dependability and confirmability can be achieved via an audit trail (Cypress, 2017). An audit trail was kept in this study in order to maintain track of the steps and/or changes throughout the processes of data collection, analysis, interpretation, and writing up of the findings. This audit trail was primarily recorded in the research diary, together with the researcher's reflections on

the research process, meeting with the participants, thoughts, feelings, and interpretations. Riessman (1993) suggested that describing how the interpretations were produced enables the reader to determine the rigor of narrative research. In this study, the interpretations of the findings were based on the participants' interview transcripts, audio recordings, reflective diaries, field notes, frequent discussions with three experts in qualitative research, and knowledge of the literature. Moreover, this study also included interviews with a family member chosen by the woman, and this data helped inform the narrative and enabled triangulation. Riessman (1993) reported that "In the final analysis, the work is ours. We have to take responsibility for its truths" (p.67). Therefore, member-checking may not necessarily be considered a hallmark against which to assess credibility in this study. Bitsch (2005) suggested that thick description and purposeful sampling could be applied to show that the findings in qualitative research can be applicable (transferability) to other contexts.

2.6 Ethical considerations

Study participation was voluntary, and written consent was obtained from each participant prior to data collection. They also have the right to withdraw at any point of the study with no consequences. The interviews were recorded with the participant's permission, and they were guaranteed confidentiality and anonymity of their data. After the Faculty of Health Sciences, University of Southampton ethics board had approved the study protocol, the researcher applied for ethical approval in Malaysia. Firstly, the researcher registered with the National Medical Research Registry of the Ministry of Health (NMRR) and submitted the study protocol to the National Institute of Health for their review and approval. Secondly, the researcher submitted an online application to the teaching hospital's Medical Ethics Committee for their approval. Finally, ethics approval obtained from the study was approved by the Faculty of Health Sciences, University of Southampton, and the Research Ethics Committee (Ethics no: 22983) and the Malaysia Ministry of Health Research and Ethics Committee (NMRR-16-1319-31877).

3. Results

3.1 Demographic characteristics of the participants

Throughout the period of data collection, 28 participants agreed to be interviewed. The background information of the participants is summarised in Table 1.

Table 1. Demographic characteristics of the participants (n=28)

Characteristics	Patient (n)	Family member (n)
Age	46.1 (mean)	43.9 (mean)
Marital status		
Single	2	3
Married	11	11
Widow	1	
Ethnicity		
Malay	9	9
Chinese	3	3
Indian	2	2
Occupation		
Government	4	1
Private	4	5
Self-employment	2	4
Not working	4	4

There are two narrative themes identified in this study indicating the early decision about conventional treatment for breast cancer. The themes are women and family members who accepted conventional treatment immediately and women and family members who refused immediate conventional treatment (Table 2).

Table 2. Theme and sub-themes

Themes	Sub-themes
Women and family members who accepted conventional treatment immediately	<ul style="list-style-type: none"> - Following the doctor's recommendation - Meeting with other patients with breast cancer - Positive thinking and attitude - Being knowledgeable about the treatment
Women and family members who refused immediate conventional treatment	<ul style="list-style-type: none"> - Fear - Need more time - Meeting with other patients with breast cancer - Meeting with significant other - Listening to the socio-cultural template of awful stories

3.2 Theme 1: Women and family members who accepted conventional treatment immediately

This theme consists of four sub-themes: following the doctor's recommendation, meeting with other patients with breast cancer, positive thinking and attitude, and being knowledgeable about the treatment.

3.2.1 Following the doctor's recommendation

One woman in this study decided to accept immediate treatment after listening to the doctor's explanation and recommendation with no hesitation. Her husband also recognised the doctor's credibility.

During the meeting with the doctor, the doctor advised and explained clearly what I should do. So, the doctor recommended doing the chemotherapy first. Undergo chemotherapy to shrink the lump. That's why the doctor said, if I did not undergo immediate treatment, it will, I'm afraid it will spread to another part of the body. So, I agreed. I started my chemotherapy. (Woman 9)

No other choice, we have to treat the cancer. I mean do the treatment. So, the doctor asked for chemo first to shrink the lump. So, we followed it, followed the suggestion like that because the doctor is the expert. (Family 9)

3.2.2 Meeting with other patients with breast cancer

Some women felt more confident when they had reassurance from patients who had already undergone the same treatment. Moreover, when the patients are their family members, with whom they share a similar cultural and social background.

I had an aunt that had breast cancer too. She has already recovered. So, many times I met her. She gave advice. She said "Don't be scared to undergo chemotherapy. Just do it. I have already recovered", she said. Not fully recovered, but she already proved that chemotherapy might cause hair loss. She had demonstrated that her hair started growing back. She said. She said like that. She said that if she was able to recover, why wouldn't I? I take it from that. Because I already had an experience. Like me, if that thing happened and I can see with my eyes, I trusted it. (Woman 9)

Yeah, I still remember how my mother, my mother fought her breast cancer. Although she suffered because of the side effects of chemotherapy, she acted as though the treatment was no big deal. She was so calm and positive, I learnt from her. My late mother told me that only chemotherapy could kill cancer. No other medicine. (Woman 7)

Another family member agreed that the advice and encouragement from a breast cancer survivor, at the very least provided guidance, helping them to decide on hospital treatment.

When we were inside the doctor's room, there were two other patients sitting behind us. It was like a blessing in disguise because they were breast cancer survivors. So, they

supported us. They said, “We already went through it. We’ve already had our treatment. Alhamdulillah”, they said like that. So, they could indirectly have been good role models for us at that time. (Family 13)

“And even my wife’s aunt also had breast cancer. So, we always visited her. She is the one who always gives advice, encouraging words. It was like her aunt became the source of reference for us.” (Family 9)

3.2.3 Positive thinking and attitude

Some participants have realised that they could no longer take their life for granted if they did not get early treatment for breast cancer. Their positive attitude indirectly influenced the treatment decision. Woman participant 6 stated: *Of course, I want to cure my disease. I have to undergo treatment if I want to get better* (Woman 6). Another woman stated the following:

I still want to do many things with my husband. And if I don’t get the treatment, my cancer will get worse. And I don’t want it happening to me. After I was diagnosed [with breast cancer], my main goal was to get healthy again, I told myself, ‘The quicker I get better, the better it will be’. (Woman 7)

Family members also had positive thinking about the treatment when they had previous experiences seeing the effectiveness of the conventional treatment. Family 6 and 7 stated: *From my experience, we have to think about what we can do for our lives. So, I believe chemotherapy is one of the treatments that is able to treat breast cancer* (Family 6); *Having experience with my mother-in-law made me believe that we could cure cancer. We have to focus on how to live, not how to die, so we have to undergo treatment* (Family 7).

3.2.4 Being knowledgeable about the treatment

Another woman was confident in the drug being used to treat breast cancer. It means that she knew about the treatment for breast cancer *because the chemotherapy is scientifically proven*. She stated: *Other things are based on people’s responses* (Woman 14).

3.3 Theme 2: Women and family members who refused immediate conventional treatment

This theme includes five sub-themes: fear, need more time, meeting with other patients with breast cancer, meeting with significant other, listening to the socio-cultural template of awful stories.

3.3.1 Fear

Surgery represents one of the central components of breast cancer treatment, but some of the women immediately refused surgery during their consultation sessions. The following extracts illustrate how some of the women in this study made a connection with their fear of surgery as a reason for refusing treatment, even though the doctor tried to convince them to undergo surgery.

I went to see the doctor. The doctor said, ‘Remove the whole [breast].’ ‘Eh, I don’t want that’, I said. ‘I don’t want to remove it.’, I said. Then, the doctor said, ‘You cannot be like that, aunty’, the doctor said. ‘You cannot be like that aunty. It is dangerous’, the doctor said. ‘I’m afraid that it will spread.’ After that, ‘It is fine’, I said. ‘Let it be, if it wants to spread or whatever,’ I said. I really did not want to have it removed. I was afraid. Because of being afraid, I was thinking about my children, grandchildren, husband. What would happen if I died during the operation?’ (Woman 1).

I should be operated on early, but I said, ‘It’s fine. I didn’t want it.’ At that time, I couldn’t think about anything. I wanted to calm myself first. Afraid, I was really afraid about what would happen next. (Woman 3).

Then, the doctor said, ‘Sister, we should remove it [breast cancer]. If not, it will get worse, spreading to other parts.’ At that time, I really didn’t want to have my breast removed. I

was afraid. I did not want to lose my breast. I said to the doctor, 'I do not want to remove it yet'. (Woman 5)

Family members also agreed when these women decided to refuse treatment because they realised that they were not emotionally ready in order to avoid tension. Family 1 and 3 stated: *But at that time, she said that she didn't want to have it removed. I knew she was sad. I just followed (Family 1); Maybe because my mum was shocked when she heard that (breast cancer). When the doctor suggested to operate, if not the condition would get worse. I just let mum calm down first. Not force her (Family 3).* Similarly, Family 5 stated:

I asked her. I asked. I said, 'So how? If you want to remove, remove it. It's up to you.' Because this thing involved her. Only she felt that. I can't tell. I can't tell. If I forced her, I worried something else would happen. So, I didn't force. It depended on her. (Family 5)

3.3.2 Need more time

One woman mentioned that she was unable to make a decision about treatment immediately during the consultation.

So, of course, the doctor wanted to operate by tomorrow. The doctor asked to do the surgery immediately. But, of course I, I needed some time first, to think so many things through. It was not easy, I wanted to have the [operation], just like that, right. (Woman 8)

3.3.3 Meeting with other patients with breast cancer

In this study, one woman constructed a coherent story that connected to others, drawing upon her personal story and the other people in her local community in order to make sense of her decision.

I then met someone at that hospital. She had cancer, too. She had had the operation and had undergone chemo. She was telling me her stories (p), of her chemo (p). It was really terrible, horrible (p). While listening to her story [laughing], I felt a little afraid. When I went into Doctor H's room (p), I didn't know. I can still remember how many hours it was (p), I stayed in Doctor H's room for a long time. Of course, I can still remember that time. He persuaded. He elaborated. He also showed pictures, of how that cancer spread inside the body. That persuasion still did not affect me. Then I told Doctor H, 'Doctor, let it be, I want to think about it first. I want to go home to think about it first'. (Woman 4)

3.3.4 Meeting with significant other

One woman explained that her decision was influenced by her yoga instructor. In this context, that yoga instructor became an important person that she trusted. She stated: *My yoga instructor said, 'Don't do [chemotherapy]' because she said, 'Our body is like a miracle; it can heal inside', like that, she said it like that, so I trusted her (Woman 13).*

3.3.5 Listening to socio-cultural template of awful stories

Two women shared how bad stories about treatment for breast cancer were inbuilt within their social context.

Because I got really scared, listening to other people's stories. Because they did not get better after being operated on. The wound then got pus. So, I was really scared actually, the story that I listened to before. Like when she got a wound, after the surgery, the wound did not heal. The doctor let it be, just like that. When I heard many people had had bad experiences, I was very scared. People asked me not to have the operation, they said it is dangerous, that it would not not not get any better if it was touched with a knife. (Woman 4).

If we take out the cancer, it will grow back on the other breast. It will get more and more. Because that thing was alive. It had a root. It could spread. That made me feel afraid. (Woman 5)

4. Discussion

This study aimed to explore early decisions among Malaysian women with breast cancer and their family members regarding conventional treatment. The early decision-making process about conventional treatment was complex, unique, and interrelated. In this study, the decision-making process to accept or refuse conventional treatment could be affected by individuals, their personal experiences, their emotions, and social and contextual factors. For some of the participants, these contributing factors were not taken to be a single cause.

This study showed that participants tended to make decisions based on a doctor's knowledge or expertise in a particular area. This finding was congruent with a previous study stating that trust in the abilities and experience of the health care providers and maximising their chances of survival influenced their treatment decision (Swainston et al., 2012). However, certain conditions, such as how the treatment of breast cancer was presented by the physicians to the patients influenced their decisions (Tariman et al., 2014). Communication is a central clinical function in building a therapeutic relationship with the patient to enhance the success of the treatment (Ferreira-Padilla et al., 2015). Some patients might have misunderstandings and not be ready to absorb the information when the doctor talks to them about their treatment options. For example, referring to the excerpts from Women 1, the patient may have been shocked when the doctor mentioned: "remove the whole breast". The doctor seemed to communicate matters related to the treatment rather than the psychology of the patient. Kim et al. (2021) reported that some participants admitted that they felt disappointed with a certain doctor's attitude that did not really care and was too pushy. Moreover, family members also played a significant role in influencing some of the women to undergo conventional treatment, which is consistent with a study by Al-Bahri et al. (2019), Kim et al. (2021), and Wang et al. (2020).

This study highlights that other patients with breast cancer were constructed as having either a positive or a negative role in terms of influencing the treatment decision-making process among the participants. This finding was consistent with the previous study by Pieters et al. (2012), in which they found that obtaining information from patients with breast cancer influenced some of the women to accept treatment for their breast cancer, while others refused. Positive experiences with patients with breast cancer who had been successfully treated gave confidence in patients' decisions (Dicks et al., 2019). In contrast, not every woman with breast cancer had a good story when it came to sharing her experiences. Sharing bad experiences led to the woman being fearful and thinking that she might have the same experience. Similar findings were found among the patients with breast cancer in Malaysia (Norsa'adah et al., 2012) and Germany (Singer et al., 2015), whereby listening to the bad experiences related to cancer treatment was found to be highly related to a fear of treatment.

Having positive thinking, including being hopeful and confident that they would survive was rarely considered an important factor that influenced treatment decision-making in Malaysia. However, in this study, this manner and thinking was consistent with the study by Hajian et al. (2017), which reported that an optimistic outlook, such as being hopeful, positive, and having cognitive acceptance, was considered to play an important role among the women in helping them cope with the challenges that they faced related to breast cancer. Saita et al. (2015) reported that the women who appraised breast cancer as a challenge or a threat mobilised their assertiveness.

Knowledge of disease and treatment is necessary before patients with breast cancer agree to undergo treatment. Relevant and understandable information is a prerequisite for patients to acquire enough knowledge to be actively involved in shared decision-making, comply with the treatment plan, make them aware of potential side effects, and understand what to do if side effects occur (Berger et al., 2018). In addition to knowledge about cancer, understanding why specific treatments are recommended may also play an important role in accepting the treatment (Almeshari et al., 2023). Therefore, it is plausible that an improved understanding of one's breast cancer and the reasons that treatments are recommended might increase rates of treatment initiation and adherence (Freedman et al., 2017).

This study revealed that some of the participants made the decision to refuse the treatment due to fear of surgery. Fear of surgery is a prevalent and relevant phenomenon among female breast cancer patients (Engel et al., 2023). Saeed et al. (2021) reported that the participants in their study purposely delayed the treatment due to the fear of mastectomy and loss of femininity. Moreover, negative experiences with cancer treatment reported in social circles (Singer et al., 2015) influenced the decision to refuse or delay the conventional treatment.

One woman in this study stated that she needed some time for herself before she was able to make a decision about the treatment. Citrin et al. (2012) found that the women in their study needed time to absorb the shock of their breast cancer diagnosis and to educate themselves about the treatment options. Although the doctors they consulted had suggested immediate surgery, the women felt that they needed time to make the decisions themselves about their own lives. Frenkel (2012) also reported that patients with cancer who initially refuse treatment may later choose to undergo conventional cancer treatment if they were given the adequate support, information, and time necessary to make the decision.

Another unique finding that extended the current knowledge base was the interrelationship between cultural beliefs and the decisions related to treatment for breast cancer. This finding is the first to identify the present socio-cultural template highlighting some of the different perspectives on culture which have not been developed in Malaysian literature before. Briley (2007) stated that people with different cultural backgrounds have different expectations, norms, and values that have the potential to influence their judgements and decisions, as well as their subsequent behaviour. The socio-cultural template, such as the statement that breast cancer will be spread to another part of the body through surgery and the belief in the self-healing capabilities of the body, was behind some of the reasons why some participants in this study refused conventional treatment. Using this template as a reference point, conventional treatment was viewed as a risky procedure that could disrupt their lives and future. Moreover, their respective community perceived the conventional treatment differently and they could possibly imagine what the women would experience if they underwent the treatment, such as dying during the surgery, the wound not getting better and the presence of pus after surgery. These scenarios exemplify how entrenched cultural beliefs can affect women's health behaviour related to the treatment for breast cancer, and that this needs to be understood by health care providers.

Another cultural belief, which led to one of the women in this study delaying treatment, is that breast cancer will not get better if it is touched by a knife, with a similar reason having also been reported in a previous study in Malaysia (Farooqui et al., 2016). This shows that the myths surrounding breast cancer treatment indicate that such myths are indeed prevalent in Malaysian culture and that they may greatly influence the study participants' beliefs. Indeed, they had a direct influence on the treatment decision-making process of some of the women in this study. These findings thus demonstrate the importance of considering socio-cultural beliefs in terms of understanding the reasons behind a decision.

5. Implications and limitations

According to the findings in this study, some women and family members still lack knowledge about the treatment for breast cancer. Therefore, healthcare staff should make a significant contribution by providing health education. At the same time, accurate knowledge will correct misconceptions, myths and negative beliefs as well as reduce the fear among the patients with breast cancer. Healthcare professionals could also suggest the participants set their own timelines for information-seeking and regulate their emotion as long as they agree to undergo conventional treatment.

In this study, the participants displayed a breadth of characteristics, including variety in their stages of breast cancer, ethnicity, age, and family member relationships. However, the small number of Chinese and Indian participants might limit the knowledge about socio-cultural beliefs within these ethnic groups. Another limitation is that this study focuses on urban areas, which might have different views regarding the early decision-making about conventional treatment from women who live in rural areas. This limits the transferability of the study findings.

6. Conclusion

This is the first qualitative study carried out in Malaysia that recruited women diagnosed across all the stages of breast cancer together with their family members. This study utilised women's narratives, and that of family members, to understand their early decisions about conventional treatment. The findings suggest early conventional treatment acceptance due to the role of the doctor, other breast cancer patients, positive attitude, and knowledge about the treatment for breast cancer. Refusal of conventional treatment for breast cancer happened because patients need more time, influenced by a significant person, personal beliefs, and feelings of fear.

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. Different decision experiences may also be obtained from women and family members from other cultures or who live in different geographical locations and contexts. Also, 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 HCPs such as doctors and nurses 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.

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Author contribution

Conception and design (NAH); Analysis and interpretation of data (WHWM, NA, AA); Drafting the article (WHWM); Critical revision of the article for important intellectual content (NJ, SL).

Conflict of interest

No conflict of interest has been declared by the authors.

References

- Al-Bahri, A., Al-Moundhri, M., Al-Mandhari, Z., & Al-Azri, M. (2019). Role of the family in treatment decision-making process for Omani women diagnosed with breast cancer. *Patient Education and Counseling*, 102(2), 352-359. <https://doi.org/10.1016/j.pec.2018.08.026>
- Almeshar, M., Alzamil, Y., Alyahyawi, A., Abanomy, A., Althmali, O., Al-Enezi, M. S., Shashikumar, C. G., Osman, H., Khandaker, M. U. (2023). Awareness level, knowledge and attitude towards breast cancer among staff and students of Hail University, Saudi Arabia. *PLoS One*, 18(3), e0282916. <https://doi.org/10.1371/journal.pone.0282916>
- Azizah, A. B., Hashimah, B., Nirmal, K., Siti Zubaidah A. R., Puteri, N.A., Nabihah, A., Sukumaran, R., Balqis, B., Nadia S. M. R., Sharifah, S. S. S, Rohayu, O., Nur Alham, O., & Azlini A. A. (2019). *Malaysian National Cancer Registry Report 2012-2016*. Ministry of Health Malaysia. <https://nci.moh.gov.my/index.php/ms/pengumuman/340-national-cancer-registry-report>
- Berger, O., Grønberg, B.H., Loge, J.H. (2018). Cancer patients' knowledge about their disease and treatment before, during and after treatment: A prospective, longitudinal study. *BMC Cancer*, 18, 381. <https://doi.org/10.1186/s12885-018-4164-5>
- Briley, D. (2007). *The effects of culture on decision making and judgement*. <http://www.ugc.edu.hk/rgc/rgcnews13/west/07.htm>
- Chang, N. T., Chang, Y. H., Huang, Y. T., & Chen, S. C. (2021). Factors associated with refusal or discontinuation of treatment in patients with bladder cancer: A cohort population-based study in Taiwan. *International Journal of Environmental Research and Public Health*, 18(2), 618. <https://doi.org/10.3390/ijerph18020618>
- Citrin, D. L., Bloom, D. L., Grutsch, J. F., Mortensen, S. J., & Lis, C. G. (2012). Beliefs and perceptions of women with newly diagnosed breast cancer who refused conventional treatment in favor of alternative therapies. *The Oncologist*, 17(5), 607-612. <https://doi.org/10.1634/theoncologist.2011-0468>
- Cypress, B.S. (2017). Rigor or reliability and validity in qualitative research: Perspectives, strategies, reconceptualization, and recommendations. *Dimensions of Critical Care Nursing*, 36(4), 253-263. <https://doi.org/10.1097/DCC.0000000000000253>
- Dicks, E., Roome, R., Chafe, J., Powell, E., McCrate, F., Simmonds, C., & Etchegary, H. (2019). Factors influencing surgical treatment decisions for breast cancer: A qualitative exploration of surgeon and patient perspectives. *Current Oncology*, 26(2), e216-e225. <https://doi.org/10.3747/co.26.4305>

- Engel, S., Jacobsen, H. B., & Reme, S. E. (2023). A cross-sectional study of fear of surgery in female breast cancer patients: Prevalence, severity, and sources, as well as relevant differences among patients experiencing high, moderate, and low fear of surgery. *Plos One*, 18(6), e0287641. <https://doi.org/10.1371/journal.pone.0287641>
- Farooqui, M., Hassali, M. A., Shatar, A. K. A., Farooqui, M. A., Saleem, F., Haq, N., & Othman, C. N. (2016). Use of complementary and alternative medicines among Malaysian cancer patients: A descriptive study. *Journal of Traditional and Complementary Medicine*, 6(4), 321-326. <https://doi.org/10.1016/j.jtcme.2014.12.008>
- Ferreira-Padilla, G., Ferrández-Antón, T., Baleriola-Júlvez, J., Braš, M., & Đorđević V. (2015). Communication skills in medicine: Where do we come from and where are we going? *Croatian Medical Journal*, 56(3), 311-314. <https://doi.org/10.3325/cmj.2015.56.311>
- Guest, G., Bunce, A., & Johnson, L. (2006). How many interviews are enough? An experiment with data saturation and variability. *Field Methods*, 18(1), 59-82. <https://doi.org/10.1177/1525822X05279903>
- Freedman, R. A., Revette, A. C., Hershman, D. L., Silva, K., Sporn, N. J., Gagne, J. J., Elena, M. K. & Keating, N. L. (2017). Understanding breast cancer knowledge and barriers to treatment adherence: A qualitative study among breast cancer survivors. *BioResearch Open Access*, 6(1), 159-168. <https://doi.org/10.1089/biores.2017.0028>
- Frenkel, M. (2013). Refusing treatment. *Oncologist*, 18(5), 634-636. <https://doi.org/10.1634/theoncologist.2012-0436>
- Hajian, S., Mehrabi, E., Simbar, M., & Houshyari, M. (2017). Coping strategies and experiences in women with a primary breast cancer diagnosis. *Asian Pacific Journal of Cancer Prevention*, 18(1), 215-224. <https://doi.org/10.22034/APJCP.2017.18.1.215>
- Hanna, T. P., King, W. D., Thibodeau, S., Jalink, M., Paulin, G. A., Harvey-Jones, E., O'Sullivan, D. E., Booth, C. M., Sullivan, R. & Aggarwal, A. (2020). *BMJ*, 371, m4087. <https://doi.org/10.1136/bmj.m4087>
- Joseph, K., Vrouwe, S., Kamruzzaman, A., Balbaid, A., Fenton, D., Berendt, R., Yu, E., & Tai, P. (2012). Outcome analysis of breast cancer patients who declined evidence-based treatment. *World Journal of Surgical Oncology*, 10, 118. <https://doi.org/10.1186/1477-7819-10-118>
- Jovchelovitch, S., & Bauer, M. W. (2000) Narrative Interviewing. In M. W. Bauer, & G. Gaskell (Eds.), *Qualitative researching with text, image and sound: A practical handbook* (pp. 57-74). SAGE.
- Kim, E., Jang, S. H., Andersen, M.R. & Standish, L. J. (2021). "I made all decisions myself": Breast cancer treatment decision-making by receivers and decliners. *Asia Pacific Journal of Oncology Nursing*, 8(3), 222-329. <https://doi.org/10.4103/apjon.apjon-211>
- Norsa'adah, B., Rahmah, M. A., Rampal, K. G., & Knight, A. (2012). Understanding barriers to Malaysian women with breast cancer seeking help. *Asian Pacific Journal of Cancer Prevention*, 13(8), 3723-3730. <https://doi.org/10.7314/APJCP.2012.13.8.3723>
- Pieters, H. C., Heilemann, M. V., Maliski, S., Dornig, K. & Menten, J. (2012). Instrumental relating and treatment decision making among older women with early stage breast cancer. *Oncology Nursing Forum*, 39(1), E10-E19. <https://doi.org/10.1188/12.ONF.E10-E19>
- Riessman, C. K. (1990). *Divorce talk: Women and men make sense of personal relationship*. Rutgers University Press.
- Riessman, C. K. (1993). *Narrative analysis*. SAGE.
- Rocque, G. B., Rasool, A., Williams, B. R., Wallace, A. S., Niranjana, S. J., Halilova, K. I., Turkman, Y. E., Ingram, S. A., Williams, C. P., Forero-Torres, A., Smith, T., Bhatia, S. & Knight, S. J. (2019). What is important when making treatment decisions in metastatic breast cancer? A qualitative analysis of decision-making in patients and oncologists. *Oncologist*, 24(10), 1313-1321. <https://doi.org/10.1634/theoncologist.2018-0711>
- Saeed, S., Asim, M. & Sohail, M. M. (2021). Fears and barriers: Problems in breast cancer diagnosis and treatment in Pakistan. *BMC Women's Health*, 21, 151. <https://doi.org/10.1186/s12905-021-01293-6>
- Saita, E., Acquati, C., & Kayser, K. (2015). Coping with early stage breast cancer: Examining the influence of personality traits and interpersonal closeness. *Frontiers in Psychology*, 6, 88. <https://doi.org/10.3389/fpsyg.2015.00088>

- Singer, S., Blettner, M., Kreienberg, R., Janni, W., Wöckel, A., Kühn, T., Felberbaum, R., Flock, F., & Schwentner L. (2015). Breast cancer patients' fear of treatment: Results from the multicenter longitudinal study BRENDA II. *Breast Care*, 10(2), 95-100. <http://doi.org/10.1159/000381933>
- Swainston, K., Campbell, C., van Wersch, A., & Durning, P. (2012). Treatment decision making in breast cancer: A longitudinal exploration of women's experiences. *British Journal of Health Psychology*, 17(1), 155-170. <https://doi.org/10.1111/j.2044-8287.2011.02028.x>
- Taib, N. A., Mujar, N. M., Dahlui, M., Emran, N. A., Hadi, I. A., Wai, Y. Y., Arulanantham, S., & Hooi, C. C. (2017). The rate and factors associated with non-adherence to surgery, chemotherapy, radiotherapy and hormonal therapy among breast cancer patients attending public hospitals in Malaysia. *Advances in Modern Oncology Research*, 3(6), 282.
- Taib, N. A., Yip, C. H., & Low, W. Y. (2014). A grounded explanation of why women present with advanced breast cancer. *World Journal of Surgery*, 38, 1676-1684. <https://doi.org/10.1007/s00268-013-2339-4>
- Tariman, J. D., Doorenbos, A., Schepp, K. G., Becker, P. S., & Berry, D. L. (2014). Patient, physician and contextual factors are influential in the treatment decision making of older adults newly diagnosed with symptomatic myeloma. *Cancer Treatment Communications*, 2(2-3), 34-47. <https://doi.org/10.1016/j.ctrc.2014.08.003>
- Teh, Y. C., Shaari, N. E. N., Taib, N. A., Ng, C. H., See, M. H., Tan, G. H., Jamaris, S., & Yip, C. H. (2014). Determinants of choice of surgery in Asian patients with early breast cancer in a middle income country. *Asian Pacific Journal of Cancer Prevention*, 15(7), 3163-316. <https://doi.org/10.7314/APJCP.2014.15.7.3163>
- Wang, C. C. & Geale, S. K. (2015). The power of story: Narrative inquiry as a methodology in nursing research. *International Journal of Nursing Sciences*, 2(2), 195-198. <https://doi.org/10.1016/j.ijnss.2015.04.014>
- Wang, L., Geng, X., Ji, L., Lu, G., & Lu, Q. (2020). Treatment decision-making, family influences, and cultural influences of Chinese breast cancer survivors: A qualitative study using an expressive writing method. *Supportive Care in Cancer*, 28, 3259-3266. <https://doi.org/10.1007/s00520-019-05161-w>
- WHO. (2021, October). *Breast cancer*. <https://www.who.int/news-room/fact-sheets/detail/breast-cancer>
- Yusuf, A., Ab Hadi, I. S., Mahamood, Z., Ahmad, Z., & Keng, S. L. (2013). Understanding the breast cancer experience: A qualitative study of Malaysian women. *Asian Pacific Journal of Cancer Prevention*, 14(6), 3689-3698. <https://doi.org/10.7314/APJCP.2013.14.6.3689>

