

The Experience of Patients with Breast Cancer at Home During Chemotherapy Treatment: A Qualitative Approach

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ABSTRACT

Introduction: Cancer is the primary cause of death worldwide and a significant barrier to increasing life expectancy. The estimates from World Health Organization (WHO) in 2019, cancer is the first or second leading cause of death before the age of 70 in 112 of 183 countries and ranks mortality third or fourth in 23 countries. Patients with breast cancer in Malaysia have one of the lowest survival rates in the Asia-Pacific region, with a 5-year survival of only 49%, compared with up to 90% in the United States. Chemotherapy is a type of cancer treatment that uses one or more anti-cancer drugs as part of a standardized chemotherapy regimen. It may be given with a curative intent (which almost involves combinations of drugs), or it may aim to prolong life or reduce symptoms (palliative). The challenges for the patient in dealing with the side effects of the chemotherapy treatment begin while they are at home.

Objective: To explore the experience of patients with breast cancer at home during chemotherapy treatment.

Methods: This study employed a qualitative research design involving 20 patients with breast cancer undergoing chemotherapy treatment. The participants were recruited via purposive sampling and data were collected by semi-structured interview with recorded. The thematic analysis approach was used to analyze the data.

Results: Two themes were revealed: including emotional changes and physiological changes. This theme revealed the preference described by emotional changes with the explanation of physiological changes.

Conclusion: Patients with breast cancer not only experience the side effects of chemo drugs but also have to deal with the changes at home during chemotherapy treatment. There is a need for healthcare workers in Malaysia to be able to provide support, especially in terms of emotional and physiological support at home for patients with breast cancer.

Keywords: Breast cancer; Chemotherapy; Experience; Home; Qualitative

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INTRODUCTION

Cancer's rising prominence as a leading cause of death partly reflects marked declines in mortality rates of stroke and coronary heart disease relative to cancer in many countries (1). Breast cancer has now surpassed lung cancer as the leading cause of global cancer incidence in 2020, with an estimated 2.3 million new cases, representing 11.7% of all cancer cases. It is the fifth leading cause of cancer mortality worldwide, with 685,000 deaths. Among women, breast cancer accounts for 1 in 4 cancer cases and 1 in 6 cancer deaths, ranking first for incidence in the vast majority of countries (159 of 185 countries) and mortality in 110 countries. There are exceptions, most notably in terms of deaths, with the disease preceded by lung cancer in Australia/New Zealand, Northern Europe, Northern America, and China (part of Eastern Asia) and by cervical cancer in many countries in sub-Saharan Africa (2).

Breast cancer is a major public health burden in Asia including Malaysia, the age-standardized incidence rate is 38.7 per 100,000 women per year, and the number of patients with breast cancer is projected to continue increasing. Notably, Malaysian patients with breast cancer have one of the lowest survival rates in the Asia-Pacific region, with a 5-year survival of only 49%, compared with up to 90% in the United States. The treatment of breast cancer depends on various factors, including the stage of cancer and the person's age (3). Breast cancer is usually treated with surgery, which may be followed by chemotherapy or radiation therapy, or both (4).

In Malaysia, the strategy for treatment and management is to detect all cancer, including breast cancer, as early as possible and initiate treatment in a timely method. Successful cancer treatment increasingly involves the multidisciplinary management of cancer patients. All treatment modalities, such as surgery, chemotherapy, radiotherapy, and psycho-oncology, are considered, and optimal individual treatment plans are designed using evidence-based guidelines and protocols (5).

Chemotherapy is a type of cancer treatment that uses one or more anti-cancer drugs (chemotherapeutic agents) as part of a standardized chemotherapy regimen. It may be

given with a curative intent (which almost always involves combinations of drugs), or it may aim to prolong life or reduce symptoms (palliative chemotherapy). The use of drugs in chemotherapy constitutes systemic therapy for cancer in that they are introduced into the bloodstream and able to address cancer at any anatomic location in the body. Many side effects of chemotherapy can damage normal cells in the bone marrow, digestive tract, and hair follicles (3).

In the current management for chemotherapy in Malaysia, the patient undergoes chemotherapy treatment at the oncology unit's daycare center based on an appointment made by the physician. Chemotherapy treatments will begin after blood samples are taken to assess whether the patient is eligible for chemotherapy treatment on the day or not. When the blood result is obtained, the doctor will see the patient for consultation and confirm that the patient is eligible to continue the treatment of chemotherapy. The patient will continue the treatment of chemotherapy until they finish the treatment for the day before returning home for the next appointment (5).

In the daycare unit, patients do not directly get the side effects of the drugs once the nurses administer the chemo drugs to the patient. The nurses will give them anti-emetic 30 minutes before administration of the chemo drugs. The environment at the daycare unit also plays a role in providing a calm and relaxed environment. The daycare unit allows the patient to seek help and care from the nurses and doctors. Different patients will perceive and encounter the side effect in different ways. Unfortunately, most of the side effects of chemo drugs are experienced by the patient at home after the daycare chemo (6). However, the home environment differs from daycare in which the nurses and doctors are available to assist the patient. In contrast, the patient and caregiver could have struggled with many life events, such as providing physical support while dealing with the side effect of chemo drugs at home (7).

In supporting this, chemotherapy, including ambulatory treatments, forces patients to actively self-manage their symptoms, but only a few patients seem to be able to manage their

symptoms adequately (8). A previous study on the effectiveness of a home care nursing program in symptoms management of patients with colorectal and breast cancer receiving oral chemotherapy found significant improvements in the home care group related to managing the symptoms of oral mucositis, diarrhea, constipation, nausea, pain, fatigue (first four cycles) and insomnia (all cycle) (9).

There are limited studies exploring the experiences of patients with breast cancer at home during chemotherapy treatment. Most of the previous studies focused on social support, body image, quality of life, and psychological reactions of patients with breast cancer (10). Due to the known various side effects brought by chemotherapy, patients may have concerns and worries prior to receiving the treatment. Therefore, a qualitative research design is suitable to be carried out to explore the perceptions of patients with breast cancer on chemotherapy, which allow researchers and healthcare providers to achieve a better understanding of patients' feelings and unreported experiences. According to Beaver et al. (10) in-depth qualitative interviews were conducted to explore the experiences of 20 women who had completed their neo-adjuvant chemotherapy for breast cancer in the North West of England. The finding from this study was to disclaim the key points that information is vital in developing services and interventions to meet the complex needs of the patients and potentially prevent late referral to psychological services.

Besides, Speck et al. (11) have conducted semi-structured interviews with 25 patients to examine the experience and coping strategies for taste alteration in female breast cancer patients treated with docetaxel or paclitaxel in the US. They found that taste alteration affects breast cancer patients' lives, and breast cancer patients develop management strategies to deal with the effect. Some self-management strategies can be seen as positively adaptive. However, the potential for increased caloric consumption and poor eating behaviors associated with some coping strategies may be a cause for concern, given the observation of weight gain during breast cancer treatment and the association of obesity with poor treatment outcomes in breast cancer patients.

Moreover, Kwok et al. (12) also carried out interviews with 17 patients to explore the experiences, dietary information, and support needs of women who gain weight during chemotherapy treatment in Melbourne, Australia. They reported the practical and information dietary support needs of women undergoing chemotherapy for breast cancer and reasons for dietary change. There are maybe gaps in information and support provisioned after diagnosis in the areas of weight management, nutrition-related side effects of chemotherapy, and healthy eating. Kwok et al. (12) also insisted that the models of dietetic practice and the provision of tailored dietary information should be explored. In Malaysia, there are limited studies regarding the experience of patients with breast cancer at home. Therefore, the present study employed a qualitative approach to explore the experiences of patients with breast cancer after receiving chemotherapy at home.

METHODS

This study was conducted using a qualitative approach: a face-to-face semi-structured interview patients with breast cancer involved in chemotherapy treatment. The semi-structured interviews enable the researcher to have a deeper understanding of the experience the patients with breast cancer at home during chemotherapy treatment. The qualitative approach would help the researchers in obtaining data on patients' experiences that could not be captured through a quantitative study (13).

Population and sampling

The population of this study was the patients with breast cancer who had post-chemotherapy treatment at daycare and are currently at home in Kuantan, Pahang.

Data collection

The participants in this study were recruited using purposive sampling by selecting the participants among patient with breast cancer who are doing chemotherapy from the Breast Cancer Support Group Kuantan, Breast Cancer Survivor Group Kuantan, and Majlis Kanser Negara (MAKNA). The inclusion criteria for recruiting the participant in this study were

patients with breast cancer who is undergoing chemotherapy treatment in the daycare, any patients with breast cancer who has at least received one cycle of chemo drugs in daycare, Malaysian citizen who able to speak Malay or English fluently and were able to provide data to answer the research question. The patients who unmet study inclusion criteria such as terminally ill patients with breast cancer will be excluded. When the potential participants showed willingness to participate in the study, participants information and consent form was obtained and an arrangement for the individual interview session was made at the place and time mutually agreed upon by the participants and researcher. All the interview session was recorded using a digital voice recorder with the agreement of the participants.

Semi-structured interview

In this study, a semi-structured face-to-face interview was conducted because the researcher wanted to ask questions and record answers from only one participant at a time between 30 minutes to 90 minutes for each participant. The topic guide interview was developed based on the synthesis of the literature, the researcher question, and the researcher objectives. To ensure the topic guide interview achieves the objective of this study, a pilot study was performed, and testing with two of participants. There was some amendment needed to the topic guide interview prepared beforehand. The item involved in the topic guide interview is how the patients with breast cancer feel towards the side effect of chemotherapy at home. The questions were included for 20 patients with breast cancer, and understanding Malay and English were included in this study as they can describe the experience of the population. The session was recorded with permission from the participants via voice recorder to help the researcher during the transcribing process. The interviews were conducted until data reached saturation, where there was no new information contributed during the interview (14). Besides, Glaser et al.¹⁶ suggested the concept of saturation for accomplishing an appropriate sample size in qualitative studies. However, there some guidelines are recommended the sample size range from 20 to 50 (16,17).

Data analysis

The data were analyzed thematically. Patterns are identified through a rigorous process of data familiarization, data coding, and theme development and revision.¹⁹ Review themes and define the themes with reporting. QSR NVivo® 1.0 software program was used to analyze the data.

The transcribing process was done instantly after each interview to maintain the originality of the data. The transcription data were analyzed via coding using NVivo® 1.0, and the transcripts were read and re-read until the meaning of the sentences was captured in a private room using headphones. This is to avoid the possibility of recordings being heard by other people. Transcripts and reflective journals were combined during data analysis to see the connection in answering the research aim.

The initial analysis was done by labeling specific interview segments with codes that might answer the research questions. Important words or groups of words in the data will be labeled with different color coding accordingly. Similar coding labels were used for a similar collection of text units that show the same concepts. All patients in this study were identified using identification (ID) numbers and pseudonyms to maintain confidentiality.

The construction of the initial codes was followed by a discussion with the researcher's committee team to resolve any differences in the coding. Next, the label transcripts were rechecked to allow consistency in labeling. Any unclear codes were confirmed by cross-checking with the researcher's committee team. To maintain the rigour in this study, the researcher maintains reflexivity by being aware of her own personal perspective or belief during the data collection and analysis to reduce biases. Audit trails were implemented to ensure the consistency of the findings. Member-checking was used in this study, where the researcher returned the findings to the participants for them to evaluate the accuracy and credibility of what they said.

Ethical consideration

This study obtained approval from the Kulliyah of Nursing Research Committee (KNRC: Reference Number IUM/313/DDPG&R/C/20/4/10) and the Ethics Committee of International Islamic University Malaysia (IREC: Reference Number IUM/504/14/11/2/ IREC 2022-092). All respondents are provided with a statement of information and consent form to be signed before participating in this study. All information gathered from respondents is kept confidential.

RESULTS

Participants' characteristics are provided in **Table 1**. The individual interview session included a total of 20 participants. The interview session continued until data saturation was reached, in which no additional information was supplied by the participants. Here, 17 married women and 3 single women were chosen through purposeful sampling. The average age is 25 years old to 58 years. The Malays (10 patients) made up most of the group, followed by the Chinese (7 patients) and Indians (3 patients). The majority of participants in this study were working (professional 45%, for example, teachers, lawyers, businesswomen, and non-professional 35%, for example, clerks and cleaners), and others were housewives.

Out of 20 patients, 55% ($n=11$) of them were in the first and second cycles of chemotherapy treatment. For prognosis status, only eight participants with a good prognosis which is on stage 1. The other was stage 2 (five participants), stage 3 (four participants), and stage 4 (three participants). All of the participants resided in the Kuantan district. They had their chemotherapy session either in a government or private hospital in Kuantan or a government hospital or private hospital outside Pahang state.

The themes were developed based on how the participants described the experiences of chemotherapy at home and how they dealt with the demanding situation at home. The theme of the changes refers to the symptoms recognized by the participant in identifying that something was wrong with their emotional health and that physical conditions changed after their treatment. Based on these

experiences, two themes were identified: emotional changes and physiological changes. The majority of participants reported these changes were the dominating sign of participants' focus. Across cultural backgrounds, it was found that Malay, Indian and Chinese participants described this using a combination of emotional and physiological changes compared to other religions. **Table 2** summarized the main themes and sub-themes that emerged from the data.

Table 1: The demographic characteristics of the participants

Variables	Frequency (n)	Percentage (%)
Age		
21-30	2	10.0
31-40	8	40.0
41-50	6	30.0
51-60	4	20.0
Marital status		
Married	17	85.0
Single	3	15.0
Race		
Malay	10	50.0
Chinese	7	35.0
Indian	3	15.0
Religion		
Islam	10	50.0
Buddha	6	30.0
Hindu	2	10.0
Others	2	10.0
Occupation		
Working		
Professional	9	45.0
Non-professional	7	35.0
Not working	4	20.0
Prognosis		
Stage 1	8	40.0
Stage 2	5	25.0
Stage 3	4	20.0
Stage 4	3	15.0
On treatment/cycle		
Cycle 1 - 2	11	55
Cycle 3 - 4	7	35
Cycle 5 - 6	2	10

Table 2: Theme and subthemes

Emotional changes	Physiological changes
Anger character	Physical discomfort
Fear of chemotherapy	Loss of appetite
Different character	Sleep disturbance
Negative thoughts	Skin changes in color
Worrying possibility of recurrence	Hair loss

There are two main themes were explored from the analysis. The first main theme is emotional changes with subtheme of anger characters, fear of chemotherapy, different character, negative thoughts and the worrying possibility of recurrence. The physiological changes are the second main theme that emerged from this study. Physical discomfort, loss of appetite, sleep disturbance, skin changes in color, and hair loss are among the subtheme identified in this second theme. The details of each theme and subtheme will be deliberated accordingly in the paragraph.

The first main theme in this study is emotional changes. The following below are the elaboration of emotional changes theme and its subthemes.

Emotional Changes

At any stage after a cancer diagnosis, participants may experience times of distress and feel a range of strong emotions, such as disbelief, fear, anxiety, anger, and sadness. These can be seen as a form of grief. Almost all of the participants spoke about emotional changes as an indicator during chemotherapy treatment. This subtheme is discussed in five categories: anger characters, fear of chemotherapy, different character, negative thoughts, and worrying possibility of recurrence.

Anger character

Ten of the participants had anger characteristics for the first time they knew about their diagnosis from the physician. This happens because they become disbelieving in the situation they had to go through. Chun said that she feels angry with what happened to her:

"When the doctor told me that I had breast cancer, you know, I was like want to shout out loudly... At home, I ask myself... Again... and again... Hey! Why me? Why me? I keep asking myself, and I simply throw the pillow to my bed..."

(Chun)

Fuzah, who is in the first stage of breast cancer with her first-time chemotherapy treatment, said that she feels angry and tries to avoid all family members.

"I was angry when I knew my prognosis. I took more than three days to calm down... I always ask, why did Allah give this disease to me? My husband is very kind to try to help me calm myself, but I was ignoring him and my kids, so I try to avoid them because I don't want my temper to go to them."

(Fuzah)

The anger character is not for them to simply get angry but because of the disbelief that made them behave under their control.

Fear of chemotherapy

The majority of the participants reported that they were worried about the side effects of chemotherapy, so they needed the courage to face the treatment. Moreover, some of them had even heard that chemotherapy could be fatal, causing them to be afraid of chemotherapy.

"I was worried actually for the first time when the doctor told me about chemo drugs... People said chemo drugs were very painful. I couldn't imagine it when the drugs came into my body... But then after the third cycle, I am still scared of the drugs..."

(Azira)

"Of course, I am afraid because everyone said the chemotherapy, especially the drugs, is killing me slowly. Because the dose of chemo drugs is high..."

(Intan)

"I was afraid of it because I had not undergone it before. Since I had heard from others about the side effects so scary when you knew that you were going to feel it later."

(Leela)

Different character

This refers to the unusual feeling women experienced after receiving chemotherapy treatment, which they felt contrasted with their normal selves. It was the feeling of being a different person that made participants aware that something was wrong with their emotions. The participant discussed having feelings of being different, such as 'being punished' and 'being not normal.' According to Nurul, she realized that she felt different from what she expected when she was not enjoying her experience after learning her diagnosis:

"After knowing my diagnosis, I just kept quiet. I didn't feel like talking to others and didn't even laugh. There was a sudden change in my life. No feeling, nothing, not at all. I'm punished by Allah."

(Nurul)

Nurul mentioned she was angry for the first two weeks before she went through the chemotherapy treatment. Moreover, 'sudden changes' explain that her loss of excitement or enjoyment was the changes she experienced after the treatment. Other participants noticed that they became easily sad and irritated when others asked about their health status. They said that they had no idea why this happened to them. Mariam pointed out that the stress that she had after receiving the treatment made her become a more sensitive person, and she would lose her temper easily:

"After the treatment, I felt easy to get sad and irritated when people asked me. I felt like I easily get sensitive in many ways things. Sometimes I easily get stressed while I am at home... I was like easily irritated."

(Mariam)

Despite a lack of understanding of these emotional changes, the participants were sure their current emotions differed from how they had felt before the treatment. For example, Leela, a first-time chemotherapy treatment participant, shared her feelings of being irritated since she knows her diagnosis from the physician as something she felt contrasted with her usual personality. As she noticed her different character, Leela tried to keep calm but perceived that it was difficult to control her emotions:

"Sometimes, I think why I should do that (chemo). I've no idea why it happened. I tried to keep calm, but I couldn't. I don't know why it happens. These changes happened to me since I know my diagnosis and now on treatment."

(Leela)

The term 'not normal' was repeatedly also mentioned by some women when describing the feelings of not being their normal selves. Low said:

"I'm not a normal person when I feel sad and angry. I was not normal before this because of the stress. Now I'm a bit okay."

(Low)

Low also adds that her life was generally full of crying all the time, even though she lives with her family:

"Almost every day, I cried. Every day I felt lost. Sometimes I tend to be angry for no reason."

(Low)

Participants also realized that they tended to think negatively, apart from recognizing that something was wrong when they felt that they had a different character.

Negative thoughts

The majority of the participant in this study reported having negative thoughts as one of the changes they felt related to their emotional changes. Negative thoughts include 'negative feelings' as described by Chan. Chan has described her 'negative feelings':

"A lot of negative things I thought of. I think about my kids. What will happen in the future without me? Can I handle them before I die? This negative feeling was a mess in my life!"

(Chan)

Chan considered the presence of doubt in her capability to manage her children as 'negative things' that made her recognize there was something wrong with her normal self. She said:

"Hmmmmmmph... When you think negative things, and then you start to cry! You can know something was wrong already with yourself."

(Chan)

Another example of negative thoughts is Malar sharing her thought she wants to die rather than attend the chemotherapy treatment.

"To some extent, I felt it better for me to die. That's how bad I felt. I don't know; my family is sad about my condition. Better I die rather than have to go through the bad treatment for the whole entire of my life."

(Malar)

Worrying possibility of recurrence

The participants were found to be worried about their future health due to the possibility of cancer recurrence. However, they felt that cancer recurrence was quite common, even in those who had completed their treatment.

Therefore, they understood that cancer might recur despite the chemotherapy received.

"Yes, I think every patient who had cancer will worry about it because it is not guaranteed that I will fully recover. Even if I had undergone this chemo treatment, I would not be able to predict when cancer will come back again..."

(Roziana)

"I and my family struggled to receive it at first since we had heard a lot about the side effects, such as some people would not be able to stand after chemotherapy, so I was worried. At night before sleep, I always worry if my cell cancer is growing and attacking another body part of mine."

(Wai)

"Yup ... recurrence is so common nowadays... so many people got it. That's why it is so scary for me. If it recurred, I have to do the chemotherapy and radiotherapy again..."

(Leela)

As outlined in the above descriptions, emotional changes can be characterized by the feelings of being punished, not being a normal person, and getting easily sad and worrying about the recurrence of cell cancer. In addition, the changes in the patient's emotional state could contribute to adverse physiological changes, which are explained in the following.

The second main theme in this study is physiological changes. The following below are the elaboration on physiological changes and its subthemes.

Physiological changes

Physiological changes refer to the disturbed body functions that were being experienced by the participant in relation to their emotional distress. The changes include physical discomfort, loss of appetite, sleep disturbance, skin changes in color, and hair loss.

Physical discomfort

Several participants reported headaches as part of their signs of having emotional changes. Mariam describes the characteristics of her headache:

"Nowadays, after receiving the treatment, I always have a headache. There was one time I felt a headache

like my head was squashed by a big stone. It just takes pain killer to solve it. If I can't tolerate the pain, I will call my husband or my daughter to slowly massage my head."

(Mariam)

Additionally, Low experienced the same as Mariam. Low said:

"I always have a headache. Not only after receiving the treatment but also before the treatment. I don't know why. Try to massage by myself, not to bother my husband."

(Low)

Loss of appetite

Almost all participant shares their experiences regarding loss of appetite due to the side effects of chemotherapy drugs. Loss of appetite is crucial for the participant after receiving chemotherapy treatment. Nurul shared her experience once coming back from treatment:

"After receiving the treatment, I felt very bad. I couldn't eat as usual. When my daughter gave me porridge, it came out of my mouth. It is suddenly coming out. I was hungry, but I can't tolerate this effect."

(Nurul)

Three participants, Siew, Leela, and Chan, mentioned their loss of appetite:

"I couldn't eat... But my husband pushed me to eat, so I ate even though it felt tasteless!"

(Siew)

"Oh my God, I couldn't eat, you know, even porridge, the soft diet. I can't swallow it!"

(Leela)

"I felt sad every time I wanted to eat, but I couldn't eat. It's really made me bad. I forced myself to eat; if not, I would not have any energy."

(Chan)

Loss of appetite makes several participants thin and unable to tolerate daily activity. This makes them cannot do anything, which may lead to emotional distress to them.

"When I couldn't eat, I could not get up. I still forced myself to eat even though the food was vomited out after eating, again and again... as long as I ate something... Every day I feel bad about myself."

Always ask Allah why this happened to me. I want back my own life."

(Intan)

Aminah also adds to the same statement. Because of loss of appetite, she always bargains about why she has to deal with this situation:

"I always ask Allah, why am I the person you chose? Why me? I can't eat, so how can I take care of my children? I am really a bad mother!"

(Aminah)

Sleep disturbance

Although participants stated related sleep disturbance to their emotions, they recognized this as either the consequence of their anxiety or other stressors, such as family and financial problems. Roziana, for instance, directly associated her anxiety levels with difficulty sleeping:

"When I've anxious, I can't sleep all day. It gets worst at night."

(Roziana)

Premathi and Wai also explained that their sleep disturbance was due to their family and financial problems:

"Sometimes I was sad because I was thinking about how to pay and settle all things, that's why I couldn't sleep. We've to pay the debts, but sometimes we've got not enough money."

(Premathi)

"My family does not have enough money, actually. Luckily, my treatment is paid for by my insurance. But I still couldn't sleep because I've always thought about my family problems and financial problems too."

(Wai)

It appeared that although sleep disturbance was mentioned by the patient in this study, it was less of a sign to the patient that something was wrong. Instead, they were perceived more as a reaction to other stressors.

Skin color changes

Almost every participant has skin changes in color. Became some of them felt distressed. For example, Sumayah reported that she has bad skin color changes:

"I felt really bad about my skin color due to this treatment. Sometimes like, it's itchy. Why does it happen? I also ask myself, and I don't know either the answer... Until I read about the side effects of chemo drugs, then I know it."

(Sumayah)

Three of the participants: Christine, Wati, Premathi, and Low, also commented the same thing regarding the skin color changes:

"My hand become black because of the treatment. I feel ashamed when I look at my own hands."

(Christine)

"When I saw my own hands, I was shocked! Why does my skin turn to black color? Then for the next circle, I asked the nurse. The nurse explained it was because of chemo drugs side-effect."

(Wati)

"The effects of the chemo drug make my skin black... my veins also show black lines..."

(Premathi)

Hair loss

The participant has hair loss related to chemotherapy treatment. Living with hair loss not permanent, the participant started feeling sad because hair began falling result of chemo, and the family was affected by the situation. Participants covered their hair loss with their own conception.

"When my hair started to fall, I was so sad... At home, I wear a scarf to cover my head. I don't want my children to see me bald... I am afraid they'll be sad..."

(Nurul)

Lela also did the same as Nurul said; she covered her head with a scarf when she goes out.

"I don't want people to look weird to me, so I wear the scarf or hat to avoid people looking at me. Even though I was sad because my hair was lost, I tried not to take it seriously."

(Leela)

This subtheme revealed that the recognition of the mainly described by emotional changes with the explanation of physiological changes. The participant described both experiences from emotional changes and physiological changes also.

DISCUSSION

This study aimed to explore the experience of patients with breast cancer after receiving chemotherapy at home. Two themes were revealed: emotional changes and physiological changes. The theme of the emotional changes refers to the symptoms, which were recognized by the participant in identifying the changes related to their emotional health, and physical conditions changed after their treatment. A life-changing diagnosis like breast cancer can dig up a lot of emotions and physiological changes. It is not uncommon to have fear, sleep disturbance, and body image issues, among others. Due to the increasing importance of patients' quality of life, it is essential for healthcare workers to understand patients' unreported experiences while on chemotherapy, as incidences of chemotherapy-induced side effects are higher than reported.²⁰ Hair loss and vomiting were the top side effects experienced by patients receiving chemotherapy in the present study. This is similar to the study by Chan and Ismail (20) where the participants experienced hair loss after chemotherapy. Despite the fact that their hair will grow again after the completion of chemotherapy, many patients still feel distressed, as they think that it represents a sign of cancer patients on chemotherapy. The majority of the participant shares their experiences regarding loss of appetite due to the side effects of chemotherapy drugs. Loss of appetite is crucial for the participant after receiving chemotherapy treatment. Vomiting was one of the most worrisome side effects because it drastically influenced their eating appetite.

The present study found that the majority of the patients interviewed were emotionally and physiologically distressed due to the side effects, and only a few patients managed to cope with the side effects experienced. Nonetheless, all patients completed the entire course of treatment, as they were encouraged to complete the entire chemotherapy recommended despite the side effects experienced. The use of chemotherapy has influenced each patient in different ways and to different degrees. Some patients reported experiencing severe side effects. However, there were also those who reported minimal side effects from chemotherapy (21). They

could inform their oncologists and discuss how to deal with those unwanted side effects to prevent them from withdrawing from chemotherapy midway (21).

In this study, participants' comprehension of chemotherapy was rather limited. Hence, there is room for improvement to meet the particular needs of this population. Moreover, many participants expressed their fear of chemotherapy regardless of their disease stage. The fear of chemotherapy treatment is due to hearing about chemo drugs can cause pain and death when entering the body. Educating the patients with accurate information is essential to let them understand all the misunderstandings (such as chemotherapy could cause death) (22). The oncology nurse should give more emphasis to patients after the oncologist gives an explanation for a better understanding of the chemo drugs. This includes giving emphasis on the effects of chemo drugs at home. The effects of chemo drugs at home will affect and change the patient's daily activities. Although patients generally receive information and education about their chemotherapy before starting treatment, they may feel overwhelmed with such information. Reeducation with support during the first few weeks of treatment and useful approach to help the patients managing the distress (9).

There are a few limitations in the present study. Patients who were willing to participate in this study were more open to expressing feelings and experiences while on chemotherapy. Those who refused may have other views on the side effects experienced by the administration of chemotherapy. Similarly, those who were skeptical or fearful of chemotherapy and discontinued chemotherapy earlier were not available for interview. These patients may have different views on chemotherapy compared to patients who completed chemotherapy. Nonetheless, the qualitative semi-structured interviews conducted were able to capture various patients' experiences and side effects related to the use of chemotherapy for breast cancer. For future research, perhaps an intervention study can be done accordingly to the level or phase of patients with breast cancer in Malaysia apart from emotional and physiological support.

CONCLUSION

Most patients with breast cancer experience side effects from chemotherapy at home. Findings from the present study suggest the importance of knowing patients' needs at home, such as the emotional and physiological support needed by patients with breast cancer after receiving chemotherapy. It is important to provide more support to participants about chemotherapy, along with potential side effects, before its commencement. Therefore, it is recommended to have counseling sessions or home care visits to ensure that patients are comfortable at home despite going through a difficult period throughout chemotherapy.

CONFLICT OF INTEREST

The Author(s) declares(s) that there is no conflict of interest.

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AUTHOR CONTRIBUTIONS

RS: drafted the manuscript and contributes to the concept development and design of the article through data collection, analysis and data interpretation for the article.

SMSE: revised the manuscript critically with intellectual contents and approved the final version of the manuscript.

LSP: revised the manuscript critically for important intellectual content.

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