ORIGINAL ARTICLE

Breast Cancer Patients’ Experience of Current Health Services as A Holistic Care: A Qualitative Study

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ABSTRACT

Introduction: Breast cancer is now one of the leading causes of death and morbidity worldwide, including in Indonesia. Every health care professional and community member should pay close attention to these issues. Women diagnosed with breast cancer will experience physical, psychological, and social issues. Methods: This study looked into breast cancer patients’ experiences with holistic nursing care. The complexity of the difficulties confronting breast cancer patients will influence their experiences and perceptions, necessitating a holistic approach to nursing services. A qualitative exploratory, descriptive method was adopted in the investigation. During data collection, fifteen participants were recruited and interviewed. Focus Group Discussion (FGD) was utilized to collect data. Result: The study’s findings provide five significant themes: (1) knowledge and understanding of breast cancer; (2) experiences felt at the beginning of breast cancer complaints; (3) non-health breast cancer treatment; (4) perception of nursing services received by breast cancer patients; (5) facts and holistic needs during and beyond treatment; and (6) patients’ expectations of nursing services to help their needs. Conclusion: The findings provide information on how breast cancer patients understand the examination procedure, accept a diagnosis, and proceed to treatments. Keywords: Breast Cancer, Experience, Health Services, Holistic Care

INTRODUCTION

Breast cancer is one of the most common cancers in countries that are developing, which means it has become an international concern for health. (1). The increasing prevalence of breast cancer implies pain, death, and the sufferer’s quality of life (2–4). Breast cancer is most common and occurs in developing countries, including Indonesia. This condition requires special attention from all parties, especially healthcare providers (5). Patients with breast cancer have a chance to live and recover from the disease by adapting to the conditions they face. The patient will experience various impacts on multiple aspects of their life, especially psychological ones. Psychological disorders in patients with breast cancer will affect these patients’ physical state and quality of life (6). Breast cancer patients need internal and external support to manage and treat the disease (7). The management of breast cancer can be pharmacological or non-pharmacological to help with the problems breast cancer patients face, including physical, psychological, and social complaints (7,8). Providing holistic nursing services is undoubtedly needed when treating breast cancer patients. The needs of breast cancer patients include biological needs such as nutrition, clothing, fluids, and rest; psychological needs such as attention and support from people around them; and social conditions to connect with family or community (3,9). Nursing services should be able to help with the problems breast cancer patients face and thereby improve their quality of life during this time, increasing their chances of survival and recovery from the disease (10).

Breast cancer leads Indonesia’s top 5 most frequent cancers (1). The prevalence of breast cancer was spreading throughout all regions of Indonesia. Based on data on the incidence of breast cancer in Indonesia, Yogyakarta province has the highest number of breast cancer cases, at 4.86 per 1000 people, followed by West Sumatra at 2.47 per 1000 people, and Gorontalo at 2.44 per 1000 people. (11). This condition requires particular concern to manage.

Along with the increasing number of breast cancer cases, it will be directly proportional to the quality of services provided to these patients. The services provided to breast cancer patients should be comprehensive and cover all aspects of their lives. The service in question...
is holistic care, Holistic nursing can define as caring for a person as a whole and emphasizes that the nurses take into account the connection between mind, body, emotion, spirit, social, cultural, environmental, and past relationships in order to restore the patient to a whole (12). Improvements in nursing service delivery must be evaluated at all times to improve the quality of care. One way that can be used for evaluation is to get input from nursing service recipients, what they understand, what their experiences are, and what their expectations are. Holistic care must be applied wherever the place of health service delivery is, especially in Indonesia, which is famous for its culture of friendliness, politeness, patient care, and good services.

MATERIALS AND METHODS

Study Design
This research used an exploratory, descriptive qualitative interpretative approach (13). This study describes the patient’s experiences and understanding of breast cancer and the health services received. The Consolidated Criteria for Reporting Qualitative Research’s checklist is used in the report (COREQ) (14).

Setting
This research is held in the community by gathering breast cancer survivors who have felt and received health services, including nursing services, in the process of breast cancer treatment and management. The interview was conducted at a place agreed upon with participants in Payakumbuh City, West Sumatera, attended by 15 breast cancer survivors, divided into two groups in Focus Group Discussion (FGD).

Participants Selection
The participants in this study were breast cancer survivors recruited through purposive sampling; the researcher chose participants who were appropriate to the research objective (11). Participants had to be diagnosed with breast cancer for at least six months, be able to speak Minang and Indonesian, and provide informed consent to participate in the research process. In total, fifteen participants met the eligibility criteria for this study.

Data Collection
From April to May 2021, data were gathered using Focus Group Discussions (FGD). Researchers use FGD because this data collection method is suitable to be used to explore data on perceptions, opinions, beliefs and attitudes towards services that have been received during breast cancer treatment and treatment (15). The researcher described the procedures for the group interview and the time needed before the interview started. After an explanation, participants are asked to sign an informed consent form. The discussions were divided into two groups, seven and eight people. The interviews were carried in the community (in one of the participants’ homes). Participants in the study were assigned a P1–P15 code. A moderator with a Master’s degree in Nursing, a concentration in women’s health, training, and expertise in qualitative and women’s health guided the interview. The moderator is joined by a co-leader who serves as an observer and assists in facilitating the interview so that participants can deliver accurate answers and responses. The authors who performed the interview were all female researchers. Each research team plays a role based on their position to ensure that the interview process runs smoothly. The primary objective was to establish a balance between structure and openness to generate more ideas, yield more profound insights into the subject under investigation, and manage the dynamics and interaction among group members. The interview guide included questions related to the participant’s perceptions and experiences of breast cancer and its treatment (16). The interviews lasted 45 to 60 minutes and were tape-recorded with prior permission. The researcher provides data-gathering tools and interview guidance. The researcher adjusts past studies’ data-gathering instruments, including citations and references, to fit them with the study’s objectives. Questions include; “What is it like to be a cancer survivor a year after treatment?” “What do you understand about breast cancer?” and “Can you tell me about your experiences with the health care services you received after breast cancer treatment?”

Data analysis
The data analysis was carried out by the authors and the team manually. Initially, the first author (interviewing author) reviewed and reread all of the transcript subgroups individually. She wrote her initial thoughts on potential themes, sub-themes, and codes. Colaizzi’s seven-step method approach was applied when evaluating the data during the step. This analysis involved the following steps; 1) reading and re-reading transcripts from participant recordings; 2) looking into noteworthy remarks that were pertinent to the phenomenon being studied; and 3) characterizing and classifying each meaning, 4) compiling all the essential ideas that were repeated, 5) developing and articulating the meaning of the meanings received, 6) incorporating and categorizing the same meaning into the topic, and 7) giving the results back to the participants for validation (17). All researchers agree that the data presented in the study results is correct because it has been verified properly and appropriately in accordance with the specified procedures. It entails identifying themes by carefully reading and rereading the transcribed materials (18). The interviews and data analysis were conducted in The Minang Language (the traditional language of West Sumatera), translated to Bahasa, and finally translated into English.

Trustworthiness
This study used credibility, confirmability, dependability, and transferability (19). To enhance the credibility of these research findings, we confirmed the final themes
to the participants. Confirmability was carried out by sending interview findings in the form of the results obtained and then asking for feedback to get approval from the representative participants. They were asked to verify the accuracy of the results. Utilizing a qualitative research professional to audit and analyze several research processes helps to preserve dependability. Transferability is achieved by distilling the study's findings and then providing a narrative explanation of the interview findings.

Ethical considerations
The research protocol for this study was approved by the Ethics Committee of the Universitas Fort De Kock Bukittinggi (No. 152/KE/VI/2021). All women received detailed information about the study and provided signed, informed consent needs before data collection. This study protected the anonymity and confidentiality of the women. Data was handled with strict confidence and was only used for this study. Pseudonyms were used when presenting the women’s comments.

RESULTS

Demographic of Participants
This study's sample included fifteen participants, seven participants below 40 years old and had only completed junior high school. Six participants graduated from high school, while the seventh had accomplished graduate school. Nine of them worked in the informal sector, such as; private employees, tailors, and sellers. All of the participants experienced surgery therapy, and eight of them received surgery along with chemotherapy (Table I).

Themes and Subthemes
Breast cancer data analysis generated five major themes reflecting participants’ experiences and perceptions of the health services. Thus are; (1) knowledge and understanding of the breast cancer; (2) experiences felt at the beginning of breast cancer complaints; (3) non-health breast cancer treatment; (4) perception of nursing services received by breast cancer patients; and (5) facts and Holistic Needs during and beyond Treatment; and (6) patients’ expectations of nursing services to help their needs (Table II).

Theme 1: Knowledge and understanding of breast cancer
The patient’s understanding and knowledge of breast cancer and its causes are inadequate. Breast cancer patients who were never exposed to breast cancer information are more likely to delay seeking appropriate treatments. Delivering and receiving positive information can directly play a role in early screening. People who have never been exposed to breast cancer information/mass media are 2.75 times more likely to develop the disease due to delays in presenting for early examinations in medical services (20). This theme was obtained based on what was expressed by participants; three of them are stated below:

“Cancer in the breast is a disease that must be operated on, cannot be solved by traditional medicine as a solution (P1A)”

“Cancer in the breast area and its initial symptoms do not have to be swollen breasts only….; they can also be other symptoms (2A)”

“Diseases that attack the breast area are malignant cancers that can cause death …(P1B)”

Related to the risk factor of breast cancer, participants have different understandings and experiences according to the understanding and information they have obtained so far. This can be seen from the statements of participants, some cases are caused by heredity, food consumed, and hormones. As stated by the three parties, including as below:

“As far as I know, there is no direct cause; it could be hereditary factors from the family in the past (1B)”

“In the past, I ever used the pill contraception, could that be the cause? But I never used it for a long time (3B)"
I thought if the services were friendly and polite, nurses would become part of the medicine. Mostly with our fellows because we have a group from which there is an experience we will share. If I can just live near the nurse’s house, that would be fantastic.

"I don’t know the truth, I’m just do like others do, the consumption of food, drink are same with others (5B)"

Theme 2: Experiences felt at the beginning of breast cancer complaints

The experience felt at the beginning of breast cancer builds a sub-theme of physical and psychological experiences formed by the participants. The physical and psychological experiences formed by the participants included:

- **At first, it was just a small lump; it didn’t hurt, I trivialized it for one year**
- **I don’t know the truth, I’m just do like others do, the consumption of food, drink are same with others**
- **At first, there was a sense of disappointment, sadness, and despair, but over time and having gathered with these comrades-in-arms, I became stronger.**
- **When I knew it, I was really stressed, crying hard, and hysterical.**
- **At first, it was just a small lump; it didn’t hurt, I trivialized it for one year.**
- **I don’t know the truth, I’m just do like others do, the consumption of food, drink are same with others**
- **At first it was a lump in one breast, which, for fear of surgery, I didn’t care about. Finally, now both of them have lumps.**
- **Yes, when we were treated, what we asked was directly assisted by the nurse. In the hospital process, the nurse also helped to do an examination with the doctor.**
- **I am more satisfied when I am here in Bukittinggi, because the treatment is more friendly and people pay attention to us, maybe because the patients are not too crowded.**
- **At first, the hospital was big, it looked slightly different. Sometimes we experience difficulty and limited time to meet the nurse. If there are many patients in big hospitals, the waiting time is long, the registration time is long, and the waiting time for an examination is also long.**
- **I thought if the services were friendly and polite, nurses would become part of the medicine.**
- **The nurse is kind, answering all the questions that are complained about, they help us.**
- **Nurses help with all needs while being treated after surgery in the operating room and also in the ward.**
- **The exposure can help communicate with nurses, like fluently communicating with the doctor “I.”**
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Table II: Themes and Subthemes

<table>
<thead>
<tr>
<th>Theme</th>
<th>Subthemes</th>
<th>Sample codes</th>
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<tbody>
<tr>
<td>Knowledge and understanding of breast cancer</td>
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<td>Cancer in the breast is a disease that must be operated on, cannot be solved by traditional medicine as a solution</td>
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<td></td>
<td>The risk factor of breast cancer</td>
<td>Diseases that attack the breast area are malignant cancers that can cause death … (5B)</td>
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<td>At first, it was just a small lump; it didn’t hurt, I trivialized it for one year</td>
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<td></td>
<td>Psychological experience at the beginning of breast cancer</td>
<td>I don’t know the truth, I’m just do like others do, the consumption of food, drink are same with others</td>
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<tr>
<td>Non-health breast cancer treatment</td>
<td>Belief in consuming traditional herbs and faith in magical abilities</td>
<td>I don’t know the truth, I’m just do like others do, the consumption of food, drink are same with others</td>
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<td></td>
<td>Treatment-seeking behaviors exhibited by individuals with breast cancer</td>
<td>At first it was a lump in one breast, which, for fear of surgery, I didn’t care about. Finally, now both of them have lumps.</td>
</tr>
<tr>
<td>Perception of nursing services received by breast cancer patients</td>
<td>The patient’s view of the role of nurses</td>
<td>Yes, when we were treated, what we asked was directly assisted by the nurse. In the hospital process, the nurse also helped to do an examination with the doctor.</td>
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<td></td>
<td>The patient’s understanding of facilities and types of hospitals</td>
<td>I am more satisfied when I am here in Bukittinggi, because the treatment is more friendly and people pay attention to us, maybe because the patients are not too crowded</td>
</tr>
<tr>
<td>Facts and Holistic Needs during and beyond Treatment</td>
<td>The Nurse Performances</td>
<td>At this time, because the hospital was big, it looked slightly different. Sometimes we experience difficulty and limited time to meet the nurse. If there are many patients in big hospitals, the waiting time is long, the registration time is long, and the waiting time for an examination is also long.</td>
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<td></td>
<td>Health Services by Nurses</td>
<td>I thought if the services were friendly and polite, nurses would become part of the medicine.</td>
</tr>
<tr>
<td>Patient’s expectation of nursing services to help their needs</td>
<td>The anticipation for nurses</td>
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impact is a change in body shape due to breast cancer (20). This statement aligns with a study that stated that several physical changes have implications for breast cancer. Patients feel lumps in the armpits with the same characteristics as in the breast. Patients further experienced changes in sleep patterns and pain in the breast that felt lumpy and quickly tired (21) (22). Other studies also found that in addition to experiencing physical problems, patients also experienced severe psychological problems starting with the cancer diagnosis and still felt them while undergoing chemotherapy. These psychological problems include helplessness, sadness, fear, body image disorders, low self-esteem, stress, depression, despair, and suicide (22) (23). Nine out of 15 participants said the symptoms began with the discovery of a small lump in the breast, and one person said it started with bleeding through the vagina, as revealed by the comments of three participants below:

“At first, it was just a small lump; it didn’t hurt, I trivialized it for one year (1A)”

“I also felt that the swelling in the breast area at the beginning was small but then increased in size and was solid (3A)”

“I just felt a lump in my breast, I told my daughters, and she said it should be checked now; it will get worse if it’s late (1B)”

Three participants described the psychological experience at the beginning of breast cancer as a feeling of fear, so they did not want to be operated on and were just left alone. Other participants said there was a sense of disappointment, sadness, despair, inability to sleep, crying, and stress. The statement was made by the participants:

“I was a bit anxious, when I took a bath in the morning, and touched it, How come it got bigger, I was getting more and more anxious too, more anxious I was, the lump grew faster, I just cried continuously (3A)”

“At first, there was a sense of disappointment, sadness, and despair, but over time and having gathered with these comrades-in-arms, I became stronger (P2A)”

“I was very anxious. In my mind, I should go directly to the hospital because I was afraid of this disease (2B)”

“When I knew it, I was really stressed, crying hard, and hysterical (P3B).”

Theme 3: Non-health breast cancer treatment
Non-health breast cancer treatment, or traditional breast cancer treatment, comes from two sub-themes: belief in consuming traditional herbs and faith in magical abilities and treatment-seeking behaviors exhibited by individuals with breast cancer. However, refusing or not taking medication is also one form of treatment-seeking behavior (21). There is a need for an adequate understanding of treatment to prevent the negative impact. In addition, various factors that influence the selection of treatment-seeking behaviors must also be considered. Based on this exposure, this study aims to find and explore the behavioral traits of women with breast cancer seeking treatment (7, 21). Belief in consuming traditional herbs and faith in magical abilities are stated by participants, three of them explain:

“After that… I was given traditional medicine by my husband, but it was difficult to find a shaman to seek treatment at that time (P1B)”

“When I was diagnosed with breast cancer, I was told by my parents to drink my husband’s pee every morning, I drank it three times in the morning (P2B)”

“The leaves of the herb were attached to the breast, he said. The shaman said I should drink the potion water, which was as much as one teapot (P3B)”

Treatment-seeking behaviors exhibited by individuals with breast cancer are explained by the fact that there are four types of treatment-seeking behaviors: doing nothing (no action), self-treatment, seeking modern medicine, and seeking traditional medicine. The behavior of patient treatment can also be influenced by psychological factors, treatment characteristics, personal factors, and environmental factors, which may be internal or external (7). Treatment-seeking is obtained by participants, two of them give statements as bellow:

“After being diagnosed with breast cancer, I tried to treat myself before finally coming to the hospital (P1A)”

“At first it was a lump in one breast, which, for fear of surgery, I didn’t care about. Finally, now both of them have lumps … (P2A)”

Theme 4: Perception of nursing services received by breast cancer patients
Perception of nursing services received: this theme reveals the perception of nursing services received by breast cancer patients. The two sub-themes are the patient’s view of the role of nurses and the patient’s understanding of facilities and types of hospitals. In the sub-theme of the patient’s view of the nurse’s role, three participants said that when there was a complaint, they would ask the nurse, and the nurse responded. Participants mentioned there was help from nurses during check-ups by the doctor in the polyclinic. Other participants said nurses assisted them during the polyclinic treatment when they were not optimistic. This statement was mentioned by participants, as shown below by breast cancer patients:

“Yes, when we were treated, what we asked was directly...
Theme 6: Patients’ expectations of nursing services to help their needs

The sixth theme, the expectation for nursing services to support the needs of breast cancer patients, was obtained from two sub-themes. Specifically, the anticipation for nurses and the expectation of peer groups. The uncertainty of the nurse came from three participants who made this statement:

“Nurses who are friendly and well-mannered with patients are most needed before treatment and at the time of treatment (P 3A).”

“We hope we received services from a friendly nurse and can communicate whenever we need (P 4B).”

The second sub-theme about the utilization of peer groups was obtained from all participants, who stated the importance of helping fellow breast cancer patients:

“Mostly with our fellows because we have a group from which there is an experience we will share (P3A)

“Ask friends in the group or close friends only; just help each other with what we know and our experiences (P5A)”

DISCUSSION

The findings of this study, related to knowledge and understanding of breast cancer, are strengthened by the results of the research carried out as follows; the delay of breast cancer patients in checking into health services is influenced by never being exposed to information/mass media about breast cancer. A woman needs to know, understand, and be aware of all the risks for anyone to develop breast cancer (24). A strong understanding of breast cancer, especially early detection, is challenging and key to reducing the morbidity and mortality rate caused by breast cancer (25,26). Likewise, a person’s understanding will affect their perception of disease and strongly impact their behavior in seeking health services. An early breast cancer diagnosis can increase the chance of early case detection and favorable outcomes, resulting in improved survival rates and quality of life for women. This is therefore a crucial public health strategy in all settings (27).

Experiences felt at the beginning of breast cancer diagnosis related to the understanding of physical disorders and psychological disorders that are pretty severe begin from the time of being diagnosed with cancer. The experience felt by breast cancer patients includes both physical complaints and psychological complaints felt since being diagnosed, during treatment, and after treatment. These psychological problems include helplessness, sadness, fear, body image disorders, low self-esteem, stress, depression, despair, and a lack of passion for life, leading to the intention to commit suicide (23,28). Women with breast cancer will experience mental health
issues as soon as they are diagnosed with cancer, during treatment, and during survivorship. Two main concerns within psychological distress have been identified for breast cancer survivors: mental health issues and distress surrounding cognitive function. One-fourth of breast cancer patients will develop anxiety and depression at some point in their journey (28). Experiences vary from individual to individual at different stages. The needs of each individual will also be different according to the conditions experienced. Understanding the transitional phases and having a holistic perspective will allow for a more holistic view of the person, thus improving their quality of life and involving them in all decisions (28).

Believing in traditional medicine or treatment by consuming herbal medicine is a popular alternative treatment among breast cancer sufferers. Local knowledge, belief systems, and therapeutic practices are used for health-related goals in poorer countries (and, in some circumstances, by ethnic minorities and indigenous peoples within richer countries) (28). In addition, various factors that influence the selection of treatment-seeking behaviors must also be considered. Based on this presentation, this study aims to discover and explore the behavioral picture of seeking treatment in women with breast cancer (21). Most Indonesian women have a negative perspective on breast cancer. It is a dangerous and deadly illness. They had a negative belief that its treatment could cause disability and have an economic impact. This negative perception causes patients to prefer traditional treatment that is considered more accessible, cheaper, and does not cause a disability in their body part. The choice of therapy is influenced by the patient’s knowledge and understanding (29).

The hospital is a facility where the community may receive medical services. The quality of services provided can be evaluated from numerous perspectives, including the service provider’s position, the view of the facility’s owner, and the service user’s perspective (30). As health care providers, nurses must also assess how patients, especially breast cancer patients, perceive the services they receive. Nursing care management includes all actions directly or indirectly related to the care of patients. The interviews of both sample groups stressed the importance of nursing consultation as a fundamental tool for managing nursing care (30). Service quality according to the five dimensions of tangibility, empathy, reliability, assurance, and responsiveness. Further research is needed to examine the relationship between patient satisfaction levels and nursing services based on these five aspects. Hospitals can use the results of this study as primary data to improve the quality of nursing services in hospitals (30).

The actual needs felt by breast cancer patients are particular needs that must be met soon when patients need them. The fulfillment of these essential needs will have a positive impact on patients both physically and psychologically. To meet these needs, nurses must perform well under nursing care standards. Breast cancer patients need the services of service delivery teams: doctors, nurses, physiotherapists, counselors, and psychologists. All teams carry out their respective duties and functions to improve patient health. In this case, the discussion is more directed at nurses as one of the service provider professions. The holistic needs of breast cancer patients will always be present at every stage of the cancer journey, as will their physical, psychological, and social needs. Breast cancer patients need the services of various service delivery teams consisting of doctors, nurses, physiotherapists, counselors, and psychologists. All teams carry out their respective duties and functions intending to improve patient health. In this case, the discussion is more directed to nurses as one of the service provider professions. The holistic needs of breast cancer patients will always be present at every stage of the cancer journey as their complex physical, psychological, and social needs (31). The role of nurses as nursing service providers in breast cancer patients is critical, particularly for the information required by patients undergoing treatment, similar to nurse-patient interactions in inpatient and outpatient settings. Meeting patients’ information needs will boost their self-efficacy during and after treatment (32).

The patient must satisfy his demands regarding what he requires, what she desires, and what is anticipated of health care, mainly the services the nurse provides. This patient expectation represents a call to improve service quality (30). Patients’ expectations from the nurses and other healthcare team members refer to their concept of care provision before hospitalization. Of course, patients’ expectations do not imply their satisfaction with the provided services. Fulfillment can only be measured during the patient’s hospital stay and after discharge; in the end, the patients may express high satisfaction while their expectations have not been met (30). The services provided by nurses can also be improved by the existence of services provided electronically or digitization, and time limitations between nurse and patient can be solved (30). The presence of peer group support also positively affects the psychological response of breast cancer patients. Peer group support can turn maladaptive psychological responses into adaptive psychological reactions among breast cancer patients. Peer group support can teach breast cancer patients to change negative perceptions about the disease into positive ones. Patients will try to learn and change attitudes that are not good and immediately make decisions to determine the treatment of the disease (30).

**CONCLUSION**

The experience at the beginning of a breast cancer diagnosis raises sub-themes of knowledge of the physical progression of breast cancer and psychological...
experiences. The experience felt by breast cancer patients also includes understanding the examination process, deciding on the diagnosis, and undergoing treatment. The kind of treatment chosen by breast cancer patients will determine the following situation or condition: Patients’ experiences of health services at breast cancer treatment with procedures received. The treatment choice will depend on what happens because the knowledge acquired will provide understanding for patients with breast cancer. The expectation of health services, especially nursing services, to help meet the needs of breast cancer patients revealed two sub-themes: expectations from nursing services and peer groups. Support from the family, people within the patient’s sphere of influence, and healthcare providers become a unit that can positively impact the treatment process and recovery of patients with breast cancer. Hospitals should improve the competence of nurses not only in physical therapy but also in the psychological treatment of cancer patients. Nurses should provide comprehensive nursing care, including bio, psycho, social, cultural, and spiritual. For peer support, it is necessary to have the patient’s readiness at the acceptance stage. The family, especially the husband, is expected to support breast cancer patients.

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