



SELF CARE EXPERIENCE OF WOMAN WITH BREAST CANCER

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ABSTRACT

Breast Cancer treatment not only causes physical but also psychological side effect that will affect Breast Cancer sufferers quality of life. Self care for Breast Cancer sufferers is needed to overcome chemotherapy side effect and help them adapt their condition, so they can improve their quality of life. This research aims to explore experience women with Breast Cancer self care. This research use a qualitative research method with a phenomenological design trough in depth interviews. Participants in this study were 12 women who were diagnosed with Breast Cancer and had undergone chemotherapy. The data analysis process in this research uses the Colaizzi analysis method. The results of data analysis from this research revealed 5 themes, seeking information and treatment at the start diagnosis, adaptation process after receiving treatment, support during chemotherapy, obstacle in carrying out treatment and hope in breast cancer treatment. Women who are diagnosed with breast cancer make various efforts to overcome their disease starting from the first symptoms discovered until the treatment process is undertaken with various obstacles and perceived support, this is done because they have high hopes for recovery in the future.

Keywords: breast cancer; experience; self care

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INTRODUCTION

In 2020, 2.3 million women were diagnosed with breast cancer or 12.5% of all cancers in the world. The number of breast cancer sufferers reaches 16.6% of all new cancer cases in Indonesia (*World Cancer Research Fund International*, 2020). Chemotherapy is the treatment of cancer using drugs that are inserted into the body of cancer sufferers. Chemotherapy is useful for destroying the structure or metabolism of rapidly growing cancer cells (Arunachalam *et al.*, 2021). Chemotherapy not only provides benefits by killing cancer cells, but also has many side effects because chemotherapy drugs also kill normal cells that grow quickly. Breast cancer has a major impact on the quality of life of sufferers from the diagnosis stage to treatment process (Mokhatri-Hesari & Montazeri, 2020). Cancer sufferers can experience extreme weight loss due to decreased appetite because nausea, vomiting and stomatitis (Efe Ertürk & Taşçı, 2021). Cancer sufferers will difficult to carry out normal physical activities due to fatigue and sleep disorders (Kawabata *et al.*, 2020). Based on research Hassen *et al* (2019).

The quality of life of cancer patients is low due to fatigue, sleep disorders, and side effects of systemic therapy. Low quality of life due to chemotherapy side effects can affect the breast cancer treatment process. The process of cancer treatment has progressed significantly over the last ten years, this can be seen from the shift in treatment, previously, the treatment was mostly done in hospitals, now patient care in hospital shorter and more home care. By reducing time in hospital, the side effects of chemotherapy treatment appear more often when the patient is at home (Ullah *et al.*, 2022). Cancer treatment is changing to treatment outside

of health care facilities, so cancer patients are responsible for their own care to recognize, report and manage health recovery (Howell *et al.*, 2021). Cancer patients must have knowledge about the side effects that will arise after treatment, how to prevent and treat them so they can carry out self-care at home. Self-care is defined as person's ability to perform activities related to person's health, such as coping with mild symptoms and evaluating the side effects of chemotherapy, having a healthy diet and exercising regularly (Dinari *et al.*, 2022). Self-care helps individuals to adapt to the chronic conditions of the disease and has a positive effect on quality of life which can ultimately help reduce the cost of care. The aim of this study was to explore the experiences of women with breast cancer in practicing self-care

METHOD

This study used a qualitative research design with a phenomenological approach using in-depth interviews to explore the experiences of women with breast cancer to perform self-care. This research has passed the ethics test with number 304/KEPK/USU/2024. The research was conducted in the working area of Medan Marelan Sub-district. The participant selection technique used purposive sampling. Participants in this study amounted to 12 women who had breast cancer, had received chemotherapy treatment, were communicative and participatory. Interviews were conducted directly at the location where the participants lived while undergoing treatment. Interviews with participants were conducted after the researcher received a research ethics approval letter and a research permit from the University of North Sumatra and from the Head of Medan Marelan Sub-district. The researcher explained the purpose of the study and the participants expressed their willingness verbally and in writing by signing the inform consent. Interviews were conducted for approximately 40 minutes related to participants' experiences during breast cancer treatment. The researcher recorded the interview process using an MP3 and recorded things that happened during the interview. Interviews were conducted in more than one session according to data needs. The results of the interviews were then made into transcripts and revalidated to the participants.

The data processing and analysis process in this study is based on the analysis stage according to Colaizzi (1978) in Polit & Beck (2018), because the steps in this method are quite clear and detailed, namely: 1) Researchers made data transcripts by listening to recordings of interviews with participants repeatedly and carefully. 2) Researchers read the data transcripts thoroughly and repeatedly to identify meaningful words in accordance with the results of interviews that have been conducted. 3) Researchers grouped significant statements from participants into keywords, then interconnected keywords were grouped again into categories. 4) The researcher grouped the categories that had been formed into theme groups. The themes that have been formed are the final results of analyzing participant data. 5) The researcher combines the results of the themes obtained to describe the phenomenon of the client's experience in carrying out breast cancer treatment completely. 6) The researcher then makes a complete, systematic and clear description of the results of the analysis. This aims to make the results of the theme analysis made easy to understand by the reader. 7) The results of the description of the data analysis that has been made are validated to the participants in the form of conclusions to get the accuracy and correctness of the data. Validation is carried out with member checking techniques by confirming the conclusions of the interview results to the participants, so that the truth and accuracy of the description with the participants' perspectives are known.

RESULT

Characteristics of Participants

The participants in this study amounted to 12 women who were diagnosed with breast cancer and were undergoing or had undergone chemotherapy and resided in Medan Marelan District. All participants were female. Participants had an age range of 36-65 years and had different educational backgrounds ranging from elementary school, high school to college. Eight participants did not work, and four participants worked. Ten participants were married, one participant was widowed and one participant was unmarried.

Research analysis results

Five themes were obtained from the results of data analysis, namely: 1) Seeking information and treatment at the start of diagnosis; 2) Adaptation process after receiving treatment; 3) Support during chemotherapy; 4) Barriers to carrying out cancer care; 5) Hope in breast cancer treatment

1) Seeking information and treatment at diagnosis

Seeking information about the disease and treatment at the first time diagnosis is done by searching for information about the disease and treatment and searching for health services. Searching for information about diseases and treatments can be done directly, for example asking questions about cancer and chemotherapy to health workers and indirectly through the internet. The following is the participant's statement:

"Yes, I also asked, what is chemo doctor, chemo is like killing cancer cells" (P10).

"When I was told to chemo, my daughter first looked on the internet what is chemo, the reaction is like this, if not 5 days or a week you feel this (the effect)" (P1).

Once a person finds symptoms of a disease, they will seek health services to confirm and treat the disease. The health services that can be found today are professional health services and traditional health services. The following is the participant's statement:

"...oh yes, it looks like there is a little bump, so I took it to the health center" (P10).

"...I'm afraid of going to the hospital, no, I said, just go to herbal treatment, it costs money too, just one treatment sometimes almost one million" (P6).

2) Adaptation process after receiving treatment

The adaptation process after receiving treatment is carried out by maintaining health, fulfilling basic needs and preventing relapse. Participants maintain health in two ways, namely overcoming the side effects of chemotherapy to maintain physical health and diverting thoughts to maintain psychological health. Participants certainly did not want the discomfort of side effects of chemotherapy unchecked, so they made various efforts to overcome it. The following is the participant's statement:

"...I don't know, i always have massage. The medicated oil is complete, from balm, Freshcare, eucalyptus oil, whatever, I keep rubbing Freshcare ... (P2)

"Because I like to consume Chinese dates for that (helps sleep), I often consume it" (P7)

"...if not take a bath with betel leaf decoction, I have to use warm water, now I can't use cold water, so when I take a bath, I rub it with boiled betel leaves" (P1)

"...so I remember every morning the herbalist comes here. There is turmeric, temulawak, kencur rice, I remember turmeric for stomach medicine" (P2).

The side effects of chemotherapy can affect cancer patients in meeting their basic needs, so the patients need to adapt in meeting these basic needs. The fulfillment of basic needs conveyed by the participants consists of six types of basic needs including nutritional needs, activity needs, rest needs, needs with a partner, socialization needs and spiritual needs. The

following are statements from several participants:

In fulfilling nutritional needs

"Yes, this is the worst, this fifth chemo, before it was only 3 days, the 3rd and 4th chemo was not like this, i can eat without blended, but the fifth one i really can't chewed, finally i blended it than i am not eat at all and sick"(P9)

In fulfilling activity needs

"I can't stand up, I can't do anything, I just lie on the bed, even going to the bathroom i asks for help to hold me, if I am alone, I walk slowly walk, my head dizzines." (P1)

In fulfilling the need for rest

"Sometimes I am accompanied my husband, my children, they give me massage,I am accompanied until I fall asleep, so they watch me when i fall asleep (laughs)"(P10)

In fulfilling needs with a partner

"...I want too (intimate intercourse) , but when I feel good, if the first chemo is never at all, the fourth one is also never, but the second one and the third one often" (P10)

In fulfilling socialization needs

"that's why at home always crowded, my friends from the recitation come, offer food, sometimes they help cook, yesterday they boiled sweet potatoes at home, bought from market" (P10).

In fulfilling spiritual needs

"If I'm anxious, I just play spiritual songs according to my beliefs, instead of stressing, crying, I play spiritual songs, sometimes it makes us realize, gives us strength" (participant 9).

The participant efforts for preventing recurrence are one of the adaptation processes to avoid the disease does not reappear. These activities are carried out in several ways, including maintaining food intake, conducting routine checks and doing physical activities. Here are some of the participants' statements:

"...after this illness I forbade everyone to eat indomie..." (P8)

"...because every three months we also have to take photos, control, so we know how things are going" (P6)

"Yes, I was force my self, I also exercised even though I couldn't, althought just 5 steps, I was force" (P9).

3) Support during chemotherapy

Support provided during chemotherapy affects a person's efforts in carrying out breast cancer treatment. the Support obtained can be in the form of external support, namely support from family; from health workers and from the environment. The following is the participant's statement:

"...sometimes at night my little daughter say, you must be strong mom, I cry heard that, i say i am not strong, it hurts, the body wants to fall off (crying), so you don't not eat, see me crying she also cries too" (P1)

"You must spirit, you will be healthy later, but you must chemo said the doctor, always keep spirit, now cancer drugs already exist, lets spirit ..." (P2)

"...i also used to be like that, experienced something like this, you will healthy later she said." (P10)

Internal support is support from ourself, namely the confidence needed to defend ourself from the side effects of treatment and the confidence to continue chemotherapy and complete treatment. Support from ourself starts from a sense of acceptance of the disease to the motivation that arises from within. The following is the participant's statement:

"...I said that fate is already arranged, we just go with it, i said, follow it, go with it, so if the God call, that's the age, that's the line," (P7)

"I just think like this, yesterday my neighbor got cancer, she can, I have to be able to, I immediately checked this out, so I remember her, even I'm in chemo I have to be strong, just like that, my thoughts are just to get well" (P1)

4) Barriers to care

In carrying out breast cancer treatment, there are several obstacles, including financial obstacles and the stigma against cancer. The following is the participant's statement:

"...the most (obstacle) is the financial factor ..." (P3)

"...i am afraid because I heard that cancer is horrible, many people have passed away, so I'm afraid." (P2)

5) Hope for cancer and the treatment

Hope in breast cancer treatment is the participant's desire for several factors related to the recovery and treatment of breast cancer. These hope are expectations of oneself, expectations of the family, expectations of the environment and expectations of health services. The following is the participant's statement:

Expectations to oneself

"...I want my body to be healthy like before, if possible my face should not have wrinkles..." (P10)

Expectations to family

"Anyway, I am grateful that there are still them (family) who help me, I sometimes say to them to be patient for take care of me, don't get bored..."

Expectations for the environment

"...I tell my neighbors about my experience of this illness, so they know what kind of cancer it is, so they not look at me strangely..." (P8)

Expectations for health services

"...for example, when the chemo is finished, they have remove the infusion, we need to be encouraged, such as they say stay healthy at home, eat a lot..." (P10)

DISCUSSION

The first response of someone who diagnosed with breast cancer is a feeling of uncertainty about the future due to the negative stigma of cancer, a feeling of fear of life changes after a breast cancer diagnosis and anxiety in facing treatment (Vardaramatou et al., 2021). These feelings of fear and anxiety also arise when they undergo chemotherapy treatment, especially after they feel the side effects of chemotherapy. Chemotherapy with its various side effects certainly affects the quality of life of cancer patients, especially in terms of self-care and emotional disorders (Lewandowska et al., 2020). According to research by Mokhatri-Hesari & Montazeri (2020) over the past ten years the quality of life of breast cancer patients has increased, this is mostly because breast cancer patients have begun to realize the benefits of physical activity and other activities related to psychosocial. Cancer patients undergoing chemotherapy in addition to overcome their fear, they also strive to deal with the side effects

of chemotherapy so that they can complete the chemotherapy cycle on time (Islam et al., 2019).

Efforts for dealing with breast cancer are to seek information about the disease and its treatment to increase knowledge and understanding about breast cancer. It can affect the decision-making process and breast cancer treatment later (Arunachalam et al., 2021; Lestari et al., 2020). Seeking of information can be done directly through health workers (Khazi et al., 2023) and sharing information with people who experience the same thing (Liu et al., 2021; Nolan et al., 2019). Beside that, information can also be obtained through online media (Sinha & Sharma, 2021) although the information has been obtained, we must selected again because the information provided is sometimes inaccurate and cannot be scientifically proven (Ahn & Lee, 2023). Proactive information seeking needed because there are still breast cancer patients receive little information about their condition (Iddrisu et al., 2020; Kudjawan & Agyeman-Yeboah, 2021; Metsala et al., 2022). Patients with breast cancer even though already have a high awareness about the symptoms they feel, they are still reluctant to seek health services to check their disease because they do not have time to go to health services and hope that the symptoms disappear by themselves (Green et al., 2023), most of them are not willing to undergo chemotherapy because they are afraid of hospitals, and most others are not willing to undergo chemotherapy because they do not have family (Nies et al., 2018) or have negative experiences with health services (Swinny & Kagee, 2021), this is causes breast cancer patients late to get treatment because they come in an advanced stage (Kartini et al., 2019; Ng et al., 2020)

The process of seeking health facilities is influenced by individuals' views on health and how they access and use available health services to improve their health status (Rufli et al., 2024), People generally seek health assistance from professional health services when the symptoms appear and bother their daily activities. Therefore, people will delay going to professional health services until symptoms get worse (Widayanti et al., 2020). Traditional medicine is chosen when people believe that the cause of their illness is supernatural and when they feel medical treatment has failed to cure their illness, but misperceptions about the disease are one of the reasons cancer patients seek alternative treatments that are not recommended by medical staff (Kugbey et al., 2020) and do not discuss them with medical staff (Keene et al., 2022; Stie et al., 2020) because of different views on this matter (García-padilla et al., 2023). Based on the results of Wu et al (2023), it is known that 78.2% of respondents have used at least one type of alternative medicine in the past year. The changes require breast cancer patients to adapt to their condition. The adaptation process is carried out by identifying, analyzing, finding solutions and solving problems related to them negative experiences (Liu et al., 2021). The adaptation process includes overcoming the side effects of chemotherapy. From several studies, the most side effects are nausea and vomiting due to chemotherapy (Kreye et al., 2022), hair loss (Chan et al., 2021), and fatigue (Abulizi et al., 2021). One of the ways to overcome the side effects of chemotherapy include the use of essential oils to reduce nausea and vomiting, pain, anxiety, sleeping disorders and fatigue (Crosby A et al., 2018; Efe Ertürk & Taşçı, 2021; Kawabata et al., 2020; Nuriya et al., 2021).

Changes in body conditions make breast cancer patients have to adapt to still be able to fulfill their basic needs. These needs are different for each individual depending on their understanding of their condition (Lewandowska et al., 2020). Activities to meet basic human needs include adjusting dietary patterns to meet nutritional needs (Tabriz et al., 2021; Tang et al., 2023), reducing activity and resting a lot to meet physical activity needs (Nolan et al., 2019), going to bed early and increasing rest and using aromatherapy to overcome sleep

disorders (Arunachalam et al., 2021; Özkaraman et al., 2018), discussing sexual needs with a partner (Hassen et al., 2019) because most chemotherapy patients have low sexual function (Hassen et al., 2019), one of that is caused by stress due to body changes (Lee & Gyeong, 2023). Breast cancer patients mostly limit themselves to their social environment due to a sense of inferiority related to changes in appearance (Lewandowska et al., 2020). Lack of socialization needs can exacerbate psychological disorders of cancer patients, therefore cancer patients need friends to share stories and experiences that can help them forget about their condition and feel that nothing has changed in themselves (Kudjawan & Agyeman-Yeboah, 2021), fulfilling spiritual needs is done by remembering God in every activity, worshiping more and participating in religious activities (Chiaranai et al., 2022; Mufidah et al., 2023; Nolan et al., 2019).

The fear of recurrence even though they have completed their treatment is related to the fear of undergoing chemotherapy again and fear of death. The fear of cancer recurrence is a psychosocial concern that affects the recovery process and quality of life of cancer patients, so the application of healthy lifestyles such as avoiding smoking, maintaining nutritional intake, avoiding ultraviolet radiation (Tabriz et al., 2021; Tang et al., 2023) and increasing physical activity such as exercise, aerobics and yoga (Mokhatri-Hesari & Montazeri, 2020) began to be widely practiced. In addition, there are also cancer patients use alternative and complementary medicine to prevent cancer from reappearing (Wu et al., 2023). Beside application healthy life style and increase physical activity, prevention of recurrence must also combined with regular control to health services and self-examination with SADARI to diagnose the early stages of disease recurrence (Tabriz et al., 2021).

The decision-making process in breast cancer treatment is influenced by support factors and barriers. The higher support for cancer patients, the better quality of life, and vice versa (Mccutchan et al., 2021). Support for cancer patients undergoing chemotherapy is needed as a provider of strength, courage and motivation for them in the treatment process (Legawinarni & Lidya., 2023). Support for breast cancer patients can be obtained through the closest people, namely family (Armayati et al., 2023; Mardhiyati, 2022) and husbands for married breast cancer patients. However, based on the results of research by Sheikhnezhad et al (2023) there are still many couples who do not provide support to their partners who have breast cancer or even blame them. Beside family support, breast cancer patients also need support from the social environment (Kugbey et al., 2020) and support from health workers in passing cancer treatment and the recovery process (Chiaranai et al., 2022). Despite getting support from family, friends and medical staff, the decision remains to breast cancer patients, therefore support from themselves, both motivation towards themselves and acceptance of diagnoses is needed (Iseki, 2023) because motivation and acceptance of conditions are part of self compassion which can increase positive behavior in the health of breast cancer patients (Abdollahi et al., 2020; Asnita et al., 2020).

Barriers breast cancer care according to Swinny & Kagee (2021) are divided into personal barriers that come from themselves and structural barriers that come from things outside the patient's control. One of the personal barriers in breast cancer treatment is socio-cultural factors including women's sensitivity, stigmatization and aversion to male medical personnel. While structural barriers are lack of financial resources and unsatisfactory medical services (Saeed et al., 2021), financial problems arising from job loss due to the long treatment process (Namukwaya et al., 2022) and various examinations to establish a diagnosis (Khazi et al., 2023). In treatment with hospitalization, family members accompany during treatment, family needs while in the hospital are additional costs that must be covered beside the cost of

treatment itself (Mccutchan et al., 2021). A cancer diagnosis can negatively stigmatize patients and families due to wrong assumptions in society, this also has an impact on how they get treatment for their illness. The stigma makes cancer patients distance themselves from the social environment because they are unable to react to other people's questions and feel uncomfortable with pity from others (Khazi et al., 2023).

Hope in breast cancer treatment is the desire of breast cancer patients in the treatment process and cancer cure. Breast cancer patients have expectations of themselves, family, environment and health facilities. Breast cancer patients hope to coexist with their disease and change their way of thinking. Change in thinking is to break away from obsession with cancer or thoughts about death and try to live a normal life, hope for a better future and free from cancer and live normally as before helps them to stay enthusiastic and continue living. (Iseki, 2023). Cancer patients with various psychological pressures become more sensitive to the others behavior towards them. They realize that they need support from the closest people, especially family, to dealing with their illness and they hope that family will always be there for them. (Lewandowska et al., 2020).

Society's perception of cancer makes cancer patients isolate themselves, they choose not to appear in the midst of the environment to avoid questions about their bodies changes (Khazi et al., 2023; Wils et al., 2019). Cancer patients hope the environment to be normal and not stay away from them so that they can continue to fulfill their socialization needs. Cancer patients' expectations of health facilities are assessed based on the facilities and services provided. Health care facilities are expected to support by providing comfortable facilities in implementation of treatment, providing convenience in the service process and giving information about disease and treatment (McKeague & Maguire, 2021). Complete facilities are one of the categories that affect the value of patient satisfaction (Marzuq & Andriani, 2022). Breast cancer patients also expect health care facilities to provide adequate information for handling chemotherapy side effects at home or provide access to them to contact a health care team that will help them overcome chemotherapy side effects at home, so they don't have to visits hospital.

CONCLUSION

Breast cancer treatment starts from the beginning of the symptoms found until the adaptation process into dealing with the side effects of treatment that affect the physical and psychological of breast cancer patients. Although breast cancer treatment has obstacles when application, it can still be done with the support from various parties who play an important role in the lives of breast cancer patients. The hope of breast cancer patients towards the disease and the treatment process keeps breast cancer patients enthusiastic in living life and completing their treatment. This research is useful in developing care for breast cancer patients undergoing chemotherapy so they can do self-care at home and not depend on health care facilities.

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