

The Lived Experience of Women

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The Lived Experience of Women with Breast Cancer

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5

Breast cancer is the most common cancer among women. Women with breast cancer face many psychosocial and physical problems. In addition, such women have to deal with treatment problems, physical changes, feelings of loss and uncertainty, self-reconstruction, and changes in social interaction and support. This study aims to explore and identify their life experiences while undergoing chemotherapy. A phenomenological approach was used to explore the meaning of life with breast cancer for women undergoing chemotherapy at Surabaya, Indonesia. The patient's feelings and life experience with breast cancer were explored by using in-depth interviews with 30 women between 26 and 65 years. The results of this study reveal that the diagnosis of breast cancer produces various emotional responses. Participants explained their experience of living with breast cancer as losing something important, lack of self-confidence, living with fear, emotional dizziness and the need to be supported in the negative aspects of breast cancer and helping to explore new aspects of life as a positive aspect of this event. These findings have the potential to lessen health disparities in increasing utilisation of psychosocial treatments by Indonesian women with breast cancer.

Key words: *Breast cancer, lived experience, chemotherapy.*

Introduction

8 Women with breast cancer experience physical and psychological disorders while undergoing breast cancer therapy (Stagl et al., 2015). Physical experiences of women with breast cancer include a decrease in physical activity, anxiety and decreased quality of life (Zhu, Ebert, Xue, Shen, & Chan, 2017). Fatigue is a factor that cannot affect physically, psychologically, and social aspects, which can yet significantly reduce the quality of life (Azza, Susilo, & Efendi,



2018). It can affect 70% -100% of women with cancer who are undergoing chemotherapy (Cramer et al., 2015).

In America, more than 212,000 women are diagnosed with breast cancer and about 41,000 women die from this disease. Data from the International Agency for Research on Cancer (IARC) showed the highest number of new breast cancer cases, which was 43.3% (Torre et al., 2015). The prevalence of breast cancer in East Java in 2013 was the second largest number with a total of 9,688 people (Torre et al., 2015). Fatigue from invading cancer affects 70% -100% of people with cancer. In addition, such patients showed a decrease in quality of life, reaching 75% -99% (Kruk, 2014). Quality of life leads to global wellbeing including physical, emotional, mental, social and behavioural components [9]. Data in 2015 at the Dr. Ramelan Hospital Surabaya and elsewhere showed the highest prevalence of breast cancer at 57.7%. Handling the disease is very necessary; more than 80% of women with breast cancer need treatment related to the symptoms they experience (Gnagnarella et al., 2016). The purpose of the present research is to reveal and discover topics related to the experience of conditional breast cancer sufferers at RSAL Dr. Ramelan Surabaya. To achieve this goal, researchers used a phenomenological approach. The method helped breast cancer sufferers in the hope of data that can be useful for them. To understand the meaning of the life experience of women with breast cancer, researchers will find out how breast cancer patients treat breast cancer and how to deal with it.

Literature Review

Cancer is an abnormal cell growth that attacks surrounding tissue and spreads to other organs; it is caused by uncontrolled cell proliferation (Xiao et al., 2016). Until now, breast cancer is still the first case in women because breast cancer is identified with a malignancy that can result in death. Cancer is a malignancy that occurs because of abnormal cell growth in organs. The danger level of malignancy and breast cancer is the same. However, the number of breast cancer sufferers is greater (around 90%) compared to breast cancer sufferers (Torre et al., 2015). Breast cancer is a malignant tumour that grows in breast tissue. Cancer can grow in the breast glands, milk ducts, fat tissue, or connective tissue in the breast. Mammary cancer is a malignancy originating from glandular cells, glandular channels and supporting breast tissue, not including breast skin. Malignant tumours grow in breast tissue. Cancer can begin to grow in the mammary glands, milk ducts, fat tissue or connective tissue in the breast (Ho, So, Leung, Lai, & Chan, 2013).

The causes of malignancy in breast cancer are still not known with certainty, but several theories explain the causes of breast cancer, namely hormonal mechanisms.



Endogenous steroids (estradiol & progesterone) when undergoing changes in the cellular environment can affect growth factors for breast cancer. Viral invasion, thought to be present in breast milk, causes an abnormal mass in cells undergoing proliferation. Mammary cancer that is hereditary can occur due to an autosomal dominant "genetic linkage" (Jafari et al., 2013). Research on cancer biomolecules states that deletion of chromosome 17 has an important role in malignant transformation. BRCA 1 and BRCA 2 gene mutations are usually found in clients with a family history of mammary and ovarian cancer, and mutation of the p tumor suppressor gene 53. Immune deficiency, especially T lymphocytes, causes a decrease in interferon production, which inhibits cell proliferation and cancerous tissue, and increases antitumor activity (Azizi et al., 2018; Wagner et al., 2019).

Malignant neoplasms consist of cancer cells that show an uncontrolled proliferation. It disrupts normal tissue function by infiltrating and entering it, by spreading scattered children cells to distant organs. In these cells biochemical changes occur mainly in the nucleus. Almost all malignant tumours grow from cells where malignant transformation has taken place, and turn into a group of malignant cells between normal cells (Lao, Fan, & Song, 2017). The long-term process of cancer has four phases (1) The induction phase is over 15-30 years: so far the cause of cancer has not been confirmed, but environmental factors may play a large role in the occurrence of cancer in humans; (2) Phase in situ: over 1-5 years in this phase, tissue changes appear into a pre-cancerous lesion that can be found in the cervix, oral cavity, lungs, gastrointestinal tract, bladder, skin and finally found in the breast; (3) Invasion phase: cells become malignant, multiply and infiltrate through the cell membrane into surrounding tissue via blood and lymph vessels. The time between phases 3 and 4 lasts from a few weeks to several years; (4) dissemination result: 1-5 years: if the tumour gets bigger then the possibility of spread to other places increases (Keren et al., 2018).

Material and Methods

Design

The study design was descriptive, using a hermeneutical phenomenological approach because it is well-suited to studying lived experience. Data analysis was accomplished by the process of intuiting, analysing, and describing the research data gathered during the interviews. Data collection consisted of in-depth, semi-structured focus groups. Focus groups are culturally appropriate with these participants. To analyse transcripts, we used grounded theory, a systematic approach that allowed us to consider alternative meanings of the data. Researchers advocate for grounded theory methodology to study women's experiences with breast cancer, and used this method to examine Indonesian women who lived with breast cancer.



Participants

Thirty Indonesian women with breast cancer participated in the study. Participants were selected from among adult women with breast cancer who received chemotherapy in the Navy Hospital Dr. Ramelan Surabaya. The selection process included choosing participants from various regimens of chemotherapy and stages of breast cancer. To participate in the study, women with breast cancer had to have the following characteristics: speak and understand Indonesian, 26 to 65 years of age, and willing to articulate the experience facing breast cancer on audiotape. Data from interviews with early participants guided the selection of later participants. Potential participants were identified through personal acquaintances and health professionals in Navy Hospital Dr. Ramelan Surabaya, Indonesia. Then the researcher contacted potential participants individually to explain the purpose of the study in more detail, and to request their participation if they met the eligibility criteria. Thirty 26- to 65-year-old women, having breast cancer and receiving chemotherapy were included in the study (see Table 1). The length of time since diagnosis of breast cancer was from less than one year to more than three years. Breast cancer from Stage I to Stage IV was represented among participants.

Table 1: Demographic data of participants

| Demographic Data | N | % |
|-----------------------|----|----|
| Age | | |
| 26-35 | 5 | 17 |
| 36-45 | 5 | 17 |
| 46-55 | 12 | 40 |
| 55-65 | 5 | 17 |
| >65 | 3 | 9 |
| Education | | |
| Primary School | 7 | 24 |
| Junior High School | 10 | 33 |
| Senior High School | 10 | 33 |
| College | 3 | 10 |
| Occupation | | |
| Housewife | 18 | 60 |
| Private employee | 1 | 3 |
| Government employee | 0 | 0 |
| Others | 11 | 37 |
| Marital Status | | |
| Single | 0 | 0 |
| Married | 27 | 90 |
| Widow | 3 | 10 |



| Menstruation | | |
|-----------------------------------|----|----|
| Menstrua's | 9 | 30 |
| Menopause | 21 | 70 |
| Treatment | | |
| Chemotherapy | 25 | 84 |
| Radiotherapy | 1 | 3 |
| Mastectomy | 0 | 0 |
| Combination | 4 | 13 |
| Chemotherapy session | | |
| I | 6 | 20 |
| II | 6 | 20 |
| III | 7 | 23 |
| IV | 1 | 3 |
| V | 3 | 11 |
| VI | 7 | 23 |
| Diagnosis of Breast Cancer | | |
| <1 year | 15 | 50 |
| 1-3 years | 14 | 47 |
| >3 years | 1 | 3 |

Instruments

Demographic questionnaire. A questionnaire designed for the study included questions about demographics (e.g., age), marital status, level of education, occupation, treatment and diagnosis (e.g., date, session of chemotherapy).

Focus group interview guide. An open-ended question clarified and probed emerging information and allowed insights to emerge. Questions were based on the literature and researchers' experience with this population.

Procedure

After obtaining institutional review board approval and participants' written consent to participate and be audiotape recorded, the researcher made appointments to conduct in-depth, face-to-face, unstructured interviews with the participants. At the beginning of the interview, a data sheet was completed on each participant to ascertain the demographic and descriptive characteristics of the sample. An interview guide was used. The interview questions explored the lived experience of women with breast cancer. The opening questions included, "What was your feeling when first diagnosed with breast cancer? What is the meaning of this experience for you?" and "How does that relate to your family?" "What is the biggest



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3

challenge when receiving chemotherapy?" Subsequent, probing questioning, aimed at gaining further clarity and insight into the participants' experience while receiving chemotherapy, was guided by the participants' responses. After the interview, field notes were written to document environmental circumstances, participant characteristics, nonverbal behaviours, effects, discussion processes, rapport, impressions, and any problems.

Analysis

Data processing and analysis took place directly after the data were collected from each participant. Processing was carried out simultaneously with coding. The analysis uses the steps from Colaizzi as follows: Preparation of transcripts: the researcher collects the data and results of interviews which, using sound, were converted to verbal forms [14]. Transcript reading: after the transcript has been compiled, the results of the transcript are repeated to get the ideas from the participants. In the process, the researcher chooses keywords related to the phenomenon under study. Determination of categories: the researcher repeats the process of reading the results of participant records. Statements that report the same or almost the same will be categorised. The compilation of categories is determined by the ability of the researcher and validates the sentences of meaning, so, in categorisation, it is also necessary to have more opinions from external reviewers, emphasising the analysis for a long time. Formulation of themes: obtained from themes or sub-themes, then grouped in a structured and conceptual form. Formation of cluster themes: data groups that have been structured and conceptualised are grouped by researchers, organising data by developing it as related to categories, sub-themes and themes. Complete description: integrates the final results in a narrative form of the phenomenon of the study. Compilation of analysis: transcripts that have been prepared based on participants.

Results and Findings

The results of the thematic analysis of the transcript data can answer questions in accordance with the research objectives. These themes are then arranged as in the table below.



Table 2: Coding category: theme and subthemes

| Theme | Sub-theme | Code |
|--------------------------------|---------------------------------|--|
| Feeling of health condition | Fear | Feel afraid |
| | Sad | Feel sad |
| Perception of health condition | Accepting as God’s plan | God’s plan |
| | Accepting as a life path | Life path |
| Effect of therapy | Physical effect | Nausea, vomiting, baldness |
| | Psychological effect | Shy, sad |
| Support for therapy | Support from husband and family | Husband gives support, children support their mother |
| | Peer-support | Support from other breast cancer patients |
| Expectations | Healing | Healthy |
| | Take care of children | Living with children and family |
| | Working | Back to work |

The thematic process of analysis of data from 17 30 participants in the in-depth interview shows answers related to the research objectives. The purpose of this study was to answer how the life experiences of cancer sufferers undergoing therapy are specified as feelings toward health conditions, perceptions of health conditions, the impact of therapy undertaken, support for therapy undertaken, and current expectations.

Feelings of Health Conditions

In general, the feeling of the illness experienced is fear. Participants express their feelings as follows:

"I'm afraid (I want to cry) ..."
"It's said to be horrified, yeah, feel scared, I'm afraid, bro?"
"I'm afraid of non, I'm crying there"

Respondents also expressed feelings of sadness when they learned they were diagnosed with cancer, as expressed by respondents as follows:

"I am sad to say that I am sick ..."
"It's really sad that time ..."



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Perception of Health Conditions

Health perceptions in cancer patients found that patients perceive what they experience as trials / tests from God, as expressed by respondents as follows:

“it will be sick, it’s from Allah. I am fear if I think too much about my sickness”

“yes, It is temptation from God”

“now, I can adapt my condition, it just a temptation from Allah. I used to think like that.”

Respondents also perceive their health conditions as a fate they must accept, as expressed by respondents as follows:

“I don’t mind, it’s just a fate (smile)”

“yes.. what should I do.. it’s my pathway from Allah”

The Impact of the Therapy

Respondents revealed the impact experienced during treatment included physical effects, including nausea, vomiting, and hair loss, as follows:

“ I feel discomfort after receiving chemotherapy such as nausea.. and difficult to eat ”

“ Usually, vomiting.. and it’s getting worse ”

“ Hair loss, yes.. but what should I do.. I just think to believe that the treatment will be successful ”

Respondents also stated that the psychological impact also affected them, as expressed by the following respondents:

“I feel so sad when my hair getting loss ”

“bald-headed.. feel shame ”

Support

Respondents stated that the most support was obtained from their husbands and families. Several respondents said their husbands and families supported them to carry out treatment or therapy.



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"Oh my child supports me, the main thing is that my mom has to recover, so you don't have to think a lot. I wish after operation can return home from the hospital. Then I immediately invited to take a walk"

*"My husband supports me as well, the point is healed ... sometimes I'm poor of myself"
"Well, my body hurts all, the stomach is not good, my husband encourages me, I eat lots of fruit. I saw my parents afraid if I getting sick"*

In addition to family support, fellow sufferers also strengthen or support respondents in carrying out therapy. As stated by respondents below:

" I accept my condition... my friend told me that she can get healthier. She has very high spirit to live"

" I get new friends who had same condition with me, I did not feel lonely"

Expectation

Respondents expressed their hopes that they were currently undergoing treatment and had willingness to be healthy, for the sake of their children.

"..... I want to get healthier, and spend my live happier and can be beneficial for other people"

" True, I want to recover from this condition, I can spend my time with my children and family"

The respondents also expressed wanting to be able to work again:

"If I recover from this disease, I will back to work.."

"mmm.. I think I cannot handle it, I cannot back to work. Even I want.."

Advances in breast cancer screening and treatment technology have enabled many women to survive for years after being diagnosed with breast cancer. However, their experiences of suffering throughout the journey for this disease have not been clearly understood. This phenomenological study aims to explore the meaning of life with breast cancer for Indonesian women. Participants explained some positive and negative feelings about their situation. This is also reflected in the qualitative study of (Williams, Yeh, & Soloff, 2016) who found women with breast cancer, in the chemotherapy phase, experienced two sets of conflicting feelings; negative (such as fear of uncertainty) and positive (such as receiving significant support from others) (Jafari et al., 2013). In explaining negative feelings, the



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participants' experiences, losing something important, in this study, are consistent with Landmark and Wahl, who found that breast loss and physical changes consequently affect women's identity (Stagl et al., 2015). In addition, losing support from significant others, such as their partners and their partners, is another problem narrated by women with breast cancer. Thomas emphasises how the contradictory messages received by women with breast cancer from the public, both voiced and not voiced, can have a long-term effect on how they react to their lumps (Wagner et al., 2019). Treatment positively affects their feelings and emotions. Themes of uncertainty and living with fear captured in this study are similar to Browall et al., who identified that breast cancer women experience a fear of uncertainty and constant worry during the chemotherapy period (Perz, Ussher, & Gilbert, 2014).

Exploring new aspects of life is another theme taken from the narratives of the participants. They explained how they gradually overcame their cancer, accepted their bodies and did not give up. This is consistent with Jensen who found themes such as accepting the challenge of continuing to live, working actively in the healing process and finding something important to live for (Larsson, Hildingsson, Ternström, Rubertsson, & Karlström, 2019). These themes are closely related to finding something new in life, which can be seen as using a mechanism to overcome disappointment. In surviving cancer, in addition to negative changes in their lives, Sadler-Gerhardt found five positive sub-themes under post-traumatic growth: new self-perceptions, new possibilities, new relationships with others, new priorities and new faith. These themes emphasise aspects of disease that can help patients to live and feel alive (Kruk, 2014).

Being diagnosed with breast cancer can be traumatic for many women. Breast cancer diagnosis produces a number of emotional responses such as stress, hopelessness, uncertainty and fear (Azza et al., 2018; Ho et al., 2013). Kernan and Lepore state they experience "existential suffering". This makes women with breast cancer "emotionally vulnerable". Often, they get news about their breast cancer unexpectedly. It is certainly a "stressful" time for them. Previous research has also revealed the emotional stress that occurs in women diagnosed with breast cancer (Azza et al., 2018; Ho et al., 2013; Reeder-Hayes, Wheeler, & Mayer, 2015).

However, after the initial shock of learning about their breast cancer, most women began to accept their condition. Others, like Kernan and Lepore recommend breast cancer women to search for "meaning in life". They should try to understand their health condition and look for reasons that can explain why they have breast cancer (Stagl et al., 2015). A diagnosis of breast cancer, Ching et al. argue, symbolises the "turning point" when a woman "Moves from disruption of life to the creation of meaning and integration, transcendence and self-reformulation. Their acceptance of breast cancer plays an important role in the meaning-making discourse because it helps women living with breast cancer to maintain a balance of



1

their emotional wellbeing” (Schellekens et al., 2016). According to Park and Folkman, acceptance is a means of resolution because it advances the life of a traumatic event with the goals, beliefs and cultural norms of the individual (Azza et al., 2018). Acceptance allows them to be able to manage their conditions because they decide to make “peace” with their living conditions (Stagl et al., 2015).

Many women in this study used their religious beliefs to overcome their health conditions more positively. Religion can be a means for individuals to overcome difficulties in their lives when there is no other hope left for them. The role of religion is important in the process of making meaning (Jim et al., 2015; Salsman, Fitchett, Merluzzi, Sherman, & Park, 2015). All women in our study were mothers. Most had adult children, but some were still young children who lived at home with them. Children are an important component of the process of making meaning among the women in our study. More often, women try to live for their children. This makes women decide to undergo mastectomy and through chemotherapy and/or radiography this will prolong their lives (Perz et al., 2014). Although there are severe side effects of this therapy, women are persistent with their care, so that they can live longer for their children. It has also been shown that women with maternal breast cancer are driven by the need to live as long as possible for their families. Having children in focus during their breast cancer trajectory may be beneficial to women in our study (Cramer et al., 2015).

Conclusions

Meaning in life makes women overcome stressful life changes due to breast cancer. It can help reduce the burden of facing breast cancer. Research has suggested that making meaning is related to improved quality of life. This includes a decrease in the level of despair and distress, increased positive influence and a better quality of life. We argue that women in our study can also gain a benefit from the process of making meaningful lives, as suggested above.

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1

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