Experience of Breast Cancer Patients Receiving Chemotherapy in Covid-19 Pandemic Conditions

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ABSTRACT

Background: In breast cancer patients receiving chemotherapy, there is a response of fear, anxiety, and a feeling of not accepting their condition.

Objectives: to determine the experience of breast cancer patients receiving chemotherapy.

Methodology: This is a qualitative study with a phenomenological approach. Furthermore, data were collected by in-depth interview conducted from July to August 2020. Furthermore, the analytical method used was the Colaizi analysis. Setting/participants: at the Sultan Agung Hospital Semarang, Indonesia. During the Covid-19 pandemic, the data were obtained using in-depth interviews with PPE (personal protective equipment) level 3. The criteria were females with breast cancer receiving chemotherapy for about 6 times or more, communicative, willing to become participants, and adults over 18 years old.

Results: There were 6 themes that described the phenomenon: (1) The first response when diagnosed, (2) The patient's experience who finally decided on chemotherapy, (3) Patient's adaptive response, (4) Feelings during chemotherapy, (5) side effects, and (6) changes after the treatment.

Conclusions: Some patients' responses when diagnosed for the first time were can and cannot accept the condition. Based on this response, the participants received family support during the treatment. Furthermore, chemotherapy causes various side effects, and after receiving the treatment process, the participants felt changes such as not feeling pain and improvement in the condition.

Keywords: breast cancer, chemotherapy, experience, phenomenology; covid 19

Introduction

Non-communicable cancer is a major health problem around the world. According to the World Health Organization (WHO) in 2018, there were 18.1 million new cases and 9.6 million cancer deaths. In fact, WHO predicts that cancer will become the number one cause of
death by the end of this century, and become a barrier to humans in increasing life expectancy. The most common types are lung, colorectal, stomach, liver, and breast cancer. In America, there were 21% cases with a mortality rate of 14.4% from 13.3% of the world population. Meanwhile, in Europe, there were 23.4% cancer cases with a mortality rate of 20.3% from 9% of the world's population.¹

The Global Cancer Observatory data in 2018 from WHO showed that most cases are breast cancer with about 58,256 out of 348,809. Meanwhile, efforts to prevent and control both types of cancer are by early detection in women aged 30-50 years, and the method used is clinical breast examination (SADANIS).¹

According to Basic Health Research (Risksdas) data in 2018, the prevalence in Indonesia reaches 1.79 per 1000 population. Furthermore, other data at Globogan in 2018 showed that the incidence was 136.2 per 100,000 population. This puts Indonesia in 8th place in Southeast Asia, and 23rd in Asia. Also, the highest incidence rate in women with breast cancer reached 42.1 per 100,000 population with an average mortality rate of 17 per 100,000 population.² The cases development in Indonesia is quite high, therefore Clinical Breast Examination (CBE) services are available in 32 provinces, 207 districts, and 717 health centers for early detection. In addition, women aged 30 to 50 years need to carry out early detection at least 5 times a year.³,⁴

Cancer cases in Central Java Province, according to the Semarang City Health Office continued to increase from 2015 to 2018. The head of this Office, Widoyono said that "there are four most common cancers found in Semarang, namely liver, breast, lung and cervical". In 2018, 4,286 cases were recorded. Furthermore, the most increased case in Semarang was breast cancer, which was 654 in 2015, and then increased to 749 in 2016. Meanwhile, in 2017, there were 2,498 cases and increased to 3,590 in 2018. In addition, this condition mostly affects women aged 45 - 65 years, totaling 1,736 cases, and 681 in women aged 15 - 44 years.⁵

Experience is something that someone has felt or lived through. The experiences of breast cancer patients differ from one another. Furthermore, perceptions, acceptance, meaning of the disease and therapy for each patient varies. As is the case when receiving treatment, patients often feel bored, depressed, sad, anxious, and disappointed.⁶

The administered treatment is adjusted to the developmental stage, and in the Ia-IIa stage, surgery is performed. At an early or advanced stage, radiation therapy is carried out, while chemotherapy is carried out at an advanced stage when it has spread. Furthermore, treatment can be administered when relapses occur.¹ Chemotherapy is palliative, where recovery is not the main goal, but rather to improve life quality and relieve symptoms.¹ Due to the increase in cases, especially breast cancer, it is necessary to conduct research on the experiences of patients in the Covid-19 pandemic conditions.
Objectives:
Therefore, this study aims to determine the experience of breast cancer patients receiving chemotherapy.

Methodology

Design: This is a qualitative study that used a descriptive phenomenological approach, which aims to describe in depth, and in a structured manner. This aimed to obtain the experience essence in the form of stories, narratives and language/words from each individual. In addition, the method used in this study was in-depth interviews.

Participants: Selection of participants and inclusion criteria were women with breast cancer who had undergone chemotherapy for about 6 times or more, communicative, willing to be participants, and adults over 18 years old. Also, there were 5 married participants who have families. Participants: at the Sultan Agung Hospital Semarang, Central Java, Indonesia.

Data collection: The data collection method was carried out by conducting in-depth interviews, and because this study was conducted during the Covid-19 pandemic, PPE (Personal Protective Equipment) was used, such as masks, face shields, aprons and handschoens. Initially, the participants were afraid during interviews using PPE, but after explaining the PPE purpose according to the hospital protocol, they were willing to be interviewed by signing the informed consent. In addition, participants' identity was kept confidential.

Data analysis: The analytical method used Colaizi analysis by describing the phenomenon under study, conducting interviews and writing it in transcript form, reading all the phenomena description that have been submitted, re-reading the interview transcripts and quoting meaningful statements. Furthermore, the method involves choosing statements according to the specific research objectives, choosing Keywords from participant statements and giving signs, describing the meaning of participant statements, reading keywords to form categories, organizing groups of several meanings into theme groups, arranging themes, and writing it into a description in the form of research results.

Data validity: The description of the analysis results was validated, as well as asked the participants again and reads the theme analysis results. This was conducted to equalize perceptions between the research and patients according to the circumstances experienced, and to analyze the data obtained. In addition, data validation was conducted using credibility, transferability, dependability, and confirmability tests.

Ethical test: An ethical test was carried out before conducting research with the number 19 / EC / KEPK / 2020.

Results
Based on the results, there were 6 themes after the data analysis process was carried out, including (1) The first response when diagnosed, (2) The experience of the patient who
finally decided on chemotherapy, (3) The adaptive response of patients, (4) Feelings during chemotherapy, (5) side effects, (6) changes after the treatment.

**Theme 1: First response when diagnosed**

1) Accept the conditions

The interview results showed that they felt calm and sincere. This is the opinion expressed by the participants:

"At first, I didn't feel it, I just ignored it, after a long time it got bigger, I became scared because of my breasts, then I checked at the Cepu hospital. I knew I couldn't operate there and was immediately referred to the Islamic Hospital" (P1)

"Yes, calm down, I am sincere. I accept that I have to undergo chemo" (P2)

"With the support from my family I can finally accept" (P3)

"I could not sleep, I only slept after I had the surgery, because I was over-thinking when I was operated, then how was the operation, anyway, what I imagined was strange" (P4)

"Fortunately, yes my children, husband, and family supported me" (P5)

2) Depression

The results of the interviews showed that they lost weight, did not eat well, were anxious, stressed, sad, could not sleep and shocked. This is the opinion expressed by the participants:

"... I immediately lost weight, ... eating and activities were not good" (P1)

"I'm calm and sincere" (P2)

"... Anxious, stressed ...." (P3)

"... Sleepless, worried, sad. I couldn't sleep until several months .... "(P4)

"I am shocked and sad ....." (P5)

**Theme 2: Patient experience when deciding chemotherapy treatment**

1) Signs and symptoms

The interview results showed that it was painful, the breasts were enlarged and there were lumps. The following opinions were expressed by participants:

"... At first, I didn't feel it and just ignored it, after a while, it got bigger ..." (P1)

"..... I feel a lump ....." (P2)

"The first time, I felt pain in my breast ..." (P3)

"...... there was a lump ....." (P4)

"... I have a lump ....." (P5)

2) The desire to heal

The interview results showed that they remained enthusiastic and optimistic in facing their illness, therefore they can recover and be healthy again.

"... yes, I am still enthusiastic and optimistic for my recovery" (P1)

"... keep spirit and optimistic for my recovery" (P2)

"...... more enthusiasm to recover from my illness“ (P3)

"... more enthusiastic and motivated to get well soon" (P4)

"... I am excited to recover ...." (P5)

3) Family support
The interview results showed that participants received support from their families. Here are the opinions expressed by participants:

"... my family always supports me ...." (P1)
"... my family always supports me ...." (P2)
"... with the support of my family ....." (P3)
"... there is family support always given to me ...." (P4)
"... there is family that encourages and supports me ..." (P5)

Theme 3: Adaptive response of patients receiving chemotherapy

1) Social adaptation

The interview results showed that the participants were still doing activities as usual, and still interacting with other people. The following are the opinions expressed:

"I do activities as usual" (P1)

"I do tahlilan (rituals/ceremonies performed by some Muslims), and also sell things in the market. I made it as usual so I don't think too much about my condition "(P2)

"I go to work as usual" (P3)

"I met people who are also sick like me" (P5)

2) Spiritual adaptations

The interview results showed that they always got closer to Allah SWT, and always prayed. The following are the opinions expressed by participants:

"I drew closer to God so that I can immediately recover and be healthy again" (P1)

"I always pray for my healing" (P2)

"I can only pray and pray" (P5)

Theme 4: Feelings during chemotherapy

1) Feelings of worry because of ignorance

The interview results showed that they were afraid while receiving chemotherapy. The following are the opinions expressed by participants:

"At first, I was afraid of chemo" (P1)

"It just feels normal" (P2)

"I am both afraid and anxious, because I have never tasted it, so it feels mixed up" (P3)

"I'm afraid, sad, and sometimes worried too" (P4)

"At first, I was afraid because I didn't know what chemo is like" (P5)

2) Increased stress

The interview results showed that they experienced increased stress. The following are the opinions expressed by participants:

"I just calmed down as if nothing had happened" (P2)

"My stress is actually increasing" (P3)

"Sometimes I get emotional too, because of pain, my emotions fluctuate" (P4)

"I am often sad, finally I surrender to my own situation" (P5)

Theme 5: Chemotherapy side effects

1) Biological response
The interview results showed that the effects that appeared were nausea, vomiting, lack of appetite, diarrhea, and constipation. The following are the opinions expressed by participants:
"Sometimes diarrhea, difficulty defecating, nausea, vomiting, weakness, body pain, lack of appetite, the food on the tongue is numb. Although people feel differently, but I feel like that" (P1)
"I don't feel any side effects, people feel nauseous but alhamdulillah I don't, I just went straight to the market" (P2)
"The side effects are nausea, vomiting, loss of appetite, weakness, my body feels hot" (P3)
"The side effects that I feel are weakness, nausea and vomiting" (P4)
"The side effect is weakness, loss of appetite, nausea, vomiting ..." (P5)

2) Physical changes

The interview results showed that there was hair and weight loss, as well as changes in skin color. The following are the opinions expressed by participants:
"Hair loss, but the people have different experiences" (P1)
"Alhamdulillah, there have never been any side effects" (P2)
"Weight loss, hair starts to fall and skin turned black" (P3)
"Hair loss, frequent urination, loss of appetite, I don't always eat food from the hospital, because it doesn't taste good in my mouth" (P4)
"Hair loss" (P5)

Theme 6: Change after chemotherapy

1) The response to the treatment process

The interview results showed that after receiving treatment, the condition became better. The following are the opinions expressed by participants:
"Alhamdulillah, it's getting better so it feels good, I don't feel kemeng (pain). Although I felt nauseous but after a week, it was gone." (P1)
“At first, it was usual, but in the third chemotherapy session, I didn't like the food from the hospital. But alhamdulillah it's getting better." (P2)
"Alhamdulillah it's getting better. At first I was in pain and after receiving chemo, it got better. I don't feel sick anymore, the effect was nausea but after 1 week it was gone." (P3)
"The changes I feel are much calmer after receiving this chemotherapy." (P4)
"The change is I don't feel any pain and alhamdulillah there are no complaints, so it's much better." (P5)

2) Hope after treatment

The interview results showed that they wanted to get well soon. The following are the opinions expressed by participants:
"It was an uneasy struggle, especially when I was receiving chemo, there were so many side effects that I felt from the first session to the present, but yes I am still enthusiastic and optimistic for my recovery" (P1)
"Yes because I believe I can recover" (P2)
"Can recover from my illness" (P3)
"I want to get well soon." (P4)
"Want to recover" (P5)
Table 1. Participant characteristics

<table>
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<tr>
<th>No</th>
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<th>Age</th>
<th>Education</th>
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<tr>
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<td>P1</td>
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<td>42</td>
<td>Elementary School</td>
<td>Married</td>
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<td>3 years</td>
<td>55</td>
<td>Bachelor</td>
<td>Married</td>
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<tr>
<td>3</td>
<td>P3</td>
<td>5 years</td>
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<td>Senior High School</td>
<td>Married</td>
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<tr>
<td>4</td>
<td>P4</td>
<td>2 years</td>
<td>59</td>
<td>Junior High School</td>
<td>Married</td>
</tr>
<tr>
<td>5</td>
<td>P5</td>
<td>1 year</td>
<td>49</td>
<td>Junior High School</td>
<td>Married</td>
</tr>
</tbody>
</table>

Discussion

1. The patient's first response when diagnosed

Breast cancer is a disease caused by abnormal and uncontrolled growth of tissue that attacks the breast. This type is most feared because it can cause anxiety, depression, and even despair. Furthermore, this condition is characterized by a hard immovable lump in the breast. This occurs because of damage to genes that function to regulate cell growth and differentiation which results in cells growing out of control. These cancer cells spread through the lymph nodes which cause the axillary lymph nodes to enlarge. In addition, the cells spread to other organs such as the brain, lungs, and liver.

Response is the reaction that appears from receiving messages after a series of communications. The interview regarding the patient's first response showed that the participants experienced panic, calm, shock, and sadness. This is in accordance with Chow et al., where the initial experiences were panic, shock, and sadness. Of the various symptoms experienced by the patients, the most common are fatigue, pain, anxiety, and depression. In fact, depression and anxiety consistently appear together, and feelings of pressure, anxiety and nervous are among the symptoms of cancer patients receiving chemotherapy (Chow et al., 2019).

One participant claimed to be calm and sincere after being diagnosed. This is in accordance with Dong, which found that patients were calm, accepted the condition, and chose to remain grateful even though they had to experience pain and undergo a series of treatments. Meanwhile, not all the patients experienced anxiety, fear, panic, shock, or worry. These feelings arise depending on the patient's characteristics and emotional state, as well as efforts made to stabilize the experience.

2. The patient's experience ultimately decides on chemotherapy

Experience is the result of "knowing", and it occurs after a person perceives an object through the five human senses, namely sight, hearing, smell, taste, and touch. One of the treatments is chemotherapy, which is the process of administering anti-cancer drugs in the form of liquid pills, capsules or by infusion with the aim of killing the cancer cells. Not only those in the breast, but also throughout the body. This is in line with, where they feel anomalies in their bodies such as the appearance of lumps and pain in the chest. The interview results found that the desire to recover is very high. This is in line with, where clients who undergo chemotherapy have a desire to recover from their diseases.
The interview results also obtained data on family encouragement in receiving treatment, which is in line with,\textsuperscript{13} where family support is the strength of clients in dealing with their condition. Also, emotional support is an important determinant of mental health in cancer survivors. Therefore, low emotional support is a risk factor for anxiety, depression, and fatigue.\textsuperscript{14}

Social support improves quality of life by enhancing mood and self-concept, reduces burdens associated with activities of daily living, and provides positive ratings. Also, emotional support, affective and social interactions influence treatment-related decision making. Several survival studies in women with breast cancer have shown an association between social networks and mortality, with higher rates in those with lower social networks.\textsuperscript{14}

3. Adaptive response of patients receiving chemotherapy

Response is reaction and answer, and it appears from receiving messages after a series of communications. In social adaptation, participant data were obtained including, doing activities as usual and interacting with other people, this is in accordance with \textsuperscript{13} where social support helps clients adapt in their daily lives.

In spiritual adaptation data, participants get closer to Allah SWT and always pray. This is in accordance with,\textsuperscript{15} where participants were overshadowed by death due to a doctor's diagnosis of breast cancer, but in facing their psychological conditions, they actually strengthened their worship and always perform night prayers to be closer to God. As a person who believes that all actions in the world will be accounted for, the participants take advantage of the remaining life to be closer to God. Furthermore, they believed that everything they experienced at this time was a test and trial, hence they remained grateful.

Chronic diseases including cancer have serious negative impacts on many aspects of human health. Therefore, feelings of belonging to God, trusting God in difficult times and having social and spiritual support are reliable ways to reduce negativity.\textsuperscript{6} Spirituality and religious beliefs have a central and important role in adapting patients and helping them achieve meaning and purpose in the course of the disease. In fact, spiritual care is a driving force to positively increase the religious coping mechanism in patients before, during, and after chemotherapy, as well as to develop an orientation towards expectations and family attitudes.\textsuperscript{16}

4. Feelings during chemotherapy.

Feelings are emotions or inner states when facing something. Chemotherapy is a treatment using drugs or hormones that reduce cancer cells. Meanwhile, there are physical side effects, which include nausea, vomiting, hair loss, blackened skin. The psychological effects are depression, anxiety, decreased quality of life, and loss of life expectancy.\textsuperscript{17}

Based on the interview results regarding feelings during chemotherapy, it was found that they were afraid during the treatment. This feeling arises due to the participants' perceptions of chemotherapy side effects. This is in accordance with,\textsuperscript{18} where in addition to killing cancer cells, the treatment process also results in damage to healthy cells in the body.\textsuperscript{10}
5. Chemotherapy side effects.

Chemotherapy is a treatment using drugs or hormones that reduce cancer cells. Furthermore, it is a process of administering anti-cancer drugs to kill the cancer cells through a chemotaxis mechanism. This medicine comes in the form of liquid pill, capsule or through an IV, and it does not only kills breast cancer cells but also those throughout the body. In addition, the side effects that arise due to chemotherapy include physical: nausea, vomiting, hair loss, blackened skin; and psychological: depression, anxiety, decreased quality of life, loss of life expectancy.\(^{19}\)

The interview results regarding side effects showed that they felt similar experiences, including nausea, vomiting, hair loss, loss of appetite, diarrhea, constipation, skin problems, weakness, fatigue. This is in line with,\(^ {20}\) that the administration of chemotherapy drugs has a biological impact on the body, which is generally in the form of nausea and vomiting.

The impact of cancer is caused by a change in physical, psychological influence in social life, such as changes in employment status, in societal relationship, or changes in the role of wife and mother. These changes have an impact on social problems. For the patients, it is not an easy thing to live with, where cancer is synonymous with death. Therefore, it has an impact on the patient's social life. Also, social support is an important factor to improve their quality of life, and it can come from friends, neighbors and the community.\(^ {21}\) This is in accordance with,\(^ {17}\) where most patients received chemotherapy treatment with high emetic potential and caused mild to severe nausea. Almost all the patients experienced this for around 1-2 hours and will subside after 48-72 hours. In fact, chemotherapy has an impact on the overall diet quality of patients.\(^ {16}\) This is in accordance with,\(^ {7}\) where the impact of the disease and the treatment process manifested physical changes.

In a study by,\(^ {22}\) there were changes in taste and smell which were reported immediately after chemotherapy and after 6 months. Meanwhile, lower taste and smell perceptions were associated with lower quality of life, which is in accordance with previous studies in cancer patients during chemotherapy.\(^ {23}\) In addition, breast cancer patients who undergo chemotherapy experience various side effects such as nail discoloration, weakness, diarrhea, nausea, vomiting, decreased appetite and changes in taste function.\(^ {7}\)

Also, cancer side effects in addition to pain, fatigue.\(^ {7,24}\) The severity of cancer-related symptoms is closely related to the psychological symptoms in patients. In fact, unhealthy psychological status has been shown to significantly lead to deaths. Out of 102 lung cancer patients treated with chemotherapy, Baczewska found that 51.5% showed symptoms of major depression, which occurred frequently in cancer patients than healthy individuals.\(^ {25}\)

6. Changes after chemotherapy.

The type of treatment is given based on the stage progression. Through treatment, there will be physical and psychological changes which can affect the patient's social life.\(^ {7,14}\) Also, chemotherapy is not only for treatment, but also to reduce the mass of cancer
cells, improve quality of life, and reduce complications due to metastases.\textsuperscript{19} The interview results regarding changes due to chemotherapy showed that patients no longer feel pain after receiving treatment and the condition was getting better, which found that all three participants were reported to be free from cancer and are currently receiving regular control. One of the supporting factors for the recovery is the determination and commitment to recover. In addition, the interview results obtained a calm feeling after chemotherapy, which is in accordance with.\textsuperscript{19}

**Conclusion**

The experience of breast cancer patients receiving chemotherapy showed that when they were diagnosed, some could not accept the condition, while some accepted. Also, there were signs and symptoms, such as pain and a lump in the breast, as well as a desire to heal and encouragement from family. The adaptive response include social and spiritual adaptation in dealing with their condition. Meanwhile, anxiety arises due to ignorance about breast cancer and increased stress. During chemotherapy, side effects will appear, but each participant has different experiences. Also, after the treatment, there were changes such as reduced pain and improvement in the condition. The desire to recover was very high and they were enthusiastic about receiving a series of treatments recommended by the doctor. In this study, it was conveyed that during the Covid-19 pandemic, cancer patients receiving chemotherapy continued to follow the program on schedule. In addition, during the data collection process, protocol was followed with the continued use of complete PPE.

**Recommendations**

The results of the study provide insight into knowledge for breast cancer sufferers in order to stay enthusiastic in facing cancer and remain enthusiastic in undergoing breast cancer treatment. Research is useful as an insight into knowledge and learning for the nursing profession in caring for breast cancer patients undergoing chemotherapy so that it can identify problems experienced by patients, so that the nursing care given to patients is appropriate and effective.

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**Authors contributions:** DR, IS conceptualized and designed the study. DR, IS, and AR drafted questionnaire. DR and IS analyze and interpreted the data. DR, IS, and AR wrote the manuscript. All authors have critically reviewed and approved the final draft and are responsible for the content and similarity index of the manuscript.
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