ORIGINAL ARTICLE

Patient Experiences With Oral Chemotherapy

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ABSTRACT

Introduction: Recently, oral chemotherapy has become a popular treatment modality in cancer treatment. However, cancer patients and their family members show limited knowledge on the use of oral chemotherapy safely. Objectives: The study's objective was to explore the life experiences of breast cancer patients undergoing oral chemotherapy. Methods: This study used semi-structured interviews to gather data using a purposeful sample strategy of 3 survivors. Collaizzi's method was selected for data analysis. Results: Six major themes emerged that described the life of experiences of the patients, including knowledge of oral chemotherapy, the participant's feelings, side effects of oral chemotherapy, coping mechanisms, support system, and expectation to nurse. Participants noted that they received less information regarding their treatment, limiting them to providing appropriate care for themselves. Conclusions: Nurses need to give more attention and tailored education regarding oral chemotherapy, improving their knowledge and adherence to the chemotherapy.

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1. Introduction

Cancer is one of the world's leading causes of death (Sung et al., 2021). In 2018, It was estimated that 18.1 million new cancer cases and almost half of this number were cancer deaths (Bray et al., 2018). According to Statistical data from the Ministry of Health, cancer prevalence in Indonesia was estimated at 1.4 per 1000 people in 2013 and increased to 1.8 per 1000 people in 2018 (Ministry of Health Republic Indonesia, 2018). Among all cancer types, breast cancer continues to be among the most prevalent cancers globally. Breast cancer cases were approximately 2.3 million, with a death incidence of 685.000 in women globally. The total number of cases in women increased significantly compared to 2018, in which the incidence of breast cancer was 11.6 %, with a mortality rate of 15-24.2 % (Sung et al., 2021). In Indonesia, the prevalence of breast cancer was found to be 8.1%, putting breast cancer as top-ranked cancer for their incidence (Idaiani & Delima, 2018). Cancer patients may have horrible experiences when diagnosed with the disease. In addition, cancer treatment can impact patients physically, mentally, financially, and breast cancer treatment comprises surgery, chemotherapy, hormonal therapy, radiotherapy, and others. However, the type of therapy, duration, and frequency of treatment will influence the side effects, which lead to decreased patient quality of life. One of the most commonly used therapies for managing breast cancer is chemotherapy which aims to destroy and control tumor growth. Chemotherapy could be given using various routes such as intravenous and oral, depending on the type of tumor and stage of cancer. As chemotherapy treatment shifts from intravenous to oral, patients have less contact with nurses and manage their care. In addition, adherence to chemotherapy and symptom management has become a challenge for nurses in ensuring safe and quality care for cancer patients (Bellomo, 2016).

Despite increased responsibility for their self-management, oral chemotherapy has been more preferred by patients since there is no need for many clinical visits reducing their costs significantly and middle replacements (Verbrugghe et al., 2013). Furthermore, oral chemotherapy has been shown to have more minor side effects and could be quickly taken at home (Aziz, Adrijono & Saifuddin, 2010). Home treatment was chosen and believed to be preferable to other routes by patients (Eek et al., 2016). It also had less time in the clinic, conveying staffing and cost savings (Schot et al., 2011). In addition, oral chemotherapy leads the patients to follow their treatment more conveniently and allows the clinician to tailor therapy more easily (Cardoso et al., 2016). Previous research revealed that approximately 89% of patients chose to have oral chemotherapy because they think it is better and has less toxicity (Schot et al., 2011).

Despite all these positives, oral chemotherapy still has side effects that need to be handled safely as it is not as safe as the patients think. Oral chemotherapy still has potentially harmful side effects. Taking the wrong dose, such as getting the wrong number of pills and wrong dosing medication, can potentially affect the drug's tolerability and efficacy. Furthermore, improper storage or handling of oral chemotherapy may also be a problem that impacts the medication's effectiveness (Goodin et al., 2011). Prompt management and safe treatment for side effects for patients undergoing chemotherapy should remain a priority. In addition, previous research shows that other patients have not yet acknowledged the use of oral chemotherapy (Kav et al., 2008). Furthermore, compliance with oral chemotherapy is entire since they often forget the medication time, feel overwhelmed, fall asleep before taking medication, and want to avoid side effects (Krikorian et al., 2019). Thus, non-adherence when using oral chemotherapy is becoming a critical issue to be considered by health workers, including nurses, as this can impact the efficacy of the treatment.

Most patients who receive oral chemotherapy often think that it's nontoxic and assume that it's similar to taking other usual pills such as vitamins which are unfortunately not true. Even though the side effects of many types of oral chemotherapy are still favorable, other serious side effects could still occur. Therefore, early recognition and appropriate intervention of oral chemotherapy-associated side effects are needed. Nurses as part of the healthcare team play an essential role in ensuring care for symptom management and health education. Since the number of cancer patients who get oral chemotherapy increases every year, Nurse support will be an essential aspect to ensure safety and support adherence (Yagasaki & Komatsu, 2013).

Current evidence demonstrates that a gap still exists on continued nursing assessment, follow-up of symptoms management, education, and adherence among patients receiving oral chemotherapy (Bellomo, 2016; Cardoso et al.,2016). In addition, there is limited research in Indonesia regarding understanding patients' life experiences for those receiving oral chemotherapy, specifical knowledge on oral chemotherapy treatment, and their adherence to the treatment. Thus, it is essential to explore all the patient's feelings, experiences, and obstacles when following the treatments to increase adherence and safety. In addition, the needs of patients and their expectations related to therapy also needed to explore that can lead them easily employ the acceptance of the therapeutic plan. Hence, we aimed to explore the lived experience of breast cancer patients receiving oral chemotherapy among breast cancer patients using a hospital-based survey in Indonesia.

2. Methods

A descriptive phenomenological approach was used to capture the life experiences of breast cancer patients who are receiving oral chemotherapy. Purposive sampling was used to select and recruit eligible participants. Using this type of sampling may select participants who can provide much relevant information (Geng et al., 2021). The inclusion criteria were as follows: (1) willingness to participate in the study, (2) breast cancer patients using Xeloda oral chemotherapy, (3) having ECOG> 3 and Karnofsky Performance Scale, and (4) being able to write, read and understand Bahasa. The data were collected between August and October 2018 using a semi-structured interview. Participants chose a quiet and convenient environment. Were all

interviews recorded; interview questions were as follows: 1) How were you feeling during oral chemotherapy? 2) What kind of physical symptoms mostly appear during oral chemotherapy? 3) What kind of mental health problem that you feel during oral chemotherapy? 4) Do you think your physical and mental health problems hurt your social and family relationship? 5) Do you think your physical and mental health problems hurt your spiritual belief? 6) How did you overcome this problem? 7) What did the family do to overcome this problem? 8) What did Nurse do to overcome this problem? 9) What are your future expectations (in terms of nursing care and hospital service)? The interviewer was AR. Each interview took about 30-45 minutes.

In addition, the researcher also took field notes regarding interaction and verbal gestures. Open-ended questions were used to stimulate the participant and gather more information, and usually, suggestive questions are prohibited as they result in bias. As the interview progressed, a provocative statement was used to explore in detail, ask further questions, and seek clarification. Once the participants approved, all interview sessions were recorded by a voice recorder. After writing a verbatim narrative transcription, the information gathered then listened to multiple times. Follow-up interviews were also conducted for some participants to get more clarifications and understand the meaning of the information given by the participants. The interview guides employed were based on the gaps in the literature and the researcher's working experiences. Overall, three cancers survivors participated in this study, and we reached a level of data saturation with this population. In addition, we were no longer getting any new information for our analysis during this period, and no new information was likely to contribute to the key themes that had already been identified in the 3 participants.

The leading researcher (AR and NH) analyzed the qualitative data obtained through indepth interviews through the Colaizzi approach. For the first step. The participant description was read repeatedly to get their sympathy for them. The researcher reviewed the verbatim to get familiar with data collected from the participants, and identified statements were highlighted. Second, every meaningful sentence or phrase concept was extracted and then transferred into the concept's titles. The next step was to form thematic categories from a set of concepts. The themes were constructed by looking across categories and linking commonalities across several categories. The comprehensive description was formed through an explicit statement. After all, stages were well done, researchers then clarified the finding to participants, and some verification was added to the finding (Colaizzi, 1978; Creswell, 2018). The validity of qualitative research data was carried out by confirming and fulfilling the elements: (1) credibility, (2) dependability, (3) conformability, and (4) transferability. Finally, six themes were identified.

3. Results and Discussion

The age of participants ranged from 42 to 60 years. Two of the three participants were diagnosed with stage IIIB diseases. All participants were not working, and none attended college/university. Regarding the duration of taking oral chemotherapy, only one person followed the treatment for more than six months. Please refer to table 2 for a clear description of the participant's background.

Category	Participant 1	Participant 2	Participant 3
Name	Mrs S	Mrs. H	Mrs. K
Age	42 Years Old	60 Years Old	48 Years Old
Gender	Female	Female	Female
Religion	Islam	Christian	Islam
Occupation	Not working	Not working	Not working
Previous education	Junior high school	Junior high school	Senior high school
Marital status	Widowed	widowed	Married
Type of cancer	Breast cancer	Breast cancer	Breast cancer
Grade	II	IIB	III B

Table 2: Background information of participants

Insurances	National health	National health	National health
	insurances	insurances	insurances
Income	Less than standard national wage	Less than standard national wage	Less than standard national wage
Time of treatment	More than 6 months	Less and similar to 6 months	Less and similar to 6 months

Six major themes were identified in this study. The themes included: (1) knowledge of oral chemotherapy, (2) Patients' feelings during treatment, (3) Side effects of chemotherapy, (4) individual coping mechanisms, (5) support system, and (6) expectation to Nurse. The current study's findings were in line with several previous studies (Costa & McGraw, 2018; Yagasaki & Komatsu, 2013). Findings obtained in line with the opinions of the patients were discussed according to the following title:

(1) Knowledge of oral chemotherapy

The patients' knowledge of chemotherapy is essential in ensuring successful treatment. Unfortunately, most of the patients get less knowledge regarding treatment. One of the participants confessed that she had just heard "oral chemotherapy" and did not know what it meant. They got a prescription from the doctors without further explanation about the medication.

"...we never heard the oral chemotherapy (P1)".

Another participant stated that she did not know that she got chemotherapy as they thought it would be given intravenously only and not through the oral route.

"I think that chemotherapy is only delivered intravenously....(P3)".

Some participants said they just followed the prescription that health workers give them without explaining additional information.

"I just followed what the health workers ask me to do, usually they explain what they will do and the reasons behind that to my son first, who later explains to me what they had said (P2).

This study showed that patients have less knowledge regarding their treatment. These results are similar to a previous study that found that patients sometimes were not provided with appropriate knowledge following their therapy (Costa & McGraw, 2018). Improving patients' knowledge is crucial to ensure successful treatment outcomes with the increasing use of oral chemotherapy. Patient-related barriers, particularly educational barriers and lack of understanding of therapy, can lead to non-adherence to the treatment. Therefore, patient education for patients undergoing oral chemotherapy should be incorporated and implemented systematically from the initial commencement of their therapy (Bellomo, 2016). However, many oncology practitioners do not have standard protocols to educate patients, particularly on managing and monitoring side effects of oral chemotherapy (Weingart et al., 2012). Nurses as educators must be proactive in offering patients information that includes the purpose of oral chemotherapy, schedule, dose, and ensuring the safety of the medication (Bellomo, 2016; Kutluturkan et al., 2020). Furthermore, it is also essential to incorporate information regarding safe, adherence, and potential side effects of oral chemotherapy (Lester et al., 2012).

(2) Patients' feelings during treatment

Chemotherapy is a cancer treatment; patients will have different feelings, including fear. However, they try to construct optimism for themselves.

"I am so scared, but I must be strong, since this is the only way to cure me from cancer (P1)".

However, the two others participants did not feel anything. They have already constructed their coping mechanism and moved to the acceptance phase.

"I felt nothing...I already knew that it is the one that I have to going through...(P2)".

"I felt no burden at all (answer spontaneiusly), I have passed the worst one, Insya Allah, I can pass this phase, just let it be...(P3)".

The findings from this study show that patients have some psychological problems during their therapy which was expressed as feeling worried and anxious. As we know, anxiety is the most common symptom among patients undergoing chemotherapy, and Unfamiliarity with treatment could be one of the causes of anxiety experienced by patients. Therefore, providing education and offering full support to patients have been proven effective in reducing anxiety (Nima et al., 2013). Unfortunately, distress management is not routinely integrated into the nursing care plan of cancer care. Patients receiving oral chemotherapy seem not to share their current feelings with the nurses willingly. Therefore, routine monitoring of mood symptoms for the patients undergoing oral chemotherapy could improve the patient's quality of life.

(3) Side effects of chemotherapy

Side effects experienced by the participants during chemotherapy were a complex challenge for them. The participants said side effects related to the digestive tract were the most common side effects that disturbed them so much. These side effects had an impact on their body weight and appetite.

"I felt nausea and vomiting sometimes...these side effects made me lose my body weigh excessively..." (P1).

"I always feel thirsty and I had swallowing problems... (P2)".

In addition, the participants also had side effects of the integumentary system and fatigue. They noted that their skin brushed quickly, had hair loss, and negatively affected their self-esteem. "I have dry skin, it brushed easily and sometimes there are black spots (P3)".

"The skin seems to have lost its moisture and is not shiny..(P2)".

"My skin has become terrible....(P1).

"When I tried to touch my hair...sometimes it loss..(P2)".

Furthermore, they often feel tired, which is detrimental when performing their daily activities.

"I felt that I have no energy to walk.." (P1).

"I felt pain deeply and restless....(P2).

"I feel easily tired and have pain in my backbone...." (P3).

Besides the physical problems, the participants also reported psychological problems during the treatment. They stated that they felt unhappy since they could not eat well. However, they tried to cheer themselves up to help them go through their treatments. At another time, they felt that their death was approaching, but they suddenly realized that they had to fight their cancer.

"When I saw the food that my family provided me, I felt unhappy, because I cannot eat well, no matter how hard I tried to eat all the food....(P2)".

"Sometimes, I am thinking about death...but I tried to cheer up my self, so I can continue the treatment...(P1)".

"I diluted the sad feeling, I talk to myself that I ever received the intravenous chemotherapy, which had worst side effects, So, this time, I can pass this problem (P3)".

Despite oral chemotherapy having tolerable side effects compared to intravenous chemotherapy, all participants in this study stated that some side effects still affected them badly. This finding aligns with a previous study that showed that those side effects had affected their quality of life and medication adherence (Jacobs et al., 2019). Patients considered these side effects a symptom burden that is not appropriately treated in the current care model. In our study, the participants reported fatigue, nausea, vomiting, and nutritional deficiency as the most common side effects and burdensome for oral chemotherapy. This finding is similar to a previous study that showed nausea and fatigue are among the significant side effects of oral chemotherapy

(Jacobs et al., 2019). As the number of patients preferring oral chemotherapy increases, the process for monitoring side effects requires more attention. Previous research found that although most patients receiving oral chemotherapy were satisfied with their therapy, they still raised their concerns regarding less preparedness for side effects and unfamiliarity with the possible management skills and techniques to take care of themselves (Simchowitz et al., 2010).

(4) Individual Coping Mechanism

Coping is one of the compelling ways that participants use to help them out from their problems regarding treatment. They found that changing behavior into a healthy lifestyle and taking traditional herbal medicine made them feel better.

"I added more calcium... and I used body lotion that help me keep my skin moist ...(P1)".

"I boiled some herbal medicine and routinely drunk it every morning and evening... (P2)".

"I reduced the use of chemical products such as lipstick and make up.... and I wear slippers at home to protect my feet.(P3)".

Regarding psychological problems, participants tried to develop positive thinking. They tried to get closer to God by doing religious activities intensively.

"Alhamdulillah, although I felt tired, I still can do Sholat and Dzikir when I lied down...(P1)".

"As a Christian, I still follow religious activities. I also invited my colleagues to pray together in my home...(P2)".

"Every midningt, I wake up and do Tahajud, then I recite the Quran until 5 am. By doing this activity, I felt fresh and burdenless... (P3)".

Coping is an effort usually used by patients to protect themselves from any threat and stressful events (Lazarus & Folksman, 1984; Huda et al., 2021). This study revealed that participants reported using non-pharmacological treatment to keep themselves from adverse side effects of oral chemotherapy. They used some traditional herbal medicine, which they believed could make them feel better and minimize their physical health. This finding is in line with Saragih (2010) found that most patients undergoing chemotherapy in Indonesia have this coping with keeping them healthy. Furthermore, participants maintained their mental health by diluting negative thinking and becoming more optimistic and engaged in religious activities. This strategy may increase patients' quality of life during treatment (Anggraini, 2015). In line with this, Wahyuni, Utami & Huda (2015) found that religious coping was the patients' strength to maintain good and positive emotional states. Thus, engaging in spiritual activities is a source of strength for the patients to face challenges during their treatment.

(5) Support System

All the participants had full support from their families and societies. The support was expressed by routinely asking about their condition, giving them some massage when they felt tired, and helping them daily.

"If I felt pain and restless, my daughters come and offer some massage for me...(P1).

"My daughters did not allow me to do housekeeping and routinely ask my condition...If they found that I had not eaten yet...they fed me and helped me to take my medication...(P2).

"My husband always reminds me to take my medicine on time...(P3)".

Their societies also provided full support. Their neighbors, friends, and colleagues always showed sympathy by sending food and praying together.

"My neighbour sometimes comes to my house and sends food. They also keep me in their prayers...(P1)".

"As Batakness, we always to go to visit sick people to cheer them up...(P2)".

The families and the healthcare system may contribute as support systems' inner strength of the patients (Huda et al., 2021). Strong family bonds are an essential part of Indonesian culture. Families will give their full support by providing direct care as they perceive caring to be

obligatory in their cultural norm (Kristanti, 2019). Patients felt safe and were no longer insecure (Firdausia et al., 2021). Therefore, patients usually try to obtain support from family by being more intimate, which directly increases their sense of wellbeing.

(6) Expectation to nurse

The participants confessed that nurses had a good performance, and however, they felt that nurses' attention was limited compared to what they received during intravenous chemotherapy. Therefore, the participants hoped that nurses could still provide good care and give more attention and communication to patients undergoing oral chemotherapy.

"Nurses provided good care here....(P2).

"In general, the nurses were very kind; however, compared to the previous care when I received intravenous chemotherapy, the care is limited, we rarely have intense communication...(P1).

Nurses' attitude and care towards patients strongly influence their strength to face the treatment. During this condition, nurses take responsibility for sharing information regarding treatment, side effects, and managing them. In this study, patients expressed that overall they were satisfied with the nursing care, although some improvements were needed. As oral chemotherapy becomes more popular, patients' orientation on oral chemotherapy should be systematically provided soon after they are initiated in the therapy (Marrs, 2009). Previous research found that health care team members have less ability to manage care for oral chemotherapy (Soubhi et al., 2019). Therefore, collaboration among an interdisciplinary team of health care members to remind each team member to focus on their role, facilitative other work strictly, and gather professional knowledge should be encouraged.

This study has limitations besides the critical finding that uncovers the experiences of using oral chemotherapy among breast cancer patients. The main limitation of this study is that the participants' life experiences in this study may not reflect the life experiences of other breast cancer survivors undergoing oral chemotherapy. All the participants in this study were not working with lower education backgrounds but had stable families. Therefore, the results of this study could not be generalized to other breast cancer survivors who have different backgrounds.

4. Conclusion

Oral chemotherapy has been acknowledged for its several advantages, including its excellent efficacy, conveniences, and flexibility. Nevertheless, some shortcomings must also be noted. This study sheds some light on the life experiences of the breast cancer survivors undergoing oral chemotherapy. Patients expressed that they were delighted with oral chemotherapy and the nurse's performance. However, the findings revealed that participants had less knowledge regarding the safe use of oral chemotherapy treatment, side effects, and symptoms management. The lack of knowledge leads to unsafe handling of oral chemotherapy and anxiety. In addition, the support from family members, community, and religions helps them cope through the treatment. A tailored education program is required to strengthen patients' knowledge. Further research is needed to determine the best practice in patient education and the gaps that may appear between the practices and the roles of nurses. This section should clearly state the main conclusions and explain the importance and relevance of the study reported.

Ethics approval and consent to participate

The Ethical Review Board for medicine and health research, Faculty of Medicine, Universitas Riau (No: 170/UN. 19.5.11.8/UEPKK/2018) approved this study. All participants provided their full consent by signing the consent form and had the right to withdraw and refuse to participate in this study. Before signing the consent form, each of the participants was informed about their rights and the research data was going to be kept confidential, and each participant will have a code instead of their actual names.

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