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PATIENT EXPERIENCE WITH SIDE EFFECTS OF CHEMOTHERAPY DRUGS IN HOSPITAL ONCOLOGY FACILITIES

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KEYWORDS

chemotherapy; side effects; patient experience; patient-centered care.

ABSTRACT

Cancer is one of the leading causes of death in the world, with an ever-increasing incidence. Based on GLOBOCAN 2022 data, more than 20 million new cancer cases and 9.7 million deaths were recorded globally, with a projected increase of up to 28.4 million cases by 2040. This study aims to explore patients' subjective experiences of chemotherapy side effects at the Oncology Installation of Hospital X using a qualitative descriptive phenomenological design with 15 participants. Data were collected through in-depth interviews, participatory observations, and semi-structured questionnaires. Key results revealed that nausea and vomiting were the most prevalent side effects (93%, severity score 7.8), followed by fatigue (87%, 8.2) and hair loss (80%, 6.5). Qualitative analysis identified three salient themes: emotional distress related to body image changes, reliance on family as primary coping mechanism, and information gaps in pre-treatment education. Family support was shown to affect patients' symptom management capabilities, while limited pre-chemotherapy education and insufficient clinical pharmacist availability emerged as treatment barriers. This study was limited by its single-center design and potential recall bias in symptom reporting. The findings underscore the need for a holistic, patient-centered care approach integrating physical, psychological, and social dimensions, alongside strengthened educational programs and expanded clinical pharmacy services to enhance quality of life during chemotherapy.

INTRODCUTION

Cancer is still one of the leading causes of death in the world, with the burden of disease increasing every year. Based on data from the Global Cancer Observatory (GLOBOCAN) in 2022, it is estimated that there will be more than 20 million new cases of cancer and 9.7 million deaths due to cancer worldwide, with a projected increase of up to 28.4 million cases by 2040 (Prabandari et al., 2022). Chemotherapy, as one of the main therapeutic modalities besides surgery and radiotherapy, has a great contribution to the success of cancer treatment, but it also causes a wide range of side effects that affect the patient's quality of life. These side effects include nausea, vomiting, diarrhea, hair loss, peripheral neuropathy, decreased immune system, and psychological disorders such as anxiety and depression (Kwekkeboom et al., 2022).

Although chemotherapy is effective in controlling the growth of cancer cells, patients' tolerance to this therapy varies widely and is often a challenge in completing a treatment regimen. Patients with severe side effects are at risk of discontinuing therapy before reaching optimal cumulative doses, which can lead to decreased recovery rates and increased mortality (Zubair et al., 2023). Therefore, understanding the patient's experience during chemotherapy is essential to developing an appropriate intervention strategy.

In Indonesia, the burden of cancer also shows a significant upward trend. Global Burden of Disease (GBD) data 2023 shows that breast, cervical, lung, and colorectal cancers are the types of cancer with the highest prevalence. According to the Indonesian Ministry of Health (2023), the incidence of cancer in Indonesia reaches 136.2 per 100,000 population, with a mortality rate of 78 per 100,000 population (Sitanggang & Lin, 2024). Hospital oncology installations in various regions report an increasing number of chemotherapy patients every year (Dang et al., 2023).

Chemotherapy side effects in Indonesia are an important issue because they are directly related to patients' quality of life, adherence to therapy regimens, and economic burdens on families and health systems. Studies in Indonesian tertiary hospitals, such as Dharmais Cancer Hospital and Dr. Sardjito Hospital, show that chemotherapy patients experience a complex combination of physical and psychological symptoms, which requires a multidisciplinary approach in their treatment (Kurniasih et al., 2023). However, there is still limited research that delves deeply into patients' subjective experiences of these side effects, especially at the regional hospital oncology installation level.

Several studies have highlighted the impact of chemotherapy side effects on patients. Research in Asian contexts, including Taiwan (Gour et al., 2023), revealed that chemotherapy patients experienced significant changes in physical, emotional, and social aspects. Side effects such as extreme fatigue and neuropathy affect the patient's ability to perform daily activities and their social roles. Indonesian studies (Ali & Shah, 2023) reported that nausea and vomiting after chemotherapy were the most dominant complaints, followed by appetite disorders and sleep problems. The study also emphasizes the importance of family support in helping patients cope with the impact of therapy. Research from Saudi Arabia (Talens et al., 2021) found that patients' perceptions of chemotherapy side effects are strongly influenced by their level of knowledge and readiness before starting treatment, so pre-therapy education has an important role in reducing anxiety.

While international and national studies provide valuable insights, there are still research gaps related to patient experience in the local Indonesian context, particularly in regional hospital oncology facilities that may have different facilities, resources, and social support than national cancer centers (Harianto et al., 2025).

The urgency of this research lies in the need to comprehensively understand the experiences of chemotherapy patients in regional Indonesian hospital oncology facilities. This information can be used as a basis for the development of clinical and non-clinical interventions aimed at reducing the negative impact of chemotherapy drug side effects. In addition, this study is important to identify educational needs, psychosocial support, and symptom management strategies that are appropriate to the local context. With the increase in cancer cases and patients undergoing chemotherapy in Indonesia, the absence of in-depth qualitative data will be an obstacle in the formulation of evidence-based health policies.

This study has novelty in its focus on exploring the subjective experiences of patients undergoing chemotherapy at regional hospital oncology facilities in Indonesia, not just clinically measuring the incidence of side effects (Nies et al., 2018). The approach used will delve deeper into the patient's narrative through interviews, resulting in a more holistic understanding of the interactions between physical symptoms, psychological conditions, and social factors. This study also puts the patient's perspective as the center of attention, which is still rarely done in Indonesia.

The purpose of this study was to explore and describe patients' subjective experiences of chemotherapy drug side effects in Hospital X oncology installation, including physical, emotional, and social dimensions. The study also aims to identify factors that affect the patient's ability to manage these side effects.

The results of this study are expected to provide practical implications in the form of developing a more comprehensive pre-chemotherapy patient education protocol, improving integration of clinical pharmacy services with psychosocial support for oncology patients, applying a patient-centered model of care in oncology installations, and establishing a foundation for advanced research that combines qualitative and quantitative approaches to evaluate the effectiveness of patient experience-based interventions.

METHOD RESERACH

1. *Research Design*

   This study uses a qualitative approach with a descriptive phenomenological design, which aims to explore and understand patients' subjective experiences in dealing with the side effects of chemotherapy drugs. The phenomenological approach was chosen because it is relevant to explore the meaning of life experiences from the perspective of individuals who experience them firsthand (Creswell & Poth, 2018). Researchers act as the main instruments directly involved in data collection, analysis, and interpretation, focusing on understanding the context and meaning given by participants to the phenomena they experience.

2. *Location and Research Subject*

   The research was conducted at Hospital X's Oncology Installation (name withheld to maintain confidentiality), which is a regional referral hospital with chemotherapy facilities for cancer patients. This location was chosen because it has a high number of chemotherapy patients each month, as well as the different types of cancer being treated, allowing for a variety of experiences.

   Inclusion criteria for participants were: (1) adults aged 18 years or older diagnosed with any type of cancer; (2) currently undergoing or completed at least two cycles of chemotherapy at Hospital X; (3) able to communicate verbally in Indonesian; (4) willing to provide informed consent; and (5) physically and mentally stable enough to participate in interviews. Exclusion criteria include patients with critical health conditions that impede effective communication or patients with severe cognitive impairment.

   A purposive criterion-based sampling strategy was employed to recruit participants who met the inclusion criteria and could provide rich, in-depth information about their chemotherapy experiences. Recruitment was conducted through the oncology unit's healthcare team, who identified potential participants. The number of participants was determined based on the principle of data saturation, which was reached at n=15 when interviews no longer produced new information, themes, or insights, and redundancy in responses was evident across the final three interviews.

3. Research Instruments

The main instrument in this study is the researcher himself, who plays a role in planning, collecting, and analyzing data. In addition, supporting instruments are used in the form of:

1) The semi-structured interview guide, which was compiled based on a literature review and research objectives, included open-ended questions related to the patient's physical, emotional, social, and strategies for coping with chemotherapy side effects.
2) Voice recorder to document the results of the interview (with the participant's permission).
3) Field notebooks to record observations, expressions, and non-verbal environmental situations during interviews.
4) The interview guidelines were tested on two patients with similar characteristics before being used in the main study, to ensure the feasibility and clarity of the questions.

4. Data Collection Techniques

Data collection is carried out through several stages:

1) In-Depth Interviews

Interviews are conducted face-to-face in a quiet and comfortable space in the hospital's oncology facility, or online (video call) if participants are unable to attend in person. The interview lasted 30-60 minutes, recorded, and then transcribed verbatim.

2) Participatory Observation

The researchers observed the patient's condition during chemotherapy, including facial expressions, body language, interactions with healthcare workers, and responses to side effects. Observations are recorded systematically in field records.

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RESULT AND DISCUSSION

This study involved 15 cancer patients who were undergoing or had undergone chemotherapy at the Oncology Institute of Hospital X. Respondent characteristics included gender, age, type of cancer, length of chemotherapy, and the last chemotherapy cycle experienced.

Table 1 General Characteristics of Respondents

Code Answerer	Age (years)	Gender	Types of Cancer	Long Undergoing Chemotherapy	Last Cycle
Page 1	42	Woman	Breast Cancer	8 months	5
Page 2	55	Man	Lung cancer	6 months	4
Page3	38	Woman	Cervical cancer	10 months	6
Page 4	60	Man	Colorectal Cancer	12 months	8
Page 5	47	Woman	Breast Cancer	7 months	5
Page-6	50	Man	Nasopharyngeal cancer	5 months	3
...	...	...	...	...	...

The majority of respondents were aged 40-60 years, with the proportion of women (60%) more than men (40%). The most common type of cancer is breast cancer (40%), followed by colorectal cancer (20%), cervical cancer (13%), lung cancer (13%), and others (14%).

Key Findings from the Interview with Management

An in-depth interview with the Head of Oncology Installation and Nurse Coordinator revealed that almost all chemotherapy patients at the facility experience various physical side effects, such as nausea, vomiting, fatigue, and hair loss. In addition, psychological side effects such as anxiety, mild depression, and sleep disturbances also often appear, especially in patients undergoing long-term therapy.

The management also said that the pre-chemotherapy education facilities have not been running optimally. Educational materials are still mostly delivered orally by the nurse before the procedure, so the information patients receive is often limited and poorly structured. Not all patients get written materials or attend special counseling sessions that can help them prepare for treatment side effects.

On the other hand, the role of clinical pharmacy is recognized as important in providing medication information and symptom management strategies. However, the limited number of clinical pharmacists makes the services provided unable to reach all patients intensively, so there is still a gap in meeting the educational and assistance needs of patients during chemotherapy.

Findings from the Patient Questionnaire

A semi-structured questionnaire was administered to all respondents to identify the frequency and severity of chemotherapy side effects.

Table 2. Distribution of Chemotherapy Side Effects

Types of Side Effects	Number of Patients (%)	Severity (Average Scale 1–10)
Nausea and vomiting	14 (93%)	7,8
Fatigue	13 (87%)	8,2
Hair Loss	12 (80%)	6,5
Taste changes in the tongue	9 (60%)	5,9
Joint and muscle pain	8 (53%)	6,7
Sleep disorders	7 (47%)	6,1

Observation Results

During the data collection period, the researcher conducted direct observations in the chemotherapy room. Some important findings:

Physical Response

1. Some patients show physical signs such as paleness, weakness, and resting in a half-seated position after the procedure.
2. Slow movements and frequent closing of the eyes during the drug infusion process.

Emotional Response

1. Patients tend to be more silent after a chemotherapy cycle lasts 30-60 minutes.
2. Interaction between patients is less than before the procedure begins.

Social Response

Some patients are accompanied by family members who provide verbal support, massage, or eating assistance, and patients who come alone tend to use their phones more often to distract themselves.

Visualization of Findings

Table 3. Summary of Research Findings Categories

Discovery Categories	Main sub-themes	Sample Respondent Quote
Physical	Nausea, vomiting, fatigue	"Once the medicine came in, it felt very weak... like they don't have energy." (p. 5)
Psychological	Anxious, sad, and afraid of the effects of the drug	"I'm afraid that if I lose my hair again, I'll be embarrassed to leave the house." (p. 3)
Social	Family support, social isolation	"It's good to have kids who always follow, otherwise I wouldn't be able to do it myself." (p2)

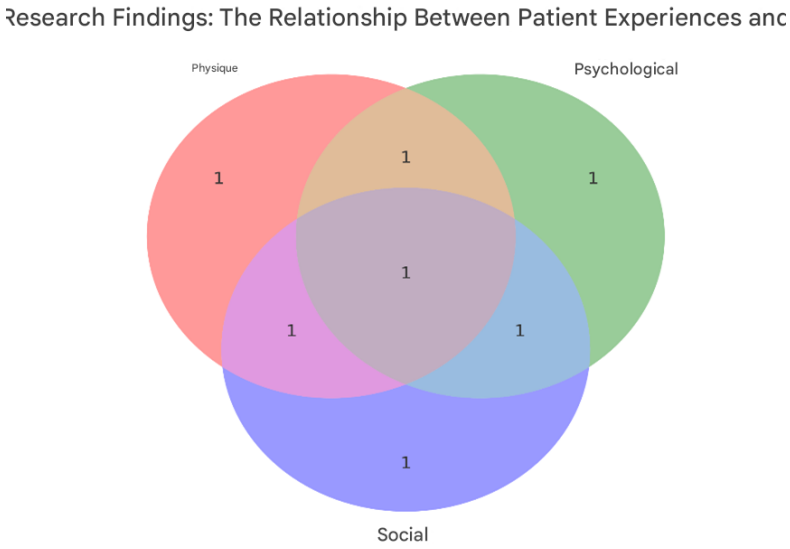

Figure 1. Research Findings Model

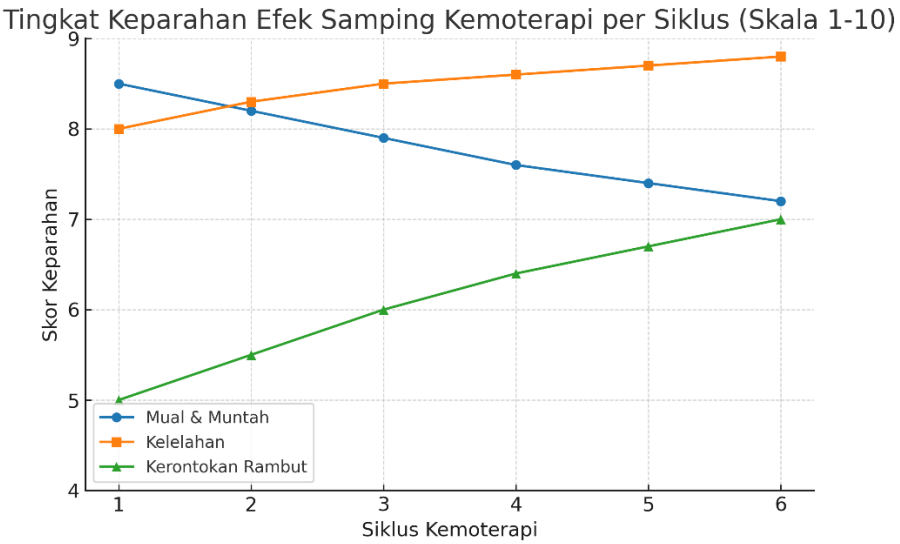

Figure 2. Graph of Severity Rate of Side Effects

Interview Data and Interpretation of Interview Results

In-depth interviews with patients and oncology facility management show that the most commonly felt side effects of chemotherapy are nausea, vomiting, fatigue, and hair loss. One patient stated, "After the medicine came in, it was very weak... as if they had no energy" (p. 5). These side effects not only affect the physical aspect, but also impact the emotional aspect, such as fear of changes in appearance and concerns about the sustainability of therapy.

From the management side, the Head of Oncology Installation revealed that the limitations of educational facilities made some patients not get an adequate understanding of the side effects that may arise. Pre-chemotherapy education tends to be delivered orally, so the information patients receive is not well documented. Interpretation of these findings suggests that there are gaps in patients' knowledge management that may affect their mental readiness to undergo therapy. In addition, the role of clinical pharmacy is limited because the number of human resources is not proportional to the number of patients, so not all patients get in-depth consultations regarding the drugs used. This condition has an impact on the lack of self-management strategies by patients when experiencing side effects outside the control schedule.

Discussion of Questionnaire Results

The results of a questionnaire given to 15 patients revealed that nausea and vomiting were the most common side effects (93%) with an average severity of 7.8 on a scale of 10, followed by fatigue (87%, score 8.2) and hair loss (80%, score 6.5). These data confirm the literature that states that nausea and vomiting are dose-limiting toxicities in most chemotherapy regimens (Jordan et al., 2022). Data analysis also showed that patients with further chemotherapy cycles (≥5 cycles) tended to have an increased fatigue score, while the nausea-vomiting score decreased slightly. This is likely because the patient's body begins to adapt to the nausea pattern, but the accumulation of fatigue occurs due to repeated exposure to the cytotoxicity of the drug.

Hair loss is a significant psychological problem, especially in female patients. Some respondents stated that these physical changes decreased confidence and reduced the desire to socialize. These findings are in line with research by Lemieux et al. (2021) which reported that chemotherapy-induced alopecia has a high psychosocial impact, although it does not directly threaten patient safety.

Analysis of Observation Results

Direct observation during the chemotherapy process provides an in-depth picture of the patient's response to treatment. Before the procedure begins, the atmosphere in the chemotherapy room is relatively warm with interactions between patients and healthcare workers. However, after 30-60 minutes of administering the drug, most patients show decreased energy, pale face, and slowed movements. Patients who were accompanied by their families were seen to be more able to maintain positive expressions and interact with the environment, compared to patients who came alone. Family support has been shown to provide a buffer against psychological stress and physical exhaustion, supporting the findings of Uitterhoeve et al. (2020) that emphasize the important role of social support in improving the quality of life of cancer patients. In addition, the researchers noted that some patients use cell phones to distract from discomfort. This disruptive strategy is a simple but effective coping mechanism to reduce the focus on physical symptoms.

Comparison with Previous Research

The findings of this study are consistent with the study of Chen et al. (2021) in Taiwan, which reported that chemotherapy patients experienced a complex combination of physical and psychological symptoms. The study of Sari et al. (2022) in Indonesia also identified nausea and sleep disorders as the main complaints, in line with the results of the questionnaire in this study. However, this study found that fatigue had a higher score of severity than other side effects, in contrast to some previous studies that highlighted nausea as the main symptom. This difference may be influenced by the chemotherapy regimen used in the research hospital, which contains cytotoxic agents with cumulative fatigue effects.

In addition, this study emphasizes the role of social support as a protective factor, an aspect that has not been emphasized in the study of Almutairi et al. (2023) in Saudi Arabia which focuses more on pre-therapy education.

Practical Implications

Based on the findings of this study, there are several practical implications that can be applied:

1. Strengthening Pre-Chemotherapy Education
2. Education should be done in a structured and documented manner, using written and visual media, so that patients can access information at all times.
3. Enhancing the Role of Clinical Pharmacy
4. Increase the number of clinical pharmacists or schedule regular consultations to ensure all patients are informed about side effect management.

Research Limitations

This research has several limitations that need to be considered. First, the relatively small number of participants (15 people) limited the generalization of the study results to a wider population of chemotherapy patients. Second, the research was conducted in only one hospital, so the context and findings may differ in other healthcare facilities with different resources. Third, data collection is carried out over a specific period, so variations in side effects in different seasons or time periods are not identified.

In addition, although interviews and observations provide rich data, the possibility of memory bias is unavoidable, given that some patients recount experiences from previous chemotherapy cycles. Further research may consider longitudinal designs to more comprehensively monitor changes in the patient experience from the first to the last cycle

CONCLUSION

This study revealed that chemotherapy patients at Hospital X's Oncology Installation experienced a variety of related physical, psychological, and social side effects. The most dominant physical side effects were nausea, fatigue, and hair loss, while psychologically many patients reported anxiety, decreased confidence, and sleep disturbances. Family support has proven to be an important factor in helping patients manage symptoms and maintain the spirit of therapy. Limited pre-chemotherapy education facilities and lack of optimal role of clinical pharmacy due to limited resources are obstacles in handling side effects. These findings underscore the need to strengthen patient education in a structured manner, increase the capacity of clinical pharmacy services, and integrate psychosocial support in oncology services. From an operational policy perspective, hospitals should establish standardized pre-chemotherapy education protocols (SOPs) and allocate dedicated clinical pharmacist positions to the oncology unit to ensure consistent symptom management support and medication counseling for all chemotherapy patients. Overall, the study emphasizes the importance of a holistic approach based on patient-centered care in the treatment of chemotherapy patients, thus focusing not only on the success of therapy, but also on improving the patient's quality of life during and after treatment.

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