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Patient Experience with Side Effects of Chemotherapy Drugs in Hospital Oncology Installations

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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 cases of cancer 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 and describe the subjective experience of patients in dealing with chemotherapy side effects in the Oncology Installation of Hospital X. The method used is a qualitative research with a descriptive phenomenological design, involving 15 patients who meet the inclusion criteria. Data were collected through in-depth interviews, participatory observations, and semi-structured questionnaires. The results showed that nausea and vomiting were the most common side effects (93%, severity score 7.8), followed by fatigue (87%, 8.2) and hair loss (80%, 6.5). Family support has been shown to affect patients' ability to manage symptoms, while limited pre-chemotherapy education and the number of clinical pharmacists are barriers to treatment. In conclusion, the treatment of chemotherapy patients requires a holistic approach based on patient-centered care that integrates physical, psychological, and social aspects, as well as strengthening education and clinical pharmacy services to improve the patient's quality of life during therapy..

Introduction

Cancer is still one of the world's leading causes of death, 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 (Khiari et al., 2024; Marella, 2025; Morgan et al., 2022; Prabandari et al., 2022; Tonga et al., 2025; Zottl et al., 2025). 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 various side effects that affect the quality of life of patients (Tilsed et al., 2022; Was et al., 2022). 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 (Haynes & Manogaran, 2025; Li et al., 2024; Nikolaou et al., 2018). Patients with severe side effects are at risk of discontinuing therapy before reaching optimal cumulative doses, which can have an impact on decreased recovery rates and increased mortality. (Zubair et al., 2023). Therefore, understanding the patient's experience during chemotherapy is crucial to developing the right intervention strategy.

In Indonesia, the burden of cancer also shows a significant increasing trend. Global Burden of Disease (GBD) 2023 data show 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 the number of chemotherapy patients that continues to increase every year (Dang et al., 2023).

The side effects of chemotherapy in Indonesia are an important issue because they are directly related to the quality of life of patients, adherence to therapy regimens, and economic burdens on families and health systems. Studies in several major 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 oncology installation level of regional hospitals.

Several studies have highlighted the impact of chemotherapy side effects on patients. (Gour et al., 2023) Conducted a qualitative study in Taiwan that 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 carry out their daily activities and social roles. (Ali & Shah, 2023) In Indonesia 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. (Talens et al., 2021) In their study in Saudi Arabia found that patients' perceptions of chemotherapy side effects are greatly influenced by their level of knowledge and readiness before starting treatment, so pre-therapy education has an important role in reducing anxiety.

While these studies provide valuable insights, there are still research gaps related to patient experience in the local Indonesian context, particularly in 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 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 the side effects of chemotherapy drugs. In addition, this study is important to identify educational needs, psychosocial support, and symptom management strategies that are appropriate to the local context. With cancer cases and patients undergoing chemotherapy on the rise 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 the focus of exploring the subjective experiences of patients undergoing chemotherapy in regional hospital oncology installations, not just measuring the incidence of side effects clinically. (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 interaction 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 is to explore and describe patients' experiences of chemotherapy drug side effects in hospital oncology facilities, including physical, emotional, and social dimensions. This 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:

1. Development of a more comprehensive pre-chemotherapy patient education protocol.

2. Improved integration of clinical pharmacy services with psychosocial support for oncology patients.
3. Application of the patient-centered care model in oncology installations.
4. Encourage advanced research that combines qualitative and quantitative approaches to evaluate the effectiveness of patient experience-based interventions.

Method

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 directly (Creswell & Poth, 2018). The researcher acts as the main instrument directly involved in the collection, analysis, and interpretation of data, focusing on understanding the context and meaning given by participants to the phenomena they experience.

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 every month, as well as various types of cancer treated, allowing for a variety of experiences.

Exclusion criteria include patients with critical health conditions that impede effective communication or patients with severe cognitive impairment. The number of participants is determined based on the principle of data saturation, which is when the interview no longer produces new information or themes.

Research Instruments

The main instrument in this study is the researcher himself, who plays a role in planning, collecting, and analyzing the 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 strategies with the side effects of chemotherapy.
2. A voice recorder to document the results of the interview (with the participant's permission).
3. Field notebook to record non-verbal observations, expressions, and 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.

Data Collection Techniques

Data collection is carried out through several stages:

1. In-Depth Interview
2. 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, was recorded, and then transcribed verbatim.

Participatory Observation

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

Results and Discussion

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

Table 1. General Characteristics of Respondents

Code Responders	Age (years)	Gender	Types of Cancer	Long Undergoing Chemotherapy	Last Cycle
P1	42	Woman	Breast Cancer	8 months	5
P2	55	Man	Lung Cancer	6 months	4
P3	38	Woman	Cervical Cancer	10 months	6
P4	60	Man	Kanker Kolorektal	12 months	8
P5	47	Woman	Breast Cancer	7 months	5
P6	50	Man	Nasopharyngeal cancer	5 months	3
...	...	...	...	...	...

Source: Data Processed

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 the Oncology Installation and the Nurse Coordinator revealed that almost all chemotherapy patients at the facility experienced various physical side effects, such as nausea, vomiting, fatigue, and hair loss. In addition, psychological side effects such as anxiety, mild depression, and sleep disorders also often appear, especially in patients who undergo long-term therapy.

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

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 needs of education and patient assistance 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. Distribusi Efek Samping Kemoterapi

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 on the tongue	9 (60%)	5,9
Joint and muscle pain	8 (53%)	6,7
Sleep disorders	7 (47%)	6,1

Source: Data Processed

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 started.

Social Response

Some patients are accompanied by family who provide verbal support, massage, or help with eating, and patients who come alone tend to use their phones more often for distraction.

Visualization of Findings

Table 3. Summary of Research Findings Categories

Discovery Categories	Main Sub-themes	Sample Respondent Quote
Physical	Nausea, vomiting, fatigue	"After the medicine came in, it felt very weak... like they don't have energy." (P5)
Psychological	Anxious, sad, and afraid of the effects of the drug	"I'm scared that if I lose my hair again, I'm embarrassed to leave the house." (P3)
Social	Family support, social isolation	"It's good that there are children who always follow, otherwise I wouldn't be able to do it alone." (P2)

Source: Data Processed

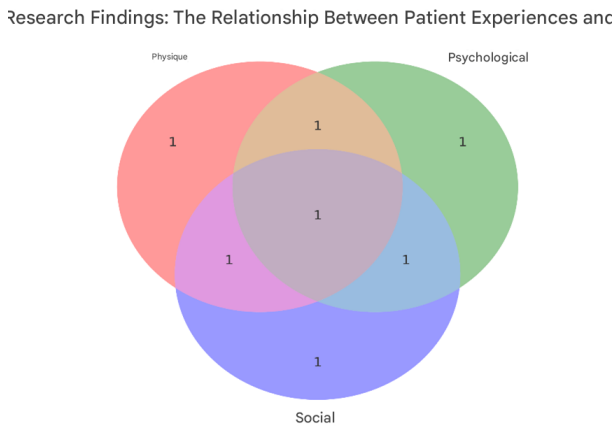

Figure 1. Research Findings Model

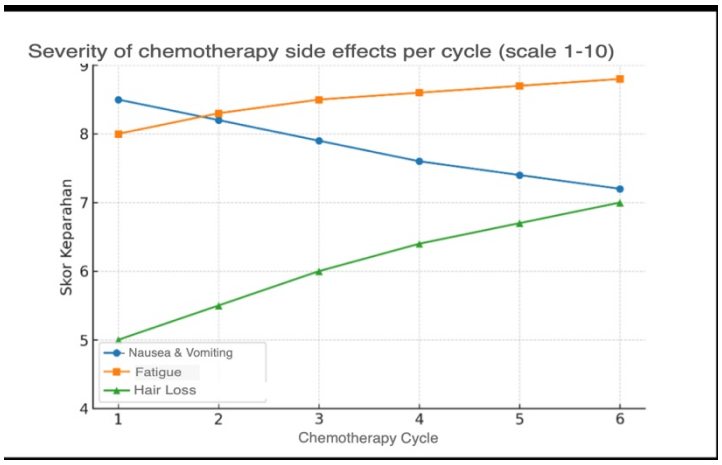

Figure 2. Graph of Severity of Side Effects

Interview Data and Interpretation of Interview Results

In-depth interviews with patients and oncology facility management showed that the most commonly felt side effects of chemotherapy were nausea, vomiting, fatigue, and hair loss. One patient stated, "After the medication came in, it was very weak... as if they had no energy" (P5). These side effects not only affect the physical aspects, but also impact the emotional aspects, 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 shows that there are gaps in patient knowledge management that can affect their mental readiness to undergo therapy. In addition, the role of clinical pharmacy is limited due to the number of human resources that is not proportional to the number of patients, resulting in not all patients receiving 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 the questionnaire given to 15 patients revealed that nausea and vomiting were the most common side effects (93%) with an average severity of 7.8 out of a scale of 10,

followed by fatigue (87%, score 8.2) and hair loss (80%, score 6.5). This data confirms the literature that states that nausea and vomiting are dose-limiting toxicity 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 pattern of nausea, but the accumulation of fatigue occurs due to repeated exposure to the cytotoxicity of the drug.

Hair loss is a significant psychological issue, 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 a study 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 interaction 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 family were seen to be more able to maintain positive expression 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, researchers noted that some patients use mobile phones to distract from discomfort. This distraction strategy is a simple but quite 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 severity score than other side effects, in contrast to some previous studies that highlighted nausea as the main symptom. This difference can 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 too much in the study of Almutairi et al. (2023) in Saudi Arabia that focused 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 must be carried out in a structured and documented manner, using written and visual media, so that patients can access information at any time.
3. Increasing 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 recall bias is unavoidable, given that some patients recount experiences from previous chemotherapy cycles. Further research may consider longitudinal design to monitor changes in patient experience from the first to the last cycle more comprehensively.

Conclusion

This study revealed that chemotherapy patients in the Oncology Installation of Hospital X experienced various 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. The limited pre-chemotherapy education facilities and the lack of optimal role of clinical pharmacy due to limited resources are obstacles in handling side effects. These findings confirm the need to strengthen patient education in a structured manner, increase the capacity of clinical pharmacy services, and integrate psychosocial support in oncology services. Overall, the study emphasizes the importance of a holistic approach based on patient-centered care in the treatment of chemotherapy patients, so that it focuses 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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