PERCEPTION OF CANCER PATIENTS ON CHEMOTHERAPY SIDE EFFECTS

Rani Lisa Indra*; Bayu Saputrab

*ab Nursing Program of Institute Health Science of Hang Tuah Pekanbaru; 5 Mustafa Sari Street Pekanbaru 28281; Indonesia

Abstract

Chemotherapy causes various side effects that can affect the patient's physical or non-physical condition. Patients' perceptions of ratings of these side effects vary. This study aimed to identify cancer patients' perceptions of the side effects of chemotherapy they are undergoing. The descriptive study was conducted on 84 samples, namely cancer patients aged > 20 years who had undergone chemotherapy at least once before. Data collection using a questionnaire that has been tested for validity and reliability. Data analysis was carried out descriptively with frequency distribution. The results showed that the perception of the physical side effects of chemotherapy that was considered very disturbing by the patient (severe symptoms) was nausea (59.5%), feeling of weakness (36.9%), hair loss (35.7%), vomiting, (29.8%), loss of appetite (28.6%). ), weight loss (27.4%), insomnia and skin discoloration (19% each), headache (16.7%) and fever (15.5%). When the perception of non-physical side effects was fear of death, affecting work/household duties and feeling fear (15.5% each), feeling anxious about my life, and the presence of family members I have to take care (14.3% each). The most disturbing side effects of chemotherapy are physical problems. The health service is expected to increase interventions to minimize the side effects of chemotherapy.

Keywords: cancer; perception; side effects

1. Introduction

Cancer is a disease that occurs due to abnormal and uncontrolled cell proliferation that can occur anywhere in the body. According to the 2018 GLOBOCAN survey, the incidence of cancer in the world is estimated at 18.1 million cases with the number of deaths reaching 9.6 million deaths (Bray et al., 2018).

In Indonesia, based on the results of Riskesdas 2018, the prevalence of cancer based on a doctor's diagnosis in a population of all ages is 1.79 per mil, and in Riau Province it is 1.67 per mil. This number increased when compared to the 2013 Riskesdas results which were only 1.4 per mil in Indonesia and 1.3 per mil in Riau (Kemenkes RI, 2018; Kementerian Kesehatan RI, 2013). Based on medical record data of Arifin Achmad Hospital in Riau Province in 2019, the prevalence of cancer was found as many as 5,676 cases, which previously in 2018 was only 5,203 cases.

Various medical actions can be done as a treatment for cancer patients. Most cancers are treated with surgery, then chemotherapy, radiation or other therapies. One of the therapies that are often given to cancer patients with metastases is chemotherapy. About 24.9% of cancer patients in Indonesia were treated with chemotherapy, while in Riau around 22.7% of
cancer patients were treated with chemotherapy (Kemenkes RI, 2018).

Chemotherapy is a process of using cytotoxic (anticancer) drugs that aim to reduce or stop the growth of cancer cells in the body (Yarbro, Wujcik, & Gobel, 2010). The use of chemotherapy drugs is not without side effects because even though they have the ability to kill cancer cells, these drugs also have an effect on normal cells of the body such as bone marrow depression, disorders of the digestive tract from mouth to intestines, hair loss, and others (Anwar, Harsono, Sasotya, Amaraullah, & Hidayat, 2013).

In addition to affecting the physical condition, recent research such as that conducted by Gurung and Pandey in Nepal or Sasaki, et al in Japan stated that chemotherapy also affects the patient's non-physical condition such as work, household duties or the patient's partner, this is even more complained by patients than physical problems (Gurung & Pandey, 2016; Sasaki et al., 2017). This indicates a possible shift from the impact of chemotherapy that is experienced based on the patient's own perceptions.

Perception is an experience produced by the senses, each individual has a different perception of the same object (Pieter & Lubis, 2012). Likewise with cancer patients who undergo chemotherapy. The perception or assessment of each patient regarding the side effects experienced is also different (Gurung & Pandey, 2016).

Short interviews were conducted with 10 cancer patients who were undergoing chemotherapy, 3 people stated that chemotherapy had a good effect on the body and their disease so that they were more enthusiastic about undergoing the next chemotherapy. While 7 other people experienced side effects that interfere with their daily activities. Based on this, a good perception of the side effects of chemotherapy or the therapy that is being undertaken will influence the patient's adherence to continuing therapy and as a whole will have an effect on the patient's quality of life. This study aims to analyze patients' perceptions of the side effects of chemotherapy they experience.

2. Method

This research was a descriptive study with a cross-sectional study approach. The study was conducted in the Seruni Room of Arifin Achmad Hospital, Riau Province, with a population of all cancer patients undergoing one day care chemotherapy in that room. Sampling of 84 people from the population was carried out by purposive sampling technique with the criteria of being willing to be respondents, aged ≥ 20 years, at least having undergone onetime chemotherapy before and the patient's vital signs were within the normal range.

Data collection was carried out using a perception questionnaire of chemotherapy side effects adapted from Sasaki et al. (2017) which consists of 2 parts, namely section A which examines perceptions of non-physical chemotherapy side effects, consists of 42 statements and section B examines perceptions of physical side effects of chemotherapy, consisting of 52 statements. The questionnaire used a Likert scale with 5 choices, namely severe symptoms (code 1), moderate symptoms (code 2), mild symptoms (code 3), minimal symptoms (code 4) and no symptoms (code 5). The questionnaire has been tested for validity and reliability on 20 different respondents from the research respondents, conducted in the same place as the study.

The test results found that the validity value of the questionnaire was in the range of 0.449 to 0.695 (the questionnaire was valid) and the results of the reliability test were that the Cronbach alpha value was 0.924 (the questionnaire is reliable). Then the data obtained were analyzed univariately using a frequency distribution. This research has also passed the ethical review of the Ethics Commission for Health Research STIKes Hang Tuah Pekanbaru with number 668/KEPK/STIKes-HTP/X/2020.

3. Result and Discussion

The occurrence of cancer is a long-lasting process consisting of an induction phase, an in situ phase, an invasion phase and a dissemination phase. The induction phase can last for 15 years where this phase is a predisposing phase for cancer. The in situ phase where the cancer cells already exist but have not spread anywhere. The invasion phase can last for 2-3 years, the last stage is the dissemination phase, where the cancer cells have spread to other organs, which takes 2-3 years (Yarbro et al., 2010). Therefore, the incidence of cancer is often found in individuals aged > 40 years, as in this study, the mean of respondents was found to be 51.3 years old with a standard deviation of 6.66 years. The lowest age is 28 years and the highest age is 68 years. Other characteristics of respondents can be seen in table 1 below.
Likewise in Indonesia, breast cancer is the most diagnosed cancer in all cancers and is also the most commonly found in women (Pangribowo, 2019). Breast cancer is related to the activity of estrogen which is predominantly found in women (Yarbro et al., 2010).

The frequency of chemotherapy that was undertaken by the respondents of this study was at most in the third cycle. Chemotherapy is usually given for several months with a time lag between recovery. The administration of chemotherapy is attempted to be as effective as possible with minimal to moderate toxicity levels (Sinaga, Hasibuan, & Setia, 2015).

The majority of respondents in this study are also no longer working, with high school education level and married marital status. According to Syse and Lyngstad, (2017), cancer patients who are married, have a high education level or partner's education level have healthier lives and behaviors and are more tolerant of cancer treatment. In addition, having a partner will affect the patient's income even though the patient himself is no longer working.

The side effects of chemotherapy include physical and non-physical side effects. Table 2 shows that all respondents in this study experienced nausea as a side effect of the chemotherapy they were undergoing. Nausea was a physical symptom in the category of severe symptoms that most patients felt (59.5%), followed by feelings of weakness (36.9%), hair loss (35.7%), vomiting (29.8%), and loss of appetite (28.6%), weight loss (27.4%), insomnia and skin discoloration (19% each), headache (16.7%) and fever (15.5%).

Previous research states that there has been a shift in patient perceptions of the side effects of chemotherapy where the focus of patient attention is psychosocial problems such as affecting the patient’s family / partner (Carelle et al., 2002; Sasaki et al., 2017). However, this study has a different result, where physical problems such as nausea, weakness, hair loss and vomiting are problems for patients related to chemotherapy side effects. This is in line with the research of Chan and Ismail, (2014) which found nausea and vomiting to be very disturbing side effects of chemotherapy for chemotherapy patients in Malaysia. A survey in Italy conducted by Lorousso et al., (2017) also found nausea and vomiting to be the most disruptive side effects of patients' quality of life. Research by Ataseven et al., (2017) also reported physical problems as a

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**Table 1. Distributions of Respondents characteristic**

| No | Characteristic          | Quantity (%) |
|----|-------------------------|--------------|
| 1  | Gender                  |              |
|    | Male                    | 10 (11.9)    |
|    | Female                  | 74 (88.1)    |
| 2  | Marital status          |              |
|    | Unmarried               | 2 (2.4)      |
|    | Married                 | 69 (82.1)    |
|    | Widow                   | 12 (14.3)    |
| 3  | Education               |              |
|    | Primary school          | 6 (7.1)      |
|    | Secondary school        | 10 (11.9)    |
|    | Senior high school      | 44 (52.4)    |
|    | Diploma                 | 2 (2.4)      |
|    | Undergraduated          | 20 (23.8)    |
|    | Postgraduated           | 1 (1.2)      |
| 4  | Occupation              |              |
|    | Teacher                 | 8 (9.5)      |
|    | Retired                 | 2 (2.4)      |
|    | Farmer                  | 8 (9.5)      |
|    | Civil servant           | 8 (9.5)      |
|    | Unemployed              | 51 (60.7)    |
|    | Self-employed           | 7 (8.3)      |
| 5  | Medical diagnosis       |              |
|    | Breast cancer           | 61 (72.6)    |
|    | Bone cancer             | 3 (3.6)      |
|    | Ovarian cancer          | 6 (7.1)      |
|    | Nasopharyngeal cancer   | 4 (4.8)      |
|    | Cervical cancer         | 1 (1.2)      |
|    | Leukemia                | 5 (6)        |
|    | Endometriosis           | 4 (4.8)      |
| 6  | Frequency of chemotherapy|            |
|    | 2nd                     | 18 (21.4)    |
|    | 3rd                     | 26 (31)      |
|    | 4th                     | 22 (26.2)    |
|    | 5th                     | 12 (14.3)    |
|    | 6th                     | 5 (6)        |
|    | 7th                     | 1 (1.2)      |
| Total |                         | 84 (100)    |

Table 1 shows that the majority of respondents in this study were female, as many as 74 people (88.1%), with a married marital status of 69 people (82.1%), high school education level of 44 people (52.4%), the employment status was not working as many as 51 people (60.7%), the medical diagnosis of breast cancer was 61 people (72.6%), and 26 people had undergone chemotherapy 3 times (31.0%).

In this study, the majority of respondents were female with breast cancer. Breast cancer is main cancer experienced by women worldwide with an incidence of 11.6% and a mortality rate of 6.6% (Bray et al., 2018). Similar results were also obtained by the Global Cancer Statistics 2020 that breast cancer is the most diagnosed cancer, beating lung cancer (Sung et al., 2021).
side effect of chemotherapy that disturbs patients, namely difficulty sleeping/insomnia. Chemotherapy also causes feelings of weakness. One of the underlying mechanisms is the developing state of oxidative stress. Many chemotherapy agents directly produce a state of oxidative stress or indirectly produce a state of oxidative stress by lowering antioxidant levels, paralyzing cell defenses against increased oxidants. And in skeletal muscle, there is increased exposure to oxidants known to cause muscle weakness and speed up the pace fatigue (Gilliam & St. Clair, 2011).

Table 2. Distribution of Respondents' Perceptions of Physical Side Effects of Chemotherapy

| No | Physical side effects | Grade of symptom* |
|----|-----------------------|-------------------|
| 1  | Nausea                | 50 (59.5) 18 (21.4) 14 (16.7) 2 (2.4) 0 (0) |
| 2  | Feelings of weakness  | 31 (36.9) 24 (28.6) 20 (23.8) 5 (6) 4 (4.8) |
| 3  | Skin discoloration    | 16 (19) 24 (28.6) 25 (29.8) 11 (13.1) 8 (9.5) |
| 4  | Hair loss             | 30 (35.7) 27 (32.1) 16 (19) 2 (2.4) 9 (10.7) |
| 5  | Loss of appetite      | 24 (28.6) 19 (22.6) 19 (22.6) 8 (9.5) 14 (16.7) |
| 6  | Fever                 | 13 (15.5) 24 (28.6) 27 (32.1) 5 (6) 15 (17.9) |
| 7  | Insomnia              | 16 (19) 29 (34.5) 15 (17.9) 6 (7.1) 18 (21.4) |
| 8  | Vomiting              | 25 (29.8) 16 (19) 11 (13.1) 12 (14.3) 20 (23.8) |
| 9  | Headache              | 14 (16.7) 17 (20.2) 22 (26.2) 10 (11.9) 21 (25) |
| 10 | Weight loss           | 23 (27.4) 19 (22.6) 9 (10.7) 8 (9.5) 25 (29.8) |

*1= severe symptoms, 2= moderate symptoms, 3= mild symptoms, 4= minimal symptoms, 5= no symptoms

Table 3. Distribution of Respondents' Perceptions of Non-physical Side Effects of Chemotherapy

| No | Non-physical side effects | Grade of symptom* |
|----|---------------------------|-------------------|
| 1  | Fear of death             | 13 (15.5) 26 (31) 26 (31) 11 (13.1) 8 (9.5) |
| 2  | Medical cost              | 6 (7.1) 21 (25) 20 (23.8) 5 (6) 32 (38.1) |
| 3  | Feeling sick              | 8(9.5) 29(34.5) 25(29.8) 14(16.7) 8(9.5) |
| 4  | Feeling fearful           | 13(15.5) 21(25) 25(29.8) 12(14.3) 13(15.5) |
| 5  | Feeling anxious about my life | 12 (14.3) 18 (21.4) 25 (29.8) 14 (16.7) 15 (17.9) |
| 6  | Affect my work/household duties | 13 (15.5) 13 (15.5) 42 (50) 9 (10.7) 7 (8.3) |
| 7  | Feeling anxious about treatment | 9 (10.7) 17 (20.2) 30 (35.7) 14 (16.7) 14 (16.7) |
| 8  | Cannot concentrate        | 4(4.8) 20(23.8) 27(32.1) 19(22.6) 14(16.7) |
| 9  | Forget things             | 10 (11.9) 6 (7.1) 13 (15.5) 16 (19) 39(46.4) |
| 10 | presence of family members I have to take care of | 12 (14.3) 16 (19) 19 (22.6) 7 (8.3) 30 (35.7) |

*1= severe symptoms, 2= moderate symptoms, 3= mild symptoms, 4= minimal symptoms, 5= no symptoms

Table 3 shows the effects of non-physical chemotherapy that “fear of death”, “affect my work/household duties”, and “feeling fearful” were the severe symptoms that concern the patient (15.5% each), followed “feeling anxious about my life” and “presence of family members I have to take care of” (14.3% each). The most of these symptoms felt by patients are in the moderate and mild symptom categories.

Cancer has a negative perspective on society. Patients who know that they have cancer will feel anxious and feel that they will die quickly in a sad condition and only become a burden for others (Sudana, Chrisnawati, & Maratning, 2016). Research conducted by Sofia, Tahlil, and Marthoenis, (2018) on cancer patients found that cancer has an effect on the patient's life, making patients unproductive due to repeated chemotherapy, fear of death threats, fear of being alone and uncertainty, anxiety, stress, optimism about treatment and life after chemotherapy.

Research by Khamidah, Indra, and Lita, (2019), also found that the majority of breast cancer patients have a negative stigma against their disease and feel that they will soon die. Research Yilmaz et al., (2019) also found that in
Turkish society there is a belief that cancer is incurable, cancer is fatal, patients with cancer are disabled, cancer patients cannot return to work, and cancer sufferers are incompetent. According to the researchers' assumptions, the development of this kind of assumption among the community is due to the often late arrival of cancer patients to health care centers so that they are already in an advanced stage where treatment options are limited and their life expectancy decreases.

Being diagnosed with cancer can cause various negative feelings in the patient such as anxiety, or fear (Ayurini & Parmitasarai, 2015). The results of the research by Andinata, Marni, dan Erianti, (2020) found that 54.2% of cancer patients undergoing chemotherapy experienced moderate anxiety and 36.5% experienced severe anxiety. Meanwhile, research by Pratiwi, Widianti, dan Solehati, (2017) found that the majority of patients undergoing chemotherapy experienced moderate anxiety. One of the causes of this anxiety is a change in the status of the role in the family, such as a wife or mother is unable to take care of her husband or child properly (Pratiwi et al., 2017; Andinata et al., 2020).

When compared between the two chemotherapy side effects experienced by patients, it can be seen that physical side effects are still the most severe symptom with the severity of the patient's complaint compared to non-physical side effects. This can be seen from the percentage for physical symptoms which are at ≥15.5% while non-physical symptoms are at ≤15.5%.

This study has limitations, namely that it was conducted in a government hospital with a small sample size, so the findings of this study may not represent the condition of patients in other hospitals, especially private hospitals whose patient characteristics may differ. Further research can be explored further on how patients' perceptions of chemotherapy side effects using qualitative methods, using a larger sample, or comparing the perceptions of cancer patients between government hospitals and private hospitals.

4. Conclusion and Suggestion

Patients' perceptions of chemotherapy side effects which were very severe were still dominated by physical symptoms. It is hoped that nurses will provide interventions related to prevention and efforts to minimize the side effects of chemotherapy experienced by patients in addition to medical therapy that has been obtained by patients.

5. Acknowledgments

We would like to thanks the Institute of Health Science Hang Tuah Pekanbaru through the Center for Research and Community Service who has provided research grants so that this article is published and then all of the patients who participated in this study.

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