Perspective of Uncertainty and Emotional Responses in Breast Cancer Patients During the COVID-19 Pandemic

Lilik Supriati, RN, MN[1,2] , I Ketut Sudiana, PhD[3],
Hanik Endang Nihayati, PhD, RN[1,4], Ahsan, PhD[2],
Muhammad Rodli, MD[4] and Rinik Eko Kapti, RN, MN[2]

Abstract

Introduction: Breast cancer is a chronic disease that has implications for many aspects of the patient's life. Contracting the COVID-19 virus places cancer patients at a higher risk of infection. This condition triggers uncertainty which causes emotional responses.

Objective: The aim of this study was to measure the relationship between the uncertainty perspective of breast cancer patients and emotional responses during the COVID-19 pandemic.

Methods: This study used an observational study with a cross-sectional design. Data was collected from May to December 2021. The total sample of this study was 110 breast cancer patients undergoing chemotherapy at the Army Hospital of Dr. Soepraeon Malang, Indonesia. We used purposive sampling. The questionnaire used was a modified questionnaire from the Mishel Uncertainty in Illness Scale, a modified questionnaire from the Concerns about Recurrence Questionnaire, a modified questionnaire from the Zung Self Rating Anxiety Scale, and a modified questionnaire from the Depression, Anxiety, and Stress Scale. Data was analyzed using SPSS with a Spearman correlation test.

Results: The mean uncertainty of the respondents was 75.98 or in the moderate category, emotional response was moderate fear with a mean score of 18.40, the average anxiety score was 41.05 or normal, and the mean depression score was 15.96 or low depression. In addition, there was a significant relationship between uncertainty and the emotional response among breast cancer patients in the era of the COVID-19 pandemic ($p < .05$).

Conclusion: This study showed that there was a relationship between uncertainty and emotional response among breast cancer patients. It is important for nurses to provide good information about the disease among patients by using therapeutic communication and paying attention to the negative emotional responses of breast cancer patients.

Introduction

Since it was first announced in December 2019, the number of COVID-19 sufferers has continued to increase. Up to July 20, 2020, the coronavirus disease (COVID-19) pandemic had reached 14,689,596 cases in 251 countries. The Ministry of Health of the Republic of Indonesia first reported cases of COVID-19 in March 2020. The incidence in East Java was the highest nationally in 2020. Based on data from the Directorate General of Disease Prevention and Control of the Ministry of Health of the Republic of Indonesia, the COVID-19 death rate in East Java reached around 6.92%. Patients who have comorbid chronic disease such as breast cancer will have a higher incidence of COVID-19 (Guan et al., 2020; Zhang et al., 2020). Preliminary data of nationwide analysis in China demonstrated

[1]Faculty of Nursing, Universitas Airlangga, Surabaya, Indonesia
[2]Nursing Department, Faculty of Health Science, Brawijaya University, Malang, Indonesia
[3]Medicine Faculty, Universitas Airlangga, Surabaya, Indonesia
[4]Anaesthesiology and Intensive Care Department, Faculty of Medicine, Brawijaya University, Malang, Indonesia

Corresponding Author:
Lilik Supriati, Faculty of Nursing, Universitas Airlangga, Surabaya, 60115, Indonesia.
Email: lilik.supriati-2019@fkp.unair.ac.id

cancer as a risk factor for developing severe complications/disease among COVID-19 patients. However, further studies are required in order to accurately estimate the risk (Vanni et al., 2020).

Breast cancer is the second most common type of cancer experienced by women in the world, including in Turkey (Ozdemir & Tas Arslan, 2018) and the United States (Reiser et al., 2019). In Indonesia, breast cancer is the most common cancer treated in hospitals. The incidence of cancer in Indonesia (136.2/100,000 population) is ranked 8th in Southeast Asia, while in Asia, it is ranked 23. The highest incidence rate for women is breast cancer, which is 42.1 per 100,000 population with an average death rate of 17 per 100,000 (Health, 2019). Cancer is the leading cause of death worldwide, accounting for 7.6 million deaths or about 13% of the total deaths in 2008 (Gopalan et al., 2019). The uncertainty felt by patients in the era of the COVID-19 pandemic caused psychological distress problems and difficulties in daily life. "We observed the patients' perception of the COVID-19 pandemic's impact on distress and everyday life, the vast majority of the patients (80%) stated that they were heeding their own health during the COVID-19 pandemic, and emphasized the only importance of adhering to their hospital appointment schedule" (Koinig et al., 2021). It is also the same in other types of cancer, "Gynaecological cancer patients expressed significant anxiety about progression of their disease due to modifications of care related to the COVID-19 pandemic" (Gultekin et al., 2021).

Review of Literature

"Preliminary data of nationwide analysis in China demonstrated cancer as a risk factor for developing severe complications/disease among COVID-19 patients" (Vanni et al., 2020). Although further studies are required in order to accurately estimate the risk among patients who underwent chemotherapy or surgery in the months prior to the outbreak, the risk of developing severe conditions seems considerably higher compared to the general population (Liang et al., 2020). The COVID-19 pandemic has also changed the service system for breast cancer patients, including the regulation of chemotherapy services (Gultekin et al., 2021). As a result, the COVID-19 pandemic affects the mental health of breast cancer patients (Koinig et al., 2021).

Facing cancer with a variety of treatment and therapy processes, life-threatening conditions, uncertain cancer course and prognosis, and future living arrangements are causes of uncertainty among patients (Clayton et al., 2017; Klungrit et al., 2019; Zhang, 2017); "Identified uncertainty felt by patients including a lack of medical information, incomplete understanding of treatment choices or the typical course of disease, and difficulty coping with the precariousness of daily life" (Zhang, 2017). In addition, the COVID-19 pandemic has caused significant disruptions to the cancer care system, including the shift to virtual consultations, restrictions on family accompanying the patient to examinations and therapy, and the abundance of information on alternative medicine offers (Verma et al., 2022). Based on previous research, it was stated that 80% patients were heeding their own health during the COVID-19 pandemic and as many as 17% reported delaying therapy appointments at the hospital for fear of being infected with the COVID-19 virus (Koinig et al., 2021). During the COVID-19 outbreak, all countries adopted social distancing strategies and individual restrictions to reduce the spread of infection, including the number of cancer patient visits (Viale et al., 2020).

Health system changes during COVID-19. It can trigger uncertainty which causes an emotional response, namely fear of recurrence, anxiety and depression (Arambasic et al., 2019; Koinig et al., 2021). These negative emotional responses have detrimental impacts on the risk of decreasing the immune system of breast cancer patients. So, it is important to investigate the relationship between the uncertainty perspective of breast cancer patients and emotional responses during the COVID-19 pandemic era in the Army Hospital of Dr. Soepraoen Malang, Indonesia.

Methods

Design

This study used a cross-sectional design with an observational approach.

Research Question

Was there any relationship between the uncertainty of breast cancer patients and emotional responses during the COVID-19 pandemic?

Sample

Data was collected from May to December 2021. The population was cancer patients aged from 26 to 60 years, with total sample of 110 breast cancer patients undergoing chemotherapy at the Army Hospital of Dr. Soepraoen Malang, Indonesia. It is a Level II hospital belonging to the Indonesian Army, which is equivalent to a class B general hospital that has received a Plenary Level Hospital Accreditation Certificate from the Hospital Accreditation Commission. This hospital is a special referral unit for handling COVID-19 cases nationally in East Java, and also provides chemotherapy services. The number of breast cancer patients undergoing chemotherapy at this hospital was approximately 10 patients every day, but during the COVID-19 pandemic, the maximum number of patients receiving chemotherapy was only 5 patients per day. The sampling technique used purposive sampling in accordance with the inclusion criteria.

Ethical Consideration

This study was granted ethical clearance under number 2386-KEPK by the Institutional Review Board (IRB) Faculty of Nursing, Universitas Airlangga.

Data Collection and Procedure

The research process begins with licensing and obtaining ethical clearance by complying with the strict COVID control protocol at the hospital. Detailed informed consent was provided to each respondent without any coercion to participate in the study. Data was collected offline by providing a self-assessment questionnaire.

This study used a paper-based questionnaire. Respondents filled the questionnaires according to their conditions. We used SPSS for data analysis. The data input process began with editing. Editing refers to checking the completeness of the data in the questionnaire. Furthermore, coding to facilitate the score and interpretation of the range value. We also checked missing and error data, after that the data were analyzed using univariate and bivariate analysis.

Instrument for Data Collection

The adult form of the Mishel Uncertainty in Illness Scale (MUIS) (Giammanco et al., 2015), frequently used for hospitalized adult patients, was translated from English into Indonesian and adapted to the context under investigation. In this version for breast cancer patients, 6 of the 33 items of the MUIS were excluded because in this study used three indicators of uncertainty. They were information ambiguity, the complexity of therapy, and unpredictability of disease. The dimension of inconsistency from original the MUIS was not used in this study. The inconsistency may also be in the information that patient received about how to manage their illness and lifestyle changes was already represented by the dimension of ambiguity of information. Ambiguity contains 9 items that concerns the indistinctness of the cues about the state of illness and inadequate information received that was not the same as previous information received. Complexity consists of nine items cues about the treatment and the system of care that were multiple, intricate and varied. Unpredictability includes nine items and refers to the lack of contingency between illness and treatment cues and illness outcome. The items of original MUIS were rated on a 5-point Likert scale: 5 = "strongly agree," 4 = "agree," 3 = "I do not know – undecided," 2 = "disagree," 1 = "strongly disagree." This study used a Likert scale consisting of four options (1): strongly disagree, (2): disagree, (3): agree, (4): strongly agree. The adopted MUIS which consists of 27 items have been tested for validity and reliability. The convergent validity test in the study was carried out on breast cancer patients who had the same characteristics as the respondents in the study, 30 people in total, and was conducted at the Army hospital of Dr. Soepraoun Malang from March to April 2021. The value of r product moment at sig 0.05 was 0.361. If r count > 0.361, the item was declared valid. The results of the 27 items validity test of the uncertainty, there were 21 valid items and 6 invalid items that have an r value $< .361$. The result of the reliability test of 21 valid items was 0.963 which indicated the 21 items were consistent for measuring the uncertainty in breast cancer woman.

The other questionnaire was the concerns about the recurrence questionnaire (Humphris et al., 2018). It consisted of seven items, all of them have an r value > 0.361 and the result of the reliability test was 0.808 which indicates that the seven items were consistent for measuring the fear variable. The questionnaire was from the Zung Self Rating Anxiety Scale (Dunstan & Scott, 2020). It has 19 valid items and the score reliability test was 0.798. The depression anxiety stress scale (DASS) was adopted (Imam, 2008). In this study, from the original 21 DASS items consisting of three domains, depression, anxiety, and stress, eight items were taken that represent the depression domain only. It showed a reliability test of 0.844 which indicates that they were consistent in measuring the depression of breast cancer woman. All of the questionnaire were translated into the local language, Indonesian. The translation of the adjustment questionnaire was performed by a native Indonesian speaker, as was the validated retranslation into English.

Data Analysis

Data were screened for missing items. Only two items were found to be missing and have been corrected. Total scale scores were computed for measures uncertainty and emotional responses. Subscale score were computed for fear of recurrence, anxiety, and depression. The score of each indicator categorized as follows: fear of recurrence score 7–14 (low), 15–21 (moderate), and 22–28 (high); anxiety score < 45: normal, score 45–59: mild-moderate anxiety, score 60–74: severe anxiety, score > 75: very severe anxiety; score depression 9–18 (low depression), 19–27 (moderate), 28–36 (high). Score indicators of uncertainty consisted of information ambiguity, therapy complexity and disease unpredictability were 7–14 (low), 15–21 (moderate), 22–28 (high level). All of them were analyzed as continuous variables. Descriptive statistics (frequency, percentage, mean, and standard deviation) were computed to describe the demographic, medical characteristics of participants, uncertainty and its subscale (information ambiguity, therapy complexity, disease unpredictability), emotional responses and its subscale (fear of recurrence, anxiety, depression). The Pearson correlation coefficient test was used for continuous and interval variables with a significance of alpha 0.05.

Results

Characteristics of Participants

Table 1 shows the description of the characteristics of the respondents. Based on Table 1, it can be seen that the majority of respondents have an elementary school education level, most of them do not work, and the highest cancer stage is stage III. The average age of the respondents was 47.05 years with the lowest age being 27 years and the maximum age being 60 years; the average length of illness was 22.37 months with minimum 6 months and maximum 60 months; the average number of chemotherapy cycles received was 4, with a minimum of two chemotherapy sessions.

Table 2 shows the description of the independent variables. It can be seen that the average respondent's information ambiguity value is 18.95 (moderate), the complexity of therapy is 18.44 (moderate), and disease unpredictability is 18.68 (moderate). The average respondent's total uncertainty score is 75.98 with a minimum value of 61 and a maximum of 100. This can be interpreted as patient uncertainty regarding breast cancer during the COVID-19 pandemic being at the moderate level.

Table 3 shows the description of dependent variables, it can be seen that the average respondent's emotional response is 75.43 (in the moderate category), with an average fear of recurrence indicator of 18.40 (moderate fear), the average anxiety is 41.05 (normal), and a mean depression score of 15.96 (low depression).

Table 4 showed the correlation among variables. The result shows that there is a significant relationship between

information ambiguity, therapy complexity, and disease unpredictability with fear, anxiety, and depression (p-value < .05); with the greatest correlation value between disease unpredictability and fear of recurrence. There is a significant relationship between the total uncertainty score with fear, anxiety, and depression (p-value <.5). The strongest relationship is uncertainty with depression ($r = 0.751$), meaning that the higher the uncertainty perceived by breast cancer patients then higher is the depression. In addition, there is also a significant relationship between the uncertainty score and emotional responses (p-value <.5) with strong relationship and positive direction, which means that the higher the uncertainty score then higher is the emotional response.

Discussion

This study aimed to measure the correlation of perceived uncertainty with the emotional response of breast cancer patients in the era of the COVID-19 pandemic, and to explore the relationship of each indicator to the fear of recurrence, anxiety, and depression. The results of this study indicate that the value of uncertainty in the COVID-19 era is in the moderate category for this limited population. This study is in line with the results of a survey conducted in Rome, Italy which showed that cancer patients also experience uncertainty and anxiety (Biagioli et al., 2021). Uncertainty is a concept related to information-processing models that involve cognitive status which represents the inadequacy of cognitive patterns that support the interpretation of disease-related events (Alligood, 2014). The ability to interpret a disease positively is influenced by the level of education. In this study, most of the respondents had a basic education level (43.6%), of course this affected the ability of breast cancer patients to absorb and interpret the information received about the disease and therapy.

Cancer symptoms, treatment efficacy, recurrence potential, health outcomes, and inadequate information can be potential sources of uncertainty (Sajjadi et al., 2016). COVID-19 may live with us for many months and perhaps years, and there is also a considerable concern over the potentially severe impact of COVID-19 on cancer patients, which

Table 1. Distribution of Respondent Characteristics.

Characteristic	N	(%)	
Level of education			
Elementary school	48	43.6	
Junior high school	24	21.8	
Senior high school	19	17.3	
College	19	17.3	
Occupational			
Employed	54	49.1	
Unemployed	56	50.9	
Stage of breast cancer			
I	2	1.8	
II	36	32.7	
III	48	43.6	
IV	24	21.8	
		Mean (SD)	Min–Max
Age	110	47.05 (6.65)	27–60
Length period of illness	110	22.37 (15.48)	6–60
Number of chemotherapy cycles received	110	4.89 (2.35)	2–16

Table 2. Description of Independent Variables.

Variable	Indicator	n	Mean (SD)	Min–Max
Uncertainty	Information ambiguity	110	18.95 (4.19)	10–28
	Therapy complexity	110	18.44 (3.79)	12–28
	Disease unpredictability	110	18.68 (3.94)	13–27
Uncertainty total score		110	75.98 (9.38)	61–100

occurs alongside the psychological effects that worsen patients' well-being. It is important to consider the needs of cancer patients at the same level as those receiving care for COVID-19 and other illnesses. Knowing that the individual is at higher risk of serious complications if infected by COVID-19, as well as loneliness and isolation as a result of social distancing, and the underlying constant fear of the cancer, makes patients' feelings of uncertainty associated with their prognosis and emotional distress have negative effects on clinical outcomes (Lissidini et al., 2022). Uncertainty occurs because the person's decisions cannot assign a definite value to the objects. Women with breast cancer who are undergoing treatment who have a lack of information about their disease, treatment, and unexpected side effects can contribute to high levels of uncertainty (Zhang, 2017). Women with breast cancer are challenged to manage distress, participate in treatment regimens, and deal with the side effects of chemotherapy, so it is necessary to obtain appropriate information to assist patients with making decisions (Zhang et al., 2015).

The condition of the COVID-19 pandemic has brought many changes to human life, including chemotherapy services at Dr. Sopraoen Malang Hospital. There are health protocol procedures for preventing the transmission of the COVID-19 virus for patients and health workers, such as a change in the number of service capacities for patients receiving chemotherapy every day, and limited interaction between patients and health workers. These conditions are similar in Rome, Italy which showed that the COVID-19 outbreak had changed the allocation of medical resources, which resulted

in breast cancer patients having to worry about cancer treatment and anxiety problems related to COVID-19, which influenced the decision making of breast cancer patients with regard to their treatment (Vanni et al., 2020).

Another indicator of uncertainty is the unpredictability of the disease, the average value of this study is 18.68 or in the fairly high category. Cancer causes its own trauma to the patient, the course of the disease, and the uncertain therapeutic prognosis create uncertainty in the patient which requires them to be able to interpret the disease (Martino & Freda, 2016). The increase in cases and the spread of COVID-19 among patients with comorbidities also contributes to the uncertainty among them (Guan et al., 2020).

The experience of emotional problems among patients with breast cancer that often occur are depression, anxiety, and fear (Castillo et al., 2019). The results showed that the fear recurrence experienced had an average of 18.40 or was in a fairly high category. The cause of increased anxiety in the COVID-19 era is the patient's fear of being exposed to the virus and this makes the condition worse. This is consistent with the previous study in Turkey which stated that gynecologic cancer patients expressed significant anxiety about the progression of their disease due to changes in treatment modifications in hospitals related to the COVID-19 pandemic (Gultekin et al., 2021). In addition, there is also a relationship between morbidity and mortality in cancer patients who are undergoing active treatment. Surgical mortality in cancer patients infected with COVID-19 on a peri-operative basis has been reported to be as high as 25%, leading to delays and modification of surgery and chemotherapy protocols during the height of the pandemic (Gultekin et al., 2021, Xia et al., 2020). In this study, the average length of illness of the respondents was 22.37 months, with the least illness duration of 6 months and the maximum 60 months (5 years). Most of the respondents can adapt and try to accept their breast cancer, but the COVID-19 pandemic condition becomes a stressor of its own uncertainty for patients.

The results of the analysis show that there is a significant relationship between uncertainty and fear (*p*-value < .05), anxiety, and depression in breast cancer patients (*p*-value < .05), whereby the higher the uncertainty the higher is the fear, anxiety, and depression. The results of this study are

Table 3. Description of Dependent Variables.

Variables	Indicator	*n*	Mean (SD)	Min–Max
Emotional responses	Fear of recurrence	110	18.40 (4.46)	11–28
	Anxiety	110	41.05 (4.06)	30–48
	Depression	110	15.96 (4.19)	9–29
Emotional responses total score		110	75.43 (9.61)	57–99

Table 4. Correlation Among Variables.

							Dependent variables	
	Fear of recurrence		Anxiety		Depression		Emotional response	
Variable independent	R	*p*-value	r	*p*-value	r	*p*-value	r	*p*-value
Information ambiguity	.283	.003	.291	.021	.297	.002		
Therapy complexity	.262	.006	.281	.003	.215	.024		
Disease unpredictability	.336	.000	.272	.004	.247	.009		
Score total uncertainty	.375	.000	.751	.000	.785	.000	.837	.000

also in accordance with another study which states that uncertainty is one of the predictors of quality of life and increases the fear in prostate cancer patients (Parker et al., 2016). These results are also consistent with other studies which state that facing cancer along the trajectory of the disease, due to the ambiguity of information about the state of the disease, the complexity of the treatment being undertaken and the seriousness of the consequences of cancer experienced, leads to uncertainty that provides emotional responses (He et al., 2016).

Conclusion

There was a significant relationship between uncertainty and the emotional response of breast cancer patients in the era of the COVID-19 pandemic. The higher the uncertainty, the higher is the fear, anxiety, and depression experienced by the patients. Therefore, it is important for nurses to help reduce this uncertainty by providing good support information about breast cancer and their therapies, such as giving health education using good therapeutic communication with an empathetic approach and motivating the patient's spirit. Nurses must increase patient knowledge by accessing information from the right sources about breast cancer and handling COVID-19 properly. In addition, nurses must also pay attention to the problem of emotional distress by providing education and training skills to think positively, be grateful, increase the ability to relax, and live a healthy lifestyle.

The research limitation was the number of respondents, which is only 110 people, which is still insufficient to describe the real situation. This study ignored treatments that patients had already received, such as mastectomy and radiotherapy, which can affect uncertainty about their breast cancer and their emotional responses.

Declaration of Conflicting Interests

The authors declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

Ethical

The procedure was reviewed and granted ethical clearance (number: 2836-KEPK) by the Institutional Review Board (IRB) at Nursing Faculty, Universitas Airlangga, Indonesia.

ORCID iD

Lilik Supriati 🆔 https://orcid.org/0000-0002-8533-3319

Supplemental material

Supplemental material for this article is available online.

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