Original Article

The Relationship between Symptom Severity and Uncertainty in Illness in Cancer Patients in Aceh

Nurul Nisah[1], Hilman Syarif[2], Marlina[3]

[1]Master Program of Nursing Science Student, Universitas Syiah Kuala, Aceh, Indonesia,
[2,3]Faculty of Nursing, Universitas Syiah Kuala, Banda Aceh, Indonesia

How to cite this article: Nurul Nisah, Hilman Syarif, Marlina. The Relationship between Symptom Severity and Uncertainty in Illness in Cancer Patients in Aceh. International Journal of Nursing Education / Vol. 17 No. 4, October-December 2025

Abstract

Objective: This study aims to determine whether there is a significant relationship between symptom severity and uncertainty in illness in cancer patients at one of the referral hospitals in Aceh province, Indonesia. Uncertainty in illness is a condition in which individuals have difficulty predicting, controlling, and understanding the development of their disease. In cancer patients, high symptom severity has the potential to increase uncertainty in illness.

Material and Methods: This study is a quantitative research using a correlational design with a cross-sectional approach. This study was conducted from January to February 2025 at one of the referral hospitals in Aceh province. The sample consisted of 142 women diagnosed with breast cancer, ovarian cancer, and cervical cancer who were selected using a purposive sampling technique. Data were collected using a questionnaire consisting of sociodemographic characteristics, MD Anderson Symptom Inventory (MDASI), and Mishel Uncertainty in Illness Scale (MUIS). For MUIS, the Cronbach's Alpha was 0.81. Data analysis utilized the Chi-square test to examine the association between categorical variables.

Results: The results showed that the majority of respondents (n=142) were patients with breast, ovarian, and cervical cancer. A total of 112 patients (78.9%) experienced a high level of uncertainty in illness, while 30 respondents (21.1%) experienced a low level of uncertainty in illness. Then out of a total of 142 respondents, 77 respondents (54.2%) experienced severe symptom severity, while 65 respondents (45.8%) experienced mild and moderate symptom severity. This shows that there is a significant relationship between symptom severity and uncertainty in illness ($p = 0.030$).

Conclusion: There was a significant relationship between symptom severity and uncertainty in illness ($p = 0.030$).

Recommendation: It is recommended that further research be conducted with longitudinal or mixed methods design to gain a deeper understanding of the dynamics of uncertainty in illness.

Keywords: Uncertainty; Cancer; Symptom; Severity

Corresponding Author: Hilman Syarif, Master Program of Nursing Science Student, Universitas Syiah Kuala, Aceh, Indonesia.

E-mail: hilmansyarif@usk.ac.id

Submission: May 14, 2025 **Revision:** June 17, 2025 **Published date: October 22,2025**

Introduction

Cancer is one of the non-communicable diseases that is of serious concern globally due to its high morbidity and mortality rates. According to the World Health Organization WHO, (2023), cancer is still the leading cause of death worldwide. Data from the International Agency for Research on Cancer (IARC) in 2022 shows that in 2022 there will be around 20 million new cancer cases with 9.7 million deaths. The most common types of cancer worldwide are lung cancer (12.4%) and breast cancer (11.6%), followed by colorectal (9.6%), prostate (7.3%), and gastric (4.9%) cancers[1,2] 7 juta kematian di seluruh dunia, dengan kanker paru-paru dan payudara sebagai yang paling umum. Ketimpangan dalam beban kanker dan kematian terjadi antara negara-negara dengan indeks pembangunan (IPM).

Cervical cancer and ovarian cancer are also epidemiologically significant types of cancer. Cervical cancer ranks fourth globally with 662,301 new cases and 348,186 deaths, while ovarian cancer ranks eighth with 324,603 new cases in 2022[3]. Asia is recorded as the region with the highest burden of cancer, accounting for 49.2% of all global cancer cases (9,826,539 cases) and 56.1% of total cancer deaths[4].

In Indonesia, cancer is a serious public health problem. Based on the latest data from Globocan 2022, there were approximately 396,914 new cancer cases and 251,272 cancer-related deaths in Indonesia. Breast cancer remains the most common type of cancer among women[1,5], Specifically in Aceh Province, data from the Aceh Health Office 2023 report indicated 1,500 new cancer cases occurred throughout the year[4,6]

While specific incidence rates per 100,000 population for breast cancer in Aceh for the most recent year are not readily available from publicly accessible official sources like Globocan, the consistently high number of reported cases underscores the significant health burden of cancer in the province[7]. In addition to the physical impact, cancer patients also experience significant psychological burdens, including anxiety, depression, and stress, which can lower their overall quality of life[8]. This burden is even heavier when patients face uncertainty in illness related to their illness.

Uncertainty in illness is a situation when individuals are unable to predict, control, or understand the condition of the disease they are experiencing[9]. This condition often occurs in cancer patients, especially women, who are dealing with physical, emotional, and long-term medical changes. Uncertainty in illness has a negative impact on patients' mental health, productivity, and quality of life.

Several studies show that uncertainty in illness correlates with increased psychological stress, mental health disorders, and decreased quality of life. About 30–50% of cancer patients experience psychological stress, and among them, about 60% report experiencing uncertainty in illness[10,12] emotional distress, and uncertainty and examine the predictive value they have on the quality of life of advanced cancer patients. A prospective, multicenter study was conducted between February 2020 and May 2021 of individuals diagnosed with an advanced, unresectable neoplasm prior to initiating systemic antineoplastic treatment. Participants completed questionnaires to quantify fatigue, emotional distress, disease uncertainty, and quality of life. A linear regression analysis was performed to study the predictive QoL variables. The study population comprised 508 patients, 53.7% of whom were male and had a mean age of 54.9 years. The most common cancers were digestive (40.6%. Further, uncertainty in illness describes the individual's difficulty in understanding the meaning and impact of illness, which leads to feelings of loss of control, feelings of hopelessness, and disruption in adaptation to illness[10] emotional distress, and uncertainty and examine the predictive value they have on the quality of life of advanced cancer patients. A prospective, multicenter study was conducted between February 2020 and May 2021 of individuals diagnosed with an advanced, unresectable neoplasm prior to initiating systemic antineoplastic treatment. Participants completed questionnaires to quantify fatigue, emotional distress, disease uncertainty, and quality of life. A linear regression analysis was performed to study the predictive QoL variables.

The study population comprised 508 patients, 53.7% of whom were male and had a mean age of 54.9 years. The most common cancers were digestive (40.6%).

Material and Methods

Research design and setting

This study is a quantitative research with a correlational design and a cross-sectional approach. This study aims to explore the relationship between symptom severity and uncertainty in illness in cancer patients at one of the referral hospitals in the province of Aceh, Indonesia.

Population and sample

The population in this study was all female patients diagnosed with breast, ovarian, and cervical cancer at Aceh provincial referral hospitals during the period of October to December 2024, with a total known population of 220 patients. Sample selection was carried out using the purposive sampling technique, resulting in 142 respondents calculated using the Slovin formula. This sampling method was chosen due to time constraints for educational purposes.

The sample criteria consist of inclusion criteria and exclusion criteria. Inclusion criteria: 1) women who are ≥ 18 years old, 2) women diagnosed with breast cancer, ovarian cancer, and cervical cancer, 3) Patients with composmentis awareness, 4) Patients in stable and cooperative conditions, 5) Patients who can see, hear, and read (all participants in this study were literate, therefore illiterate participants were not an issue for data collection), and 6) Diagnosed with ≥ cancer 1 year. The criterion of being diagnosed for ≥ cancer 1 year was included to focus on patients who have had longer experience with their illness, as many cancer patients in the region unfortunately do not continue treatment beyond the initial diagnosis phase. Meanwhile, patients with mental/ psychological disorders and patients who were experiencing severe pain at the time of data collection were excluded from this study.

Data collection for this study was carried out from January to February 2025. The MD Anderson Symptom Inventory (MDASI) questionnaire was distributed to measure the severity of symptoms, consisting of 27 question items with a Cronbach's alpha of 0.80. Uncertainty in illness was measured using the Mishel Uncertainty in Illness Scale (MUIS) questionnaire, which consisted of 10 question items with a Cronbach's Alpha of 0.81. All procedures in this study were carried out after obtaining proof of passing the research ethics with Number 329/ETIK-RSUDZA/2024.

Statistical Analysis

Descriptive statistics (frequency and percentage) were used to summarize sociodemographic characteristics and the distribution of symptom severity and uncertainty in illness. Given that the variables in this study were categorical, the Chi-square test was used to examine the association between symptom severity and uncertainty in illness.

Results

Table 1: Distribution of Sociodemographicin Cancer Patients (n = 142)

No.	Sociodemographic	Frequency (f)	Percentage (%)
1.	Respondent Age		
	≤ 30 years old	3	2.1
	> 30 years old	139	97.9
2.	Educational background		
	Basic	4	2.8
	Secondary	117	82.4
	College	21	14.8

No.	Sociodemographic	Frequency (f)	Percentage (%)
3.	Work		
	Homemaker	107	75.4
	Civil servant	21	14.8
	Self employed	8	5.6
	Unemployed	6	4.2
4.	Income/month		
	≤ IDR 3,000,000.00	114	80.3
	> IDR 3,000,000.00	28	19.7
5.	Marital status		
	Unmarried	3	2.1
	Married	137	96.5
	Life/death divorce	2	1.4
6.	Types of Cancer		
	Breast cancer	118	83.1
	Ovarian cancer	22	15.5
	Cervical cancer	2	1.4
7.	Long diagnosed		
	≥ 1 year	36	25.4
	>2year	106	74.6
8.	Chemo cycle		
	Cycle I	8	5.6
	Cycle II	58	40.8
	Cycle III	34	23.9
	Cycle IV	19	13.4
	Cycle V	14	9.9
	Cycle VI	9	6.3
9.	Stage of cancer		
	II	5	3.5
	III	112	78.9
	IV	25	17.6

Table 2: Description of Symptom Severity and Uncertainty in Illness in Cancer Patients (n = 142)

Variables	f	%
Symptom Severity		
Mild and moderate symptoms	65	45.8
Severe symptoms	77	54.2
Uncertainty in Illness		
Low Uncertainty	30	21.1
High Uncertainty	112	78.9

Table 3: Relationship Between Symptom Severity and Uncertainty in Illness (n = 142)

Symptom Severity	Uncertainty in illness				Total		*p*
	Low		High				
	n	%	n	%	n	%	
Mild and moderate symptoms	19	29.2	46	70,8	65	100	0.030
Severe symptoms	11	14.3	66	85.7	77	100	

The results of the study showed that out of a total of 142 respondents, the majority were aged Over 30 years old, namely 139 respondents (97.9%). In terms of education level, as many as 117 respondents (82.4%) had a secondarylevel. In addition, 107 respondents (75.4%) were not working or had the status of housewives (IRT), and 114 respondents (80.3%) had an income of less than 3 million rupiah/month. Meanwhile, the marital status of 137 respondents (96.5%) was married. The majority of respondents diagnosed with breast cancer were 118 respondents (83.1%), and 106 respondents (74.6%) had been diagnosed with cancer more than 2 years ago. Among the respondents who underwent chemotherapy, the majority of respondents (40.8%) underwent the second cycle of chemotherapy and most of the respondents were in stage III cancer with a total of 112 respondents (78.9%).

A total of 142 cancer patients participated as respondents in this study, 77 respondents (54.2%) experienced severe category of symptoms, and 112 respondents (78.9%) experienced high level of uncertainty in illness. The results of the analysis indicated that among the 77 respondents with severe symptom severity, 66 (85.7%) experienced a high level of uncertainty. These findings suggest a significant association between symptom severity and uncertainty in illness ($p = 0.030$).

Discussion

Symptom severity is one of the key factors influencing patients' perception of their illness, particularly among individuals with chronic diseases such as cancer. Severe, persistent, or unpredictable symptoms often trigger uncertainty in illness, which refers to a patient's difficulty in understanding or interpreting their health condition.

According to Mishel's Uncertainty in Illness Theory, uncertainty arises when individuals are unable to clearly interpret bodily signals or medical information. Severe and fluctuating symptoms such as pain, extreme fatigue, and sleep disturbances serve as sources of ambiguity and can heighten uncertainty regarding prognosis and treatment effectiveness.

These symptoms may also disrupt patients' sense of self-control and contribute to psychological distress[9,13].

The results of this study indicated that the majority of respondents (97.9%) were over the age of 30. Most participants were married, identified as housewives, and were in an advanced stage of cancer (Stage III). Breast cancer emerged as the most prevalent diagnosis among respondents. Furthermore, the majority had been diagnosed for more than two years and were undergoing the second cycle of chemotherapy. These findings reflect a clinical context characterized by a high and complex symptom burden. Being a housewife, for instance, may exacerbate the severity of symptoms due to the added responsibilities of managing household duties and caring for family members. The symptom burden experienced by these patients likely extends beyond physical complaints to include psychological distress, both of which may contribute to heightened levels of uncertainty in illness.

This is supported by the findings of the study, which showed that more than half of the respondents (54.2%) were in the group experiencing severe symptom severity, and 85.7% of them reported a high level of uncertainty in illness. These results indicate a significant association between symptom severity and uncertainty in illness (p = 0.030). This suggests that the more severe the symptoms experienced, the higher the level of uncertainty perceived by cancer patients.

Severe symptoms such as chronic pain, extreme fatigue, sleep disturbances, and cognitive decline have a direct impact on the physical and psychological well-being of patients. When these symptoms are unpredictable or do not respond to treatment, patients may experience increased anxiety, stress, and even feelings of helplessness in dealing with their illness. Such conditions lead to a perceived loss of control over one's own body, which in turn exacerbates the experience of uncertainty.

Previous studies support these findings. Fardell et al. found that symptoms such as fatigue, cognitive impairment, and pain affect the work ability and social roles of cancer survivors, which are associated with uncertainty in social and economic domains[14]. Similarly, Büthe et al. reported that symptoms such as dry mouth and loss of appetite led to changes in eating patterns among older cancer patients, potentially triggering uncertainty related to nutritional status and overall health condition[15]. Guan emphasized that managing uncertainty is a critical component of patient care, as it can enhance the adaptation process, promote more effective coping strategies, and support the psychological well-being of both patients and their families[11].

Consistent with the findings of this study and supported by Hall et al. symptom severity is a significant factor contributing to increased uncertainty in illness among cancer patients. Hall and colleagues emphasized that greater uncertainty is associated with higher levels of fatigue, insomnia, and negative affect, particularly in younger breast cancer survivors, highlighting the critical impact of symptom burden on patients' psychological and physical well-being[16].

This is also in line with previous research, which states that uncontrolled symptoms are associated with increased emotional burden, anxiety, and depression, thereby exacerbating uncertainty[17]. Severely ill COVID-19 patients experienced a high level of uncertainty in illness, particularly related to ambiguous symptoms and a lack of information[18].

Wei et al. also found that lung cancer patients undergoing chemotherapy experienced a high symptom burden, which was associated with feelings of social alienation mediated by low social support and poor psychological conditions, ultimately contributing to increased uncertainty[19]. Safar added that symptom severity was negatively associated with the quality of life in cancer patients, emphasizing that symptom management plays a crucial role not only in addressing physical aspects but also in reducing uncertainty in illness[17]. Palliative care interventions were found to significantly reduce the severity of physical symptoms such as pain, dyspnea, and fatigue in advanced cancer patients, although psychological symptoms like anxiety and depression often persisted[20] and graded on a scale of 0 to 4 (0 = none, and 4 = extreme).

Based on the findings of this study and existing theoretical frameworks, symptom severity is a key factor that can increase uncertainty in illness among cancer patients. Therefore, it is essential for healthcare professionals to implement a comprehensive symptom management approach that includes both pharmacological and non-pharmacological interventions. Strategies such as cognitive-behavioral therapy, relaxation techniques, and therapeutic communication can assist patients in coping with symptoms and developing a more adaptive perception of their illness.

A holistic approach to symptom management is expected not only to reduce the physical burden experienced by patients but also to lower the level of uncertainty in illness, thereby improving the overall quality of life of individuals living with cancer.

Conclusion

There was a significant relationship between symptom severity and uncertainty in illness ($p = 0.030$).

Limitations of The Study

This study has limitations in assessing the causal relationship due to the design used. In addition, other factors such as social, cultural, and economic conditions have not been considered, and the absence of long-term data limits the understanding of changes in uncertainty in illness over time. Further studies are recommended using a more thorough design and more diverse methods for more in-depth results.

Recommendation

It is recommended that further research be conducted with longitudinal or mixed methods design to gain a deeper understanding of the dynamics of uncertainty in illness.

Ethical Consideration

All procedures in this study were carried out after obtaining proof of passing the research ethics with Number 329/ETIK-RSUDZA/2024.

Source of Funding: This research was funded independently by the researcher

Conflict of Interest: The author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

References

1. WHO. Cancer. World Health Organization. 2023. p. 1–8.
2. Globocan. Globocan 2022: Latest global cancer data show rising incidence and striking disparities [Internet]. Geneva: Union for International Cancer Control (UICC); 2024 [cited 2024 Jul 10]. p. 1–9. Available from: https://www.uicc.org/news/globocan-2022-latest-global-cancer-data-shows-rising-incidence-and-stark-inequities
3. World Cancer Research International. Global cancer data [Internet]. London: World Cancer Research International; 2022 [cited 2024 Sep 12]. p. 5. Available from: https://www.wcrf.org/cancer-trends/worldwide-cancer-data/
4. Ferlay J, M. Lam F E, Laversanne M, Colombet M ML, Piñeros M ZA, Soerjomataram I, et al. Global Cancer Observatory: Cancer Today [Internet]. International Agency for Research on Cancer. 2024. p. 1–2. Available from: https://gco.iarc.who.int/today
5. Ministry of Health Indonesia. Support system: a friend in every situation. In: Directorate General of Health Services [Internet]. Jakarta: Ministry of Health Indonesia; 2022. p. 1–5. Available from: https://yankes.kemkes.go.id/view_artikel/613/support-system-teman-dalam-segala-situasi
6. Dwi A. Number of cancer survivors in Aceh reaches 1,318. In: Republik Merdeka Political News Agency RMOLID. 2024. p. 1–4.
7. Cleeland CS, Zhao F, Chang VT, Sloan JA, O'Mara AM, Gilman PB, et al. The symptom burden of cancer: Evidence for a core set of cancer-related and treatment-related symptoms from the Eastern Cooperative Oncology Group Symptom Outcomes and Practice Patterns study. Cancer [Internet]. 2013 Dec 15;119(24):4333–40. Available from: https://acsjournals.onlinelibrary.wiley.com/doi/10.1002/cncr.28376
8. Siegel RL, Miller KD, Jemal A. Cancer statistics, 2020. CA Cancer J Clin [Internet]. 2020 Jan 8;70(1):7–30. Available from: https://acsjournals.onlinelibrary.wiley.com/doi/10.3322/caac.21590

9. Alligood RM. Nursing Theorists And Their Work Eighth Edition. In: Alligood, R M, editor. Nursing Theorists And Their Work Eighth Edition. 8th ed. United States of America: ELSEVIER MOSBY; 2014. p. 1–765.

10. Gonzalez G, Durantez VV, Martin-Abreu C, Cruz-Castellanos P, Hernandez R, Gil-Raga M, et al. Fatigue, Emotional Distress, and Illness Uncertainty in Patients with Metastatic Cancer: Results from the Prospective NEOETIC_SEOM Study. Curr Oncol [Internet]. 2022 Dec 8;29(12):9722–32. Available from: https://www.mdpi.com/1718-7729/29/12/763

11. Guan T. PATIENTS, CAREGIVERS, AND ILLNESS UNCERTAINTY: INFLUENCES ON COPING AND QUALITY OF LIFE. 2019;1–23.

12. Guan T, Qan'ir Yousef, Song L. A systematic review of illness uncertainty management interventions for cancer patients and their family caregivers. Exp Hematol Oncol [Internet]. 2021;4623–40. Available from: https://link.springer.com/article/10.1007/s00520-020-05931-x

13. Reilly CM, Bruner, Deborah Watkins Mitchell SA, Minasian. LM, Basch E, Dueck AC, Cella D, et al. A Literature Synthesis of Symptom Prevalence and Severity in Persons Receiving Active Cancer Treatment. Support Care Cancer [Internet]. 2015;21(6):1525–50. Available from: https://pmc.ncbi.nlm.nih.gov/articles/PMC4299699/

14. Fardell JE, Yee S, Tan C, Kerin-ayres K, Dhillon HM, Vardy JL. Symptom Clusters in Survivorship and Their Impact on Ability to Work among Cancer Survivors. Cancers (Basel) [Internet]. 2023;15(21):1–11. Available from: https://www.mdpi.com/2072-6694/15/21/5119

15. Büthe L, Westhofen G, Hille A, Büntzel J. Symptom Burden and Dietary Changes Among Older Adults with Cancer : A Cross-Sectional Study. Curr Oncol [Internet]. 2024;31(12):7663–85. Available from: https://www.mdpi.com/1718-7729/31/12/565

16. Hall DL, Mishel MH, Germino BB. Living with cancer-related uncertainty: associations with fatigue, insomnia, and affect in younger breast cancer survivors. Support Care Cancer [Internet]. 2014 Sep 12;22(9):2489–95. Available from: file:///C:/Users/Carla%0ACarolina/Desktop/Artigos%0Apara%0Aacrescentar%0Ana%0Aqualificação/The%0Aimpact%0Aof%0Abirth%0Aweight%0Aon%0Acardiovascular%0Adisease%0Arisk%0Ain

17. Safar H. The relationship between symptom burden, illness uncertainty, perceived social support, and health-related quality of life in Kuwaiti women with breast cancer [Internet]. Case Western Reserve University; 2021.Availablefrom:https://www.proquest.com/openview/3bdcb1617f79f7a09e29cbfa25a4fa83/1?pq-origsite=gscholar&cbl=18750&diss=y

18. Lan CF, Nie CL, Lin YJ. Uncertainty in illness and the coping styles of severe patients with COVID-19: current status and correlation. Epidemiol Infect [Internet]. 2021 Jul 8;149:e174. Available from: https://www.cambridge.org/core/product/identifier/S0950268821001448/type/journal_article

19. Wei J, Bai Z, Bu M, Dang G, Wu X, Zhou J. Influence of symptom burden on social alienation in lung cancer patients receiving chemotherapy : the chain mediating effect of perceived social support and positive psychological capital. BMC Psychol [Internet]. 2025;13:1–10. Available from: https://bmcpsychology.biomedcentral.com/articles/10.1186/s40359-025-02403-x

20. Tai SY, Lee CY, Wu CY, Hsieh HY, Huang JJ, Huang CT, et al. Symptom severity of patients with advanced cancer in palliative care unit: Longitudinal assessments of symptoms improvement. BMC Palliat Care [Internet]. 2016;15(1):1–7. Available from: http://dx.doi.org/10.1186/s12904-016-0105-8