

# Understanding Unmet Needs and Correlated Factors in Patients with Cancer Undergoing Medical Treatment

Wahyu Dewi Sulistyarini<sup>1</sup>, Rusdi<sup>2</sup>

<sup>1,2</sup> School of nursing, Wiyata Husada Institute of Health Technology and Science Samarinda, Indonesia

\* Corresponding author Email : [wahyudewis@stikeswhs.ac.id](mailto:wahyudewis@stikeswhs.ac.id)

## ABSTRACT

**Background:** Cancer is increasing, while advanced cancer treatment patients can even live a relatively long life. However, this condition is allowed the possibility of unmet needs increasing in cancer patients and lead to considerable symptom for patients including physical, psychological, emotional and social issues. Understanding unmet needs can help in the treatment of cancer patients. **Purpose:** to examine the unmet needs of patients with cancer undergoing medical treatment and correlated factors. **Methods:** this was cross-sectional survey conducted by online report. Patients with cancer undergoing treatment were recruited and completed the Short Form Survivor Unmet Needs Survey (SF-SUNS) Indonesian version. **Results:** two hundred and thirty-five cancer patients completed this survey. Patient's unmet needs were mainly related to financial and education level (p value < 0.001). It reported that unmet needs focused on the domain of financial (1.88), information (1.61), coping and emotional (1.54) and access and continuity care unmet needs (1.42). **Conclusions:** The results suggest that understanding unmet needs in patients with cancer would help health professionals to arrange specific intervention and give more clinical attention based on the needs of patients.

**Keywords:** unmet needs, cancer, financial, education, information need.

## 1. INTRODUCTION

The rising of cancer incidence becomes major health concern and serious problem in worldwide. According to World Health Organization (WHO) data, new cancer cases are expected to increase by 70% in the next two decades [1]. Indonesia has the eighth highest cancer rate in Southeast Asia (136.2/100,000 people), whereas Asia ranks 23<sup>rd</sup>. According to data from 2018, there were 18.1 million new cases with a 9.6 million fatality rate, with 1 in every 5 males and 1 in every 6 women in the world suffering from cancer. According to the data, one in every eight males and one in every eleven women died of cancer [2]. The illness trajectory and prognosis have changed as cancer treatment has progressed, allowing cancer patients to live longer [3]. However, long period living of patients and treatment make them experience

polysymptomatic distress. As a result of the lengthy treatment and care process, it has an impact on all part of their lives, including physical, psychological, social, and spiritual well-being [4, 5, 6]. This condition stimulates increasing of unmet needs among patients with cancer [7]. Previous research showed that high unmet needs affecting a person's resilience in undergoing the treatment process and decreasing the quality of life which has an impact on the self-performance of cancer patients [8, 9].

As a first step in discovering problems and needs in cancer patients, a thorough understanding of unmet needs is critical in order to create an appropriate needs-based nursing response. The complexity and severity of personal needs should be considered when providing care to patients, as should the setting in which it is delivered [10, 11].

Research conducted in Australia and Canada found that the highest unmet needs were financial problems (39.9%) and fatigue (76.17%) [12]. Other study mentioned that the three most commonly domains of unmet needs reported by cancer patients were psychological, health services and information issues [13]. The various factors of unmet needs in cancer patients are very diverse. Sociodemographic factors including age, gender, marital status, education, types of treatment, financial ability and time duration being diagnosed with cancer are also important things to consider in determining the level of unmet needs [14, 15, 16]. Physical and psychological conditions, as well as the patients' own quality of life, are other predictors of unmet needs among cancer patients [17]. It is depending on how the needs is defined and assessed [18]. This would be a reference for health professionals in providing health services for cancer patients. Hence, unmet needs in cancer patients must be well understanding and can be handled properly in order to patients can undergo the treatment and care process. Based on this background, the goal of this study was to look at the unmet needs of cancer patients and determine the factors that influence them. This research is very important to be carried out as the basis consideration for health professionals in improving the quality of their services.

## **2. METHODS**

A cross-sectional survey with convenience sampling was conducted in across cities in Indonesia. The instruments included demographic data and the SF-SUNS questionnaire. Data is collected in two ways: by directly filling out a paper form and by filling out a google form that can be found in any cancer community. Since we did

research during the Covid-19 pandemic, we have followed health protocols such as physical distancing, wearing a mask, and washing hands before interacting with others to prevent Covid-19 spreading.

### **2.1 Participants**

A total of 235 cancer patients were approached about participating in this study and completely filling out the questionnaire. The inclusion criteria included: 1) being diagnosed with cancer, 2) being able to communicate Indonesian language 3) more than 18 years old 4) able to complete the whole questionnaire 5) no history of mental illness.

### **2.2 Instruments**

#### *2.2.1. Demographic and Clinical Information.*

Patient demographic consist of age, sex, marital status, educational level and household income was self-reported. Clinical information such as cancer diagnosis, time since diagnosed and cancer treatments was collected.

#### *2.2.2. Unmet Needs.*

The SF-SUNS Indonesian version questionnaire was adapted from the original version [19] and had translated in Indonesian version of SF-SUNS which consists of 24 items to assess unmet needs among cancer patients. The SF-SUNS has four domains including unmet information needs (3 items), unmet financial needs (5 items), unmet coping and emotional needs (11 items), unmet needs for access and continuity of care (5 items). This instrument used five-point Likert scale to rate the unmet needs in cancer patients with each item scoring 0-4, higher scores indicating high levels of

unmet needs. This instrument is well validated and had good fit CFI = 0.95, RMSEA = 0.073, IFI = 0.95, SRMR = 0.065 with internal consistency Cronbach's Alpha=.73 to.93.

### **2.3 Data Collection**

Prior to data collection, the patients were informed the research purpose, procedure and the right to reject or drop out from this study any time with no effects. The furtiveness was also assured. After patients agree to be participants in this study, a consent form was provided then continue to fill out the questionnaire completely. If data collection was collected directly with the participants who are unable to read and write, the researcher assists to read the questions for them and recorded their answers.

### **Statistical Analysis**

First, we conducted univariate analysis for the unmet needs description. The prevalence of unmet needs using mean score was performed to identify the unmet needs of cancer patients by the SF-SUNS total score and the subscale of score for each domain were calculated. To obtain the mean of subscale score, the subscale scores of each domain was divided by the number of items in each domain. Second, we continue to perform Pearson correlation to evaluate the association between unmet needs and demographic data variable. A p value of < 0.5 was regarded as being statistically significant. SPSS version 20.0 for windows is used for data analysis. (IBM Corp, Armonk, NY, USA).

### 3. RESULTS

#### 3.1. Demographic Data and Clinical Information

**Table1.** Demographic Data and clinical Information (n=235).

Variables	N	%
Age	mean (SD) 50.71(11.76) range 18 – 95	
Gender		
Male	62	26.4
Female	173	73.6
Marital status		
Single	7	3.0
Married	204	86.8
Widowed	15	3.8
Divorce	9	6.4
Educational level		
Elementary	89	37.9
middle	113	48.1
College	33	14.1
Household income per month		
< 125 USD	144	61.3
125 – 250 USD	68	28.9
> 250 USD	23	9.8
Diagnose		
Breast cancer	78	33.2
Cervical cancer	55	23.4
Colon cancer	24	10.2
Nasopharyngeal cancer	11	4.7
Lung cancer	16	6.8
Others	51	21.7
Time since diagnosed		
Less than 1 year ago	138	58.7
1 year – 2 years ago	47	20.0
More than 2 years ago	50	21.3
Treatment		
Chemotherapy only	83	35.3
Chemotherapy and surgery	70	29.8
Chemotherapy, radiotherapy and surgery	26	11.1
Surgery and radiotherapy	9	3.8
Medical therapy and complementary therapy	47	20.0

Table 1 presents demographic and clinical information about the study sample. This study included 235 cancer patients who completed the survey. Offline mix online-based was performing to collect data regarding of Covid-19 pandemic. Health protocol procedures included physical distancing, hand wash before and after interaction, and less contact to others were always done during collecting data to prevent the spreading of Covid-19.

Females made up the vast majority of those who took part (73.6%) with the mean of age was 50.71. Most of them were married (86.8%) and had completed their education in the middle level (48.1%). More than sixty percent participants had income less than 125 USD. The highest number of cancer diagnosis was breast cancer (33.2%). Nearly 60% (n=138) of participants were diagnosed with cancer within one year. Most of the patients (35.5%, n=83) only received chemotherapy. In

addition, 20% (n=47) of participants received complementary therapy along with standard medical treatments.

**3.2. Unmet Needs**

The mean total score of SF-SUNS Indonesian version was 1.59. The highest mean subscale score

was unmet financial needs (1.88) then followed by unmet information needs (1.61), unmet coping and emotional needs (1.54) and the last position was unmet needs for access & continuity of care (1.42).

**3.3. The association between unmet needs and demographic data and clinical information**

Table 2 dan 3 shows that education level and income had negative correlation with a total score of unmet needs and all subscale in unmet needs. Moreover, other variable of demographic data (sex, age and marital status) had no association with unmet need.

**Table.2** unmet needs in cancer patients

Subscale	Mean (SD)	Min	max
Unmet financial needs	1.88 (0.94)	0.0	4.0
Unmet information needs	1.61 (0.79)	0.0	3.8
Unmet coping and emotional needs	1.54 (0.75)	0.0	4.0
Unmet needs for access & continuity of care	1.42 (0.74)	0.0	3.4
Total score unmet needs	1.59 (0.58)	0.0	2.8

**Table 3.** the correlation between unmet needs and demographic data

	Sex	Age	Marital	Education	Income	subscale1	subscale2	subscale3	subscale4	Total score
Sex	1									
Age	.088	1								
Marital	-.130*	.195**	1							
Education	-.159*	-.206**	-.118	1						
Income	.057	-.087	-.098	.042**	1					
Subscale1	-.046	-.043	-.034	-.202**	-.135*	1				
Subscale2	-.061	.005	.012	-.159**	-.190**	.195**	1			
Subscale3	-.065	.009	.073	-.197**	-.176**	.238**	.510**	1		
Subscale4	-.070	-.042	.066	-.293**	-.369**	.334**	.317**	.456**	1	
Total score	-.085	-.029	.023	-.311**	-.345**	.541**	.645**	.744**	.867**	1

\*correlation is significant at the 0.05 level

\*\*correlation is significant at the 0.01 level

Subscale 1: unmet information needs

Subscale 2: unmet financial needs

Subscale 3: unmet needs for access & continuity of care

Subscale 4: unmet coping and emotional needs

**4. DISCUSSION**

In this study, we found that the top rank for unmet needs in cancer patients was unmet financial needs. From the result showed among 235 people who undergo medical treatment of cancer have

financial problems. Cancer is a disease that requires high medical costs in its care and treatment, financial problems and cost concerns are things that often occur in cancer patients [20]. They have to adjust between income and expenses. Hence,

finance can be one of the unmet needs for cancer patients who undergo medical treatment as a result of continuous treatment and care for cancer patients. The previous study found that increasing used of chemotherapy and radiation therapy in cancer patients correlated with the increasing of financial burden [21, 22]. Cancer patients will experience financial distress as a result of the financial burden, which will have an impact on their quality of life [23].

According to [24], 50 percent of the financial burden is due to loss of income due to inability or decreased productivity/work by cancer patients, and there are numerous costs that cancer survivors must bear, including treatment and regular care. As a result, even though the average patient's treatment is covered by the government or health insurance, it costs quite a bit of money to treat them on a monthly basis. The data from Central Statistics Agency Indonesia identified the average work of people in Indonesia was 37.02% of the Indonesian population are workers and employees with low salaries, hence the income earned every month is also less and even uncertain [25]. As well as declining income, related to work problems such as frequent work permits, being unable to come to work regarding their disease. It becomes one of the main causes of financial toxicity in cancer patients [26].

Information needs regarding the disease also should be considered. The majority of patients do not know the disease, this shows that the patient's knowledge about cancer is lacking. According to research by [27], the factors that can affect a person's level of knowledge about his disease are education, mass media / information, socio-cultural and economic, health services, environment, experience, age and place of residence of the

patient. Living in rural or remote areas will have an impact on the lack of information about the disease and the treatment that will be carried out. A person with a high level of education will not care to get information from his own experience, the experience of others or the available information facilities [28].

Other unmet needs that must be emphasized was coping strategy among cancer patients. A good coping strategy can produce a better quality of life and result in a positive action. In contrast, if the coping strategies used are ineffective, it can lead to a poor quality of life and severe psychological distress. [29] mentioned that there are four strategies for good coping mechanisms which include (1) social support, (2) spirituality, (3) positive attitudes or thoughts, and (4) getting information or education. In improving coping mechanisms, it takes positive aspects of thinking and emotional support by the family. Effective coping will help individuals free from prolonged stress. Each individual uses different coping to deal with problems that involve changes in society and living systems from conditions that are considered unsatisfactory to a better state [30].

## **5. CONCLUSION**

In conclusion, the study provides essential information regarding unmet needs among cancer patients. Cancer patients stated the highest unmet need was unmet financial needs the followed by unmet informational needs, unmet coping and emotional needs and the last unmet needs for access and continuity of care. It can assist health professionals to deep understanding their condition and provide better care for cancer patients based on their needs.

## ACKNOWLEDGMENTS

We would like to acknowledge Institute of Health and Science Technology Wiyata Husada Samarinda that gave grant for this research. We are also grateful to the many cancer survivors and the support persons who have helped us. who gave their time to participate in this research and all cancer survivors who always fight for their disease. The contribution of assistant researchers and cancer home of Samarinda, Indonesia has been the partner in this research.

## REFERENCES

- [1] World Health Organization. (2017). World Health Statistics 2017 monitoring health for the SDGs, Sustainable Development Goals. Geneva:World Health Organization. Licence: CC BY-NC-SA 3.0 IGO
- [2] Ministry of Health Indonesia. 2019. <https://www.kemkes.go.id/article/view/19020100003/hari-kanker-sedunia-2019.html>
- [3] Thorne SE, Oliffe JL, Oglov V, Gelmon K (2013). Communication challenges for chronic metastatic cancer in an era of novel therapeutics. *Qual Health Res* 23(7):863-875.
- [4] Ferrell B. & Coyle, N. (2010). Oxford textbook of palliative nursing. New York: Oxford University Press
- [5] Vallurupalli, M., Lauderdale, K., Balboni, M., Phelps, A., Block, S., & Ng, A. et al. (2012). The role of spirituality and religious coping in the quality of life of patients with advanced cancer receiving palliative radiation therapy. *The Journal of Supportive Oncology*, 10(2), 81-87. <http://dx.doi.org/10.1016/j.suponc.2011.09.003>
- [6] Effendy, C., Vissers, K., Osse, B., Tejawinata, S., Vernooij-Dassen, M., & Engels, Y. (2014). Comparison of problems and unmet needs of patients with advanced cancer in a European country and an Asian country. *Pain Practice*, 15(5), 433-440. <http://dx.doi.org/10.1111/papr.12196>
- [7] Taylor, K., Bulsara M., Monterosso, L. (2018). Test-Retest Reliability of the Short-Form Survivor Unmet Needs Survey. *Asia-Pacific Journal of Oncology Nursing*, 5(2). DOI:10.4103/apjon.apjon\_4\_18
- [8] Hansen, D., Larsen, P., Holm, L., Rottmann, N., Bergholdt, S. and Søndergaard, J. (2012). Association between unmet needs and quality of life of cancer patients: A population-based study. *Acta Oncologica*, 52(2), pp.391-399. doi:10.3109/0284186X.2012.742204
- [9] Rosario Costas-Muniz, Jennifer Leng, Abraham Aragones, Julia Ramirez, Nicole Roberts, Mohammed Imran Mujawar & Francesca Gany (2016) Association of socioeconomic and practical unmet needs with self-reported nonadherence to cancer treatment appointments in low-income Latino and Black cancer patients, *Ethnicity & Health*, 21:2, 118-128, DOI: [10.1080/13557858.2015.1034658](https://doi.org/10.1080/13557858.2015.1034658)
- [10] Waller, A., Girgis, A., Johnson, C., Lecathelinais, C., Sibbritt, D., & Forstner, D. et al. (2012). Improving Outcomes for People with Progressive Cancer: Interrupted Time Series Trial of a Needs Assessment Intervention. *Journal Of Pain and Symptom Management*, 43(3), 569-581. doi: 10.1016/j.jpainsymman.2011.04.020
- [11] Haryani, H., Afyanti, Y., Besral, B., Gayatri, D., Wahidi, K., Pramiasti, H. and Milanti, A. (2020). Cross-cultural adaptation and validation of the cancer survivors' unmet needs measure among gynecological cancer patients in Indonesia. *Archive of Oncology*, 26(2), pp.23-29.
- [12] Hall, A., Campbell, H., Sanson-Fisher, R., Lynagh, M., D'Este, C., Burkhalter, R. and Carey, M. (2013). Unmet needs of Australian and Canadian haematological cancer survivors: a cross-sectional international comparative study. *Psycho-Oncology*, 22(9), pp.2032-2038. doi: 10.1002/pon.3247
- [13] Ying-Hsiang Chou, Vivian Chia-Rong Hsieh, XianXiu Chen, Ting-Yi Huang, Shwn- Huey Shieh. (2020). Unmet supportive care needs of survival patients with breast cancer in different cancer stages and treatment phases. *Taiwanese Journal of Obstetrics and Gynecology*, 59(2). <https://doi.org/10.1016/j.tjog.2020.01.010>.
- [14] Puts, M. T. E., A. Papoutsis, E. Springall, and A. E. Tourangeau. 2012. "A Systematic Review of Unmet Needs of Newly Diagnosed Older Cancer Patients Undergoing Active Cancer Treatment." *Supportive Care in Cancer*.
- [15] Okediji, Paul T., Omolola Salako, and Olamijulo O. Fatiregun. 2017. "Pattern and Predictors of Unmet Supportive Care Needs in Cancer Patients." *Cureus*. Hal. 2-11. DOI: 10.7759/cureus.1234
- [16] Fong, Emmanuel Joseph and Whye Lian Cheah. 2016. "Unmet Supportive Care Needs among Breast Cancer Survivors of Community-Based Support Group in Kuching,

- Sarawak.” *International Journal of Breast Cancer*. Hal.1-9. <http://dx.doi.org/10.1155/2016/7297813>
- [17] Wang, Tao, Alex Molassiotis, Betty Pui Man Chung, and Jing Yu Tan. 2018. “Unmet Care Needs of Advanced Cancer Patients and Their Informal Caregivers: A Systematic Review.” *BMC Palliative Care*. Hal.1378-1394. DOI 10.1007/s00520-012-1450-7
- [18] Carlson MD, Marrison RS, Bradley E. (2008). Improving access to hospice care:informing the debate.*J Palliat Med*. 11:438-443.
- [19] Campbell HS, Hall AE, Sanson-Fisher RW, Barker D, Tumer D, Taylor-Brown J. (2014). Development and validation of the Short-Form Survivor Unmet Needs Survey (SF- SUNS). *Support Care Cancer*. 22(4):1071-9
- [20] Lentz R, Benson 3rd AB, Kircher S (2019). Financial toxicity in cancer care: prevalence, causes, consequences, and reduction strategies. *J Surg Oncol*. 120:85-92. DOI: <https://doi.org/10.1002/jso.25374>
- [21] Kent EE, Forsythe LP, Yabroff KR et al. (2013). Are survivors who report cancer-related financial problems more likely to forgo or delay medical care? *Cancer*. 119 (20):3710-3717.
- [22] Carrera PM, Kantarjian HM, Blinder VS. (2018). The financial burden and distress of patients with cancer: understanding and stepping-up action on the financial toxicity of cancer treatment. *CA Cancer J Clin*. 68:153-65. DOI: <https://doi.org/10.3322/caac.21443>
- [23] Barbaret, Cécile, Christelle Brosse, Wadih Rhondali, Murielle Ruer, Léa Monsarrat, Patrick Michaud, Anne Marie Schott, Marvin Delgado-Guay, Eduardo Bruera, Stéphane Sanchez, and Marilène Filbet. 2017. “Financial Distress in Patients with Advanced Cancer.” *PLoS ONE*. Hal.1-10. <https://doi.org/10.1371/journal.pone.0176470>
- [24] Fathollahzade, A., Rahmani, A., Dadashzadeh, A., Gahramanian, A., Esfahani, A., Javanganji, L., & Nabiolahi, L. (2015). Financial Distress and its Predicting Factors among Iranian Cancer Patients. *Asian Pacific Journal Of Cancer Prevention*, 16(4), 1621-1625. doi: 10.7314/apjcp.2015.16.4.1621
- [25] BPS- Statistics Indonesia.2021. *Laborer Situation in Indonesia*. Directorate of Population and Labor Satatistics. ISBN:1979.7702
- [26] Susilowati, M., & Afiyanti, Y. (2021). The socio-demographic factors correlated with financial toxicity among patients with breast cancer in Indonesia. *Journal of Public Health Research*, 10(s1). <https://doi.org/10.4081/jphr.2021.2403>
- [27] Rispandi, D. E., Brahmantia, B., & Falah, M. (2021). Health seeking behaviour among advanced Ca mamae in Tasikmalaya. *Healthcare Nursing Journal*, 3(2), 107-115.
- [28] Grimsbo, G.H., Ruland, C.M., & Finset,A. (2012). Cancer Patients' expressions of emotional cues and concern and oncology nurses' responses, in an online patient-nurse communication service. *Patient Education and Counseling*, 88(1), 36-43.doi: 10.1016/j.pec.2012.01.007.
- [29] Mukwanto, K.P., Mweemba, P., Makukula, M.K., Makoleka, M.M. (2010). Stress and coping mechanisms among breast cancer patients and family caregivers. *Medical Journal of Zambia*.37(1), 40-45.
- [30] Nurhikmah, W., Wakhid, A., & Rosalina, R. (2018). The association of Coping Mechanism and Quality of Life in Cancer Mamae patients. *Jurnal Ilmu Keperawatan Jiwa*, 1(1), 38-47.