



## Unmet supportive care needs of Indonesian gynecological cancer survivors<sup>☆</sup>



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### KEYWORDS

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### Abstract

**Objective:** This study aimed to assess the unmet supportive care needs of gynecological cancer patients in Indonesia.

**Method:** A quantitative descriptive cross-sectional study using survey was used. We recruited 298 gynecological cancer survivors from three hospitals in different provinces in Indonesia, i.e., Soetomo Hospital in East Java; Sardjito Hospital in Yogyakarta; and Dharmais Cancer Hospital in Jakarta. Demographic and clinical characteristic and the Cancer Survivor Unmet Needs (CaSUN) questionnaires were given to measure supportive care needs (i.e. comprehensive care need, existential need, quality of life need, relationship need, and informational need). Descriptive statistics including frequency, percentage, and mean were used to analyze the demographic and clinical characteristics and unmet supportive care needs of participants.

**Results:** 98% of the survivors reported at least one supportive care need. The highest percentage of unmet supportive care need was an informational need (37.8%) followed by comprehensive care need (37.3%), quality of life need (36.1%), existential need (31.5%), and relationship need (23.9%). However, the highest mean of unmet needs was existential survivorship need 6.4 (5.7).

**Conclusions:** Gynecological cancer survivors in Indonesia marked various unmet needs. Nurses should identify the supportive care needs of the women diagnosed with gynecological cancer early in cancer trajectory and also at the critical points of cancer care such as after including primary treatment.

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## Introduction

Despite being a major cause of morbidity and mortality worldwide, the number of cancer survivors, including gynecological cancer survivors, is increasing due to early detection and improved treatments.<sup>1,2</sup> Gynecological cancer is the most frequent cancer in women after breast cancer in Indonesia.<sup>1</sup> It is among the ten highest cancer rates for women contributing to 26% female cancer incidence which is predicted to rise by 15% in 2020.<sup>1</sup>

Cancer survivors commonly experience sequelae not only in their bodies but also in their psychological, social, and spiritual life.<sup>3,4</sup> Furthermore, the incidence of cancer recurrence is considerably high in the survivors of gynecological cancer.<sup>5</sup> Women who had lived through gynecological cancer experience uncertainty, despair, anxiety, depression because of fear of having their cancer back.<sup>6,7</sup> In this regards, fear of cancer recurrence is an instance of how a psychological problem can have a multitude of implications for gynecological cancer survivors.

Comprehensive cancer care should be provided by the nurses in collaboration with the multidisciplinary cancer team to help the gynecological cancer survivors have a positive and meaningful life after cancer.<sup>4</sup> Managing symptoms related to the physical, psychological, social, sexual, and spiritual life of the gynecological cancer survivors begins with identifying the supportive care needs of the patients.<sup>8</sup> Need assessment is the key to support the survivors to develop adaptive coping mechanisms to the sequelae of cancer and its treatments and to empower them in decision making pertinent to their health.<sup>4</sup>

In Indonesia, limited studies have examined the unmet supportive care needs of gynecological cancer survivors. A prior study in Indonesia found that gynecological cancer survivors had various unmet needs that were associated with poorer quality of life.<sup>9</sup> This past study, however, was a cross-sectional study conducted in a city in Indonesia, hence the limited generalisability. The supportive care assessment is not a routine practice for cancer patients in Indonesia. Indonesia is not yet implementing a standard of oncology nursing practice in general, let alone the cancer survivorship care practice. Therefore, the present study aimed to assess the unmet needs of gynecological cancer survivors on a broader population of Indonesia.

## Method

### Study design

We conducted a quantitative descriptive cross-sectional study at the oncology outpatient units of the Sardjito General Hospital, Yogyakarta; Dharmas National Cancer Hospital, Jakarta; and Soetomo General Hospital, East Java during six months. A total of 298 participants were recruited using a convenience sampling method. The criteria of inclusion were women aged 20–70 years who had been diagnosed with gynecological cancer of any type for at least one year, had completed primary cancer treatment and had no severe accompanying illness or psychological illness. Patients receiving palliative care or having cancer recurrence were excluded from the study. The main variable

in this study was supportive care needs including comprehensive care, existential, informational, quality of life and relationship domains.

The instruments consisted of a demography questionnaire and the Cancer Survivors' Unmet Needs Measure (CaSUN). The CaSUN questionnaire has 35 question items across the need domains of (1) existential survivorship, (2) comprehensive care, (3) information, (4) quality of life, and (5) relationship.<sup>10</sup> Participants filled out the 3-point scale questionnaire to indicate whether a need in a particular domain was currently met, unmet, or there is no need at all. While each domain is summed and calculated for its average to get the score of the unmet needs per domain, the level of the overall unmet needs was obtained from the mean of the total score of all answers.<sup>10</sup> In this tool, higher scores indicate greater unmet needs.<sup>10</sup> This tool has demonstrated good internal consistency, validity, and reliability (Cronbach's alpha 0.96).<sup>10</sup> The questionnaire was translated from English into the Indonesian language.

The data analyses were performed using IBM SPSS Statistic Base version 22. Descriptive statistics including frequency, percentage, and mean were used to analyze the demographic and clinical characteristics and unmet supportive care needs of participants. The ethical approval for the study was obtained from the Ethical Committee of the Faculty of Medicine, Universitas Gadjah Mada, and Faculty of Nursing, Universitas Indonesia.

## Results

### Participants' characteristics

Mean age of the participants was 50.3 years-old. The majority of participants were married (88.3%) and had lower educational status (35.6%). Most participants (48.7%) were housewives of low-income families whose monthly family income was lower than the average minimum wage of the region (approximately 85 USD per month). The majority of participants were diagnosed with stage III gynecological (i.e. ovarium, cervical, and endometrium) cancer (37.6%), had received chemotherapy (50%) and had no metastatic cancer (80.9%). The summary of the demographic and clinical characteristics of the participants is presented in [Table 1](#).

### Prevalence of unmet needs

[Table 2](#) shows the score of participants' unmet needs in each domain of the supportive care needs. Of all participants, 98% reported at least one unmet supportive care need. Two most frequently reported unmet needs were in the domains of the informational needs (37.8%) and comprehensive care needs (37.3%). The rest of domains were quality of life (36.1%), existential needs (31.5%), and relationship needs (23.9%). However, the highest mean of unmet needs was existential survivorship need 6.4 (5.7)

[Table 3](#) enlists fifteen most frequently reported unmet needs of the Indonesian gynecological cancer survivors. In the domain of comprehensive care, the top three unmet needs were concerned to the need to find out about financial support and government benefits, the need to access legal services, and the need to obtain to local health care

**Table 1** Demographic and clinical characteristics of participants (*n* = 298).

Characteristics	<i>f</i> (%)	Mean (SD)
Age (years)		50.3 (9.6)
<i>Marital status</i>		
Single	12 (4.0)	
Married	263 (88.3)	
Widow	23 (7.7)	
<i>Educational background</i>		
Not attending school	20 (6.7)	
Elementary school	106 (35.6)	
Junior high school	54 (18.1)	
Senior high school	90 (30.2)	
Undergraduate	26 (8.7)	
Postgraduate	2 (0.7)	
<i>Monthly family income (IDR)</i>		
<1 million	143 (48.0)	
1–2 million	75 (25.2)	
2–3 million	28 (9.4)	
3–4 million	23 (7.7)	
4–5 million	8 (2.7)	
>5 million	21 (7.0)	
<i>Employment</i>		
Government employee	11 (3.7)	
Private employee	27 (9.1)	
Retired	12 (4.0)	
Entrepreneur	59 (19.8)	
Labor	44 (14.8)	
Housewife	145 (48.7)	
<i>Stage of cancer</i>		
I	54 (18.1)	
II	86 (28.9)	
III	112 (37.6)	
IV	13 (4.4)	
Unknown	33 (11.1)	
<i>Having metastatic cancer</i>		
Yes	57 (19.2)	
No	241 (80.9)	
<i>Primary treatment history</i>		
Chemotherapy	149 (50)	
Radiation	38 (12.8)	
Chemoradiation	49 (16.4)	
Surgery	26 (8.7)	
Other	36 (12.1)	

**Table 2** The score of each domain on supportive care needs (*n* = 298).

Items	min	max	Mean	SD	<i>f</i> (%)
Existential survivorship	0	14.0	6.4	5.7	31.5
Comprehensive care	0	11.0	5.0	3.4	37.3
Information	0	3.0	1.4	1.3	37.8
Quality of life	0	2.0	0.9	0.9	36.1
Relationship	0	4.0	1.3	1.3	23.9

services when required. In addition, the participants also commonly reported the unmet needs in the existential survivorship domain were to manage cancer coming back. The domains of information need and quality of life needs were also endorsed by the participants requiring up-to-date information (52%), report that they could understand (44%), and adjustment to changes in quality of life as a result of cancer (44.2%).

## Discussion

The results found that nearly all gynecological cancer survivors in this study reported that 98% at least one unmet supportive care need. The prevalence of unmet needs in this study is noticeably higher than those reported in other studies of women with gynecological cancers (50–56%).<sup>10,11</sup> The previous study in Indonesia confirmed this finding and showed that the Indonesian cancer patient has high unmet supportive care needs.<sup>12</sup> In this study, most women said that they mostly needed help to find out about financial support and government benefits to which they were entitled and to access legal services, hence their most frequent unmet needs. The domain of the comprehensive cancer care need is the most highly endorsed unmet needs, which is consistent to prior study findings of Hodgkinson et al.<sup>10</sup> and Rowland et al. in Australia<sup>13</sup> as well as of Ellegaard in Denmark.<sup>14</sup>

The most ranked unmet need in comprehensive care need domain is pertinent to the health care system in Indonesia. The health care services for cancer patients in Indonesia are primarily based in the hospital and mostly focus on the physical problems of the patients, overlooking the social and economic implications of the illness to the patients and the family. Since our participants were mostly of lower socio-economic status, it is reasonable that the health care cost emerged to be their primary concern. Indonesia is still struggling with the universal health insurance program and has been providing subsidized social health insurance for the poor.<sup>15</sup> However, in practice, the social protection for the poor still has some administrative hurdles resulting in yet patchy coverage of the insurance.<sup>16</sup> Also, despite the government subsidy, cancer patients and the family must always have to make out-of-pocket payments for some procedures, transportation, and alike while utilizing the health care service.<sup>15</sup>

Gynecological cancer survivors in this study also reported having an unmet need for up-to-date and understandable information. The information-related unmet needs seem to be prevalent not only among lower educated patients as in our study but also in patients with a higher educational background in the top resource countries such as Denmark<sup>14</sup> and Australia.<sup>17–19</sup> Cancer patients in Iran also highlighted a greater informational need.<sup>20,21</sup> A prior review of the informational needs of breast cancer survivors also suggested that most survivors had lack of understandable information from the health care professionals.<sup>22</sup> Another study reported that patients need adequate information from the health care providers in the whole cancer treatment trajectory.<sup>23</sup>

Another common unmet need is related to cancer recurrence. The gynecological cancer survivors in our study marked their unmet needs to receive help in managing their concerns about cancer coming back (the fourth most

**Table 3** The 15 most frequent unmet supportive care needs of participants CaSUN ( $N = 298$ ).

Items: In the last month I needed. ....	Total		Met		Unmet		Domain
	<i>n</i>	% <sup>a</sup>	% <sup>b</sup>	% <sup>c</sup>			
1. Find out about financial support and government benefits .....	259	86.9	18.9	70.5	Comprehensive care		Comprehensive care
2. Accessing legal services. ....	233	78.2	15.9	65.8	Comprehensive care		Comprehensive care
3. Find out about services .....	249	83.6	30.5	58.1	Comprehensive care		Comprehensive care
4. Manage about the cancer coming back	249	83.6	32.9	56.0	Existential survivorship		Existential survivorship
5. Local health care services that are available. ....	263	88.3	40.3	52.7	Comprehensive care		Comprehensive care
6. Up-to-date information	290	97.3	46.6	52.0	Informational		Informational
7. Adjust to changes the quality of life as a result of cancer. ...	258	86.6	44.2	48.3	Quality of life		Quality of life
8. Make the life count. ...	278	93.3	52.8	44.0	Existential survivorship		Existential survivorship
9. Move with the life. ....	277	93.0	52.7	44.0	Existential survivorship		Existential survivorship
10. Information provided in a way that understood. ....	294	98.7	55.4	44.0	Informational		Informational
11. Any complaints to be properly addressed. ....	291	97.7	56.3	42.6	Comprehensive care		Comprehensive care
12. Information for family and/or partner which are relevant to them. ...	286	96.0	56.7	41.6	Informational		Informational
13. The very best medical care. ....	293	98.3	58.0	41.3	Comprehensive care		Comprehensive care
14. Talk to others who have experienced cancer. ...	260	87.2	53.1	40.9	Existential survivorship		Existential survivorship
15. Adjust to changes in the quality of life as a result of cancer. ....	244	81.9	50.4	40.6	Quality of life		Quality of life

<sup>a</sup> Percent to total ( $n = 298$ ).

<sup>b</sup> Percent to the total patients in met.

<sup>c</sup> Percent to the total patients in unmet.

common unmet need). This finding agrees with the results of a previous study in women having endometrial cancer by Rowland et al.,<sup>13</sup> which found slightly more than half of women felt the unmet needs to manage their concerns of cancer recurrence. Recurrence is particularly relevant in gynecological cancer as this cancer group has high recurrence rates.<sup>6</sup> Many women with gynecological cancer experience a constant fear about having their cancer back over time.<sup>24</sup> Therefore, one of the goals of health care for cancer survivors is to prevent recurrence along with overcoming the long-term side effects of cancer therapy.

Our study confirmed previous study's findings related to supportive care needs in Indonesia. However our study has a bigger sample size and represents the biggest referral hospitals for cancer patients in Indonesia. In addition, we used CaSUN instrument that we already tested using rigid psychometric testing proved CaSUN Indonesian version is valid and reliable. However, the sampling method was a limitation in this study. This study used a convenience sampling which lately might affect the generalizability of the results.

Unmet needs are highly prevalent among Indonesian gynecological cancer survivors. The highly reported unmet needs are related to financial issue and information from the health care professionals. Nurses should identify the supportive care needs of the women diagnosed with gynecological cancer early in cancer trajectory and also at the hallmark of cancer care such as after concluding primary treatment. While assessing the supportive care needs, nurses should be sensitive to the holistic aspect of care, including the financial or practical requirements that are shown to be the significant burdens of the patients. Being reliable and competent to address such issues are also necessary since practical problems typically demand handy and fast response. This study implies the need to develop the resources to help patient get comprehensive, understandable, and accessible information related to cancer care. To

what extent the unmet supportive care needs especially in the comprehensive care and information domains impact the patients' quality of life needs to be examined in further studies.

### Conflict of interests

The authors declare no conflict of interest.

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