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The Unmet Needs of Women Living with Cancer in Community Setting: A Professional Concern

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ABSTRACT

Background: In the community of Surabaya, the 2nd largest city of Indonesia, women living with cancer are mostly the long-term survivors of advanced-stage cervical cancer, but the number of women living with breast cancer cannot be ignored. There were various physical and psychological problems related to the total suffering and worsening phenomena. The limited resources available in the community have led to various levels of unmet needs in their perspective. This study aimed to analyze and describe the unmet needs of female cancer survivors in the community of Surabaya.

Methods: This descriptive study involved five Public Health Centers (PHCs) among 63 PHCs in Surabaya (7.94%), Indonesia, which were selected by one-stage cluster random sampling. There were 41 and 40 women living with breast and cervical cancers, respectively, participating in this study (n = 81). The Supportive Care Needs Survey – Short Form 34 (SCNS-SF34) was used to collect the data of unmet needs (r = 0.234 – 0.821; Chronbach Alpha = 0.939). Descriptive statistic was used in data analysis (frequency, Mean, and Standard Deviation). Ethical clearance was issued.

Results: Most respondents were late adult married women with low socioeconomic status. They were mostly short-term survivors and already had surgery. Most of them reported a moderate level of unmet needs (Mean ± SD = 109.30 ± 27.66). Health system and information needs became their top priorities (45.75), followed by patient care and support needs (37.89), physical and daily function needs (32.20), psychological needs (31.11), and sexuality needs (22.00). There were 9.88% of respondents who reported that there were no unmet needs.

Conclusions: Female cancer survivors in the community reported a moderate level of unmet needs. Health system and information needs were the most reported unmet needs.

INTRODUCTION

Cancer starts when cells begin to grow out of control [1]. Having breast or cervical cancer for women means that their breast or cervical cells start to grow out of control. At first, the cancer cells start in the breast or cervix; then, they will grow out of the breast or cervix and invade the other tissue, whether it is near or far from the breast or cervix itself. Every year, more than two million women worldwide are diagnosed with breast or cervical cancer [2]. Breast and cervical cancers are the commonest cancers diagnosed in women living in low- and middle-income countries [3]. They have emerged as major global health challenges and disproportionately, leading to excess morbidity and mortality, especially in low- and middle-income countries [4]. It can be estimated that the incidence of cancer in Indonesia is 0.1% of the population [5]. In 2017, breast cancer reached the 1st position as the highest new cases and deaths in Indonesian cancer statistics, followed by cervical cancer in the 2nd position [4].

Generally, the stages of survivorship in cancer are categorized into three, namely: acute (< 1 year), short-term survivorship (1–5 years), and long-term survivorship (> 5 years) [6]. Nowadays, we could see many survivors of breast or cervical cancer in our surroundings; thanks to not only the advances in cancer diagnosis and therapy but also the integrated palliative care system in clinical and community settings. Being the 2nd largest city in

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Indonesia, after the capital of Indonesia, Jakarta, Surabaya was populated by more than 1.5 million females in 2017 and already had an existed structure of palliative care networking system. A study towards 140 and 139 women living with breast and cervical cancer in Surabaya's communities (n = 279) based on 9.68% of the cluster of the city area showed that female cancer cases, especially breast and cervical cancers, were frequently found in the community setting, and most respondents were found to be short-term survivors (81.36%) because they were diagnosed with cancer for less than five years [7].

Surabaya, the city of palliative in Indonesia (declared in 2010), has been the pioneer of the palliative care delivery system in the country since 1989 [5]. Ideally, there are four parties involved in the palliative care delivery process, known as palliative care stakeholders, such as patients, family caregivers (FCGs), health care professionals (HCPs), and palliative volunteers. Surabaya with its existing structure of palliative care networking system has involved collaborations of aforementioned parties linking clinical resources in the hospital and public engagement in the community context. In the management of female cancer in the community setting of Surabaya, the Public Health Center (PHC) plays a key role in delivering primary care services to cancer patients.

One indicator of the effectiveness of cancer management in the community setting is the current cancer stage. The study of Sari also showed that most respondents were diagnosed with cancer for less than five years; most advanced stage cervical cancer patients were found to be long-term survivors, and the first time of cancer diagnosis correlated significantly with the current stage of cancer in the case of breast and cervical cancers [7]. Therefore, if most cancerous women in Surabaya's community were firstly diagnosed with cancer for less than five years and, currently, they were in an advanced stage, the palliative care delivery system or the cancer management in a community setting was not adequate. There are various limitations as potential contributing factors to this phenomenon, namely limited human resources, budgeting, facilities, connections, accessibility, etc. They potentially sacrifice the fulfillment of the need of cancer patients in the community. This study aimed to analyze and describe the unmet needs of women living with cancer in the community of Surabaya. These study findings may enable the HCP in the community setting and health researchers to formulate and develop a suitable and effective intervention to adequately meet the needs of cancerous women in the community setting.

METHODS

This was a descriptive study utilizing a cross-sectional design. This study involved five PHCs in Surabaya (7.94% over 63 PHCs available in the city), Indonesia, selected by one-stage cluster random sampling. This sampling was applied to get the big picture of the Surabaya community nowadays. It was done simply by using a paper lottery. Firstly, the researcher made a list of 63 PHC names, wrote each name on a piece of paper, flipped it, and put it in a plastic can. By doing the lottery, the researcher only withdrew five PHC names, PHCs Pacar Keling, Pucang Sewu, Klampis, Mulyorejo, and Pakis. The researcher then contacted one volunteer in each PHC's area and asked for a list of female cancer survivors, who had breast or cervical cancer, which matched this study's needs. There were no specific inclusion criteria for the respondent recruitment in this study. As long as the PHCs confirm the breast or cervical cancer diagnosis, the individual was eligible to be this study respondent. Regarding the capability in filling out the instrument, a good educational background was very supportive but not compulsory. Exclusion criteria were the rejection of filling out the consent form. Finally, 81 female cancer survivors were participating in this study (n = 81), 41 of whom had breast cancer and the rest had cervical cancer.

Data were collected from February to March 2020. The Supportive Care Needs Survey – Short Form 34 (SCNS-SF34) was used to collect the data of unmet needs (r = 0.234–0.821; Chronbach Alpha = 0.939). This instrument was specifically made for assessing the perceived needs of people diagnosed with cancer. The SCNS was developed by the Centre for Health Research & Psychology (CHeRP), Cancer Council New South Wales, Australia. SCNS-SF34 is the development and the shorter version of SCNS-LF59. The 34 items in SCNS-SF34 map to the following five domains, which are identical to those of the longer version of SCNS-LF59, such as psychological needs (10 items), health system & information needs (11 items), physical & daily living needs (5 items), patient care & support needs (5 items), and sexuality needs (3 items). The SCNS-SF34 has a reading level of the seventh to eighth grade (aged 12 to 14 years) and takes only approximately 10 minutes to complete [8]. For each item of SCNS-SF34, the respondents were asked to indicate their level of need for help over the last month because of having cancer using the following response options, 1. No need: consist of "not applicable" (score 1), and "satisfied" (score 2); 2. Some needs: consist of "low need" (score 3), "moderate need" (score 4), and "high need" (score 5).

Based on the above score for each item (Likert scale of 1 to 5), the researcher divided the level of patient's unmet needs into four categories, such as no need (total score: 34–68), low (total score: 69–102), moderate (total score: 103–136), and high (total score: 137–170). Descriptive statistic (frequency, mean, and standard deviation or SD) was used in data analysis.

RESULT

Most respondents were late adult married women who were housewives with low socioeconomic status. Educational background was mostly sufficient according to the Indonesian standard. Most of them live with their spouse and children. **Table 1** below explains the demography of study respondents in detail.

Most respondents were found in an advanced stage, and they had surgery already. Currently they were mostly categorized as short-term survivor. **Table 2** below explains the specific data related to cancer experienced by the study respondents in details.

Table 1. Demography characteristic

Characteristic	Frequency	Percentage
Age (years old)		
<21	0	0
21–30	4	4.9
31–40	11	13.6
41–50	20	24.7
51–60	25	30.9
61–70	17	21.0
>70	4	4.9
Marital status		
Single	8	9.9
Married	56	69.1
Widowed	17	21.0
Divorced	0	0
Education level		
Primary school	25	30.9
Secondary school	15	18.5
High school	37	45.7
University graduates	4	4.9
Occupation		
Housewife	59	72.8
Entrepreneur	4	4.9
Civil servant	10	1.2
Private employee	4	4.9
Jobless	4	4.9
Gross Domestic Product (GDP) in IDR		
Less than minimum wage	52	64.2
Minimum wage – 5 million	17	21.0
More than 5 million	7	8.6
No income	5	6.2
House mate		
Spouse	53	65.4
Children	40	49.4
Sibling	2	2.5
Parents	8	9.9
None	4	4.9

Results showed that 90.12% of respondents reported unmet needs at various levels. Most respondents reported a moderate level of unmet needs (50.62%). Descriptive statistics showed that the mean value was 109.30 (moderate) and SD value 27.66. **Table 3** below explains the level of unmet needs in detail.

Furthermore, the researcher tried to identify which needs among all five domains of unmet needs based on the instrument of SCNS-SF34 become the respondents' priority: 1) health system and information needs (45.75), 2) patient care and support needs (37.89), 3) physical and daily function needs (32.20), 4) psychological needs (31.11), and 5) sexuality needs (22.00). Therefore, the patients put their highest priority on the health system and information needs which were unmet by the HCP (mainly) or FCG (secondarily).

Table 2. Specific data related to cancer

Characteristic	Frequency	Percentage
Stage		
I	4	4.9
II	23	28.4
III	34	42.0
IV	8	9.9
Unknown	12	14.8
Diagnosis period		
Less than 1 year (acute survivor)	21	25.9
1–5 years (short term survivor)	42	51.9
More than 5 years (long term survivor)	18	22.2
Therapy		
Surgery	24	29.6
Chemotherapy	16	19.8
Surgery + chemotherapy	10	12.4
Surgery + radiotherapy	1	1.2
Chemotherapy + radiotherapy	6	7.4
Surgery + chemo-radiotherapy	17	21.0
Alternative therapy	7	8.6

Table 3. The level of unmet needs of women living with cancer in the community setting

Characteristic	Frequency	Percentage
No need (34–68)	8	9.9
Low (69–102)	21	25.9
Moderate (103–136)	41	50.6
High (137–170)	11	13.6

Questions about sexual needs seemed to be not applicable for most respondents in this study context, especially item 33 about "Changes in your sexual relationships" (38.2%). Based on the deeper analysis towards each item in SCNS-SF34, it was found that item 30 about "Being informed about things you can do to help yourself to get well" from the domain of health system and information needs was on the top of the top priorities of unmet needs in female cancer survivors (44.4%). Oppositely, item 16 about "More choices of the hospitals you visit" from the domain of patient care and support needs was the most satisfying need met by the government in Indonesia (32.1%). **Table 4** below explains in detail the results of the frequency test in descriptive statistics according to the measurement results of each item in SCNS-SF34.

Table 4. The level of unmet needs of each item in SCNS-SF34 (n=81)

Domain	Item	No Need		Some Need		
		Not Applicable	Satisfied	Low Need	Moderate Need	High Need
		Frequency (%)				
	1	15 (18.5)	2 (2.5)	37 (45.7)	20 (24.7)	7 (8.6)
	2	25 (30.9)	4 (4.9)	32 (39.5)	14 (17.3)	6 (7.4)
	3	18 (22.2)	8 (9.9)	27 (33.3)	19 (23.5)	9 (11.1)
	4	8 (9.9)	5 (6.2)	22 (27.2)	17 (21.0)	29 (35.8)
Psychological needs	5	12 (14.8)	5 (6.2)	24 (29.6)	21 (25.9)	19 (23.5)
	6	16 (19.8)	14 (17.3)	22 (27.2)	19 (23.5)	10 (12.3)
	7	5 (6.2)	19 (23.5)	22 (27.2)	19 (23.5)	16 (19.8)
	8	11 (13.6)	20 (24.7)	18 (22.2)	14 (17.3)	18 (22.2)
	9	26 (32.1)	8 (9.9)	24 (29.6)	13 (16.0)	10 (12.3)
	10	23 (28.4)	6 (7.4)	20 (24.7)	25 (30.9)	7 (8.6)
	11	7 (8.6)	9 (11.1)	25 (30.9)	19 (23.5)	21 (25.9)
Physical and daily function needs	12	10 (12.3)	8 (9.9)	28 (34.6)	26 (32.1)	9 (11.1)
	13	14 (17.3)	13 (16.0)	25 (30.9)	18 (22.2)	11 (13.6)
	14	18 (22.2)	12 (14.8)	26 (32.1)	15 (18.5)	10 (12.3)
	15	3 (3.7)	18 (22.2)	20 (24.7)	12 (14.8)	28 (34.6)
	16	4 (4.9)	26 (32.1)	9 (11.1)	15 (18.5)	27 (33.3)
	17	11 (13.5)	17 (21.0)	17 (21.0)	10 (12.3)	26 (32.1)
	18	8 (9.8)	20 (24.7)	24 (29.6)	4 (4.9)	25 (30.9)
Patient care and support needs	19	8 (9.8)	21 (25.9)	20 (24.7)	15 (18.5)	17 (21.0)
	20	6 (7.4)	21 (25.9)	15 (18.5)	14 (17.3)	25 (30.9)
	21	7 (8.6)	19 (23.5)	12 (14.8)	19 (23.5)	24 (29.6)
	22	8 (9.8)	14 (17.3)	17 (21.0)	12 (14.8)	30 (37.0)
	23	9 (11.1)	17 (21.0)	17 (21.0)	14 (17.3)	24 (29.6)
	24	6 (7.04)	18 (22.2)	18 (22.2)	11 (13.6)	28 (34.6)
	25	6 (7.4)	12 (14.8)	20 (24.7)	13 (16.0)	30 (37.0)
	26	7 (8.6)	13 (16.0)	11 (13.6)	17 (21.0)	33 (40.7)
Health system and information needs	27	8 (9.8)	12 (14.8)	17 (21.0)	13 (16.00)	31 (38.3)
	28	8 (9.8)	9 (11.1)	17 (21.00)	18 (22.2)	29 (35.8)
	29	7 (8.6)	9 (11.1)	14 (17.3)	17 (21.0)	34 (42.0)
	30	8 (9.8)	8 (9.9)	14 (17.3)	15 (18.5)	36 (44.4)
	31	15 (18.5)	8 (9.9)	17 (21.0)	15 (18.5)	26 (32.1)
	32	29 (35.8)	18 (22.2)	19 (23.5)	7 (8.6)	8 (9.9)
Sexuality needs	33	31 (38.2)	15 (18.5)	20 (24.7)	7 (8.6)	8 (9.9)
	34	12 (14.8)	5 (6.2)	28 (34.6)	15 (18.5)	21 (25.9)

DISCUSSION

Results showed that 90.1% of respondents reported unmet needs at various levels. This finding is consistent with that of the study in Australia towards 396 cancer patients by using a similar instrument (SCNS). McDowell et al. [9] found that unmet needs were reported by 2/3 patients at baseline and half of patients at the six-month follow-up. Having unmet needs at baseline was the strongest predictor of unmet needs at six months. Longer time upon diagnosis was a consistent predictor of greater unmet needs, associated with the change in physical/daily living, psychological, health system, and information unmet needs over time. In this study, most respondents were short-term survivors (51.8%), which means their first time of cancer diagnosis was varied between one to five years before this study was conducted. Therefore, the unmet needs found in this study were varied from low to a high level with the highest percentage of the moderate level.

Most respondents reported unmet needs mainly due to low resilience. A study towards 68 cancer patients showed that ambulatory patients with higher levels of resilience express fewer unmet needs. Lower resilience scores were significantly and strongly associated with higher levels of unmet information needs, psychological needs, and overall supportive care needs in cancer patients. Predictors of resilience in cancer were age, metastasis, recurrence, and living alone [10].

It was also found that most respondents reported unmet health system and information needs, which became their top priority. This finding was consistent with a study towards 167 cancer patients by using the same instrument (SCNS-SF34) which showed that almost all patients had more than one unmet need from the low to moderate level, and most of the top ten moderate to high levels of unmet needs were identified in the health system and information domains, in which age, time since diagnosis, and symptom interference were significantly associated with supportive care needs in cancer patients [11].

Information needs may affect health outcomes and cancer patients' satisfaction. A study towards 323 cancer patients showed that younger respondents had a higher level of unmet information needs. In this study, there were only 18.5% of the respondents less than 40 years old, but most respondents reported unmet information needs. The most significant predictor for unmet information needs is a good clinician-patient relationship, which was unidentified in this study, rather than the age alone. The subjective perception of a high level of trust and caring attention from nurses with the physician high empathy seem to be predictive for inclusion in the subgroup with no unmet information needs. Nurses and physicians seem to be able to reduce cancer patients' unmet information needs by establishing a good relationship with the patient, which is trusting, caring, and empathic [12].

A more specific study towards 346 young adult female cancer survivors showed that 43–62% of respondents reported unmet information needs regarding fertility information topics, in which their greater concerns were related to fertility potential and the health of future offspring. Greater unmet information needs were found to be related to greater decisional conflicts; greater reproductive concerns were associated with the trend level. Respondents with limited awareness or knowledge of their risk of premature menopause and fertility preservation options reported higher levels of decisional conflicts regarding future fertility preservation. Post-treatment survivor care should include comprehensive reproductive health counseling, including post-treatment fertility preservation options and family-building alternatives [13].

Other than younger age, another study towards 138 newly diagnosed cancer patients showed that educational attainment, rather than health literacy, is a significant predictor of information needs. In this study, most respondents had basic education only; only 4.9% of university graduates participated in this study. Overcoming barriers to information needs may be more dependent on the issues of the levels of educational attainment. Oncologists and hospital staff should be attentive to the fact that many cancer patients require additional assistance to meet their information needs [14].

Another reason most respondents in this study reported unmet information needs was potentially the lack of enough knowledge in using the health information in both electronic and printed resources. A study towards 69 immigrants with cancer in Iran showed that there was no significant difference between the health information needs of cancer patients and their gender, age, marital status, level of education, job, lifestyle, and rural-urban residency. The most information needs were about access to healthy living, and the main obstacle to access health information was the lack of enough knowledge in using the health information in both electronic and printed resources. It is inevitable to pay enough attention to the health information needs of cancer patients because of their cultural and social differences [15].

The results showed that among all items in the domain of health system and information needs in SCNS-SF34, item 29 (given information about uncontrolled cancer or cancer recurrence) and item 30 (given information about what can be done independently to make better health status) were the top two questions with the highest extreme response among all respondents. These findings were consistent with a study towards 143 cancer patients which showed that respondents had a lack of information about cancer and its treatment and side effects; they expressed greater needs for information about managing their illness, receiving explanations about diagnostic tests, the benefits, and side-effects of treatments before making choices [16]. In addition, a qualitative study revealed that patients perceived that information provision regarding diet, exercise, and weight management is insufficient, especially when they want more of it during the treatment. Barriers to information provision described included lack of resources and time and practitioners' uncertainty regarding appropriate messages to provide [17].

Overall, this study's findings indicate that women living with cancer in the community setting want more adequate information about the health system and cancer management at home from HCP especially. Due to the moderate level of unmet needs found, it could be assumed that HCP has attempted to fulfill the needs of their clients, but the study respondents desire more of it or the attempt itself was not adequate. HCP who work in the PHC may feel lacking in the time provided for each client in the field regarding their role as an information source, or the client needs more time to understand the given information due to their various educational backgrounds. Interaction between HCP and cancer patients in the PHC setting or community setting is another issue that needs further investigation in the cancer management research field. This study findings open a new perspective about what should be done better by the HCP in the field to meet the needs of women living with cancer, especially related to the health system and information needs in the community setting.

There were also limitations in this study. Firstly, the nature of cross-sectional design has made this study unable to capture the changes of the variable's value over time. The level of unmet needs of female cancer survivors might change over time because it was not a static variable; many factors are affecting it. Secondly, the researcher used free translation in translating SCNS-SF34 into Indonesian; after that, it was directly used in the data collection process so that the assessed aspects might not precisely match the desired aspects as planned in the first time of the instrument developed by the Centre for Health Research & Psychology (CHeRP), Cancer Council New South Wales, Australia. Thirdly, the cancer cases were not differentiated strictly between breast and cervical cancers in the data analysis process. The descriptive statistic was done globally among 81 respondents so that there the findings between breast and cervical cancer respondents might be different regarding the levels of unmet needs (affecting mean and SD values).

CONCLUSIONS

Most female cancer survivors in the community setting have a moderate level of unmet needs, in which they put their highest priority on the health system and information needs, followed by patient care and support needs, physical and daily function needs, psychological needs, and sexuality needs.

DECLARATIONS

Ethics Approval

Ethical clearance was issued by the Faculty of Medicine, Widya Mandala Surabaya Catholic University, with a certificate number 082/WM12/KEPK/DOSEN/T/2020.

Competing of Interest

I declare that there are no known conflicts of interest associated with this publication, and there has been no significant financial support for this work that could have influenced its outcome.

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