

Psychosocial Needs among Indonesian Women Diagnosed with Breast Cancer

Siti Ulfah Rifa'atul Fitri
Master of Nursing Science
Faculty of Nursing, Prince of Songkla University
Hatyai, Thailand
sitiulfah2paradise@gmail.com

Khomapak Maneewat
Assistant Professor of Surgical Nursing Department
Faculty of Nursing, Prince of Songkla University,
Hatyai, Thailand
khomapak.m@psu.ac.th

Hathairat Sangchan
Doctor in Department of Surgical Nursing
Faculty of Nursing, Prince of Songkla University,
Hatyai, Thailand
hathairat.s@psu.ac.th

Abstract— The aim of this study was to examine the importance of psychosocial needs and to identify the extent to which they are unmet among Indonesian women diagnosed with breast cancer. The descriptive with cross sectional study was used. The participants (n=132) were asked to complete the Psychosocial Needs Inventory (PNI), which consists of 7 categories with 48 items. The most important psychosocial needs was in 'child care' category, followed by 'support network', 'interaction with health professionals', 'information', 'practical', 'identity', and 'emotional and spiritual', respectively. Moreover, 'practical needs' was the most unmet psychosocial needs category, followed by childcare needs, emotional and spiritual needs, interaction with health professional needs, identity needs, support network needs, and information needs, respectively. The most unmet need item was 'help with financial matters' (42.4%). The high level of unmet needs across a wide range of psychosocial needs among cancer patients was related to low income in particular of the practical need. The findings provide useful information for nurses and health care providers to improvement the intervention to meet psychosocial needs among breast cancer patients.

Keywords-psychosocial; breast cancer; unmet needs, treatment, cancer care

I. INTRODUCTION

Globally, breast cancer is the most frequently diagnosed cancer and the leading cause of cancer death among women. The incidence of breast cancer in developed countries is higher than in developing countries whereas breast cancer death is much higher in less developed countries [1, 2]. Similarly with other developing countries, the prevalence of breast cancer in Indonesia has been increasing [3, 4]. According to the International Agency for Research on Cancer (IARC), breast cancer is the second-most female cancer and ranks among the top-five mortalities of all types of cancer. More than 48,000 Indonesian women are approximately

diagnosed with breast cancer and as a cause of death for more than 19,000 Indonesian women [5].

Diagnosis and treatment of cancer may impact on physical, psychological and social aspects of patients [6, 7]. The routine identification correctly of psychosocial need is important as well as physical needs to adapt their changes during illness trajectory. A previous study found that meet of the psychosocial need has important for treating their disease [8].

Similarly with other cancer, women diagnosed with breast cancer face multiple stressors. The diagnosis and treatment of breast cancer can be challenging [9] or can be one of the most frightening events and experiences for women [10]. The impacts and consequences of cancer and treatments also impact on the psychosocial needs of women diagnosed with breast cancer [11, 12, 13].

Some previous studies revealed that to identify and meet the psychosocial needs among cancer patients, it is necessary to differentiate between the importance of psychosocial needs and the extent to which they are met [8, 14]. The unmet of psychosocial needs are still high among cancer patients and approximately two thirds of them have experienced at least one unmet psychosocial needs [15]. A systematic review found that during treatment of cancer, patients has the highest and the most varied of unmet psychosocial needs [16]. Among the type of psychosocial needs, the practical needs were commonly unmet in the terminal stage, while emotional and spiritual needs were unmet at the diagnosis of cancer [17].

Several studies have examined the psychosocial needs of cancer patients. However, previous studies are limited to specific cancer and lack of cultural diversity aspect. In particular, research addressing psychosocial needs among women diagnosed with breast cancer in Indonesia is rare. Therefore, it is important to assess and identify of unmet

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psychosocial needs of women diagnosed with breast cancer in developing country such as Indonesia. Through detailed understanding about the prevalence of psychosocial needs and unmet needs in breast cancer patients, it is expected to provide and support the development of clinical services to maintain the psychological, social and emotional wellbeing that meet their psychosocial needs.

This study was planned as a descriptive study in order to examine the psychosocial needs and to identify the extent to which they are unmet among Indonesian women with breast cancer.

II. METHODOLOGY

A. Design

This study used the descriptive cross sectional design to examine the psychosocial needs and to identify the extent to which they are unmet among Indonesian women diagnosed with breast cancer. This study was conducted at a chemotherapy unit, radiotherapy unit, and female surgical ward, at Hasan Sadikin General Hospital, Bandung, West Java, Indonesia.

B. Participants

The participants in this study were women diagnosed with breast cancer and were treated at Hasan Sadikin General Hospital. A purposive sampling method was used using the following inclusion criteria: (1) already informed of the breast cancer diagnosis, (2) 18 years of age or older, (3) able to understand the Indonesian language, and (4) no history of mental illness. Proportionately, the eligible participants were selected: 115 participants from the chemotherapy unit, 16 participants from the radiotherapy unit, and 8 participants from the female surgical ward. Among those, seven participants from the chemotherapy unit were excluded from the analysis due to incomplete participation. Finally, 132 participants were studied.

C. Measures

The socio-demographic and medical status questionnaire.

The socio-demographic questionnaire included information about age, marital status, religion, level of education, employment status, household income, health insurance status, family history of breast cancer, and living with family. The medical status questionnaire included length of breast cancer diagnosis, co-morbidity, staging of breast cancer, and type of treatment.

The Psychosocial Needs Inventory (PNI)

The psychosocial needs of this study were measured using the Psychosocial Needs Inventory PNI, which was developed by Thomas and colleagues (2001) [8]. The PNI is a relevant, discriminative and sensitive instrument to assess and measure psychological needs of cancer patients [8, 14, 18]. The PNI consists of 48-item under seven needs categories; (1) needs related to interaction with health professionals (9 items), (2) information needs (5 items), (3) needs related to support

networks (5 items), (4) identity needs (5 items), (5) emotional and spiritual needs (15 items), (6) practical needs (8 items), and (7) childcare need (1 item). Each item was used to measure both the psychological needs by a 5-point Likert scale ranging from 1 (not at all important) to 5 (very important) and the extent to which the participants satisfied in acquiring support to meet their psychosocial need by a 5-point Likert scale ranging from 1 (unsatisfied) to 5 (very satisfied). The PNI for this study was translated into Indonesian. The content validity index of this instrument was checked by three experts. The Croanbach's alpha using reliability was .92.

A significant psychosocial in this study was identified if a psychosocial need item is marked by over 50% of the subjects as either 'important' or 'very important'. While the significant unmet psychosocial needs was identified as 'important' or 'very important' and the level of satisfaction of their received was being met was reported as 'unsatisfied' or 'very unsatisfied' [8, 14].

D. Data Collection Procedure

Data collection was conducted between January 2016 and March 2016. The researcher explained this study, including potential risks and benefits and ethical conduct to the head nurses and staff nurses in every unit. Then, the researcher identified the lists of potential participants who met the inclusion criteria from medical record in each setting. After, gaining a breast cancer woman's consent for participation, the researcher distributed and explained the questionnaires to the participants and asked them to fill out all questionnaires completely. The time spent to complete the questionnaires took 30 to 45 minutes.

E. Data Analysis

Descriptive statistics (mean, standard deviation, frequency, and percentage) were used to analyze and describe socio-demographic and medical status of participants as well as to identify the examine the prevalence of psychosocial needs and unmet psychosocial needs.

F. Ethical Considerations

The study received ethic approval from the Institutional Review Board (IRB), Faculty of Nursing, Prince of Songkla University, Thailand and Hasan Sadikin General Hospital, Indonesia. Ethical principles in conducting research were employed in every step of the study, especially in the stage of data collection, analysis, and interpretation, with particular attention to informed consent and confidentiality. The permission to approach the breast cancer patients was granted from the Director of Hasan Sadikin General Hospital, Indonesia.

III. RESULTS

The socio-demographic and medical status questionnaire.

A total of 132 Indonesian women who had been diagnosed with breast cancer participated in this study. The response rate was 94.9%. Seven out of the 139 women approached did not participate completely. Sample characteristics are presented in

Table 1. The mean age of the participants was 48.64 years old (SD = 9.56) ranging from 30 to 74 years old. Most of the participants were Muslims (98.5%), living with family (96.2%), married (83.3%), working as a housewife (75%), had health insurance (95.5%), and a half of the participants (51.5%) had household income less than 1,000,000 IDR (< 75 USD). More than one third of the participants had completed elementary school (46.2%). The majority of the participants had no family history of breast cancer (89.4%).

In terms of medical status, the length of breast cancer diagnosis was between 2 to 48 months (M = 10.94, SD = 9.79). Most of the participants had no physical condition of morbidity (85.6%). More than half of the participants (56%) were at stage IIA (28%) and IIB (28%). Most of the participants received chemotherapy (81.8%).

TABLE 1. SAMPLE CHARACTERISTICS (N=132)

Characteristic	N	%
<i>Socio-demographics characteristics</i>		
Age (years) (M = 48.64, SD = 9.56, min-max = 30-74)		
30-44	43	32.6
45-59	71	53.8
60-74	18	13.6
Marital Status		
Single	1	.8
Married	110	83.3
Widowed	18	13.6
Divorce	3	2.3
Religion		
Muslim	130	98.5
Christian	2	1.5
Educational level		
No school	7	5.3
Elementary school	61	46.2
Junior high school	27	20.5
Senior high school	30	22.7
Others	7	5.3
Employment status		
Employed for wages	15	11.4
Self employed	6	4.5
A housewife	99	75.0
Retired	2	1.5
Unable to work	8	6.1
Out of work but not currently looking for work	2	1.5
Household income		
No Income	17	12.9
< IDR 1,000,000 (< 75 USD)	68	51.5
IDR 1,000,000-3,000,000 (75– 225 USD)	37	28.0
> IDR 3,000,000 (> 225 USD)	10	7.6
Health Insurance		
Yes	126	95.5
No	6	4.5
Family history of breast cancer		
Yes	14	10.6
No	118	89.4
Living with family		
Yes	127	96.2
No	5	3.8

Characteristic	N	%
<i>Medical Status</i>		
Length of breast cancer diagnosis (months) (M = 10.94, SD = 9.79, min-max = 2-48)		
2 - 17	42	31.8
18 - 33	56	42.4
34-48	34	25.8
Morbidity		
Yes	19	14.4
No	113	85.6
Staging of breast cancer		
Stage IB	1	.8
Stage IIA	37	28.0
Stage IIB	37	28.0
Stage IIIA	32	24.3
Stage IIIB	7	5.3
Stage III C	2	1.5
Stage IV	16	12.1
Type of treatment		
Chemotherapy	108	81.8
Radiotherapy	16	12.1
Surgery	8	6.1

Significant psychosocial needs

As shown in Table 2, the highest mean prevalence of significant psychosocial needs was in ‘child care’ category (94.2%), followed by support network needs (93.6%), interaction with health professionals needs (91.2%), information needs (79.3%), practical needs (78.9%), identity needs (73.6%), and emotional and spiritual needs (73.5%), respectively.

Almost all items (47 items out of 48 items), were reported as ‘important’ or ‘very important’ by more than 50 percent of the subjects (Table 2), representing significant psychosocial need items. The items no. 10, ‘information about treatment plans’; item no. 12, ‘information about medication side effects’; and item no. 15, ‘support from family’ had the highest positive response (100%). On the other hand, item no. 38, ‘help with any feelings of guilt’ (2.3%) was the lowest; followed by item no. 47 ‘help in filling out forms’ (50.8%); and item no. 39, ‘help in considering my sexual needs’ (51.5%).

Significant unmet psychosocial needs

As displayed in Table 2, the highest mean score of unmet psychosocial received were practical needs (40%), followed by childcare needs (24.6%), emotional and spiritual needs (12.5%), interaction with health professional needs (9.8%), identity needs (5.8%), support network needs (5.1%), and information needs (4.22%), respectively.

With a total of 48 items of significant psychosocial need were also examined to be significant unmet needs. The highest percentage of significant unmet psychosocial needs were item no. 46, ‘help with financial matters’ (42.4%), followed by item no. 39, ‘help in considering my sexual needs’ (25%), and item no. 48, ‘help with child care’ (24.6%). Whereas, item no. 47, ‘helping in filling out forms’ (2.3%) were lowest of unmet psychosocial needs, followed by item no. 33, ‘opportunities for meeting others who are in a similar’ (2.3%); and item no. 17, ‘support from care professionals’ (3%).

IV. DISCUSSION

The participants in this study required the significant psychosocial needs by more than 50% in all categories. Among seven needs categories, 'child care' needs was reported as the most important of psychosocial need among Indonesian woman participants, followed by needs regarding 'support network'. This study finding was congruent with a previous study that the cancer patients worried and unsatisfied about persons who will take their roles in taking care of their family member if they go to hospital or during treatment [19]. Therefore, breast cancer women who had child more likely to experience high demand for childcare during their treatment.

The findings of this study showed that the most of participants were housewife, married, and Muslim. In general, married Islamic women devoted most of their time to children and husband [20]. Under Indonesian culture, the major roles and responsibilities of married women are mother and wife [21]. Here, being diagnosed with breast cancer and time spent for treatments and visit medical doctor can be stressful for participants. From this, significant needs about 'child care' as well as maternal role limitation remain paramount among women diagnosed with breast cancer in this study. Congruently, 'child care' need was reported as the second most significant unmet psychosocial needs in this study. Consequently, 'support network' need was required as the second highest significant psychosocial need among the Indonesian woman participants in this study.

In addition, support network is activity or to support the process of interaction and relationship which effects person's wellbeing and emotional adjustment to cancer [22]. Social network as well as social support has been most commonly used as one of the important strategies to help people cope with cancer [23]. The support network includes health professional, friends, co-worker, partner, family or family support [24]. In this study, all participants required support from family, followed by friends, and health care professionals. Being diagnosed with breast cancer and receiving treatment made breast cancer women experienced physiological and psychological stress throughout the trajectory of illness and survivorship [6, 7]. From this, significant needs about 'support network' remain of paramount importance among women diagnosed with breast cancer in this study.

In contrast, while 'support network' is the second highest significant psychosocial need, 'practical' needs was reported as the most significant unmet psychosocial needs. Previous study revealed that practical needs were developed among cancer patients to manage and maintain the demand of their lives resulted from the responses to cancer and consequences or impacts of cancer treatments [25]. In this study, the highest unmet practical need item was 'help with financial matters'. Although the majority of participants in this study had health insurance (95.5%), they still reported the highest unmet need in helping with financial matters. This can be inferred that financial help might not be of financial regarding hospital care cost but then they need to support for transportation fee as

well as meal allowance while visiting medical doctors to the hospital regularly far from their residence. Accordingly, previous study revealed transportation affordability as well as poor economic status becomes a major barrier factor of breast cancer patients' delay in seeking a medical care [26].

In addition, 'information need' category was similar to the finding of other previous studies. These findings revealed that cancer patients rely heavily on health professionals and they want specific information regarding treatments, medication, and side effects regardless level of economic status and across health environments and ethnicities [8, 14, 27]. Additionally, previous study found lack of information about breast cancer in rural area [21]. They suggest that information through media campaign, treatment decision aids, and caregiver and patients education are needed to meet one of their psychosocial needs [21].

In summary, a high level of unmet needs across a wide range of psychosocial needs among cancer patients in this study was related to low income in particular of the practical need [14, 28]. As discussed previously, the majority of Indonesian woman in this study had family income less than the average income in West Java, Indonesia. Moreover, the health insurance does not include the transportation fee and food allowance. As seen, the highest item of unmet needs of the subjects in this study was 'help with financial matters', followed by item 'help with transport'. Thus, the economic status of the Indonesian women subjects in this study caused their unmet of psychosocial needs.

VI. CONCLUSION

This descriptive cross sectional study was conducted to examine the psychosocial needs and to identify the extent to which they are unmet among Indonesian women with breast cancer. The findings of this study showed that participants required significant psychosocial needs by more than 50% in all categories. Whereas, the 'practical' need in 'help with financial matters' item is the high of unmet psychosocial needs. Nevertheless, almost all participants have health insurance but they need financial support for accommodation as well as meal while visiting the hospital regularly. The general findings of this study can also facilitate other breast-cancer-care services in Indonesia to providing supportive care being meet their psychosocial needs.

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TABLE 2. PREVALENCE OF SIGNIFICANT PSYCHOSOCIAL NEEDS AND UNMET NEEDS

Need Category/Items	Rating as important or very important	Rating as unsatisfied or very unsatisfied
	n (%)	n (%)
Interaction with Health Professionals		
Confidence in the health professionals I meet	128 (97.0)	13 (9.8)
Health professional have time to discuss issues with me	124 (93.9)	23 (17.4)
Easy and quick access to doctors (n = 132)	124 (93.9)	22 (16.70)
Honest information	129 (97.7)	9 (6.8)
Health professional who treats me with respect	124 (93.9)	5 (3.8)
Information given sensitively	128 (97.0)	9 (6.8)
Health professional who listen to me	124 (93.9)	8 (6.1)
Easy and quick access to health professionals other than doctors	87 (65.9)	20 (15.2)
Opportunities to participate in choices around treatment	116 (87.9)	8 (6.1)
<i>Mean prevalence</i>	120 (91.2)	13 (9.8)
Information		
Information about treatment plans	132 (100.0)	4 (3.0)
Information about what to expect	127 (96.2)	5 (3.8)
Information about medication and side effects	132 (100.0)	7 (5.3)
Advise on what services help are available	126 (95.5)	6 (4.5)
Access to other sources of information	125 (94.7)	6 (4.5)
<i>Mean prevalence</i>	128 (79.3)	6 (4.2)
Support Network		
Support from family	132 (100.0)	4 (3.0)
Support from friends	128 (97.0)	6 (4.5)
Support from care professionals	122 (92.4)	4 (3.0)
Someone to talk to	121 (91.7)	7 (5.3)
Support from neighbors	115 (87.1)	13 (9.8)
<i>Mean prevalence</i>	124 (93.6)	7 (5.1)
Identity		
Help in maintaining independence in the face of illness	120 (90.0)	9 (6.8)
Help in maintaining a sense of control in my life	112 (84.8)	6 (4.5)
Support in dealing with changes in my body	97 (73.5)	7 (5.3)
Support in dealing with any changes in the way others see me	83 (62.9)	8 (6.1)
Support in dealing with any changes in my sense of who I am	80 (60.6)	8 (6.1)
<i>Mean prevalence</i>	98 (73.6)	8 (5.8)
Emotional and Spiritual		
Hope for the future	112 (84.8)	11 (8.3)
Help with any fears	105 (79.5)	15 (11.4)
Help in dealing with the unpredictability of the future	77 (58.3)	11 (8.3)
Time for myself	103 (78.0)	10 (7.6)
Helping with finding a sense of purpose and meaning	100 (75.8)	5 (3.8)
Help with any sad feelings	118 (89.4)	19 (14.4)
Help in dealing with the feelings of others	83 (62.9)	14 (10.6)
Opportunities for personal prayer	127 (96.2)	30 (22.7)
Opportunities for meeting others who are in a similar situation	123 (93.2)	3 (2.3)
Help with any loneliness	111 (84.1)	8 (6.1)
Support from people of my faith (n = 132)	123 (93.2)	11 (8.3)
Help with any anger (n = 132)	87 (65.9)	21 (16.7)
Support from a spiritual advisor (n = 132)	116 (87.9)	32 (24.2)
Help with any feelings of guilt (n = 132)	3 (2.3)	13 (9.8)
Help in considering my sexual needs (n = 132)	68 (51.5)	33 (25.0)
<i>Mean prevalence</i>	97 (73.5)	16 (11.9)
Practical		
Help with any distressing symptom	113 (85.6)	9 (6.8)
Help with transport	124 (93.9)	31 (23.5)
Help in dealing with any tiredness	122 (92.4)	15 (11.4)
Advise about the food and diet	128 (97.0)	11 (8.3)
Help with housework	122 (92.4)	7 (5.3)
Help with getting out and about socially	97 (73.5)	11 (8.3)
Help with financial matters	128 (97.0)	56 (42.4)
Help in filling out forms	67 (50.8)	3 (2.3)
<i>Mean prevalence</i>	104 (78.9)	18 (40.0)
Child Care		
Help with child care (n = 69) ^a	65 (94.2)	17 (24.6)
<i>Mean prevalence</i>	65 (94.2)	17 (24.6)

^aMissing n: number of reply on 'does not apply to me'

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