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Supportive care needs in predicting the quality of life among gynecological cancer patients

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ABSTRACT

Unmet supportive care needs have been shown to lower the quality of life of cancer patients, including those with gynecological cancer. Therefore, we examined how the unmet supportive care needs might predict the quality of life of gynecology cancer patients undergoing therapy. We had a convenience sample of 153 patients from two major cancer hospitals in Jakarta, Indonesia, complete the SCNS-SF34 and EORTC QLQ-30. Analysis showed that unmet supportive care needs predict poorer quality of life (i.e., lower global health status and functional status, and more cancer-related symptoms). This study emphasizes the need for supportive care services in the areas of psychological, physical, and sexuality to be prioritized to improve the patients' quality of life.

INTRODUCTION

The magnitude of the impact cancer has on an individual extends beyond the physical dimension. Evidence shows that aside from the physical impacts, the course of cancer diagnosis and treatments potentially causes psychosocial effects in both the short and long term (Montgomery & McCrone, 2010; Treanor & Donnelly, 2014; Van Weert et al., 2005). Some of the effects are psychological distress, depression and anxiety, and post-traumatic stress disorders (Milanti, Metsälä, & Hannula, 2016; Treanor & Donnelly, 2014). Cancer patients may also experience problems related to relationships, employment, finance, and spiritual life (Cebeci, Yangin, & Tekeli, 2010; Treanor & Donnelly, 2014).

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Addressing multidimensional cancer implications requires a comprehensive supportive care service. Supportive care is a person-centred approach to deliver the essential services for people living with or affected by cancer to fulfill their physical, psychological, spiritual, sexual, social, practical, and informational needs during cancer pre-diagnostic, diagnostic, therapy and survivorship (Fitch, 2008; Maguire, Kotronoulas, Simpson, & Paterson, 2015). Supportive care focuses on controlling symptoms and enhancing quality of life (Hui, 2014). Quality of life has been an emphasis in cancer care to address cancer implications in a patient's life. Improving quality of life helps to minimize the physical and psychological effects of the cancer diagnosis and treatments (Aranda et al., 2005).

Identifying and facilitating supportive care needs can reduce patient's distress and improve patient satisfaction and quality of life (Fitch & Maamoun, 2016; Sanders, Bantum, Owen, Thornton, & Stanton, 2010). According to Liao et al. (2012), by identifying the patient's need for supportive care, the health care provider can also get a sense of the patient's expectation for care which he or she has not yet received. Studies have found that the predominant supportive care needs of cancer patients undergoing diagnostic and treatment procedures were information, healthcare service, and psychological support (Hubbard, Venning, Walker, Scanlon, & Kyle, 2015; So et al., 2014). These studies also pointed out that unmet supportive care needs are linked to low quality of life.

While many have studied supportive care needs and their related aspects, data on how supportive care needs predict the quality of life of cancer patients are still limited. This matter is particularly important in women having gynecological cancer, as this population tends to have lower quality of life and higher distress when compared to other cancer patient groups (Mendle, Eisenlohr-Moul, & Kiesner, 2016).

Moreover, despite the plentiful literature regarding supportive care needs and quality of life, data from lower and middle income countries (LMIC) such as Indonesia are under-reported. Many reviews lack coverage of such socio-demographic settings (Gonçalves, 2010; Maguire et al., 2015). Women with cancer in Indonesia must deal with many environment stressors related to their lower socio-economic, education, and cultural background (Ell et al., 2005).

Eighty-five percent of the global gynecological cancer burden occurs in LMIC (Jemal, Bray, & Ferlay, 2011). The survival rate in LMIC is less than 40%, while the survival has reached higher than 70% in the high-resource countries (Allemani et al., 2015). In Indonesia, there are 95.9 million women at risk for cervical cancer (Bruni et al., 2017). It is estimated there are around 20,928 new cervical cancer

cases and 9,428 deaths of cervical cancer in Indonesia annually (Bruni et al., 2017). Other gynecological cancers (i.e., ovary and corpus uteri) are among the five most frequent cancers in Indonesian women. Therefore, studies from Indonesia and other LMICs need more global attention to mobilize support and resources to address these multifaceted problems.

This study is a part of a larger study to develop gynecological cancer care in Indonesia (Afiyanti, Milanti, Putri, Larasati, & Nasution, 2016). The purpose of this study was to examine the supportive care needs as a predictive factor of quality of life for gynecology cancer patients undergoing therapy.

METHODS

Study Design and Setting

A cross-sectional study to predict quality of life from the supportive care needs was completed among patients with gynecological cancer undergoing therapy in two central hospitals in Jakarta, Indonesia. Our study sites included a national cancer centre, to which advanced cancer cases from all over the country are referred, and a central hospital for the Indonesian army. It also serves cancer patients from many regions of Indonesia, especially those with affiliation to the national army.

The study was designed, conducted, and reported with respect to the ethical principles of study with human subjects. Prior to the commencement of the study, we attained ethical clearances from the local Ethics Review Boards.

Sample

We used a convenience sampling method to recruit patients with gynecological cancer (specifically cervical and ovarian cancer) undergoing cancer therapy. Every accessible patient who was attending the one-day care, outpatient, and inpatient units of the two hospitals during May–June 2016 was approached to enroll in our study. The eligibility criteria for the participants were: (1) diagnosed with stage I–IV cervical or ovarian cancer; (2) at present undergoing cancer therapy; (3) formerly received a therapy at least once; (4) physically and mentally able to complete the questionnaires; and (5) able to read and write in standard Indonesian language.

Procedure and Instruments

After giving their written informed consent, participants completed a self-report Supportive Care Needs Survey (SCNS)-SF34 (McElduff, Boyes, Zucca, et Girgis, 2004) to examine their supportive care needs and the European Organization of Research and Treatment of Cancer Quality of Life (EORTC) QLQ-30 to assess their quality of life. We accompanied the participants while completing the questionnaires for 15–20 minutes and clarified any emergent questions from the participants.

The SCNS-SF34 is a 34-item questionnaire composed of five domains regarding physical, psychological, care support, health system and information, and sexuality needs (Boyes, Girgis, & Lecathelinais, 2009). This questionnaire has a five-point Likert scale. Responses that fell into the 1–2 part of the scale were considered a category of ‘no need’ for supportive care, while those that fell into the 3–5 part of the scale fall into the ‘some need’ of supportive care). We used standardized

Likert summated score by summing the individual items, subtracting the value of maximum response for each item (k), and multiplying the resulting value by 100 [$m \times (k-1)$, m is the number of questions], as suggested by McElduff, et al., (2004). Apart from the original assessment of its construct validity and internal reliability (Bonevski et al., 2000), this instrument has been well-evaluated and adopted in different countries (Li et al., 2013; Okuyama et al., 2009; Schofield, Gough, Lotfi-Jam, & Aranda, 2012; Zeneli et al., 2016). Since it has not been examined in Indonesia previously, we tested it on a different homogenous group of participants and found the validity score of 0.302–0.792, with the Cronbach’s alpha score of 0.933.

The EORTC QLQ-30 has 30 questions covering the three domains of global health status, functional, and symptoms (Scott et al., 2008). This tool has been translated to many languages including Bahasa Indonesia, and widely recognized for its good reliability and validity (Ayana, Negash, Yusuf, Tigeneh, & Haile, 2016; Azmawati, Najibah, Hatta, & Norfazilah, 2014; McCarthy, 2011; Michels, Latorre, & Maciel, 2013; Nejari et al., 2014). Previous study in Indonesia found this tool to be valid and reliable with the validity score of 0.14–0.48 (Perwitasari et al., 2011).

Statistical Analysis

The univariate data were analyzed with descriptive analysis consisting of frequency distribution and percentages. Furthermore, we conducted multivariate linear regression to scrutinize the supportive care need variables in predicting the quality of life. Clinical variables (i.e., cancer type, stage, period of therapy, and type of therapy) and variables of supportive care needs component summaries (i.e., physical, psychological, patient care, sexuality, health information system) were analyzed to identify which variables specifically contributed to the quality of life. The probability level of 0.05 was set for statistical significance. Analysis of data was performed using Statistical Package for Social Sciences (SPSS version 22.0, IBM Corp.).

RESULTS

Selected Demographic

A total of 153 participants out of the 167 patients approached were included in this study. The third author was mainly responsible for the data collection and approached all patients in the study setting. Fourteen patients declined to participate due to various reasons: some did not feel like filling out questionnaires and some said they were busy with hospital procedures. All participants completed the questionnaires fully, as we checked directly after the participants filled them out.

Table 1 summarizes the demographic characteristics of the sample in this study. The majority of participants were 55 years of age or younger, worked as housewives, and had lower socioeconomic status (see family income variable) than the average regional minimum wage. Slightly more than half of the participants (59.5%) completed high school or college. In Indonesia, basic education is nine years, consisting of six years of elementary school and three years of junior high school. Nearly 65% of the participants were diagnosed with cervical cancer, while 68% were in early stage (stage I or II). Most participants had been undergoing single therapy for less than or equal to one year.

Table 1: Demographic profile (n=153)	
Variable	n (%)
Age	
≤ 55 years old	118 (77.1)
> 55 years old	35 (22.9)
Education	
Basic (Elementary school, Junior high school)	62 (40.5)
Higher (Senior high school, college/university)	91 (59.5)
Occupation	
Housewife	126 (82.4)
Employee	27 (17.6)
Family income	
< Regional Minimum Wage	93 (60.8)
≥ Regional Minimum Wage	60 (39.2)
Chemotherapy cycle	
1-weekly	52 (40.6)
3-weekly	76 (59.4)
Cancer type	
Cervical	99 (64.7)
Ovary	54 (35.3)
Cancer stage	
Early (Stage I and II)	104 (68)
Advanced (Stage III and IV)	49 (32)
Period of cancer therapy	
≤ 1 year	141 (92.2)
> 1 year	12 (7.8)
Therapy type	
Single	95 (62.1)
Combined	58 (37.9)

Supportive Care Needs

Ninety-six percent of participants stated that their needs for supportive care had caused them a lot of concern, thus needing additional help. Of all supportive care need domains, the highest number of patients reported their needs in the physical domain (80.4%). In contrast, only a minority of participants (35.5%) stated some needs in sexuality.

The detailed unmet supportive care needs of the participants are presented in Table 3. Of all items in the supportive

Table 2: Patient supportive care needs (n = 153)	
Variable	n (%)
Supportive care needs	
Patients with no need*	6 (3.9)
Patients with some need**	147 (96.1)
Physical	
Patients with no need	30 (19.6)
Patients with some need	123 (80.4)
Psychological	
Patients with no need	43 (28.1)
Patients with some need	110 (71.9)
Patient care	
Patients with no need	39 (25.5)
Patients with some need	114 (74.5)
Health system Information	
Patients with no need	45 (29.4)
Patients with some need	108 (70.6)
Sexuality	
Patients with no need	99 (64.7)
Patients with some need	54 (35.3)
*Patients indicate that either this issue is not a problem for them or they do need help with this issue but the need has been satisfied at the time.	
**Patients indicate that this issue causes them concern or discomfort, and their need of additional help ranges from low, moderate, and high.	

care needs questionnaire, the most frequently identified unmet need was “concerns about the worries of those close to the patients” (89.5%) in the psychological domain. The unmet need reported least frequently was changes in sexual feelings (19%) in the sexuality domain.

Unmet supportive care needs predicted poorer global health status and functional quality of life, as well as more symptoms among participants (see Table 4). In the global health status domain, the strongest predictor was unmet psychological needs. In the functional domain, the unmet physical, psychological, sexuality, and health system information needs explained 28.1% of the variance in patients’ quality of life, with unmet needs in the sexuality domains as the strongest predictor. Of the symptom scale domain, 27.1% of it was determined by the unmet supportive care needs, and the strongest predictor was the unmet physical needs.

Table 3: Prevalence of unmet supportive care needs (n = 153)	
Unmet supportive care needs	n (%)
Physical	
Pain	97 (63.4)
Lack of energy/tiredness	120 (78.4)
Feeling unwell a lot of the time	124 (81)
Work around the home	115 (75.2)
Not being able to do the things you used to do	120 (78.4)
Psychological	
Anxiety	103 (67.3)
Feeling down or depressed	96 (62.7)
Feelings of sadness	103 (67.3)
Fears about the cancer spreading	116 (75.8)
Worry that the results of treatment are beyond your control	119 (77.8)
Uncertainty about the future	105 (68.6)
Learning to feel in control of your situation	74 (48.4)
Keeping a positive outlook	63 (41.2)
Feelings about death and dying	116 (75.8)
Concerns about the worries of those close to you	137 (89.5)
Sexuality	
Changes in sexual feelings	29 (19)
Changes in your sexual relationships	36 (23.5)
To be given information about sexual relationships	59 (38.6)
Patient care	
More choice about which cancer specialists you see	98 (64.1)
More choice about which hospital you attend	95 (62.1)
Reassurance by medical staff that the way you feel is normal	97 (63.4)
Hospital staff attending promptly to your physical needs	93 (60.8)
Hospital staff acknowledging, and showing sensitivity to, your feelings and emotional needs	105 (68.6)
Health system Information	
Being given written information about the important aspects of your care	95 (62.1)
Being given information (written, diagrams, drawings) about aspects of managing your illness and side-effects at home	101 (66)
Being given explanations of those tests for which you would like explanations	100 (65.4)
Being adequately informed about the benefits and side-effects of treatments before you choose to have them	
Being informed about your test results as soon as feasible	100 (65.4)
Being informed about cancer which is under control or diminishing (that is, remission)	107 (69.9)
Being informed about things you can do to help yourself to get well	99 (64.7)
Having access to professional counselling (e.g., psychologist, social worker, counsellor, nurse specialist) if you, family or friends need it	105 (68.6)
Being treated like a person not just another case	80 (52.3)
Being treated in a hospital or clinic that is as physically pleasant as possible	80 (52.3)
Having one member of hospital staff with whom you can talk to about all aspects of your condition, treatment and follow-up	104 (68)

Table 4: Supportive care needs to predict quality of life					
Quality of Life	Unstandardized B	Standardized beta	p	R2	Adjusted R2
Global Health Status					
Unmet supportive care needs					
Physical	-9.027	-0.189	0.015*	0.172	0.156
Psychological	-11.286	-0.268	0.001*		
Sexuality	-6.369	-0.161	0.035*		
Functional					
Unmet supportive care needs					
Physical	-8.623	-0.229	0.002*	0.281	0.261
Psychological	-5.732	-0.172	0.021*		
Sexuality	-9.847	-0.315	<0.001*		
Health system Information	-4.191	-0.128	0.099		
Symptom					
Unmet supportive care needs					
Physical	9.837	0.260	<0.001*	0.290	0.271
Psychological	4.420	0.132	0.074		
Sexuality	7.876	0.251	0.001*		
Health system Information	7.370	0.224	0.004		
* significant at the 0.05 level					

DISCUSSION

The main finding of this study was that unmet supportive care needs predict poorer quality of life of the gynecological cancer patients in Indonesia. Patients with more unmet supportive care needs tend to have lower global health status and functional status, as well as more symptoms related to cancer or cancer treatment. Furthermore, this study found that different domains of supportive care needs made different contributions towards the quality-of-life scores. The strongest predictor of the global health status was the unmet psychological needs. Unmet sexual needs and unmet physical needs were the strongest predictors of the quality of life in the functional and symptom domains, respectively.

This finding is consistent with previous studies that indicated insufficient treatment to address cancer and its treatment side effects is related to poor quality of life (Bayram, Durna, & Akin, 2014; Cramarossa et al., 2013). Prior study among testicular cancer survivors also showed those reporting more unmet supportive care needs had lower quality of life (Smith et al., 2013). A study in breast cancer survivors also found the link between unmet supportive care needs and quality of life (So et al., 2014).

The gynecological patients in this study expressed physically-related unmet needs as the most frequently reported unmet

supportive care needs, slightly above unmet psychological needs. Previous studies in different countries yielded different results with the health and information domain (Li et al., 2013) or the psychological domain (Brédart et al., 2013; Molassiotis et al., 2014) being the most prevalent unmet need. However, as mentioned by Molassiotis, Wilson, Blair, Howe, and Cavet (2011), comparison to other studies regarding supportive care needs in different cancer groups could be tricky due to varied approaches in the calculation of needs, assessment methods and timing, and sample characteristics. Patients' problems can also differ because of various culture and personal values (Effendy et al., 2014).

Quality of life in terms of global health status is strongly predicted by the unmet psychological needs. The unmet psychological needs represent psychological concerns of the patients that ought to be addressed with appropriate supportive care. Thus, psychological care is an essential area to target for significantly improving the general sense of patients' quality of life.

In this study, even though the psychological domain was second in overall prevalence after physical supportive care, the most frequently reported unmet need among all supportive care items was in the psychological domain: "concerns, worries of those close to the patients". In other words, the female

patients with gynecological cancer were worried about their significant others rather than themselves. McMullin (2016) describes this phenomenon as the sociality of cancer, where the social context affects how the cancer patients attend to their disease. Livingston (2012) highlights that most patients in poor-resource settings are more concerned about the needs of their family instead of their own biomedical concerns. This is closely related to the female identity and role performance, as a wife and mother, that are disrupted by the effects of cancer (Little, Paul, Jordens, & Sayers, 2002).

Despite the markedly low number of patients reporting unmet supportive care needs in sexuality, interestingly, unmet sexual need was found to be strongest predictor of the quality of life in terms of functioning difficulties. A qualitative study in Indonesia (Afiyanti & Milanti, 2013), however, revealed a contrasting result in that the patients with cervical cancer experienced sexual concerns, including pain during sexual intercourse, bleeding, and loss of sexual desire. Previous studies in other countries also support the evidence of sexual issues among gynecological cancer patients (Abbott-Anderson & Kwেকেboom, 2012; Chow, Wong, & Shek, 2014; Hautamäki-Lamminen, Lipiäinen, Beaver, Lehto, & Kellokumpu-Lehtinen, 2013). Moreover, sexuality is still considered to be a taboo topic to raise, so it tends to be ignored in Indonesian culture (Afiyanti, Rachmawati, & Milanti, 2016). Considering the cultural context of this study, even with the in-depth interview approach, the female patients often failed to express their concerns regarding sexuality (Afiyanti & Milanti, 2013). Hence, the self-report questionnaire might not reflect the true sexuality problem of the gynecological patients in this study. In

addition, our patients may not expect to receive supportive care for sexual concerns since such service is still rarely found in Indonesia (Afiyanti et al., 2016).

The unfulfilled physical needs, on the other hand, strongly predicted more perceived symptoms in the quality-of-life measurement. The supportive care needs in the physical domain encompassed the needs to overcome physical symptoms, the treatment side effects, and to maintain the daily activities (McElduff, Boyes, Zucca, & Girgis, 2004). Addressing the physical needs of the patients, therefore, is a key area of supportive care. Improving physical well-being is also highly correlated with increased psychological well-being and overall quality of life (Ashing-Giwa & Lim, 2010).

IMPLICATION FOR PRACTICE AND FUTURE RESEARCH

The results of this study imply that the supportive care services in the area of psychological, physical, and sexuality must be prioritized for resource allocation and action to better improve the patients' quality of life. Nurses should identify the supportive care needs of the patients with gynecological cancer, as the first step to improve the quality of life of these patients. Our study findings also encourage health care providers and management to make supportive care service available, not only for the patients, but also for their significant others who are their caregivers. It is necessary to tailor nursing care according to the patient's personal needs. Future studies should assess approaches in effectively managing supportive care needs of the cancer patients.

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