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Understanding Patients' Condition: Physical, Psychological and Spiritual Aspects of Advanced Cancer Patients in Central Java, Indonesia

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ABSTRACT

Background: Patients with advanced cancer may experience many symptoms in their life including physical, psychological, and spiritual problems. Researchers point out that palliative care should be provided to these patients focusing on comfort, pain control and enhancing patients' quality of life. The focus on palliative care is to care for patients as well as possible before they die, by understanding their problems in physical, psychological and their spiritual aspects.

Objective: To examine advanced cancer patients' condition including symptom distress, anxiety, depression and spiritual well-being.

Methods: A cross-sectional survey was conducted with convenience sampling in Central Java, Indonesia. The survey questionnaire included demographic data, clinical information, Symptom Distress Scale (SDS) - English version, the Functional Assessment of Chronic Illness Therapy- Spiritual Well-Being (FACIT-Sp-12) – Indonesian version and Hospital Anxiety and Depression Scale (HADS) – Indonesian version. The original English version of SDS questionnaire was translated into Indonesian. Descriptive statistics were used to present each variable and Pearson correlation was used to evaluate the relationship between variables.

Result: A total of 363 patients with advanced cancer were recruited. After translated to Indonesian version of SDS questionnaire, we found value of content validity index was 0.95. Appetite, fatigue and pain were three major distress symptoms among patients while only less than 20% patients experienced mild and moderate anxiety and depression. Patients had a high spiritual well-being (M=38.01). Furthermore, there was a significant correlation between HADS with SDS and HADS with FACIT-Sp-12.

Conclusion: The findings represent advanced cancer patients' condition regarding physical, psychological and their spiritual aspects. It can assist healthcare professionals to understand advanced cancer patients' degrees of symptom distress, the levels of anxiety and depression and states of spiritual well-being which will provide better care for advanced cancer patients.

Keywords

Palliative care, Advanced cancer, Symptom distress, Psychological aspect, Spiritual well-being.

Introduction

Most patients with advanced cancer have experiences in suffering many symptoms including physical, psychological, and spiritual problems. In physical aspect, pain being the most common

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symptom among advanced cancer patients [1-3]. The previous study reported that around 64% of advanced cancer patients experienced pain [4]. Unrelieved pain will cause significant emotional burdens to patients and may hasten death because of the poor quality of life [2]. Other studies also point out that fatigue, constipation, dry mouth, shortness of breath, sleeping difficulty, dyspnea and appetite loss are physical symptoms commonly occuring among advanced cancer patients [5-7]. A survey of 112 advanced cancer patients in Indonesia showed that pain, fatigue, and nausea were three major symptoms among cancer patients [8].

Psychological burdens also influence advanced cancer patients in different levels. Emotional disorders of patients could have negative impacts on patient diseases progress and physical status [9]. Mixed depression and anxiety disorder commonly increase over time when the cancer patients are close to death, particularly in the last month of their life [10]. On the other hands, patients with advanced cancer may face uncertainty such us the meaning and purpose life, financial needs, functionality and continuity of social support. Patients and family may feel hopeless. Spirituality is important to help them find hope, meaning and acceptance of uncertainty [11]. When a patient's condition declines, many of them suffer a variety of discomforts, then forcing to try in finding the meaning of life. During those times, spirituality plays an important role in coping with their suffering [12]. A study supported that advanced cancer patients seek spiritual well-being to cope with their illness [13].

All of those aspects have identified to be a multi factors that affect adaptation of trauma and burden in advanced cancer patients [14]. Interaction of physical, psychological and spiritual variables contribute in the course of progressive disease [15]. Consideration of previous finding may help in anticipating further patients' condition. It is important to be aware that patients with progressive malignant have multidimensional symptoms that reflect their needs [16]. Hence, issues related to patients' condition in physical, psychological and spiritual aspects may be responsive to palliative care interventions [17]. But, in fact only few studies in Indonesia explored about patients' condition in advanced stage of malignance disease. Therefore, the aim of this study was to understand advanced cancer patients' condition including physical, psychological and spiritual aspects in Central Java, Indonesia.

Materials and Methods Sampling Process and Sample Size

Study participants were recruited from oncology department (Mawar Unit) of Dr. Moewardi hospital Solo, Central Java. A total of 363 patients with advanced cancer were selected to participated in this study. All participants were diagnosed with advanced cancer (stage 3 or 4 and or already got metastatic cancer), being able to communicate and complete the questionnaire and older than 18 years old. Patients with psychiatric and cognitive disorders, which affect their cognitive ability, were excluded. Patient who suffered during collecting data was allowed to stop and excluded.

Instruments

The study questionnaire included 4 parts: 1) demographics and clinical information, 2) Symptom Distress Scale (SDS) – English version, 3) Hospital Anxiety and Depression Scale (HADS) – Indonesian version, and 4) version the Functional Assessment of Chronic Illness Therapy- Spiritual Well-Being (FACIT-Sp-12) - Indonesian version. Clinical information included cancer diagnoses, time since diagnoses, cancer treatments, and performance status and diseases awareness.

The Symptoms Distress Scale (SDS)

The SDS was used to measure patients' symptom distress. It contains 11 symptoms including nausea, appetite, insomnia, pain, fatigue, bowel pattern, concentration, appearance, outlook, breathing and cough and 2 questions about frequency of nausea and pain. Each symptom is rated by 5-point Likert scale from 1-5 (1 referring to normal or no distress, 5 referring to extensive distress, 2-4 referring to intermediate levels of distress). The total scores more than equal 25 indicate moderate distress and scores of 33 or more represent severe distress [18]. This instrument provide in English version, so it need to translate to Indonesian language.

The Hospital Anxiety and Depression Scale (HADS)

The Hospital Anxiety and Depression Scale (HADS) assessed patients' anxiety and depression. The HADS consists of two subscales; anxiety (7 items) and depression (7 items). Each item is rated on a 4-point Likert scale of 0-3. The scores were classified into 4 categories; 0-7 represent normal, 8-10 indicate mild cases of anxiety or depression, while the scores of 11-15 represent moderate cases of anxiety or depression and 16-21 score means severe cases of anxiety or depression [19].

The Functional Assessment of Chronic Illness Therapy-Spiritual Well-Being

The FACIT – Sp 12 was used to assess spiritual aspect which comprises of three factors with 12 items; meaning (four items), peace (four items) and faith (four items). A five-point Likert scale is applied, ranging from 0 (not at all) to 4 (very much). Two items are negative statements and need to be reversed for the score. Patient's responses are summed for each subscale and for the whole FACIT Sp-12. The higher scores of FACIT-Sp indicate the better spiritual state. High spiritual well-being state was interpreted a total score of Facit-Sp 12 \geq 36 [16].

Translation

Given that only SDS has English version, the study conducted instrument translation process after obtaining the original author's permission. According to Beaton, Bombardier, Guillemin & Ferraz [20], there were several steps for translation process. The first step was a forward translation, which was, translated the questionnaire from English version to Indonesian language. Two bilingual experts studying in international program for more than 2 years were invited to participate in this stage. Then, the forward translation version was synthesized into one Indonesian version. After that, a backward translation was conducted to translate this Indonesian version into English. Another two bilingual experts were invited to participate in this process. Finally, four experts in oncology area were invited as a reference group to discuss the results of the forward and backward translation version and provide some suggestions to make the Indonesian version questionnaire fulfil the original English meaning and meet the Indonesian culture context.

Data Analysis

SPSS version 17 software for windows has been used for data analysis. Descriptive analysis was used to present sample characteristics, symptom distress, HADS and spiritual well-being. Pearson correlation was used to evaluate the relationship between variables.



Figure 1: Translation Process of Symptoms Distress Scale.

Result and Discussion Sample Characteristics

The majority of the participants were female (73.6%) with the mean of age was 54.79 and range between 20-95. Most of them were married (94.5%) and had completed education on elementary school (43.5%). Moslem is being the majority religion of participant (96.7%) and more than fifty percent participant has household income less than 100 USD. Cervical cancer (27.5%, n=100) and breast cancer (26.2%, n=95) were top two cancers. Nearly 70% (n=234) of participants were diagnosed with cancer within one year. Forty-three precent of patients (n=156) only received chemotherapy. In addition, 10.5% (n=38) of participants received complementary therapy along with standard medical treatments. Less than 50% patients aware about their prognosis and only nearly 5% patients had performance status score above 3 (Table 1).

Symptoms Distress	Mean	SD	F	%			
Appetite	2.49	1.23					
Fatigue	2.40	0.97					
Pain	2.33	1.03					
Nausea	2.20	0.98					
Insomnia	2.00	1.15					
Outlook	1.73	0.82					
Cough	1.46	0.72					
Bowel	1.44	0.79					
Appearance	1.39	0.65					
Breathing	1.28	0.63					
Concentration	1.28	0.65					
Total score SDS	23.86	6.36					
Hospital Anxiety and Depression							
Anxiety	4.20	3.20					
Normal			311	85.7			
Mild			36	9.9			

moderate			15	4.1		
Severe			1	0.3		
Depression	3.61	3.45				
Normal			305	84.0		
Mild			40	11.0		
moderate			18	5.0		
FACIT Sp. 12 (spiritual well-being)						
Meaning	12.95	2.19				
Peace	12.12	2.48				
Faith	12.94	2.69				
Total score FACIT Sp. 12	38.01	6.33				

Table 1: Mean Scores of SDS, HADS and FACIT Sp-12.

Correlation between ECOG, SDS, HADS and Facit Sp-12

Table 2 shows that ECOG had positive correlation with SDS, HADS-anxiety and HADS-depression (p<0.01) and had negative correlation with meaning, peace (p<0.05) and total Facit Sp-12 (p<0.01). The symptom distress had positive correlation with HADS-anxiety and HADS-depression (p<0.01), but it had negative correlation with peace (p<0.01). HADS-anxiety had negative correlation with Facit Sp-12, meaning and peace (p<0.01), while HADS-depression had negative correlation with all domains of Facit Sp-12 (p<0.01). Moreover, negative correlation could be observed in overall domain Facit Sp-12 with other variables, however only faith showed no significant correlation with ECOG, SDS and HADS-anxiety.

Discussion

In this study, the majority participant was women. Previous literature mentioned that cancer prevalence was higher in women regarding with the number of breast cancer and cervical cancer, which have highest prevalence in Indonesia [21]. This study also found that most patients diagnosed with breast and cervical cancer [22], and they seek hospital treatment during less than 6 months, so it is means that they knew their condition when cancer had already in advanced stage. It was being a major health issues in Indonesia. Similar to the finding of previous study found that about 60-70% patients had come to the hospital when the cancer in stage 3 and 4. In Indonesia, many patients tend to postpone their medical help because of several reasons such as lack of financial support, knowledge about treatment option and side effect of cancer treatment [23] and some of them added complementary therapy in their treatment.

Patient's Symptom Experiences Loss of Appetite

Patients with advanced cancer experienced many suffering symptoms. This study found that loss of appetite was rated as the most severe symptom of distress. Several studies mentioned that loss of appetite could be a result of cancer treatments (e.g. radiation, or surgery, chemotherapy) or may be a manifestation of diseases progression that leads to inadequate nutrition intake [24,25]. Up to 80% cancer patients reported that loss of appetite was one of their problems associated with loss of weight [26].

	ECOG	SDS	HADS-A	HADS-D	Facit Sp-12	Meaning	Peace	Faith
ECOG	1							
SDS	.183**	1						
HADS-A	.307**	.487**	1					
HADS-D	.308**	.514**	.472**	1				
Facit Sp-12	114**	103	154**	264**	1			
Meaning	115*	068	119*	250**	.881**	1		
Peace	222**	177**	315**	282**	.840**	.648**	1	
Faith	042	022	.024	159**	.859**	.658**	.525**	1

 Table 2: Correlation between ECOG, SDS, HADS and Facit Sp-12.

* correlation is significant at the 0.05 level.

** correlation is significant at the 0.01 level.

Fatigue

Fatigue is the other common problem in patients with advanced cancer. It is defined as a feeling of over tiredness and weakness, manifesting from physical and psychological problems deteriorating the quality life [27]. The previous study reported fatigue as a top five symptom in cancer populations estimating between 60% and 90% [28]. Several factors influence fatigue including disease progression, under treatments and medications or other physical and psychosocial condition [29]. Most patients did not discuss with health professionals regarding interventions to improve fatigue symptoms. Therefore, it is poorly managed [30].

Pain

Another symptom, which is commonly correlated with advanced cancer patients, is pain. Ross and Alexander [31] reported anorexia, fatigue and pain as the top three-symptom distress. One study in Indonesia also described that pain, fatigue, and nausea were three major symptoms among cancer patients influencing patients' quality of life [8]. Other studies mentioned that pain is the most common symptom among advanced cancer patients [1-3]. The previous study reported that around 64% of advanced cancer patients experienced pain and the proportion was higher than patients in treatment [4].

Anxiety and Depression

This study found that only around 15% of patients had experienced anxiety and depression from mild to severe levels. Compared to other studies, the results are slightly different from other studies, which pointed out that advanced cancer patients tended to have anxiety and depression [32-34]. However, some studies also revealed small percentages of anxiety and depression in cancer patients. This result may be due to the strong support of family and relatives that help patients to cope with their condition and reduce their anxiety and depression [35]. Another study also found that people with higher levels of spiritual well-being have lower levels of depression [36].

Spiritual Issues

Spiritual well-being is placed as an important role in patient centred care [37]. The study result also showed that patients had strong spiritual well-being. Patients with a better religious and spiritual well-being would be more satisfied in their life and have a positive influence on their quality of life [38]. This also demonstrated that

the spiritual care in Indonesia is well established. Most hospitals in Indonesia have spiritual caregivers that support patients and family in preventing spiritual distress [1]. Hospitals provide spiritual caregivers according to the patient's religion and help patients religiously in finding their spiritual comfort. Spiritual caregivers would give attention, sustainance, guidance, inner healing and prayer for patients to achieve their life balance and positive impact in facing situation [39]. Hence, spiritual issues among advanced cancer are not a big problem in Indonesia, and most of them have strong spiritual beliefs.

Correlation between ECOG Score, Symptom Distress, Anxiety & Depression and Spiritual Well-Being among Advanced Cancer Patients

The current study shows that the levels of depression and anxiety had positive correlations with poor performance status and levels of symptom distress. The results are consistent with other studies. Depression is the result of physical symptoms that going to more suffer [2,40]. Another study also mentioned that diseases progress and decline physical status would increase the levels of anxiety [41]. The literature reported that depression was associated with physical symptom burden among advanced cancer patients [42]. Other studies also indicated that pain and fatigue were predictors of anxiety and depression [43].

In this study, spiritual well-being was measured by FACIT-Sp 12, which contains three domains; meaning, peace and faith. Faith has strong correlation with religiosity [44]. As predicted, faith was found to be an important domain correlated with depression. Patients with strong faith had lower depression. Previous studies revealed that faith has negative correlation with depression [38,45]. Religion is important in people's daily life, religious beliefs and practices as reflected of faith help patients to cope with their stressful life, episode of depression symptoms and enhance health outcomes. They would tend to be more positive outlook and has stronger stress control in building up the coping mechanism [38,45].

Conclusion

In conclusion, the study provides essential information regarding advanced cancer patients' condition including physical, psychological and their spiritual aspects. Advanced cancer patients stated the most symptoms were appetite, fatigue, pain and only few patients experienced mild and moderate anxiety and depression. Mostly patients had a high spiritual well-being; hence, faith was the most important predictor of good death. It can assist healthcare professionals to understand advanced cancer patients' degrees of symptom distress, the levels of anxiety and depression and states of spiritual well-being, which will provide better care for advanced cancer patients.

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