

# Need Assessment on Patients with Advanced Stage Cancer

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**Abstract:** *Need assessment is one of the important steps that should be conducted to be able to provide health care to patients with advance stage cancer because by understanding the needs of the patient, an appropriate and proper care can be provided. Inadequate efforts to meet the needs of patients will affect their quality of life and their satisfaction towards health care. This descriptive study uses Needs Assessment for Advanced Cancer patients (NA-ACP) questionnaire to describe the patient needs based on seven main need domains of advanced cancer patients as well as several additional needs. The results of this study show that the three most needed domains (100%) by advanced cancer patients are medical information and communication, psychological/emotional support and other needs. Meanwhile, the most frequently felt need, i.e. from moderate to high, (98%) is other needs. Based on those results, it is recommended that hospitals and health care workers should pay more attention to the advanced cancer patients, especially the need for medical information and communication, psychological/emotional needs, financial need, and other needs. To address the issue, training on communication can be provided to health care workers, health education can be given to patients through picture/video media, palliative care counseling unit and cancer support group can also be established. In addition, a clear information media on how to access financial support available for the patients should also be provided.*

**Keywords:** *Advanced cancer, need assessment, patients*

## 1. INTRODUCTION

Cancer is known as the primary cause of death in the world. According to the World Health Organization (WHO), cancer has killed 9.6 millions people in 2018 and will continue add the figure to 11 millions in 2030 [1]. WHO also stated that more than 70% of the deaths due to cancer are found in low-income and middle-income countries. Data from Basic Health Research or *Riset Kesehatan Dasar* (Riskesdas) in 2007 shows that the prevalence of cancer in Indonesia is 4.3 per a thousand population [2]. The Ministry of Health information in 2007 stated that almost 70% of cancer patients in Indonesia are found in advance stage.

According to the Ministry of Health (2007), the health care services in Indonesia have not reached the hard-to-cure patients, especially advanced cancer patients, where the care is not focused on healing anymore but also on care to achieve the best quality of life possible for the patient [3]. The fulfillment of all need aspects in advanced cancer patients is important because the inability to meet one of the need domain will affect the other need domains. The

fulfillment of overall patient needs will very much determine the adaptation ability of patients for coping with cancer and its treatment as well as the quality of life for patients living with this disease. To prevent morbidity among cancer patients, a need assessment is one of the steps that cannot be ignored.

Dr. Hasan Sadikin Central General Hospital is the referral center for the whole West Java area and one of the patient types most frequently referred to this hospital is the cancer patients. The Hemato-Oncology clinic is one of the clinics in this hospital that serve cancer patients. The number of new cancer patients in 2010 in this clinic has reached around 400 patients with more than 50% of them are advanced cancer patients. The results of the interview conducted to advanced cancer patients in this hospital has shown that there are still needs of advanced cancer patients that are not met yet. Thus, the research aims to describe the need of advanced cancer patients, specifically to understand the level of needs of advanced cancer patients based on the following domains: physical symptom management, psychological/emotional needs, medical information and communication, social need, spiritual need, daily living need, financial need and other needs.

## 2. METHOD

This study applies quantitative descriptive method using advanced cancer patient need variables at the Hemato-Oncology Clinic of Dr. Hasan Sadikin Central General Hospital. The population for this study includes advanced cancer patients treated at the Hemato-Oncology Clinic of Dr. Hasan Sadikin Central General Hospital Bandung. The monthly average number of advanced cancer patients in this clinic is around 32 patients. The sampling is conducted using purposive sampling technique with the following criteria: a) Inclusion criteria: Patients who are diagnosed as suffering from stage III or IV cancer for more than 4 months and understand Indonesian language b) Exclusion criteria: Patients who refuse to participate in this study and those who cannot read and cannot speak (e.g. patients with tracheostomy).

Data were collected using translated Needs Assessment for Advanced Cancer Patient (NA-ACP) questionnaire with 1 to 5 choices in each item. If respondent chooses 3, 4, or 5 in at least 1 item in certain domain, then he or she was categorized as "having needs" in that domain. If the respondent chooses 4 or 5 in at least 1 item then he or she was categorized as "moderate to high need". The results of the analysis were then calculated using frequency distribution and percentage to recognize the level of need in general and medium to high level need based on domain and item. The translated NA-ACP questionnaire was tested for its content validity by an expert in the field need assessment and the result shows that the Indonesian NA-ACP can be used for data collection. This study was conducted at the Hemato-Oncology Clinic of Dr. Hasan Sadikin Central General Hospital for 4 months, i.e. from August to November 2011.

## 3. RESULTS

### A. Demographic and Disease Characteristics

More female respondents (70%) were recruited. The proportion of respondents who are married reaches 84% with various distribution of education level with most of them graduate from elementary school. The two most frequently stated occupation are laborer/farmer and housewife.

The three most frequent cancers found among the respondents are Non-Hodgkin Malignant Lymphoma, breast cancer and nasopharynx cancer. Most of respondents have never experience any remission (82%). The type of treatment that is most frequently received by the respondents is chemotherapy (70%). The results also show that almost one fifth (20%) of the respondents receive more than one type of therapy.

Table 2. Demographic Characteristics

<b>Gender</b>	<b>Frequency</b>	<b>Percentage (%)</b>
F	35	70
M	15	30
Total	50	100

  

<b>Marital Status</b>	<b>Frequency</b>	<b>Percentage (%)</b>
Married	42	84
Divorced/Widow/Widower	3	6
Single	5	10
Total	50	100

  

<b>Education</b>	<b>Frequency</b>	<b>Percentage (%)</b>
Elementary School	23	46
Junior High School	11	22
Senior High School	9	18
University (Bachelor)	1	2
No formal education	6	12
Total	50	100

  

<b>Occupation</b>	<b>Frequency</b>	<b>Percentage (%)</b>
Laborer/Farmer	8	16
Housewife	39	78
Others	7	14
Do not work	6	12
Total	50	100

## **B. Results of the Need Assessment**

- 1) *Overall need:* The analysis on all respondent data (n = 50) shows that all respondents need help (low, moderate or high) to deal with problems in at least 32 out of 132 items asked. In addition, around 90% (n = 45) of respondents stated a “high need” for more than one item asked.
- 2) *Domain-based need:* Table 4.2 and table 4.3 present items of the need domains that are most frequently felt by the patient, i.e. Medical information and communication, Other Needs, Psychological/Emotional Need and Financial Need. Table 4.3 shows that all patients (100%) feel that they have needs in the three domains, i.e. Medical information and communication, Other Needs, Psychological/Emotional Need. Out of the three domains, there is one domain which is considered as “moderate to high need” by patients, i.e. other needs with a prevalence of 98%. The information/communication, psychological/emotional and financial domains are also among the need domains that are most frequently felt by patients with moderate to high needs. The same percentage in the table shows that all patients have moderate to high need.

Table 4. Prevalence of need in at least 1 item for each domain

Domain	Frequency Need	%	Frequency No Need	%
Medical information and communication	50	100	0	0
Other needs	50	100	0	0
Psychological/emotional need	50	100	0	0
Financial need	48	96	2	4
Spiritual need	43	86	7	14
Symptom management	43	86	7	14
Daily living	25	50	25	50
Social need	21	42	29	58

Table 5. Prevalence of moderate/high need in at least 1 item in each domain

Domain	Frequency MHN*	%	Frequency Not MHN	%
Other needs	49	98	1	2
Medical information and communication	48	96	2	4
Psychological/emotional need	48	96	2	4
Financial need	48	96	2	4
Spiritual need	36	72	14	28
Symptom management	33	66	17	34
Daily living	22	44	28	56
Social need	16	50.00	34	50.00

\*MHN: Moderate to high need

- 3) *Item-based needs*: Table 4.4 lists the three most prevalent “moderate to high need” items in each domain. The prevalence range of the three most prevalent items in each domain is 16% to 88%. The domains that have items with lowest prevalence are the Social and Daily living domains while the domains with the highest prevalence items are Financial and Medical information and communication domains.

Table 6. Three most prevalent highest “moderate/high needs” items by domain

Daily living	% moderate/high need
Performing daily tasks at home	20

Getting help to do daily tasks at home	20
Getting help in performing activities that are usually conducted during leisure time	20
<b>Financial</b>	<b>% moderate/high need</b>
Dealing with financial problems	80
Getting enough financial support	80
Getting adequate health insurance	80
<b>Medical Information/Communication</b>	<b>% butuh sedang / tinggi</b>
Getting adequate information from the medical staff about your treatment	88
Getting adequate information from the medical staff about your prognosis	84
Having someone who can help you understand your disease, treatment and its side effects	84
<b>Other needs</b>	<b>% moderate/high need</b>
Having medical staff handle your physical problems immediately and accurately in the hospital	70
Having transportation available for getting to places where you get treatment, work, shop	62
Having opportunity to share what is going on with you with someone who has similar experience	58
<b>Symptom management</b>	<b>% moderate/high need</b>
Dealing with losing appetites	46
Dealing with difficulties when eating and/or swallowing	24
Accepting weight loss	28
<b>Psychological/emotional</b>	<b>% butuh sedang / tinggi</b>
Coping with fear related to the possibility of cancer spread	66
Coping with grieves	68
Coping with fear of pain or suffering	64

<b>Social</b>	<b>% butuh sedang / tinggi</b>
Maintaining good relationship with friends	18
Wanting to discuss cancer with friends and/or family	16
Hanging out with friends and/or family	16
<b>Spiritual</b>	<b>% moderate/high need</b>
Coping with the issue that there are some goals in life that are not achieved yet	50
Able to see a spiritual guide (priest, imam...)	44
Making new priorities in life	38

Table 4.5 shows a list of eleven most prevalent “moderate to high need” items. The prevalence range of the need in the 11 most prevalent items is 76% to 88%. The most frequently felt moderate to high needs by the respondents are “Getting adequate information from medical staff about your treatment”, which is followed by the need for “having someone who help you to understand your disease, treatment and its side effects” and “getting adequate information from the medical staff about your prognosis”.

Table 7. 11 most “moderate/high need” items

No	Domain	Item	% moderate/high need
1	Medical information/communication	Getting adequate information from the medical staff about your treatment	88
2	Medical information/communication	Having someone who can help you understand your disease, treatment and side effects	84
3	Medical information/communication	Getting adequate information from the medical staff about your prognosis	84
4	Financial	Dealing with financial problems	80
5	Financial	Getting adequate financial support	80
6	Financial	Getting adequate health insurance	80
7	Medical information/communication	Getting information on the types of support that are available for you, your	80

No	Domain	Item	% moderate/high need
		spouse/partner, family or friends	
8	Medical information/communication	Getting adequate information from the medical staff about treatment side effects	80
9	Financial	Having treatment cost paid	78
10	Financial	Coping with concerns related to financial problems	76
11	Medical information/communication	Getting adequate information from the medical staff on disease symptoms	76

#### 4. DISCUSSION

In general, advanced cancer patients at the Hemato-Oncology Clinic have some unmet needs. The results of the analysis show that all patients need support (low, moderate or high) to deal with problems in at least 32 items of 132 items asked. Furthermore, around 90% (n = 45) of respondents have expressed a “high need” in more than one items asked. This result is quite consistent to the findings of Rainbird, et al., (2009) who stated that there are at least 95% of patients have unmet need in one or more items [4]. The high proportion of this unmet need may be due to the failure of the medical staff in identifying patients’ need while the patients are notwilling to express their feeling/emotion to the medical staff [5].

Another factor that may lead to the high unmet needs among patients is the high workload of the medical staff, especially those in outpatient department, so that the time for interaction between medical staff and patients is very limited to be able to identify patients’ need [5]. This can be observed at the outpatient unit of the Hemato-Oncology Clinic where the medical staff only consists of three staff members and two doctors. Furthermore, the service for cancer patients is only available on Wednesday and Thursday, making the time for patient interaction very limited.

Demographic factors and disease condition of the patients included in the sample may also influence the results. The analysis shows that most of the respondents (70%) are women with most of them come from low socioeconomic class (based on the respondent occupation) and 82% respondents have never experience any remission at all and, as stated by Abrahamson et al. (2010), those three factors are factors that may make patients feel that their needs are not adequately met yet [5]. According to Abrahamson, et al., (2010), patients who do not have spouse/partner or significant other tends to report inadequate fulfillment of needs. From the analysis in this study, the proportion of respondents who are married is 84% [5]. However, there is another opinion stating that social support does not influence inadequate fulfillment of needs [6], [7].

The results of the analysis shows that the needs (low, moderate or high) that are most frequently felt by the patients are Medical Information and Communication, Other Needs, and Psychological/Emotional Needs. All patients (100%) feel that they have a need in the three domains, i.e. Medical Information and Communication, Other Needs, and Psychological/Emotional Needs. Consistent information on disease, treatment alternatives,

treatment side effects and prognosis are among important issues for patients and their family because it will affect the patients' ability to adapt to their condition [8], [9].

Poor communication with doctors and nurses is the most frequently stated problem by the patients and their family. A study found that around 65% advanced cancer patients report poor communication with doctors and nurses in the hospital, especially at diagnosis [9], [10]. There are several causes that may make the communication with medical staff poor including the difficulty to tell bad news, difficulty to identify patients' concern, and uncertainty from medical staff [9], [11]. Girgis & Sanson-Fisher (1995 in Rainbird, et al., 2009) also stated that the lack of training and knowledge among medical staff, limited time and incompetency perceived by clinicians in terms of communication will affect the patient's needs [4], [12].

Meanwhile, the patient factors may also lead to high need for medical information and communication. According to Leydon (2000) and Beadle, et al. (2004), medical staff may have already provided necessary information but patient forgets about it because patient tries to avoid certain information to maintain the sense of hope [4]. Communication is vital for medical staff in providing care to advance cancer patients to assure accuracy and speed (no delay) in giving information to patients. Giving communication training to medical staff may increase their confidence in breaking bad news to patients [4], [13], [14]. Clinicians do not have enough knowledge on information source and other supports that can be recommended to the patients. Information related to those support can be provided to the clinicians [4], [15].

Analysis on patient's disease characteristics shows that 88% of the respondents have undergone therapy (radiation, chemotherapy, or surgery) and almost one fifth of the respondents (20%) have undergone more than one types of therapy. Skala, et al. (2004 in Brunner & Suddarth, 2008) conducted a research among patients who underwent chemotherapy, radiation therapy or combination of the two therapies and found that patients stated that they do not receive the information wanted or needed to be able to improve their adaptation ability [16]. Most patients want as much information as possible on treatment and treatment side effects and they expect that the information received is individual and practical in nature such as how treatment affects daily living because patients have to undergo the therapy in outpatient manner [16].

This study is consistent with the results of this study that shows all patients at the Hemato-Oncology Clinic of Dr. Hasan Sadikin Central General Hospital have at least one need in medical information and communication domain. In addition, it is also revealed that items in the medical information and communication, i.e. "Getting adequate information from medical staff about your treatment", "Getting adequate information from medical staff about the possibility of your prognosis", and "Having someone to help you understand your disease, treatment and its side effects" are included in the ten most prevalence moderate to high need items of the 132 items.

Patients who reported that it was difficult to accept and remember the information provided consider that the information provided is too much because it was given using traditional teaching method. Based on the results of the observation, the nurses at the Hemato-Oncology Clinic provide health education using the traditional method (explain everything that patients should know or answer patients' questions briefly and rapidly) without using any specific education media. The implication for the nursing department regarding this situation is that the department needs to develop a teaching method that can meet the need for information among cancer patients. The use of multimedia technology such as picture, video and audio is an innovative approach to improve patient's ability in receiving information [16].

Other Needs is the most prevalent domain. From 100% of patients who complain of having

the need in the Other Needs domain, 98% have moderate/high need. The items that mostly considered as a need by the patient include dealing with inability to sleep well (66%), dealing with lack of energy and fatigue (72%), getting information on conventional/alternative therapy (62%), dealing with pain (62%), dealing with weakness (68%), having physical problems handled rapidly and appropriately by the medical staff at the hospital (72%), availability of transportation to take patient to treatment place, workplace, shopping, (64%), dealing with boredom (54%), having an opportunity to share with someone who has the same experience (64%) and dealing with uncomfortable feelings (62%). Among the 10 items mentioned, the need to “have the physical problems rapidly and appropriately by medical staff at the hospital” (70%), “availability of transportation to go to treatment place, workplace, shopping” (62%), having an opportunity to share with someone who has the same experience (58%) are the three items most frequently reported as a moderate/high need.

The high need for item “Dealing with your physical problems rapidly and appropriately by medical staff at the hospital” may be due to the fact that 82% of the respondents never experience any remission. Meanwhile, regarding transportation, the oncologists, nurses and social workers stated that transportation is often a big problem for their patients [17]. This should be managed because the lack of access to transportation will affect patient’s adherence to the therapy program and medical care. Cancer patients with low income, older age, living far away from the treatment center tend to have problems with transportation. Providing information on transportation alternatives cannot help the patient because even when they know about the alternatives, the patient may need help to understand and deal with the administration issue [18]–[21]. Most patients who come to the Hemato-Oncology Clinic for treatment do not live in Bandung. They live in cities outside Bandung which are quite far from the hospital. Around 65% of respondents live in another city that needs more than one hour travel and, in average, patients at the Hemato-Oncology Clinic come from low income population, which is represented by the fact that more than a half of the patient population use *Jamkesmas*<sup>1</sup> or *Askeskin* to pay their treatment.

The third highest need in Other Needs domain is the need for “dealing with inability to sleep well” (66%). Parker (2007) stated that advanced cancer patients have poor sleep quality [22]. A study performed by the Associated Professional Sleep Societies (2007) found that cancer patients have a difficulty to maintain sleeping condition and stay awake. Cancer patients experience reduced quantity and quality of sleep at night and scattered sleeping episode during the day. The primary cause of sleeping disorder in cancer patients is not clear yet. Factors that are suspected as contributing to the disorder are demographic factors, depression, pain, fatigue and the type of cancer [22].

The psychological/emotional needs among patients at the Hemato-Oncology Clinic is a need domain with the highest prevalence both in the general need-based analysis (100%) and analysis based on the moderate to high needs (96%). This result is similar to that of Rainbird, et al. (2009) who stated that most needs of advance cancer patients fall into the psychological/emotional domain and medical information/communication [4]. Increased emotional distress among patients may be seen during disease process, at certain points such as diagnosis making, receiving treatment, et cetera [9], [23]. However, this is often neglected by the medical staff (Maguire, 1980; Higginson, 1992 in Higginson, 1993) when actually a good care provided by the nurse or other medical staff who is responsible for the patient will reduce the emotional distress and will be able to improve the patient’s ability to adapt [9], [11], [24].

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<sup>1</sup> Jamkesmas and Askeskin are insurances provided by Indonesian Government for poor people

From the analysis it is apparent that all patients who have needs in financial domain stated that the need is moderate to high that the prevalence is similar between the general need and moderate to high need (96%). In addition, the item analysis shows that the two most prevalent items (the need for “dealing with financial problems, getting adequate financial support and getting adequate health insurance”) are financial domain items. This issue is very significant since USA Today (2006 in IOM, 2008) stated that 8% of cancer patients do not receive or delay treatment due to the implied cost [17]. Based on that condition, it can be predicted that the financial problem becomes more significant for patients who do not have health insurance. The moderate to high need to get adequate insurance reaches 80%. At the Hemato-Oncology Clinic, patients often delay therapy due to financial problem despite the availability of *jamkesmas* or *askeskin*, since there are some types of treatment/therapy and diagnostic tests needed by cancer patients are not covered in *jamkesmas*.

A study that involved 954 advance cancer patients in the United States found that financial problems have a close correlation with advance patient satisfaction on his/her quality of life. This finding indicates that there are non clinical factors such as financial difficulties (from the patient’s perspective) that affect cancer patient’s quality of life that these factors cannot be neglected [25].

The same problem is also seen in Indonesia. According to Sulastomo (2011 in Health.Kompas.com, 2011), the *Jaminan Kesehatan Masyarakat (Jamkesmas)* from the government for poor people does not cover the overall needs or accessible by all people. This does not solve problems because people keep complaining on the minimum health care access [26]. Budi (2011 in Health.Kompas.com, 2011) stated that even though a patient is already covered by health insurance, the current provisions require patients to pay additional cost to pay for medicines that are not included in the prescription list provided by the insurance company [27].

The demographic characteristics and disease of the respondents show that 16% of the respondents work as laborer/farmer, 12% of the respondents experience nasopharynx cancer and 24% of the respondents suffer from Non-Hodgkin Malignant Lymphoma in stage IIIb or IV. Spelten et al., (2002) and Short et al., (2005) (in IOM, 2008) revealed that based on the income level, patients whose work need physical work and those who are attacked by head and neck cancer, central nervous system cancer and blood cancer or lymph cancer in stage IV will have a higher risk for reduced income. Therefore, patients in this group may complain more about the need for financial support [17].

## 5. CONCLUSIONS

It is concluded from this study that the advance cancer patients in Dr. Hasan Sadikin Central General Hospital have some unmet needs. The needs include physical needs (symptom management), psychological/emotional needs, financial needs, social needs, spiritual needs, medical information and communication needs, daily living needs and some other needs that are not included into the seven main domains.

The medical information and communication needs, psychological/emotional needs and other needs are then most prevalent domains that are often needed by the advance cancer patients in this hospital. From those domains, the psychological/emotional needs and other needs are the most frequently felt needs by the patients with a moderate to high need level. The financial domain is also one of the domains that are most frequently felt by the patients in moderate to high manner.

Referring to the phenomena above, it is recommended that the medical institution or medical staff should pay more attention to the needs of advance cancer patients especially in terms of

psychological/emotional needs, the need for medical information and communication, financial needs and other needs. It is recommended that the hospital establishes a specific counseling unit for palliative treatment or a cancer patient support group that can help advance cancer patients to adapt with their disease and to meet the need for psychological/emotional support and other needs such as sleeping disorder.

To meet the need for medical information and communication, it is recommended that the nurse provides health education on the disease and treatment to the patient by using specific teaching media such as picture or video so that the patient is able to absorb information better. Furthermore, the hospital can also give training to the medical staff to improve their communication skill in dealing with advance cancer patients and to give information to the medical staff on the source of information and types of other support that can be accessed by the patient if necessary.

Nurses can also help in identifying patient's financial needs caused by treatment costs and refer the patient to the social worker (if any) or give information on various available financial support as well as helping patients in dealing with administration matters related to treatment cost in the hospital. The hospital can also provide a clear information board on the financial support that can be accessed by advance cancer patients such as how to get health insurance and the types of tests and treatment that can be accessed by the patients using the insurance.

Another recommendation is to assess the needs of cancer patient family because family is one of the social support for cancer patients and that cancer does not only affect the psychosocial, financial, spiritual, and medical information and communication needs of the patient but also the family.

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