

## Criteria for palliative care referral in oncology practice: An instrument development



Maria A Witjaksono<sup>1</sup>, Christantie Effendy<sup>2</sup>, Sri Mulatsih<sup>3</sup>,  
Iwan Dwiprahasto<sup>4</sup>, Adi Utarini<sup>5\*</sup>

<sup>1</sup>Department of Palliative Care, Dharmas National Cancer Center Hospital, West Jakarta, Jakarta, Indonesia;

<sup>2</sup>Department of Medical Surgical Nursing, Faculty of Medicine, Public Health and Nursing, Universitas Gadjah Mada, Sleman, Yogyakarta, Indonesia;

<sup>3</sup>Department of Child Health, Faculty of Medicine, Public Health and Nursing, Universitas Gadjah Mada, Sleman, Yogyakarta, Indonesia;

<sup>4</sup>Department of Pharmacology and Therapy, Faculty of Medicine, Public Health and Nursing, Universitas Gadjah Mada, Sleman, Yogyakarta, Indonesia;

<sup>5</sup>Department of Health Policy and Management, Faculty of Medicine, Public Health and Nursing, Universitas Gadjah Mada, Sleman, Yogyakarta, Indonesia;

\*Corresponding author:

Adi Utarini;  
Department of Health Policy and Management, Faculty of Medicine, Public Health and Nursing, Universitas Gadjah Mada, Sleman, Yogyakarta, Indonesia;  
adiutarini@ugm.ac.id

Received: 2020-12-08

Accepted: 2021-04-12

Published: 2021-04-30

### ABSTRACT

**Introduction:** Cancer patients experience significant physical symptoms and psychosocial problems during cancer treatment that negatively impact on quality of life which can be intervened by palliative care. However, the referral of cancer patients to palliative care is still low. Therefore, this study aimed to explore the need of palliative care among doctors working in oncology in order to develop an instrument of criteria for palliative care referral in oncology practice.

**Methods:** A mixed method research with a sequential variant exploratory, quantitative dominant design was used. Using phenomenology orientation, the qualitative study exploring the needs of palliative care referral was conducted and data were obtained through in-depth interviews with 32 oncologic care doctors. Identified dimensions, criteria, sub-criteria and indicators were then used to develop the instrument. In the quantitative study, validity of the instrument was tested through expert judgement and Aiken's V content-validity coefficient was calculated.

**Results:** The study found that palliative referral criteria consisted of 20 indicators, i.e., 15 medical indicators of the aspects related to disease stage, patient's condition, treatment status, and status of care; and 5 non-medical indicators, included the aspects associated with psychological, social, spiritual, communication and decision making. The validity of the instrument was confirmed through the expert panel, in which the Aiken's V coefficient of all indicators ranged high from 0.825 to 0.975.

**Conclusion:** The instrument of palliative care referral criteria was developed which consist of 20 indicators and had good validity.

**Keywords:** palliative care referral, oncology doctors, adult cancer patients, mixed methods study.

**Cite This Article:** Witjaksono, M.A., Effendy, C., Mulatsih, S., Dwiprahasto, I., Utarini, A. 2021. Criteria for palliative care referral in oncology practice: An instrument development. *Bali Medical Journal* 10(1): 281-290 DOI: 10.15562/bmj.v10i1.2120

### INTRODUCTION

The World Health Organization (WHO) defined palliative care as an approach aimed to improve the quality of life of the patients and their family facing the problem(s) associated with life-threatening illness. Palliative care approaches through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems- physical, psychosocial and spiritual. It is applicable early in the course of illness in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy and includes those investigations needed to better understand and manage distressing clinical complications.<sup>1</sup>

Cancer patients and their families experience significance physical symptoms

and psychosocial problems during cancer treatment that negatively impact the quality of life.<sup>2</sup> Integration of palliative care in oncology has been proven beneficial to the patients, the families, and health institutions.<sup>3,4</sup> Successful integration improves quality of life, quality of end-of-life care, better understanding of illness, physical and psychological symptoms, survival and patient's satisfaction. It also reduces futile oncology treatments, family burden, and cost of care.<sup>5-10</sup> Interest to support integration of palliative care in oncology practice has been shown globally by well-established professional societies in oncology, such as The Institute of Medicine (IOM), The American Society of Oncology (ASCO), The European Society of Medical Oncology (ESMO), and The Multinational Association for Supportive

Care in Cancer (MASCC).<sup>3,6,11</sup>

Referral to palliative care has become one of indicators of quality of end of life care including in oncology.<sup>12</sup> Despite its benefit and recognition as an integral part in oncology care, referral of cancer patients to palliative care is still low.<sup>3,13-16</sup> Numerous factors have been identified in contributing to low referral in palliative care for cancer patients, such as oncologist perspectives, health care policy, lack of resources, and the public perspectives. Timely referral to palliative care is essential to provide the best possible care for cancer patients<sup>3,8,17</sup> and explicit criteria of referral is necessary to prevent ambiguity about who and when a patient should be referred.<sup>3,4</sup>

Various criteria of palliative care referral are available globally. However, the standardized criteria were not available

until 2016. Hui stated that it is essential to assist clinicians in identifying patients who are potential to refer, assessing the quality of care, developing clinical pathway, and standardizing study design in palliative care.<sup>18</sup> In Indonesia, each institution providing palliative care adopts different international criteria, which may not be suitable to our health care system, available resources, and patient's conditions. With current low referral, developing criteria for palliative care referral for cancer patients according to the needs of doctors working in oncology is essential. Therefore, this study aimed to explore the needs of palliative care among doctors working in oncology in order to develop an instrument of criteria for palliative care and to validate the instrument.

## METHODS

### Study design and respondents

We adopted a mixed-method study with a sequential variant exploratory, quantitative dominant design. The qualitative study exploring the needs of palliative care referral was first conducted through semi-structured, face to face in-depth interviews using a phenomenology orientation. The qualitative data were then used to identify the dimensions, criteria, sub-criteria, and indicators of palliative care referral. The quantitative study was applied to establish the validity of the instruments through a national expert panel consisting of oncology and palliative care experts. Ethical clearance was issued by The Committee of the Medical Research Ethic of the "Dharmais" Cancer Hospital, no: 056/KEPK/IV/2018. Verbal and written information was given to all participants prior to the study. Participants were assured about confidentiality and anonymity, and the rights to withdraw their contributions to the study at any time. Their individual agreement of participation was signed in the written informed consent.

### Qualitative assessment

The qualitative study was conducted at the Dharmais National Cancer Hospital, a tertiary referral and academic hospital for cancer patients in Indonesia, located in the capital city of Jakarta. The hospital is equipped with 450 beds and more than

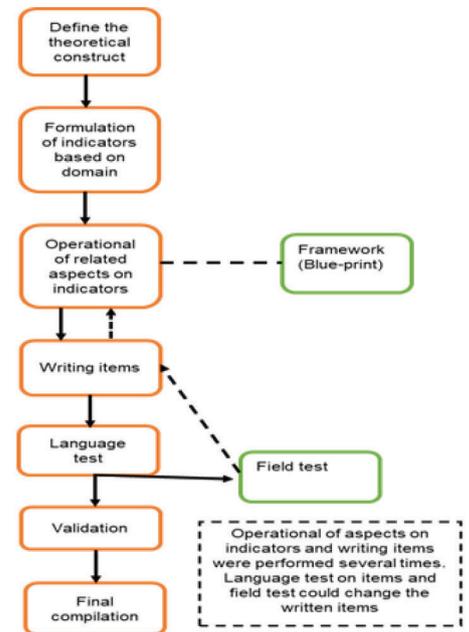
150 doctors with 20 different specialties/subspecialties providing oncology care. One palliative care doctor, five specialists (i.e., medical oncologist, anesthesiologist, internist, neurologist, pediatrician), one psychologist, one social worker, and three nurses who serve palliative care patients in the palliative care clinic, inpatient, ICU/HCU, Emergency Department and homecare. Annually, more than 140,000 patients visited the outpatient, and nearly 14,000 were admitted from all over Indonesia. The three most common types of cancers were cervical cancer, breast cancer, and respiratory cancer.

We applied a purposive, maximum variation sampling to obtain rich information from those who provided oncology care and to capture the needs of palliative care referral. They consisted of those with oncology and non-oncology specialties/subspecialties, male and female with various lengths of working experience (senior and junior doctors). Pediatricians, radiologists, pathologists, and non-tenure were excluded as participants. Validation using expert judgment was performed with five senior oncologists and five senior palliative care practitioners working in five major cancer care hospitals in Indonesia.

All interviews were carried out by the first author (MW), a female palliative care doctor who has been working at the Dharmais Cancer Hospital for more than fifteen years. She was trained in conducting qualitative research. A relationship with participants was established as colleagues in the management of adult cancer patients.

Semi-structured in-depth interviews were conducted face to face, guided with four main open-ended questions to ensure that the same basic lines of inquiry were pursued each interview. The questions were reviewed by one oncologist and two qualitative study experts and were not necessarily asked in the same sequence. The questions consist of: (1) In what stage of cancer do you consider a patient needs palliative care referral?; (2) What physical and non-physical aspects are important in palliative care referral?; (3) When does a patient with pain need palliative care?; (4) At what stage of cancer and patient's condition do you define as terminal?.

All interviews were carried out in



**Figure 1.** The process of developing the instrument of criteria for palliative care referral in oncology using method of developing of psychological scale as a measurement. After all of the indicators were assessed, the blueprint was constructed. Also, the blueprint was tested in the field to assess its reliability and would be returned to the writing/ revising phase if the result was not satisfying.

the Dharmais Cancer Hospital with no one else present during the interview. Confidentiality and anonymity of the transcripts were ensured, and all participants gave written informed consent. Data concerning the needs of palliative care was analyzed using content analysis. Familiarization was initially done individually by listening to the voice recording, and reading the transcript and field notes several times, followed by constructing the comments. At the latter steps, we worked collaboratively in refining and interpreting the data related to dimensions and indicators of referral.

A similar process was carried out to all transcripts. Saturation of the data was reached when there was no new information and the decision was made. Familiarity through the long

engagement with the participants and the clinical practice situation ensured the trustworthiness of the interview data. The coding was then used to develop the criteria of palliative care referral using the method of developing a psychological scale as a measurement<sup>19</sup> with the construct of the need for palliative care in adult cancer patients (Figure 1).

### Validation of the indicator

The validation was calculated using the Aiken's V method to have a rational analysis of indicators; whether each indicator reflected the needs of palliative care among adult cancer patients; and whether all domains were covered in the indicators and no irrelevant indicators existed.<sup>19</sup> Aiken's V, a formula to calculate a content-validity coefficient based on the experts' panel judgment was used, with a score of each indicator ranged from 1 (very irrelevant) to 5 (very relevant). The validity of each indicator was ranged from 0-1 and a V score of > 0.5 was considered valid. The following is the Aiken's V formula:

Lo : the lowest score (1)

c : the highest score (5)

r : the score given by the experts

s :  $r - lo$

V :  $\sum s / [n(c-1)]$

One of the characteristics of a qualified instrument is reliable in its ability to provide precise scores with minimal error.<sup>19</sup> A reliability test for this instrument, however, was not required as we did not use a scoring system.

## RESULTS

### Characteristics of informants

Thirty-two doctors were interviewed, consisting of 18 senior and 14 junior doctors, 11 female, and 21 male doctors, with various medical backgrounds (i.e., eight oncologists and 24 non-oncologists from different specialties and subspecialties). Their mean age was 50 years old, ranging from 34 to 66 years old. The duration of each interview was approximately 50 minutes (ranged from 37 to 101 minutes).

The need of criteria for palliative care referral was strongly recommended by the subjects in our qualitative study. Our study found that doctors providing oncology care considered various aspects of care

when discussing palliative care referral as follows:

*Stage of cancer.* The informants stated a range of cancer stages that need palliative care, i.e. from diagnosis to end of life, with the terminal stage commonly mentioned. An exception was identified for stage 1 head and neck cancer that already needs palliative care to prepare patients in dealing with worsening symptoms of pain, difficulty swallowing, and wound. Other informants believed that palliative care is needed earlier in higher-grade cancer. As patients may already be at the advanced stage when seeking medical attention, some informants were aware of the need for the referral at the time of diagnosis. Surprisingly, when the diagnosis cannot be confirmed due to the patient's condition or unavailability of diagnostic tools, there was also an opinion that the patient should already be referred to palliative care.

*Type of and the number of metastases.* All informants agreed that patients with metastases needed palliative care referral. However, which organs and what number of metastases varied: one or any vital organs such as brain, liver, or lung; one organ with extensive metastases including bone metastases; two organs metastases such as liver and brain or lung and brain or one of the two organs was lung or liver; to metastases in multiple organs. Some informants expressed several requirements of the organ metastases that must be further fulfilled to refer patients to palliative care, such as induce severe organ failures that could not be managed, hydrocephalus or herniation, cause poor performance status or metastases that prevented cancer treatment.

*Survival.* Poor prognosis or short life expectancy was stated as an indicator for palliative care referral. We found the various lengths of time regarding short life expectancy, i.e., from three years to only view hours, with 6 months as the most common responses. Others used prognosis less than 5% to indicate short life expectancy.

*Disease progression.* Disease progression on therapy was viewed as an indicator for palliative care referral. Most informants stated that poor response to cancer treatment which was defined by less than 50% reduction of the tumor after

treatment needed palliative care referral, or disease progression which was measured using Response Evaluation Criteria in Solid Tumor (RECIST). Some informants argued that palliative care is needed when the total mass increased by more than 50% accompanied by a new or worsening symptom such as neurology deficit, or imaging or laboratory result. Relapse within 6 months was also mentioned as an indicator for palliative care referral.

*Quality of life.* Suffering was mentioned to indicate poor quality of life. Poor quality of life at any stage of cancer was considered as an indicator for palliative care referral. However, some informants argued that only those with poor quality of life and short life expectancy needed palliative care.

*Vital organs condition.* Most informants expressed that severe organ dysfunction of single or multiple organs (such as lung, liver, brain, heart, central nerve system, kidney) due to cancer or co-morbidity or adverse effects of cancer treatment became indicators of palliative care referral when there was no improvement after 3-14 days of treatment. Tools that were recommended by most informants to measure organ failures were the Glasgow Coma Scale (GCS), Child-Pugh Score, Glomerular Filtration Rate (GFR), Ejection fraction (EF), and Partial portion of oxygen (PaO<sub>2</sub>). Patients with severe organ failure were determined as terminal conditions, regardless of the stage of cancer.

*Functional status.* According to some informants, functional status was one of the important indicators of palliative care referral. All informants suggested either the Eastern Cooperative Oncology Group (ECOG) or Karnofsky Performance Scale (KPS) to assess the functional status. However, it should be used in conjunction with other criteria. ECOG score of 3-4 or KPS ranged from 20 - <70 was considered as poor performance status that needs palliative care if there is no improvement after 3- 14 days of treatment.

*Pain or other symptoms.* Almost all informants perceived that uncontrolled pain in 1 to 7 days of intervention or unwillingness of the primary physician to manage pain was considered as an indication for palliative care. However,

acute pain due to surgery was considered as an exception. Any pain which is unresponsive to morphine, or related to psychological distress, or requires non-medical interventions could also be referred to palliative care. In addition to pain, other symptoms that were considered as indicator for palliative care referral included poor nutrition, wound, stoma, edema, jaundice, severe anemia, thrombocytopenia less than 80,000, short of breath, seizure, decreased consciousness, sexual problems, end of life symptoms and basic life needs.

*End of life and dying process.* Most informants perceived that patients who were at the end of life or in the dying process need palliative care. Interestingly, none of the doctors could further describe in detail the sign or symptoms of end of life or dying process.

*Risk of treatment.* Palliative care was needed to anticipate the need of a long or permanent life support, risk of death, or if the benefit of the intervention is somewhat considered to be smaller than the risk that may arise, or futile.

*Aim of the treatment.* Several informants stated that palliative care was indicated when the treatment was provided to prolong life or to relieve symptoms, and no longer to cure the disease. Some informants believed that symptomatic treatment by the palliative care team could be provided not only at the terminal stage but also concurrent with cancer treatment which aimed to cure or to palliate. Others mentioned that when palliative cancer treatment failed to prolong life, or symptomatic treatment did not successfully control the symptoms, palliative care is indicated. Another opinion was when definitive therapy was not or could not be performed to fulfill the basic needs and to improve functional status.

*Standard of treatment.* Albeit challenging to put into practice, some informants expressed that palliative care was useful to prevent sub-standardized therapy. Others described that non-standard therapy or therapy on clinical trial was usually offered to terminal stage patients whom standard therapy was exhausted, but they still want to receive further therapy. In such cases, palliative

care was considered appropriate.

*Attempt to resuscitate.* There was a different opinion whether patients in DNR state need palliative care. However, most informants indicated that palliative care should at least be involved in caregiving when the patients or their families decided for no resuscitation.

*Status of cancer treatment.* The timing to initiate palliative care in regards to cancer treatment was expressed differently by informants, i.e. whether it could be performed concurrently with cancer treatment or when treatment was discontinued due to disease progression, short survival of less than 3 months, or unresponsive to treatment or deterioration. For those whom home care was intended for terminal care, palliative care was expected to prevent hospital readmission. Other informants perceived that when cancer treatment could no longer be given due to financial constraints, not covered by the National Health Insurance, palliative care could become an option.

*Status of care.* Informants highlighted the importance of home care for terminally ill patients or patients whom treatment is no longer necessary. As most families were unready for providing care at home, the preparation had to be provided by the palliative care team. The task of the palliative team in-home services was perceived as to supervise and to guide the families in providing symptoms control, using simple medical equipment as well as supporting psychosocial and spiritual needs.

*Psychological distress.* Most informants explained that psychological problems requiring expert intervention were an indicator of palliative care referral. According to most informants, anger, depression, anxiety, fear, loss, worry, sadness, shock and regret were the common feelings experienced among patients and their families. Other psychological conditions that were expressed by informants that might need specific interventions by the palliative care team included irrational expectation, very low motivation, the feeling of having no hope, adjustment issues, lack of trust, demanding toward others, feeling unprepared, panic, unstable, body image issue and denial. According to some

informants, all the above psychological issues could be experienced at any stage of cancer where palliative care could be initiated.

*Social difficulties.* Social difficulties faced by cancer patients or their families were expressed as potential problems to hinder the continuation of the treatment. Issues in accommodation, transport, lack of support from the family or friends, no caregiver, family exhaustion, and cultural problems were expected to be solved by the palliative care team. Other informants would refer their patients to palliative care when the family needed knowledge and skills in providing care at home.

*Spiritual concerns.* Spiritual concerns of the patients were much discussed by the informants and these indicated the need for palliative care. Withdrawal, fear of death, and religious matters such as the relationship with God, loss of faith, negative emotions, or protesting God were considered as spiritual concerns that need palliative care referral. Other informants mentioned that palliative care could provide spiritual support according to the patients' beliefs and prepare a good dying process.

*Communication problem.* A significant number of informants found that providing clear information, breaking the bad news, listening to the patients' or families' needs were challenging in oncology practice. Therefore, referral to palliative care was helpful to bridge them to the patients or their families and to solve the communication problems. Some oncologists specifically appreciated the palliative care team in providing a family meeting to assist them in disclosing the truth about the patient's condition and further therapy is no longer necessary.

*Decision-making issues.* The involvement of palliative care is also commonly triggered by complex situations in making decisions. For illustration, treatment rejection from the patients or their families, the pressure to administer futile treatment, or dispute among doctor, patient, or family.

### Dimensions and criteria

We found two dimensions in the criteria for palliative care referral, i.e. medical and non-medical dimensions. The medical

**Table 1. Dimensions and criteria: Codes and examples of quotations**

Dimensions	Criteria (no. of codes) and subcriteria	Examples of quotations
MEDICAL	State of disease (66)	
	Stage of cancer	Until recently, only when there is no curative treatment or end stage the patients are consulted to palliative care. I think it is better to start when they have cancer treatment. Actually, patients can be called palliative since the diagnosis as patients sometimes need special attention to control the symptoms (6)
	2 Type and number of metastases	Well, it is worse when we find brain, liver or bone metastases. Oh...they need palliative care. A single or multiple metastasis when targeted therapy cannot be given, when we consider as a lost case (28)
	3 Survival	Steroid and radiation can prolong maximum 6-8 months but cannot cure them. In my opinion, this is the time for palliative care (4)
	4 Disease progression	Usually, when progression occurs, the medical oncologist will send the patient back to the lung team. What are we going to do? That means no response, and we refer to palliative care (13)
	Patient's conditions (103)	
	5 Quality of life	Quality of life needs to be improved not only at the end stage. Many patients in early stage have already had poor quality of life at diagnosis (6)
	6 Vital organs condition	It is not multiple organ metastases, but when we found irreversible organ failure, that needs palliative care (2)
	7 Functional status	Yes, I think patients with ECOG 3 will not be able to receive treatment except radiation if possible. So palliative care will be offered (27)
	8 Pain or other symptoms	Palliative care is not only for terminal illness. From the other aspects, particularly pain, we haven't got the right time to refer to palliative care (11)
	9 End of life phase or dying process	I think, palliative care will provide all the things when patients are at stage 4 or in the dying process (21)
	Status of cancer treatment (39)	
	10 Risk of treatment	We need palliative care when cancer treatment cannot improve quality of life. For instance, they need longer time for the healing process, and finally end up using ventilator, or prolonged stay in the ICU and got sepsis. (2)
	11 Aim of treatment	When the aim of treatment is to prolong life and not longer to cure the disease, then palliative care is called (4)
	12 Standard of cancer treatment	It is important that palliative prevents patients from giving up and receiving substandard (24)
13 Attempt to resuscitate	Once a patient is clinically considered as terminal and the status is Do Not Resuscitate, palliative care is then involved (14)	
14 No cancer treatment	When the patient mentioned that financially he/she can't afford chemotherapy, that means the treatment can no longer be given. (15)	
Status of Care (7)		
15 Need homecare supervision	It is good to refer terminally ill cancer patients to palliative care. Hospital care is not for terminally ill patients. However, if the family is not prepared to give care at home, this will become a problem as they will bring the patient back to hospital once the condition deteriorated. The family should be prepared (25)	
NON-MEDICAL	Psychological distress (54)	From the beginning, palliative care prepares the patients related to the expected condition after the treatment, symptoms control due the disease or complication of the treatment and make adjustments. (9)
	Social difficulties (30)	Palliative care is needed in solving financial problem, including to liaise with an NGO that can give a donation (19)
	Spiritual concerns (31)	Patients need palliative care when we found withdrawal, restless, fear of death, anger to God, no longer have faith to God, perceived that God has been unfair (1)
	Communication problem (54)	We cannot explain in detail because of time constraints. But we are supported by the palliative team for the family meeting. This is helpful.(27) Palliative care is good in delivering bad news (8).
	Decision making issue (28)	The palliative team gets involved when the family does not support the treatment plan. (2)

**Table 2. Dimensions, criteria and indicators for referral to palliative care among adult cancer patients**

Dimensions	Criteria and subcriteria	Indicators
MEDICAL	State of disease:	
	Stage of cancer	Diagnosis of suspected advanced cancer cannot be confirmed
	Type of and number. of metastases	Lung/liver/brain metastases induces severe organ failures
	Survival	The life expectancy is 6 months or less
	Disease progression	Disease progression cannot be halted by all available cancer treatment
	Patient's conditions	
	Quality of life	Poor quality of life
	Vital organs condition	Any severe vital organ failure which prevents any modality of cancer treatments
	Functional status	Poor functional status cannot be restored in two weeks
	Pain/other symptoms	Pain or other symptoms need symptomatic therapy after 48 hours of any intervention fail to control
	End of life phase or dying process	Signs or symptoms of end of life or dying process is identified
	Treatment status	
	10. Risk of treatment	Risk of having a long or permanent care or life support when an intervention is performed
	11. Aim of treatment	Having a palliative or symptomatic treatment
	12. Standard of treatment	Having an unstandardized cancer treatment
NON-MEDICAL	13. Attempt to resuscitate	Patient is in do not resuscitate (DNR) state
	14. No cancer treatment	No cancer treatment due to any reason including financial constraint
	15. State of care	Need of home care supervision
	16. Psychological distress	The need of expert interventions for a psychological distress of the patient or his/her family
	17. Social difficulties	The need of support for social difficulties
	18. Spiritual concerns	The needs of assistance for spiritual concerns
	19. Communication problem	Doctor-patient/family or patient-family communication problem
20. Decision making issue	Issues in the decision making of the treatment or care	

dimension includes the stage of the disease, patient's condition, the status of cancer treatment and status of care, and the non-medical dimension consists of psychological distress, social difficulties, spiritual concerns, communication problems, and decision-making issues. [Table 1](#) shows the dimensions, criteria, sub-criteria, and examples of quotations. The medical dimensions consisted of 15 indicators, while the non-medical dimensions contained 5 indicators as shown in [Table 2](#).

The instrument, namely Instrument for Identification of the Need of Palliative Care for Adult Cancer Patients, is a screening tool that consists of 20 indicators to assist health care professionals in recognizing

patients or their families of the need for obtaining support from the palliative team. This instrument is specifically used in oncology care for adult patients with solid or hematological cancer who are already diagnosed or suspected of malignancy. The timing of assessment can be performed throughout the course of the disease, e.g., at the time of diagnosis, during treatment, or when treatment is no longer effective, from early to terminal stage and end of life. The assessment is performed by doctors or nurses with doctor's confirmation for each patient and information obtained from history taking, physical examination, pathology, and radiology report. Further details on the assessment and description of each

indicator were provided in a manual and booklet format specifically designed. The manual contains the aim, target of the instrument, and detailed explanation of the indicators; while the booklet describes the measurements used and how to apply the instrument.

[Table 3](#) showed the characteristic of ten experts who validated the instrument. The experts were senior doctors working in the major centers for cancer care in Indonesia, i.e., in Jakarta, Yogyakarta, Surabaya, Denpasar, and Makassar.

The score of the 20 indicators ranged from 0.825 to 0.975, demonstrating their validity ([Table 4](#)). The highest validity score was found for the following indicators: indicator 4 (Lung/liver/brain

**Table 3. Characteristics of the experts who validated the instrument (n 10)**

Sex	Profession	Medical Specialties	Institution	City, Province
Female	Oncologist	Radiotherapy	Dr.Soetomo Provincial General Hospital	Surabaya, East Java
Female	Palliative Care practitioner	General Practitioner	Dr.Soetomo Provincial General Hospital	Surabaya, East Java
Female	Palliative care practitioner	Internist	Dr.Soetomo Provincial General Hospital	Surabaya, East Java
Male	Palliative care practitioner	Surgical oncology	Dr.Soetomo Provincial General Hospital	Surabaya, East Java
Male	Oncologist	Surgical oncology	Dr.Sardjito Central General Hospital	Yogyakarta, Yogyakarta Special Province
Female	Palliative Care practitioner	Physical and Rehabilitation	Cipto Mangunkusumo, National Central General Hospital	Jakarta, Jakarta Special Province
Male	Palliative Care practitioner	Internist, Psychosomatic	Cipto Mangunkusumo, National Central General Hospital	Jakarta, Jakarta Special Province
Female	Oncologist	Internist, Haematology-oncology	Dharmais National Cancer Hospital	Jakarta, Jakarta Special Province
Male	Oncologist	Internist, Haematology-oncology	Dr.Wahidin Sudirohusodo Central General Hospital	Makasar, South Sulawesi
Male	Oncologist	Surgical oncology	Sanglah Central General Hospital	Denpasar, Bali

**Table 4. The validity of medical and non-medical indicators**

Indicators	No. of experts giving the scores (n 10)					$\Sigma s$	V	
	1	2	3	4	5			
<b>MEDICAL</b>								
1	Diagnosis of suspected advanced cancer cannot be confirmed	0	0	1	2	7	36	0.900
2	Lung/liver/brain metastases induces severe organ failures	0	0	1	5	4	33	0.825
3	The life expectancy is 6 months or less	0	1	0	2	7	35	0.875
4	Disease progression cannot be halted by all available cancer treatment	0	0	0	2	8	39	0.975
5	Poor quality of life	0	0	0	5	5	35	0.875
6	Any severe vital organ failure which prevents any modality of cancer treatments	0	0	0	1	9	39	0.975
7	Poor functional status cannot be restored in two weeks	0	0	0	6	4	34	0.850
8	Pain or other symptoms need symptomatic therapy after 48 hours of any intervention fail to control	0	0	0	3	7	37	0.925

Indicators	No. of experts giving the scores (n 10)					Σ s	V	
	1	2	3	4	5			
<b>MEDICAL</b>								
9	Signs or symptoms of end of life or dying process is identified	0	0	0	7	3	33	0.825
10	Risk of having a long or permanent care or life support when an intervention is performed	0	0	0	2	8	38	0.950
11	Having a palliative or symptomatic treatment	0	0	0	2	8	38	0.950
12	Having an unstandardized cancer treatment	0	0	0	2	8	38	0.950
13	Patient is in do not resuscitate (DNR) state	0	0	0	1	9	39	0.975
14	No cancer treatment due to any reason including financial constraint	0	0	0	1	9	39	0.975
15	Need of home care supervision	0	0	0	2	8	38	0.950
<b>NON-MEDICAL</b>								
16	The need of expert interventions for a psychological distress of the patient or his/her family	0	0	0	2	8	38	0.950
17	The need of support for social difficulties	0	0	0	3	7	37	0.925
18	The need of assistance for spiritual concerns	0	0	0	4	6	36	0.900
19	Doctor-patient/family or patient-family communication problem	0	0	0	2	8	38	0.950
20	Issues in the decision making of the treatment or care	0	0	1	3	6	35	0.875

metastases induces severe organ failure/s), indicator 6 (Any severe vital organ failure which prevents all modalities of cancer treatment), indicator 13 (Having a therapy that has not become standard of cancer treatment and indicator 14 (Cancer treatment cannot be performed including due to financial problem). Whereas the lowest score was given for indicators 2 and 14 (Poor quality of life and Do Not Resuscitate status).

## DISCUSSION

Qualitative exploration with doctors providing oncology care, followed by validation through national expert

judgment suggested 20 medical and non-medical criteria as screening instruments in the inpatient to improve palliative care referral among adult cancer patients in Indonesia. Dissemination and consistent use of this instrument in oncology care is expected to facilitate decision making to refer patients to palliative care in order to improve timely referral, and hence, the patient's quality of life.

The criteria used in this instrument has similarities and differences compared to other criteria for palliative care referral, such as the International Consensus of Referral Criteria for Out-patient Specialty Palliative Cancer Care,<sup>18</sup> Palliative Care

Council of New Zealand,<sup>20</sup> ASCO criteria<sup>9</sup> or Center to Advance Palliative Care (CAPC) criteria.<sup>21</sup> The similarities were found regarding the following indicators: disease stage, life expectancy, disease progression, no standard treatment, symptoms, unstable condition, the dying process, need for psychological or social intervention.<sup>9,20</sup> While conditions such as hypercalcemia, spinal cord compression or cauda equina, peritoneal/lymphangitic carcinomatosis, delirium, Vena Cava Superior Syndrome, malignant effusion/ascites, grade IV hematologic toxicities, cachexia, and severe hypoalbuminemia are considered as indicators in other criteria<sup>18</sup>

were not directly expressed as indicators in this instrument, but those conditions were used as components which described indicators such as poor performance status, organ failure, or severe conditions.

Health care professional distress as a minor-criteria in the international consensus of referral criteria was used as a component in communication problems or decision-making issues in our instrument. Other indicators such as a request for hastened death, patient's request of palliative care, unrealistic hope, and the patient's expectation to have aggressive cancer treatment at the time of diagnosis were also covered in our instruments, particularly in the indicators related to the need for spiritual assistance or issues in decision making. Unlike the international consensus on referral criteria for outpatient specialty palliative care cancer criteria,<sup>21</sup> this instrument includes patients who are in the clinical trial, in financial difficulties, or ECOG performance 4. Moderate physical/emotional symptoms that were considered as a minor category of the international consensus, were not specifically included in this instrument as we focused more on the need for specific intervention rather than the intensity of the symptoms.

This study sufficiently collected data used to develop the instrument and the measurements that will be applied for each indicator, except for indicators on the poor quality of life, and end of life and dying process, which were unfamiliar to the subjects. We, therefore, decided to use the McGill Quality of Life-Revised Indonesian version<sup>22</sup> and the sign and symptoms of end of life and dying process developed by Hui<sup>23</sup> which were both accepted by the expert panel due to familiar use in palliative care practices.

Finally, how the criteria were used to make decisions for palliative care referral was different from other criteria. With currently low referral to palliative care, our instrument emphasizes screening for all patients who need palliative care. Missed opportunities are minimized as when a patient meets one criterion, either medical or non-medical criteria, he or she is already entitled to be referred to palliative care. For practical implementation in a clinical setting, we didn't use a scoring system.

The International Consensus of Referral Criteria is specifically applied for outpatients and uses major and minor criteria.<sup>18</sup> Patients with any major criteria alone could be considered to need palliative care referral; while the presence of minor criteria might support but not enough to trigger the referral.<sup>18</sup> While the CAPC criteria used different criteria for palliative care assessment at the time of admission and during any hospital day and patients need to meet any primary criteria to be assessed using the secondary criteria,<sup>21</sup> this instrument is simpler to use in making clinical decisions. Its simplicity, however, should be balanced with the potentially high number of patient referrals to palliative care needing more hospital resources to provide palliative care.

Regarding the strengths and limitations of this study, the development of these first criteria of palliative care referral in Indonesia was grounded on the understanding of the doctors' needs who provide oncology care in their clinical practice, followed by national expert judgment. The design of a mixed-method study allowed this study to obtain in-depth information from doctors with all medical disciplines involved in providing care to cancer patients. This process is expected to enhance high acceptance among clinicians when using the instrument and better suitability to the Indonesian's healthcare system. Nevertheless, common criteria were documented when compared to existing international criteria which were developed based on various available criteria in the literature;<sup>18</sup> finding from previous studies and national standard.<sup>21</sup>

## CONCLUSION

This study found 15 medical and 5 non-medical indicators to identify the need for inpatient palliative care referral among adult cancer patients treated at secondary and tertiary hospitals. The instrument had a good validity according to Aiken's V method. These criteria should be further disseminated and applied in oncology care to evaluate the improvement of palliative care referral in oncology practice, quality of end-of-life care, patient's satisfaction, families, and care providers.

## DISCLOSURE

### Conflict of Interest

The authors declare that they have no conflicts of interest in this work.

### Ethic Approval

This study has been ethically approved by The Committee of the Medical Research Ethic of the "Dharmais" Cancer Hospital, no: 056/KEPK/IV/2018.

### Funding

This study was self-funded by the authors.

### Author Contribution

All of the authors contributed equally in the research and writing process of this article.

## ACKNOWLEDGEMENTS

The authors acknowledged the valuable support from the participants and experts. We thanked Ns. Ria Anjani, Ns. Ame, Ns. Isma, Ns. Vera, Ns. Dwiyaningsih, Ns. Rita, Ns. Hesti, Ica for assisting data collection; Rani Asdiniah and Siti Nadiroh, M.D for producing the transcripts; and Sri Agustini, M.D and Mrs. Retna Siwi Padmawati for reviewing the interview guide.

## REFERENCES

1. World Health Organization. WHO definition of Palliative Care [Internet]. 2020 [cited 2020 Oct 20]. Available from: <http://www.who.int/cancer/palliative/definition/en/>
2. Davis MP, Temel JS, Balboni T, Glare P. A review of the trials which examine early integration of outpatient and home palliative care for patients with serious illnesses. *Ann Palliat Med*. 2015;4(3):99–121. doi:10.3978/j.issn.2224-5820.2015.04.04
3. Zhi WI ri., Smith TJ. Early integration of palliative care into oncology: evidence, challenges and barriers. *Ann Palliat Med*. 2015;4(3):122–31. doi:10.3978/j.issn.2224-5820.2015.07.03
4. Schenker Y, Park SY, Maciasz R, Arnold RM. Do patients with advanced cancer and unmet palliative care needs have an interest in receiving palliative care services? *J Palliat Med*. 2014;17(6):667–72. doi:10.1089/jpm.2013.0537
5. Kaasa S, Knudsen AK, Lundebj T, Loge JH. Integration between oncology and

- palliative care: A plan for the next decade? *Tumori*. 2017;103(1):1–8. doi:[10.5301/tj.5000602](https://doi.org/10.5301/tj.5000602)
6. Hui D, Bruera E. Models of integration of oncology and palliative care. *Ann Palliat Med*. 2015;4(3):89–98. doi:[10.3978/j.issn.2224-5820.2015.04.01](https://doi.org/10.3978/j.issn.2224-5820.2015.04.01)
  7. Hui D, Kim YJ, Park JC, Zhang Y, Strasser F, Cherny N, et al. Integration of Oncology and Palliative Care: A Systematic Review. *Oncologist*. 2015;20(1):77–83. doi:[10.1634/theoncologist.2014-0312](https://doi.org/10.1634/theoncologist.2014-0312)
  8. Vanbutsele G, Van Belle S, De Laat M, Surmont V, Geboes K, Eecloo K, et al. The systematic early integration of palliative care into multidisciplinary oncology care in the hospital setting (IPAC), a randomized controlled trial: The study protocol. *BMC Health Serv Res* [Internet]. 2015;15(1):1–8. doi:[10.1186/s12913-015-1207-3](https://doi.org/10.1186/s12913-015-1207-3)
  9. Smith T, Temin S, Alesi E, Abernethy A, Balboni T, Basch E, et al. American Society of Clinical Oncology Provisional Clinical Opinion: The Integration of Palliative care into standard oncology care. *J Clin Oncol*. 2012;30:880–7.
  10. Hawley P. Barriers to Access to Palliative Care. *Palliat Care*. 2017;10.
  11. Von Roenn JH. Optimal cancer care: Concurrent oncology and palliative care. *JNCCN J Natl Compr Cancer Netw*. 2013;11(SUPPL.1):1–2. doi:[10.6004/jnccn.2013.0208](https://doi.org/10.6004/jnccn.2013.0208)
  12. Wachterman MW, Pilver C, Smith D, Ersek M, Lipsitz SR, Keating NL. Quality of end-of-life care provided to patients with different serious illnesses. *JAMA Intern Med*. 2016;176(8):1095–105. doi:[10.1001/jamainternmed.2016.1200](https://doi.org/10.1001/jamainternmed.2016.1200)
  13. Hui D, Kilgore K, Park M, Liu D, Kim YJ, Park JC, et al. Pattern and Predictors of Outpatient Palliative Care Referral Among Thoracic Medical Oncologists. *Oncologist*. 2018;23(10):1230–5. doi:[10.1634/theoncologist.2018-0094](https://doi.org/10.1634/theoncologist.2018-0094)
  14. Ogle KS, Mavis B, Wyatt GK. Physicians and hospice care: Attitudes, knowledge, and referrals. *J Palliat Med*. 2002;5(1):85–92. doi:[10.1089/10966210252785042](https://doi.org/10.1089/10966210252785042)
  15. Fischer SM, Gozansky WS, Kutner JS, Chomiak A, Kramer A. Palliative care education: An intervention to improve medical residents' knowledge and attitudes. *J Palliat Med*. 2003;6(3):391–9. doi:[10.1089/109662103322144709](https://doi.org/10.1089/109662103322144709)
  16. Snow CE, Varela BR, Pardi DA, Adelman RD, Said S, Reid MC. Identifying factors affecting utilization of an inpatient palliative care service: a physician survey. *J Palliat Med*. 2009;12(1):231–7. doi:[10.1016/s0165-0114\(97\)90015-4](https://doi.org/10.1016/s0165-0114(97)90015-4)
  17. Khan SA, Gomes B, Higginson IJ. End-of-life care - What do cancer patients want. *Nat Rev Clin Oncol*. 2014;11(2):100–8. doi:[10.1038/nrclinonc.2013.217](https://doi.org/10.1038/nrclinonc.2013.217)
  18. Hui D, Mori M, Watanabe SM, Caraceni A, Strasser F, Saarto T, et al. Referral criteria for outpatient specialty palliative cancer care: an international consensus. *Lancet Oncol*. 2016;17(12):e552–9. doi:[10.1016/S1470-2045\(16\)30577-0](https://doi.org/10.1016/S1470-2045(16)30577-0)
  19. Azwar S. *Penyusunan Skala Psikologi*. 2nd ed. Yogyakarta: Pustaka Belajar; 1995.
  20. Bennett M, Adam J, Alison D, Hicks F, Stockton M. Leeds eligibility criteria for specialist palliative care services. *Palliat Med*. 2000;14(2):157–8. doi:[10.1191/026921600669491513](https://doi.org/10.1191/026921600669491513)
  21. Weissman DE, Meier DE. Identifying patients in need of a palliative care assessment in the hospital setting: a consensus report from the Center to Advance Palliative Care. *J Palliat Med*. 2011;14(1):17–23. doi:[10.1089/jpm.2010.0347](https://doi.org/10.1089/jpm.2010.0347)
  22. Cohen SR, Sawatzky R, Russell LB, Shahidi J, Heyland DK, Gadermann AM. Measuring the quality of life of people at the end of life: The McGill Quality of Life Questionnaire-Revised. *Palliat Med*. 2017;31(2):120–9. doi:[10.1177/02692163166659603](https://doi.org/10.1177/02692163166659603)
  23. Hui D, Santos R, Chisholm G, Bansal S, Silva TB, Kilgore K, et al. Clinical Signs of Impending Death in Cancer Patients. *Oncologist*. 2014;19(6):681–7. doi:[10.1634/theoncologist.2013-0457](https://doi.org/10.1634/theoncologist.2013-0457)



This work is licensed under a Creative Commons Attribution