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The association of prognostic awareness with quality of life, spiritual well-being, psychological distress, and pain severity in patients with advanced cancer: Results from the APPROACH Study in Indonesia

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Abstract

Background and objectives. Advanced cancer patients' understanding of their illness is key for making informed treatment decisions. Despite the known importance of patients' awareness of their disease prognosis, it is debatable whether this awareness is positively, negatively, or not associated with clinical and psychological outcomes among patients with advanced cancer. This paper aims to determine the prevalence of and factors associated with prognostic awareness and its association with quality of life (QoL), spiritual well-being, pain control, and psychological distress in patients with advanced cancer in Indonesia.

Methods. This cross-sectional questionnaire-based survey was part of a multicountry study titled "Asian Patient Perspectives Regarding Oncology Awareness, Care and Health (APPROACH)." Patients were asked what they knew about their cancer and treatment. QoL and spiritual well-being were measured using the Functional Assessment of Cancer Therapy – General (FACT-G) and Functional Assessment of Chronic Illness Therapy – Spiritual Well-being (FACIT-Sp) questionnaire. Psychological distress experienced by patients was recorded via the Hospital Anxiety and Depression Scale. Pain severity was also assessed. Data from 160 patients were analyzed using descriptive statistics and multivariable regression models.

Results. Of the 160 patients who participated, 55 (34.4%) were unaware of their cancer stage. Those who were aware of their stage of cancer were younger than those who were not aware (45.7 years vs 50.4 years, $p = .015$). There was no significant difference in spiritual well-being and other domains of QoL between those who were aware and those who were not aware of their advanced cancer stage. There was also no significant difference in anxiety depression or pain severity, even after adjustment for demographic and clinical characteristics.

Significant of results. Given the high prevalence of patients who wrongly thought their cancer was curable, more could be done to improve disease and prognostic understanding among patients with advanced cancer in Indonesia. Those who were aware of their advanced cancer stage did not have a poorer QoL, nor did they have more anxiety or depression than those who were unaware. This finding suggests that concerns about the negative impact of prognostic disclosure may be unfounded.

Introduction

Cancer ranks as a leading cause of death worldwide (Sung et al. 2021). In Indonesia, 18.6% of premature death in 2016 was caused by cancer (WHO 2020). For patients with advanced cancer, awareness that their disease is at the advanced stage is the first step in respecting patients' autonomy and facilitating informed medical decision-making (Chou et al. 2013; Kang et al. 2020). However, there is concern that diagnosis and prognosis disclosure can cause distress, and family members may urge physicians to hide information from patients (Butow et al. 2020;

Dey et al. 2015; Psyd Bovero et al. 2015). Consequently, there are differing clinical practices regarding the disclosure of cancer diagnosis and prognosis to patients with advanced cancer, based on concerns that prognostic awareness would adversely affect psychoemotional well-being (El-Jawahri et al. 2014; Lai et al. 2017; Lee et al. 2020).

Current evidence for the association between prognostic awareness and patient well-being is inconsistent. Prognostic awareness has been positively, negatively, or not associated with psychological symptoms (Kang et al. 2020; Tang et al. 2016). Based on a study by Lai et al. (2017), patients' awareness of diagnosis was associated with a lower level of anxiety and depression. However, another study by Nipp et al. (2017) had a different result, in which, patients with an accurate understanding of their health status and treatment goal reported worse quality of life (QoL) and mood. Ozdemir et al. (2022) similarly suggest that prognostic awareness was associated with worse anxiety, depression, and spiritual well-being. The association between prognostic awareness and pain intensity in patients with advanced cancer was also conflicting. Some studies found that there was no association between the pain experienced by patients and prognostic awareness (Chochinov et al. 2000), while others found that pain scores were better in those with a lack of prognostic awareness (Lee et al. 2020). Until this study was conducted, no known research had been done in Indonesia.

Indonesia is a state with islands full of cultural diversities, ethnicities, and religions (Zarbaliyev 2017). Numerous studies have indicated the significance of religiosity in positively influencing the psychological health of patients with cancer (Dewi et al. 2013). For instance, one of the beliefs of Islam is that when a believer is being tested by God through an illness, he or she should keep their faith and stay patient – this stance may mitigate worries that prognosis disclosure would lead to psychological distress (Basri et al. 2015).

The aims of this study were to (i) describe what patients with advanced cancer believe about their cancer and treatment; (ii) explore factors associated with prognostic awareness; and (iii) assess whether prognostic awareness was associated with clinical and psychological outcomes. We hypothesize that prognostic awareness is associated with less psychological distress, better pain control, better QoL, and better spiritual well-being. The results from this study will inform clinical practice in the Indonesian healthcare context regarding the provision of information regarding cancer prognosis to patients with advanced cancer. We also expect that the findings in this study will provide insights that are relevant to other healthcare contexts with similar religious and cultural beliefs.

Methods

Setting and participants

This cross-sectional questionnaire-based study was part of a multicountry study titled "Asian Patient Perspectives Regarding Oncology Awareness, Care and Health (APPROACH)" to assess gaps in care received by patients with advanced cancer across diverse settings in low- and middle-income countries in Asia. Data presented in this paper were collected from one of the sites, Cipto Mangunkusumo National Hospital, Indonesia. The study was initiated after approval from the Universitas Indonesia Ethics Committee [599/UN2.F1/ETIK/2017] and the National University of Singapore [B-15-319]. Patients were recruited from both oncology and palliative medicine clinics from May 2019 to November 2020. Patients with stage IV solid cancer who were aged 21 years or older and received cancer-directed treatment before the interview date were included in the study after obtaining written informed consent. Patients unaware of their cancer diagnosis were excluded from the study. Patients who were judged potentially eligible via their medical records were invited to participate. Informed consent was obtained from all participants. Questionnaires were interviewer-administered, and each interview lasted for an average of 60 minutes.

Variables and measures

Demographic data – age, gender, years of education, marital status, employment status, religion – were obtained from the patient, and cancer type was retrieved from the medical records. A patient questionnaire, administered in Indonesian language, was used to survey patients on what they knew about their cancer stage, duration since the initial diagnosis, how informed they are about how their cancer would change over time, whether their current treatment will cure their cancer, and whether there are other treatments they think will cure their cancer. Prognostic awareness was assessed by how participants responded to the question on their cancer stage; as all included patients had advanced cancer, those who answered "advanced stage" were considered to have prognostic awareness.

QoL and spiritual well-being were measured using the Functional Assessment of Cancer Therapy – General (FACT-G) and Functional Assessment of Chronic Illness Therapy – Spiritual Well-being (FACIT-Sp) questionnaire.

The FACT-G is a 27-item survey that covers 4 core domains in QoL: physical well-being (7 items), social/family well-being (7 items), emotional well-being (6 items), and functional well-being (7 items). Examples of items include "I have a lack of energy" for physical well-being; "I feel close to my friends" for social/family well-being; "I feel sad" for emotional well-being; and "I am able to enjoy life" for functional well-being. Each item has response choices on a 5-point Likert scale from "not at all" to "very much." We adopted the official scoring method: the domain score was obtained by summing individual item scores within each domain, subject to imputation for item nonresponse by the "half rule." Total FACT-G score was computed by summing the 4 domain scores (Cella et al. 1993; Webster et al. 2003). Higher scores indicate a better QoL.

The FACIT-Sp is a 12-item survey on spiritual well-being, comprising 2 subscales: meaning/peace (8 items) and faith (4 items) (Peterman et al. 2002). Examples of items in the FACIT-Sp measure include "I feel peaceful" and "I feel a sense of purpose in my life" for meaning/peace; "I find comfort in my faith or spiritual beliefs" for faith. Higher scores indicate better spiritual well-being.

Psychological distress experienced by patients was recorded via the Hospital Anxiety and Depression Scale (HADS). The 14-item (7 each for anxiety and depression) questionnaire is a tool for the identification of psychological distress. Each item was answered on a 4-point response (0–3) by the patient. Following the reverse coding instructions for 6 items, the mean scores for anxiety and depression were obtained separately. For both anxiety and depression, a score of 8–10 indicates a borderline case and ≥ 11 indicates a probable case (Annunziata et al. 2011; Snaith 2003; Stern 2014). Its psychometric properties have been found acceptable in patients with cancer and the Indonesian population (Nasution et al. 2020, 2020; Sjamsudin et al. 2018; Tiksnadi et al. 2023; Widyaningsih et al. 2014).

Pain severity was measured using 4 items scored on a scale of 11-point Likert scale from 0 to 10 and pain severity was computed by the mean of the 4 items.

Besides the FACT-G, FACIT-Sp, HADS, and pain severity instruments described above, all the other survey questions were first developed in English. Subsequently, they were translated by professional translators into Indonesian, which is spoken by majority of the population at the study site, and then back-translated into English. The original and back-translated English versions were compared and reconciliations were made where necessary. Further revisions were made to these questions based on feedback from the physicians and cognitive interviews with 10 eligible patients at the study site.

Sample size

The sample size considerations were not based on a single endpoint, but rather to enroll an appropriate number of subjects that ensures sufficient precision and power in answering the research questions while maintaining feasibility. Therefore, a total of 160 patients were enrolled in the study.

Statistical analysis

Categorical variables were presented as counts (percentages) and differences between groups were analyzed using the chi-square test. Continuous variables were presented as means (SDs) and differences between groups were analyzed using the independent t-test. Demographic (age, gender, years of education, marital status, employment status, religion) and clinical characteristics (cancer type) associated with awareness of advanced disease status were assessed by multivariable logistic regression analysis. Association between awareness of advanced disease status and both QoL domains and psychological distress were examined by multivariable linear regression analysis, adjusting for all available demographic and clinical variables. Data were analyzed using StataCorp. 2021 (Stata Statistical Software: Release 17. College Station, TX: StataCorp LLC).

Results

Medical records of 607 patients were assessed for eligibility for study participation, of which 392 were not eligible to participate. Oof thr 215 patients approached by the study team for screening, 36 patients did not qualify based on the eligibility criteria. Of the remaining 179 eligible patients, 11 did not give consent to participate. Of the 168 patients who consented to participate, 6 were excluded from analysis as they could not complete the questionnaire and a further 2 were withdrawn from the study as they were subsequently found to be less than 21 years old. This left 160 patients included in the sample for analysis.

The mean age of patients was 47.5 (22–76) years, 48.1% were male, 82.5% were married, 81.9% were Muslim, and the mean number of years of education was 11.2 years. The most common cancer types were nasopharyngeal cancer ($n = 43$, 26.9%) followed by breast cancer ($n = 23$, 14.4%) (Table 1).

Despite knowing that they had cancer, roughly a third of patients ($n = 55$, 34.4%) did not know what the current stage of their malignancy was. A few of them believed that their disease was at stage I, II, or III ($n = 6$, 3.8%) though all had advanced-stage cancer (Table 2). Only 11.3% reported being very informed about their disease; Even though all had incurable advanced cancer, 85.6% thought their current treatment would cure them.

Characteristics of those who were aware versus those who were not aware of their advanced cancer stage are shown in Table 3.

Table 1. Characteristics of the study sample

Characteristic	
Age in years, mean (SD), range	47.5 (11.8), 22–76
Gender, *N* (%):	
Male	77 (48.1)
Female	83 (51.9)
Years of education, mean (SD), range	11.22 (3.9), 1–22
Marital status, *N* (%)	
Married	132 (82.5)
Unmarried	28 (17.5)
Employment status, *N* (%)	
Yes	33 (20.6)
No (I1)	127 (79.4)
Religion, *N* (%)	
Muslim	131 (81.9)
Christian	28 (17.5)
Buddhist	1 (0.6)
Type of cancer, *N* (%)	
Breast	23 (14.4)
Colorectal	22 (13.8)
Nasopharyngeal	43 (26.9)
Others	72 (45.0)

Those who were aware of their stage of cancer were younger than those who were not aware (45.7 years vs 50.4 years, $p = .015$). This remained statistically significant after adjustment for covariates in multivariable logistic regression. Gender, marital status, employment status, religion, and type of cancer were not statistically different between groups (Table 3).

There was no significant difference in spiritual well-being and other domains of QoL between those who were aware versus those who were unaware. There was also no significant difference in anxiety, depression or pain severity, even after adjustment for demographic and clinical characteristics (Table 4).

Discussion

This is the first study to explore the association of awareness of advanced stage of diseasewith QoL, spiritual well-being, psychological distress, and pain control in Indonesia. All 160 enrolled patients in this study had advanced stage of cancer, but only 11% of participants reported being very informed about their disease. Although all participants had incurable cancer, 85% believed that their current treatment would cure their cancer. These results indicate that participants had a poor understanding of their disease prognosis.

Nearly a third of patients were not aware that their cancer was advanced. This result may be due to a cultural belief in Asian countries where caregivers are less likely to inform patients of their actual prognosis than in Western countries (Lee et al. 2020). Although previous studies (Brandt et al. 2012; El-Jawahri et al. 2014; Kang et al. 2020; Nipp et al. 2017; Psyd Bovero et al. 2015) have shown that patients with prognostic awareness

Table 2. Patient perspectives about their cancer and cancer treatment

Question	Response Categories	No. of patients (%)
Do you know the current stage (i.e. severity) of your cancer?	Early stage (stage I–III)	6 (3.8)
	Advanced stage (stage IV)	99 (61.9)
	I don't know	55 (34.4)
(For those who knew that the current stage of cancer was advanced, $N = 99$) When did you first learn that you have advanced cancer?	<6 months ago	44 (27.5)
	6 months to 1 year ago	21 (13.1)
	1–2 years ago	21 (13.1)
	2–3 years ago	3 (1.9)
	>3 years ago	10 (6.3)
	N/A (does not know that cancer is an advanced stage)	61 (38.1)
How informed are you about your disease?	Very informed	18 (11.3)
	Somewhat informed	96 (60.0)
	Unsure	9 (5.6)
	Not informed	36 (22.5)
The current treatments you are taking for your cancer will help you live longer?	Yes	142 (88.8)
	No	5 (3.1)
	Not sure	13 (8.1)
The current treatments you are taking for your cancer will cure you?	Yes	137 (85.6)
	No	6 (3.8)
	Not sure	16 (10.0)
There are other treatments (besides your current treatment) that will help you live longer	Yes	39 (24.4)
	No	67 (41.9)
	Not sure	54 (33.8)
There are other treatments (besides your current treatment) that will cure you?	Yes	31 (19.4)
	No	69 (43.1)
	Not sure	60 (37.5)

had lower QoL, we found no difference in QoL, spiritual well-being, psychological well-being, and pain severity between patients who were aware versus unaware that their cancer was advanced. Considering these results, information on the advanced stage of cancer could be carefully conveyed to patients, while providing adequate support for them.

Our study found that younger patients are more likely to be aware of their advanced cancer stage. In contradiction to our result, a study of breast cancer awareness in India showed that awareness was higher with increasing age (Dey et al. 2015). Similar to the result of our study, a systematic review of factors associated with prognostic awareness in patients with cancer by Vlckova et al. (2020) showed that the level of prognostic awareness is worse with increasing age. The reason for this is that older persons might have lower health literacy or they may even struggle with the idea of participating in a discussion about their prognosis. An international collaborative study from 11 countries across the world showed that higher education was associated with a more accurate perception of curability (Yennurajalingam et al. 2018).

Our study results show that there was no difference in the FACT-G total and domain scores. A study of the relationship between emotional well-being and understanding of prognosis in patients with acute myeloid leukemia in Taiwan showed that patients who were fully aware of their prognosis at treatment initiation had lower (worse) median emotional well-being scores and lower overall FACT-G scores (Singh et al. 2022). Similarly, the study by Vlckova et al. (2020) in the Czech Republic found that unaware patients experienced a better QoL compared to aware patients. However, similar to our findings, a study by Montazeri et al. (2004) at Glasgow showed that knowledge of cancer diagnosis does not cause any difference in QoL between those who knew and did not know their cancer diagnosis. These varied results demonstrate how patients from various cultural backgrounds may approach their illness and treatment in different ways (Montazeri et al. 2009).

In our study sample, there was no difference in spiritual well-being among those who were aware versus those who were not aware of their advanced cancer stage. A study by Ozdemir et al. (2022) showed that compared with patients who were not aware of their prognosis, patients who were aware of their prognosis had lower meaning and faith scores. Another study in India also showed that patients who were aware of their advanced cancer stage had poorer spiritual well-being in the faith domain compared to those who were unaware (Satija et al. 2021). In this study, there was no difference in spiritual well-being between the 2 groups. This may be because the majority of participants were Muslim. Muslim patients

Table 3. Demographic characteristics of patients who were aware versus not aware of advanced cancer stage

	Aware of advanced cancer stage, n = 99	Not aware of advanced cancer stage, n = 61	*p*-value	Multivariable regression analysis for being aware compared to not being aware of advanced cancer stage			
				Odds ratio	95% CI		*p*-value
Age, mean (SD)	45.7 (11.8)	50.4 (11.4)	0.015	0.947	0.898	0.999	0.045
Gender (Males), N (%)	42 (42.4)	35 (21.9)	0.066	1.493	0.399	5.588	0.552
Years of education, mean (SD)	10.9 (10.2)	11.7 (10.6)	0.212	0.900	0.778	1.042	0.159
Marital Status, N (%)							
- Married	79 (79.8)	53 (86.9)	0.252	0.165	0.0293	0.933	0.042
- Unmarried	20 (20.2)	8 (13.1)					
Employment status, N (%)			0.568	1.595	0.470	5.408	0.454
- Yes	19 (19.2)	14 (23.0)					
- No	80 (80.8)	47 (77.0)					
Religion, N (%)							
- Muslim	80 (80.8)	51 (83.6)	0.697	0.517	0.130	2.049	0.347
- Christian	18 (18.2)	10 (16.4)					
- Buddhist	1 (1.0)	0 (0)					
Type of cancer, N (%)							
- Breast	18 (18.2)	5 (8.2)	0.332	4.511	0.796	25.554	0.089
- Colorectal	13 (13.1)	9 (14.8)		2.191	0.549	8.735	0.266
- Nasopharyngeal	27 (27.3)	16 (26.2)					

believe that their prognosis lies in the hands of God and that the fate of the patients is beyond the control of the responsible treating patients. This is because they have trust and faith in God's will and do not perceive illness as a punishment but, rather, as a way to atone for sins (Movafagh et al. 2017). This result also emphasizes the importance of providing spiritual care in the Islamic context among patients with advanced cancer.

There was no difference in anxiety and depression scores among those who were aware versus those who were not aware of their advanced cancer stage. This agrees with a study that involved 325 patients with terminally ill cancer in Taiwan, that accurate prognostic awareness was not associated with the likelihood of severe anxiety or depressive symptoms (Tang et al. 2016). However, another study involving 1184 patients with stage IV solid cancer across 4 Asian countries found that being aware or unsure of their prognosis was associated with higher anxiety and depressive symptoms (Ozdemir et al. 2022). The majority of our patients practice Islam which asks the believer to have faith and be patient during sickness (Basri et al. 2015; Dewi et al. 2013). This may be the reason why even those who were aware of their disease prognosis did not feel anxious or depressed.

As one of the dimensions of bio-psycho-social well-being that may be affected by prognostic awareness, pain severity scores were not significantly different between the 2 groups. This may be because pain was well controlled among the study participants, whose mean pain score was 3 out of 10, which is categorized as mild

pain. A study previously done in Iran by Montazeri et al. in which 2 groups of patients with gastrointestinal cancer were prospectively evaluated similarly showed that pain symptoms in the aware and unaware of diagnosis group did not show any significant difference (Montazeri et al. 2009).

There are several limitations to this study. First, this study was conducted at a single site and the findings may not be extrapolated to other sites in Indonesia and other countries. However, every effort was taken to ensure that the study population was a diverse group of patients with cancer. All of the findings are based on cross-sectional data; thus, we can only infer correlations rather than causality. Furthermore, we only included patients who were already aware of their cancer, because of ethical concerns with recruiting patients who were not aware of their cancer diagnosis. While we examined prognostic awareness from the point of view of awareness of advanced cancer stage, future studies could explore other dimensions of illness understanding.

Despite these limitations, our research advances our understanding of the relationship between illness prognosis awareness and pain control, psychological discomfort, and spiritual well-being in Indonesian patients with advanced cancer, and emphasizes the necessity of holistic approaches. Further studies could be conducted with a longitudinal perspective or using qualitative methodology to explore the impact of other possible confounding factors. For example, the impact of Islam religion on QoL and psychological well-being could be explored in future studies.

Table 4. Differences in quality of life, psychological well-being, and pain severity among patients who are aware versus not aware of advanced cancer stage

	Aware (n = 99)	Not aware (n = 61)	Difference		Adjusted difference (adjusted for all variables in Table 1)	
			Mean (95% CI)	*p*-value	Mean (95% CI)	*p*-value
Physical well-being	15.43	15.06	−0.37 (−2.50, 1.75)	0.729	0.22 (−3.46, 3.89)	0.907
Social well-being	21.69	21.11	−0.58 (−1.88, 0.72)	0.380	1.35 (−0.48, 3.17)	0.147
Functional well-being	17.07	17.75	0.68 (−1.21, 2.57)	0.476	−1.88 (−4.77, 1.02)	0.200
Emotional well-being	16.17	16.54	0.37 (−1.35, 2.09)	0.670	1.44 (−1.22, 4.09)	0.285
FACT-G total	70.37	70.47	0.10 (−5.05, 5.25)	0.969	1.12 (−7.41, 9.66)	0.794
Meaning/peace	23.81	24.39	0.58 (−1.11, 2.27)	0.499	−0.78 (−3.35, 1.79)	0.547
Faith	13.38	13.56	0.17 (−0.80, 1.15)	0.726	−0.73 (−2.14, 0.68)	0.306
Facit-Sp total	37.19	37.95	0.75 (−1.69, 3.20)	0.543	−1.51 (−5.14, 2.12)	0.410
HADS anxiety	5.67	4.91	−0.75 (−2.02, 0.52)	0.247	−0.35 (−2.46, 1.77)	0.746
HADS depression	6.44	5.90	−0.54 (−1.97, 0.88)	0.453	−0.15 (−2.40, 2.09)	0.891
HADS total	12.11	10.82	−1.29 (−3.71, 1.13)	0.294	−0.50 (−4.47, 3.47)	0.803
Pain severity (0−10)	3.23	3.20	−0.02 (−0.55, 0.51)	0.934	0.11 (−0.74, 0.96)	0.802

Conclusion

Our study found that those who were aware of their advanced cancer stage did not have a poorer QoL, neither did they have more anxiety or depression than those who were unaware. This finding suggests that concerns about the negative impact of prognostic disclosure may be unfounded and that perhaps more could be done to improve the disclosure of the cancer stage among those with advanced cancer. This is the first step toward understanding disease incurability and expected survival, which would, in turn, facilitate better-informed treatment decision-making. Pain symptoms and psychological distress are common in patients with advanced cancer. Recognizing these symptoms and discussing what they signal may be an opening for sharing prognostic information and having goals of care conversations.

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