Original Article

Severity of self-reported outcomes in patients with cancer in West Java Province, Indonesia

Chandra Isabella Hostanida Purba[1,2]*, Bridget Johnston[3,4], Grigorios Kotronoulas[3]

[1] School of Medicine, Dentistry & Nursing, University of Glasgow, Glasgow, United Kingdom
[2] Fakultas Keperawatan (Nursing Faculty), Universitas Padjadjaran, Indonesia
[3] School of Medicine, Dentistry & Nursing, University of Glasgow, Glasgow, United Kingdom
[4] NHS Greater Glasgow & Clyde, Glasgow, United Kingdom

Abstract

Background: Assessing cancer-related patient-reported outcomes is rare in Indonesia. A prior study identified the need for cancer management at the clinic level to overcome low screening, late diagnosis, late treatment, and awareness of cancer.
Purpose: This study aimed to describe cancer patients' self-reports of the severity of symptoms and how it correlates to their characteristics in West Java Province, Indonesia.
Methods: A cross-sectional survey of patients with cancer was conducted. As many as 227 patients (response rate 90.8%) were recruited from RSHS Hospital and nearby shelters using purposive sampling technique. Data were collected via respondent's characteristics questionnaire and the Integrated Palliative Care Outcomes Scale. Data were analysed using bivariate and multivariate chi square tests.
Results: A total of 227 questionnaires were received and analysed (response rate 90.8%). The participants were Sundanese (84%), married (81.5%), 36–55 years old (63.9%), housewives (51.5%), and had primary-level education (57.5%). These patients had been diagnosed between 6 and 12 months (35.7%), with a mean of 1.69 years (SD 2.7), and most patients were without comorbidities (85%). The mean distance to the hospital was 149.3 km (SD=271.7). The most prominent physical symptom experienced was pain (72.2%), while the most prominent emotional concern was family anxiety (45.4%). More than 50% of participants reported severe symptoms. Further statistics show that there is a correlation between performance and pain scale level with severity of patient-reported outcomes (p-value 0,001;α 0,05).
Conclusion: The results suggest that patients reported severe outcomes in physical and psychological. Patients with severe physical showed significantly higher pain levels. Systematic assessment of patient-reported outcomes via inexpensive measures can be a key starting point for the management of patients' symptoms, especially in countries where palliative care services are less organised. Introducing systematic assessment of reported outcomes tools in local practice can help staff perform assessments with a low budget. Nurse-led interventions can be implemented to provide holistic care for physical and psychological symptoms.

Keywords: cancer; palliative care outcomes scale; patient-reported outcomes

Jurnal Keperawatan Padjadjaran (JKP)

Volume 14(1), 89-102

http://dx.doi.org/10.24198/jkp.v14i1.2775

Article Info

Received	: March 24, 2025
Revised	: October 26, 2025
Accepted	: April 27, 2026
Published	: April 30, 2026

Corresponding author

Chandra Isabella Hostanida Purba*
School of Medicine, Dentistry & Nursing, University of Glasgow, United Kingdom. Fakultas Keperawatan Unpad, Kampus Jatinangor Jawa Barat, Indonesia; Address: Wolfson Medical School Building, University Ave, Glasgow G12 8QQ, United Kingdom 3QCF+PR9, Hegarmanah, Jatinangor, Sumedang Regency, West Java 45363; Phone: +6282124522715; E-mail: chandra.isabella@unpad.ac.id

Citation

Purba, C.I.H., Johnston B., & Kotronoulas G. (2026). Severity of self-reported outcomes in patients with cancer in West Java Province, Indonesia. *Jurnal Keperawatan Padjadjaran, 14*(1), 89-102. http://dx.doi.org/10.24198/jkp.v14i1.2775

Website

http://jkp.fkep.unpad.ac.id/index.php/jkp

E-ISSN: 2442-7276
P-ISSN: 2338-5324

Introduction

Indonesia has a high burden of communicable diseases and noncommunicable diseases (Ministry of Health of the Republic of Indonesia, 2023), with a sharp increase in cancer incidence (Mahendradhata et al., 2017). The incidence of cancer is 14 cases per 1,000 people, with 70% of patients diagnosed in the end stages; however, only half of them continue with medical treatment (Ministry of Health of the Republic of Indonesia, 2019). The significant increase in the prevalence of cancer has led to severe problems, as cancer treatment centres can treat only 15% of patients. In general, only three hospitals with 434 beds are available to serve 3,676,463 patients with cancer (Ministry of Health of the Republic of Indonesia, 2023). Approximately 300 patients with cancer visit hospitals every day and can wait up to three months for their first chemotherapy treatment due to the limited number of hospitals. This situation delays treatment and shows that appropriate supportive and palliative care is limited (Ministry of Health of the Republic of Indonesia, 2023).

Worldwide, the Hospice and Palliative Care global report indicated that almost 53 million adults need palliative care globally, most of whom were aged 50-69 years (27%) and aged 20-47 years (26%) in 2020. The proportion was relatively high in all regions; however, 76% of those 53 million live in upper- and lower-middle-income countries, with the highest ratio in the adult population being in low-income countries (Connor et al., 2020).

Patients in Indonesia face issues with autonomy that make them unable to choose suitable treatment unless the family agrees (Iskandarsyah et al., 2014; SchrÖDer-Butterfill & Fithry, 2014). There is a culture in which sick people belong to their families (SchrÖDer-Butterfill & Fithry, 2014; Schröders et al., 2017; Wessner, 2018). Even if the government is applying for health insurance, the family still needs expenses while seeking cancer treatment at the referral hospital (Wessner, 2018). Therefore, treatment depends on the burden of family availability. This can also place physical, emotional, and financial burden on patients and family caregivers during treatment (Purba et al., 2022).

Assessing cancer-related patient-reported outcomes (PROs) is limited in Indonesia. A prior study identified the need for cancer management at the clinic level to overcome the low screening, late diagnosis and treatment, and awareness of unrealistic beliefs regarding cancer among the population (Iskandarsyah et al., 2014; Schröders et al., 2017). These misconceptions delay treatment, and people tend to believe traditional healers (Iskandarsyah et al., 2013). In line with a prior study among noncommunicable diseases in Yogyakarta, the number of people who needed palliative care identified by nurses was 17.7%, and that identified by physicians was 9.7% (Effendy et al., 2022). These findings highlight the lack of patient outcome measurements in Indonesia and show the utility of PROMs for both by physicians and nurses in Indonesia

Nurses have a strategic role in assessing PROs. The PROs reported the patient's condition from their point of view without healthcare or the family caregiver's interpretation (Johnston et al., 2016). It is a direct patient indicator without clinician interpretation (Almeida et al., 2021). The PROs could also help but multidisciplinary teams predict interventions for elderly individuals with cancer. The nurse, as the first contact to the patient, can collect the data form the patient.

The more detailed and reliable the instrument used to measure PROs is, the more valid the information from the patient is so that crucial information from PROs enhances decision-making for clinicians, patients, and policy (Gagnier & Johnston, 2019). A previous study revealed that patients who completed PROs were more motivated to participate in their care (Kane et al., 2018). A routine PRO assessment should be performed every day to predict the probability of dying in the ward (Coym et al., 2020). In addition, PROs are a significant indicator of medical effects (Kotronoulas et al., 2019). It can be performed online to reduce costs and receive fast feedback from healthcare providers (Kotronoulas et al., 2016). It is also beneficial to report results across multicentre settings (Furlong et al., 2019) by empowering patients to report and prioritise their needs (Kotronoulas et al., 2017). The patient perspective promotes patient-centred care by including the PROs instrument (Tractenberg et al., 2017).

The PROs are the basic data to ensure the health care providers the suitable intervention to reduce the symptoms, which in turn increase the patients' quality of life. The implications of self-reported outcomes will benefit the patient as they can measure their own symptoms. Person-centred care means that the patient is involved in their care (McCormack, 2020). They should have an opportunity to choose and evaluate the interventions they have. Their person-centred outcome should result in satisfaction with care, involvement with care, a feeling of wellbeing and the creation of a therapeutic culture (McCormack, 2020). On the other hand, palliative care staff should provide a service to satisfy the patient and to deliver person-centred outcome (McCormack & McCance, 2017). However, little is known about the relationship of other patient characteristics with PROs. Understanding these effects can help nurses to provide interventions, evaluate how an intervention works, and determine how and why it works, as well as identify which interventions work, including their methods and criteria for success (McCormack & McCance, 2017). This study aimed to describe the severity of PROs patients with cancer in West Java Province, Indonesia and how it links to patients' characteristics.

Materials and Methods

This cross-sectional PROs survey was part of a mixed methods study (Purba et al., 2025). This study was conducted at Hasan Sadikin Hospital and 13 Shelters around the hospital in West Java Province, Indonesia. The population was 700 people with cancer, and the sample size was 248–254 people, determined using the Krejcie and Morgan formula (Taherdoost, 2017). A total of 227 samples were recruited using convenience sampling with the inclusion criterion of adult patients with cancer

Demographic data collected included: age, sex, marital status, occupation, ethnicity, education level, and distance to the hospital. Clinical data were obtained from medical records, including the diagnosis, type of cancer, comorbidities, and duration since diagnosis. One of the main PRO measures in palliative care is the Integrated Palliative Care Outcomes Scale (IPOS). It was first developed in 1999 by Hearn and Higginson as the Patient Outcomes Scale (POS) to evaluate outcomes for patients with advanced cancer (Hearn & Higginson, 1999). The IPOS aims to measure the effects of patients' physical and psychological needs to help health care provide suitable interventions and observe significant changes in patients. The IPOS questionnaire focuses on two areas; physical and emotional symptoms (Hearn & Higginson, 1999). The IPOS has good construct validity and reliability (Spearman rho =0.43–0.80, with an internal consistency of Cronbach's alpha =0.65 (Bausewein et al., 2011). It has 10 items to assess physical symptoms; psychological, emotional, and spiritual needs, and the provision of information and practical support (Collins et al., 2015) tool has been translated into several languages, tested for its psychometrics, and found to be valid and reliable. The IPOS questionnaire has never been used in Indonesia. The researchers conducted a back translation by three native speakers of Indonesia and English. Internal consistency of the translated IPOS was good with a Cronbach's alpha value of 0.838. The level of need and burden of patients with cancer and how nurses can provide lead interventions constitute a part of this research. The IPOS begins with an open-ended questionnaire asking about the greatest number of problems, followed by 10 physical outcomes related to cancer or the treatment effects. The following questions ask about assessing the physical, emotional, psychological, spiritual, support, family and provision of information. One addition is asking who helps the patient fill in the questionnaires (Bausewein et al., 2011). Five response options are given on a Likert scale ranging from not at all (0) to overwhelmingly (4). The higher the scores are, the higher the outcomes. Only one answer is allowed for each question. The patient chose a score depending on their condition. The total score reflects their original condition. The overall profile score helps understand the overall experience and their needs and strengths at a specific time. Data were analysed using statistical chi-square test to see the correlation between demographic data and the PRPs.

To avoid selection bias, the researcher approached all the participants with cancer in the hospital and shelters. Participants were relatively homogeneous, as they shared similar geographic, educational, and socioeconomic backgrounds. To avoid justify external validity, researcher conducted visits to every shelter and also to the cancer clinic every day so that all participants who fulfilled the criteria had the same opportunity to be recruited. To ensure that the patient choose the best answer for themselves, the researcher informed the benefit of the reported outcomes to gain the best intervention to them. The family members only assisted to check the answer when patients were too tired to complete the questionnaire themselves. To minimise blank answers, the researcher checked the respondent why they did not fill out all the questions. In most cases, they needed more information about the most appropriate answer based on their condition. After clarifying the information, the researcher asked the participants to complete all the questions so that there was no missing answer.

Data are analysed using SPSS version 42 (Ewertowski et al., 2018); Univariate analysis was conducted to show descriptive statistics (means-median, frequency, percentage). Beside descriptive analysis, additional correlational analysis was also conducted to further describe what the respondents' characteristics link to the respondents' PROs level.

Ethical consideration

The researcher respected the participants' rights, including respect for persons, beneficence, and justice. The respondent recruitment was conducted voluntarily. The researcher was able to recruit participants quickly, as every day around 150 patients with cancer attend the clinic and there are 10 new residents in 13 shelters. Research participants were free to withdraw at any point if they wished without any requirement to justify their decision. No participant dropped out of the study.

Ethics approval was obtained from the University of Glasgow ethics committee (Project No: 200180198) and ethics approval from the hospital (number LB.02.01/X.6.5/344/2019).

Results

All participants accepted the privacy notice and signed the patient information sheet before joining the research (Purba et al., 2022). Around 227 samples were recruited between November 2019 and February 2020 (90.7% participation rate). Just over 75% of the participants completed this questionnaire with family assistance (77.5%). Most participants were female (160, 70.5%), married (185;81.5%), mean age 45.3 years (SD 12; 16–75), Sundanese (84.6%), housewives (51.5%), primary school education (131, 57.7%), mean distance from the patients' hometowns to the hospital was 149.3 km (SD 271.67), had been diagnosed with breast cancer (15.9%) out of 32 types of cancer, 193 participants without comorbidities (85%), and the mean period of illness was 1.69 years (SD 2.7) (Table 3).

Table 3 outlines that almost all the participants had high scores. The total IPOS mean score was 30.2 (SD 13.0, range 3-62, possible maximum 68). The mean physical outcome score was 16.0 (SD

Table 1. The participant's recruitment process and the result

Process	Patient	Family caregivers
Questionnaires Distributed	250	250
Questionnaires returned	227	220
Response rate (%)	91%	88%
Reason for not returning the questionnaires:		
Not able to	3	7
Had died	11	0
Go back home temporarily	3	15
Did not understand how to complete it	3	3
Lost the questionnaire accidentally	3	5

9.4, range 0-40, possible maximum 40), and the mean psychological outcome score was 14.1 (SD 4.5, range 2-24, possible maximum 24). The most prominent physical symptoms experienced included pain (50%), weakness (27.8%), a sore mouth (18.5%), poor mobility (17.6%), and drowsiness (16.3%). Most of them reported not experiencing constipation (56.8%), vomiting (52.9%), or shortness of breath (49.3%).

Similarly, the top emotional concerns reported were the anxiety of family or friends (45.4%), practical problems resulting from the illness (38.3%), feeling at peace (23.3%), not feeling depressed and sharing their feelings with family or friends as much as they wanted (21.6%). Notably, most patients reported not feeling depressed (27.8%), were able to share their feelings (22.5%) and did not have as much information as they wanted (15%). Beyond the 10 suggested outcomes, 73.6% of participants reported that they did not have other symptoms, and only 18.1% reported that they had one other symptom.

A chi square test was carried out to see whether there was a correlation between the severity and respondents' characteristics. Table 4 shows α for performance and pain scale are 0.001, which is < 0.005. It means Ho is rejected. It can be concluded that there is a significant correlation between performance and pain and PROs severity while other factors do not have correlation (α 0,001).

Discussion

Almost all the participants had high scores mostly in physical symptoms (pain, weakness, and sore mouth) and emotional concerns (anxiety of family or friends, practical problems resulting from the illness, feeling at peace). Around 70% of the patients have been diagnosed with end-stage cancer with symptom as large tumour, cancerous wounded, bleeding, made the patient suffer with pain. Close to 50% of the participants reported high pain levels outcomes. This finding was similar to that of a prior study concluding that pain remains a common symptom among patients with cancer, a typical symptom in developing countries where there is limited access to painkillers, which impacts their quality of life (Silvoniemi et al., 2012). Even though the World Health Organisation (WHO) has already recommended reducing the layer used for painkiller access, patients in Indonesia still face difficulties in receiving painkiller such as morphine (Setiabudy et al., 2015). With respect to the policy in Indonesia, only physicians in the referral hospital can prescribe morphine. It is dispensed only in a pharmacy in large cities; the patients should be present in front of the physician, and the amount of the drugs given to the patients can cover their needs for only one month. Therefore, rural patients face many barriers to receiving painkillers (Knaul et al., 2017). On the other hand, the painkiller policy makes patients face many barriers. The pain experience is an uncomfortable situation for people with cancer. Moreover, the annual consumption of morphine in Indonesia is only 0.054 mg/capita. As a result, people die from pain (Setiabudy et al., 2015).

The result from PROs can be used to standardised pain assessment protocols. For example, the patient assessment should be performed in the community by physician or nurse and the result can be sent to the physician in the tertiary hospital. The painkiller dispensing should be applied in the primary health care. Furthermore, the community-based opioid stewardship also can be done as the alternative solutions to ensure patients have easy access to the painkiller.

In comparison, four-fifths of the 61 million patients lived in low and middle-income countries with limited access to palliative care. Moreover, half of the global population receives only 1% of the available morphine; this causes them to suffer from severe pain and health-related complaints (Knaul, 2017). Vietnam consumes 9% of painkillers per capita, India consumes 4%, and China consumes 16% (Knaul et al., 2017). Compared with the United States of America, which has less than 5% of the world's population but consumed approximately 30% of the world's opioids in 2009, nearly 40% of the European Union in 2021 consumed opioids. Although the World Health Organisation has stated that all countries reduce the number of controlled drugs, many countries still face difficulty in having morphine. For example, some travel costs are

Table 2. Demographic data of the patient participants (n=227)

Variable/Category	Patients
	Mean (SD); Range
Age	45.3 (12); 16-75
Distance home to hospital (km)	149.3 (271.67); 2-3000
Duration since been diagnosed as cancer	1.69 (2.7); 0-20 years
	n/+%
Gender	
Female	160 (70.5)
Age in years	
<36	40 (17.6)
36-55	145 (63.9)
>55	42 (18.5)
Marital status	
Married	185 (81.5)
Single	14 (6.2)
Widow	28 (12.3)
Ethnicity	
Sundanese	192 (84.6)
Javanese	30 (13.2)
Others	5 (2.2)
Education level	
No school	3 (1.3)
Primary	131 (57.8)
Junior	42 (18.5)
High	47 (20.7)
Bachelor	4 (1.7)
Duration since been diagnosed as cancer	
0-6 months	81 (35.7)
>6-11 months	68 (30.0)
1-2 years	34 (15.0)
>2 years	44 (19.4)
Pain level (face scale)	
Light	22 (9.7)
Moderate	67 (29.5)
Severe	138 (60.8)
Distance (home-hospital in km)	
1-200	196 (86.4)
>200	31 (13.7)

SD=standard deviation: Standard deviation measures the dispersion of a data set relative to its mean.
km=kilometres

needed for people in small cities in Nigeria to find morphine. In Morocco, prescriptions could be approved only after exclusive application. Physicians in the Philippines should pay for prescription forms. In Turkey, physicians have difficulty obtaining painkiller forms. Only referral hospitals can dispense opioids in China (Li et al., 2018). Pain reduces quality of life, including sleep quality.

Fatigue can be related to cancer, treatment, and psychological factors. It could worsen participants' health status and could persist for several years. One study reported that 72% of participants

Table 3. Patients' symptoms and concerns of Pros according to the IPOS (n=227)

No		Item	Not at all		Slightly		Moderately		Severely		Overwhelmingly	
			f	%	f	%	f	%	f	%	f	%
1	A	Pain	31	13.7	32	14.1	35	15.4	81	35.7	114	50.2
2		Shortness of breath	112	49.3	22	9	39	17.2	22	9.7	32	14.1
3		Weakness	49	21.6	34	15	45	19.8	36	15.9	63	27.8
4		Nausea	93	41	38	16.7	47	20.7	20	8.8	29	12.8
5		Vomiting	120	52.9	34	15	34	15	13	5.7	26	11.5
6		Poor appetite	67	29.5	2	11.9	54	23.8	40	1.6	39	1.2
7		Constipation	129	56.8	23	10.1	29	12.8	17	7.5	29	12.8
8		Sore mouth	5	33	40	17.6	41	18.1	29	12.8	42	18.5
9		Drowsiness	83	36.6	24	10.6	46	20.3	37	16.3	37	16.3
10	Q	Poor mobility	93	41	34	15	39	17.2	21	9.3	40	17.6
12		Feeling anxious about your illness or treatment.	20	8.8	10	4.4	61	26.9	47	20.7	89	39.2
13		Have any of your family or friends been anxious or worried about you?	8	3.5	9	4	30	13.2	77	33.9	103	45.4
14		Have you been feeling depressed.	63	27.8	29	12.8	52	22.9	34	15	49	21.6
15		Have you felt at peace?	30	13.2	30	13.2	70	30.8	44	19.4	53	23.3
16		Have you been able to share how you are feeling with your family or friends as much as you wanted?	51	22.5	27	11.9	52	22.9	48	21.1	49	21.6
17		Have you had as much information as you wanted?	34	15	31	13.7	102	44.9	25	11	35	15.4
18		Have any practical problems resulting from your illness been addressed?	17	7.5	16	7	31	13.7	6	33.5	87	38.3
11		Number of other symptoms.	None		One		Two		Three		Four	
			f	%	f	%	f	%	f	%	f	%
			167	73.6	41	18.1	14	6.2	5	2.2	0	0
19		How did you complete this questionnaire?	Myself		Family		Staff		Mixed			
			f	%	f	%	f	%	f	%		
			1	0.4	164	72.2	6	2.7	56	25.4		

* Total number of participants answering.
A* A list of physical symptoms, which participants may or may not have experienced.
Q* A List of psychological/emotional symptoms.
The bold items are the most reported outcomes

reported that pain made them more fatigued (Matias et al., 2017). These findings support those of prior studies where weakness, fatigue, or exhausted-related cancer were the most common symptoms of cancer treatment and the most distressing syndrome (Poort et al., 2017). The uniqueness of fatigue requires multifactorial treatments, including both physical and psychological factors. Several studies have indicated that fatigue is associated with the hypothalamic adrenal system, nervous system, other conditions (Tong et al., 2019), and maladaptive immune systems (Black et al., 2018) and is correlated with poor quality of life.

Sore mouth was reported which can be related to low water intake and tropical weather, where the temperature is between approximately 27 degrees Celsius every day. Too weak to move could prevent people from drinking water from moving from the bed to the toilet. However, patients and family caregivers should understand that patients need enough hydration all day. They could prevent this by providing drinking water next to the patient's bed.

Table 4. Statistical analysis (Chi Suare test)

PROs	0-6 Months N	%	7-12 months N	%	>12 months N	%	Total	p-value
Duration since got cance							47	0.0589
Low outcomes	50	22.02	47	20.7	56	24.66	22	
High outcomes	29	12.77	22	9.69	23	10.13	69	
Total	79		69		79		227	
Distance from home to the hospital								**0.623**
Low outcomes	1-200km		201-500km		>500km			
High outcomes	132	58.14	19	8.37	2	0.8%		
Total	65	28.63	7	3.08	2	0.8		
Age category								**0.737**
	<36yo		36-55		>55			
Low outcomes	17	7.48	25	11.01	111	48.89		
High outcomes	10	4.40	14	6.16	50	22.01		
Total	27		39		161			
Gender								**0.416**
	Male		Female					
Low outcomes	44	19.38	109	48.01				
High outcomes	23	10.13	51	22.24				
Total	67		160					
Ethnics								**0.152**
	Sunda		Jawa		Sumatra		Sulawesi	
Low outcomes	124	54.62	24	10.57	1	0.44	4	
High outcomes	68	29.95	6	2.64	0	0	0	
Total	192		30		1		4	
Employment								**0.416**
	Farmer	Trader	Entrepreneur	Jobless	Housewife	Others	General Worker	
Low outcomes	15 (6.60%)	4(1.76)	16 (7.04)	17 (7.4)	77 (33.92)	10 (4.4)	12 (5.2)	
High outcomes	4	0 (0)	10 (4.4)	11 (4.8)	40 (17.62)	1 (0.44)	73.08)	
Total	19	4	26	28	117	11	85	
Education level								**0.614**
	No School	Primary	Junior	Senior	Bachelor			
Low outcomes	1 (0.44)	88 (38.76)	28(12.33)	34 (14.97)	2 (0.8%)			
High outcomes	2 (0.8%)	43 (18.94)	14 (6.16)	13 (5.7)	2 (0.8%)			
Total	3	131	42	47	4			
Comorbid								**0.168**
	NONE		1-3 other diseases					
Low outcomes	133	58.59	20	0.88				
High outcomes	60	26.43	14	6.16				
Total	193		34					

Cont. Table 4. Statistical analysis (Chi Suare test)

PROs	0-6 Months N	%	7-12 months N	%	>12 months N	%	Total	p-value
			Performance (ECOG)					**0.001**
	Light		Moderate		Very Sick			
Low outcomes	20	8.8	58	25.55	75	33.03		
High outcomes	2	0.8%	9	3.96	63	27.75		
Total	22		67		138			
			Pain level					**0.001**
	Light		Moderate		Worst pain			
Low outcomes	26	11.45	37	16.29	37	16.29		
High outcomes	2	0.8%	8	3.52	8	1.57		
Total	28		45	184				

In line with the findings of a previous study, the symptom cluster of nausea, vomiting, and loss of appetite were common among people with cancer (Pirri et al., 2013), leading to sore mouth and malnutrition. Poor appetite in people with cancer is also the most common syndrome related to cancer treatment such as chemotherapy and radiotherapy. People with cancer need supportive care to improve their quality of life (Kotronoulas et al., 2017a; Kotronoulas et al., 2017b). The family approach of talking about food, feelings, and reciprocity positively affects the patient's body weight (Hopkinson & Richardson, 2015).

Weakness could lead to poor mobility. Most of the respondents were in advanced stages of cancer, which made them suffer from fatigue. A previous study reported that health conditions can be maintained with adequate self-care in physical, psychosocial, emotional and functional domains (Nasution & Afiyanti, 2024). Doing more activities could improve patients' quality of life. Thus, keeping patient's mobile will help reduce poor mobility outcomes. Social support from family members, especially the husband or wife, is the support needed to achieve successful outcomes (Winarti, Prasetyanti, & Said, 2021).

Drowsiness has been reported to be significantly associated with a desire for death, so it should be assessed routinely (Yennu et al., 2014). Symptom monitoring has clinical implications in palliative care since advanced cancer patients have a high symptom burden (Newcomb et al., 2020).

As a top emotional concern, anxiety of the family or friends was similar to that of a prior study that reported that family anxiety was the typical missing value (Sakurai et al., 2021). Most participants in this study stayed in the shelter with one of their family caregivers, which automatically made the relative unable to do their job. This condition might explain why almost 100% of the participants worried about their families. People with depression or anxiety consequences have multiple complaints (Nipp et al., 2017).

Most of the practical problems resulting from the illness in this study were financial issues, which are common problems among patients in Indonesia. Moreover, if they were breadwinners, it was more challenging to support their lives. Financial difficulties significantly reduce quality of life. The government funded payments for 96.1 million people, as stipulated in the Minister of Social Affairs Decree No. 1, 2021 (Indonesia National Health Insurance Agency (BPJS Kesehatan), 2019). This means that patients can access health care services without any payment. However, they also need money during their stay in the hospital or shelter.

It was understandable that people with pain and anxiety rarely felt at peace because they struggled with symptoms and emotional challenges. People with cancer are more likely to experience practical spiritual, physical, and emotional problems (Nguyen, Do, & Pham, 2021). A prior study reported that spiritual support and talking to someone could increase anxiety (Ross & Austin, 2015). Spiritual support is already well known as enormous support for people to feel peace. However, most people do not receive enough spiritual and psychological support from professional health care providers. The spiritual legacy enabled patients to discuss critical issues regarding their beliefs and values (Piderman et al., 2017). Interestingly, females participate more in religious rituals and are more religious than males are (Munoz et al., 2015).

Many participants did not feel depressed and could share their feelings with family or friends as much as they wanted. If patients express their wishes, the family burden decreases because they know what to do after (Green et al., 2015). This symptom might be associated with participants from Asian communal cultures, whereby families and friends are counted as family. Indonesia has communal culture where other relatives are counted as a family (Subandi et al., 2021). This allowed them to share their information about the disease and treatment. This culture makes people feel safe under the influence of their large family. When a family member suffers from chronic illness, it automatically affects other relatives (Wessner, 2018). It is common to donate money to relatives when they got sick (Chan, Menon, & Goh, 2015).

The support from psychologists may increase patients' use of constructive strategies. Several studies have shown that patients who receive frequent sessions reliably receive support (Scheffold et al., 2018). Another study revealed that faith in God was the main component of patients' meaning of life that helped them cope with anxiety and death (Testoni et al., 2018).

Depression and anxiety in people with cancer are commonly related to pain, treatment, body function and structural changes, job loss, and authority. Hence, healthcare providers should be aware of this symptom. Pathological symptoms can be considered if the patient rejects treatment (Pitman et al., 2018). Anxiety and depression are also strongly associated with sexual dysfunction and poor quality of life (Akyol et al., 2015). Some people perceived that cancer was guilt or shame that increased their anxiety.

People who are sick tend to receive information from their family/friends in Indonesia (Subandi et al., 2021) without rechecking whether there is incorrect information. Patient-reported outcomes could prevent patient and family burdens because it can be used to monitor and evaluate symptoms and burdens and provide suitable interventions at home (Kotronoulas, 2021). Since families play a vital role in patient treatment and emotional support, they should have the correct information. Health care professionals could offer self-management programs to those people (Cheng & Kotronoulas, 2020).

People in East Asia share a similar culture and love chatting even with strangers. This culture currently seems to exist since 65% of the participants in this study shared their feelings with family or friends as much as they wanted. This culture benefits patients. However, self-awareness and correct information should be spread broader to ordinary people to support or provide accurate information to patients. For example, In India, families still believe in myths, traditional healing, and stigma (Alexander & Murthy, 2020). People with cancer need supportive care to improve their quality of life (Kotronoulas et al., 2017a; Kotronoulas et al., 2017b). Accurate information has contributed to better survival.

All participants needed psychological support to help patients die in peace and to help families in the mourning period. The patient has a right to have their needs met, to live in the here and now, to enjoy the moment and receive effective palliative care (Dönmez & Johnston, 2020). If they understood this concept, the staff could help patients live in the moment until they died in peace (Dönmez, Alici, & Borman, 2021). Nurses can identify this stress by initially discussing how patients want to be treated at the end of life, including issues such as support while dying, autonomy, medication, respecting personhood and treating someone like a human being (Johnston et al., 2021). The dignity issue might be subjective and not always explicitly captured in conversation, so nurses should explore this issue (Johnston et al., 2015).

Statistical analysis shows that all factors partially do not have a partial correlation on the PROs value except performance and pain scale. These findings in line with the previous study where the pain level was the most outcome reported among the patients with cancer (Duff et al., 2021). Hence, pain symptoms management should be provided to the patients. There is a correlation between the characteristic and severity of PROs (0.445). Furthermore, there is the significant influence of the dependent variable on PROs (15.3%). This data supports that the type of cancer and the time since diagnosed have effect on the patient outcomes (Yennu et al., 2014). Using PROs can reduce the feeling of embarrassment between patient if they felt uncomfortable to tell their sensitive issues directly to the nurse (Lind et al., 2019).

Information about PROs produces a clinical description of the patient, improves symptom assessment, improves the interaction between staff and patient, increases patient satisfaction, and supports person-centred care (Johnston et al., 2017). The palliative performance is to classify a patient according to their functional impairment, compare the effectiveness of therapies, and assess the prognosis of a patient (Zou et al., 2024). The nurse should assess rating performance scale to help better decision making for patient, especially relate to their chemotherapy (Neeman et al., 2019). Healthcare providers should provide suitable interventions for people with cancer in Indonesian settings in terms of their outcomes. Interventions based on PROs have become standard treatments for evaluating services (Johnston, Walker, & Lakzadeh, 2019).

Strength and Limitations of the study

This study holds some strength, including the instrument used and the data collected. IPOS was used in the Indonesian language for the first time. IPOS can measure the actual reported outcomes between patients with cancer with good validity and reliability. A significant number of participants, 227 out of 250 targets (91%). Disparity of the participants showed that the Indonesian version could describe a wider population. This heterogeneity stems from demographic data, including gender, age, education, occupation, cancer type, duration of illness, supportive needs, and distance to the hospital. These results are critical for providing better interventions for people with cancer in Indonesia. Identifying the reported outcomes can help health care providers provide comprehensive nurse-led interventions in palliative care.

Beside those strengths, there were some limitations must be acknowledged. The study needs to be replicated in a wider Indonesian cancer patient population. Even when the sample reached a >90% rate, a specific background is needed to identify specific needs. Additionally, the sample comes from one cancer centre in Indonesia, which cannot generate a population in Indonesia. However, this population represents the second largest ethnic population, with approximately 46 million lives in this hospital setting (Purba, Johnston, & Kotronoulas, 2022).

Implication of the study

Implications for nursing knowledge; the findings inform hypothesis generation for targeted interventions so that need future validation across cancer types and settings by using assessment of supportive care needs via PROMs in local practice. Implications for practices is providing time to discuss any questions and concerns of patients reported outcomes and families using simple language. Future research can explore many issues in providing and running a palliative care system, including cultural barriers and facilitators in running the palliative care services.

Conclusions

The participants reported the severity of their PROs in both physical and psychological domains. Almost all patients reported pain as a physical symptom, and family or friends worried as the most common psychological symptom. There is a relationship between performance and pain scale and severity of PROs among people with cancer in West Java (α 0,001). Other characteristics (gender, age, education level, cancer types, duration since diagnosis, employment, marital status, comorbid) do not show the correlation. The routine PROM uses and nurse-led interventions should be done to ensure the patient outcomes can be addressed every day particularly for patient at the end of life.

Declaration of interest

We have no conflicts of interest to disclose. All authors contributed to the design of the research concept. All the authors contributed to the preparation of the manuscript. CIHP performed the data collection and statistical analysis. BJ & GK performed the statistical analysis and provided discussions and conclusions.

Funding

The first author would like to thank Universitas Padjadjaran Indonesia for funding this research (funding grant number 7812/UN6.WR2/KP/201770).

Data availability

Supporting data from this study are available from the corresponding author upon request.

References

Akyol, M., Ulger, E., Alacacioglu, A., Kucukzeybek, Y., Yildiz, Y., Bayoglu, V., . . . Tarhan, M. O. (2015). Sexual satisfaction, anxiety, depression and quality of life among Turkish colorectal cancer patients [Izmir Oncology Group (IZOG) study]. *Japanese Journal of Clinical Oncology, 45*(7), 657-664. https://doi.org/10.1093/jjco/hyv051

Alexander, A., & Murthy, R. (2020). Living with cancer: Urgent need for emotional health support. Indian Journal of Cancer, 57, 360. https://doi.org/10.4103/ijc.IJC_113_19

Almeida, A., Martins, T., & Lima, L. (2021). Patient-reported outcomes in sarcoma: A scoping review. *European Journal of Oncology Nursing, 50,* 101897. https://doi.org/10.1016/j.ejon.2021.101897

Bausewein, C., Daveson, B., Benalia, H., Simon, S., & Higginson, I. (2011). Outcome measurement in palliative care the essentials (Higginson Ed.). London: London, King's College London.

Black, D. S., Cole, S. W., Christodoulou, G., & Figueiredo, J. C. (2018). Genomic mechanisms of fatigue in survivors of colorectal cancer. *Cancer, 124*(12), 2637-2644. https://doi.org/10.1002/cncr.31356

Chan, N., Menon, S., & Goh, C. R. (2015). Policies on palliative care for older people in Asia. *Palliative Care for Older People: A Public Health Perspective, 60*.

Cheng, L., & Kotronoulas, G. (2020). How effective are self-management interventions in promoting health-related quality of life in people after primary treatment for breast cancer? A critical evidence synthesis. *European Journal of Oncology Nursing, 47,* 101776. https://doi.org/10.1016/j.ejon.2020.101776

Collins, E., Witt, J., Bausewein, C., Daveson, B., Higginson, I., & Murtagh, F. (2015). A systematic review of the use of the palliative care outcome scale and the support team assessment schedule in palliative care. *Journal of pain and symptom management, 50*(6), 842-853.e819. https://doi.org/10.1016/j.jpainsymman.2015.07.015

Connor, S., Morris, C., Jaramillo, E., Harding, R., Cleary, J., Haste, B., . . . Radbruch, L. (2020). Global atlas of palliative care, 2nd edition. Retrieved from http://www.thewhpca.org/resources/global-atlas-on-end-of-life-care

Coym, A., Ullrich, A., Hackspiel, L. K., Ahrenholz, M., Bokemeyer, C., & Oechsle, K. (2020). Systematic symptom and problem assessment at admission to the palliative care ward – perspectives and prognostic impacts. *BMC palliative care, 19*(1), 75. https://doi.

org/10.1186/s12904-020-00576-3

Dönmez, A., Alici, N., & Borman, P. (2021). Lived experiences for supportive care needs of women with breast cancer-related lymphedema: A phenomenological study. *Clinical Nursing Research, 30*(6), 799-808. https://doi.org/10.1177/1054773820958115

Dönmez, Ç., & Johnston, B. (2020). Living in the moment for people approaching the end of life: A concept analysis. *International Journal of Nursing Studies, 108,* 103584. https://doi.org/10.1016/j.ijnurstu.2020.103584

Duff, J., Cornell, A., Jayanthi, S., Tharakanara, S., Romero, P., & Davis-Castro, C. (2021). Consumption of prescription opioids for pain: A comparison of opioid use in the United States and other countries [Online]. USA: Coordinator Analyst in Health Policy, Analyst in Global Health and International Development, Research Librarian. Available: https://crsreports.congress.gov [Accessed 30 Jan 2022].

Effendy, C., Silva, J., & Padmawati, R. S. (2022). Identifying palliative care needs of patients with non-communicable diseases in Indonesia using the SPICT tool: A descriptive cross-sectional study. *BMC Palliat Care, 21*(1), 13. https://doi.org/10.1186/s12904-021-00881-5

Ewertowski, H., Tetzlaff, F., Stiel, S., Schneider, N., & Jünger, S. (2018). Primary palliative care in general practice – Study protocol of a three-stage mixed-methods organizational health services research study. *BMC palliative care, 17*(1), 21. https://doi.org/10.1186/s12904-018-0276-6

Furlong, E., Darley, A., Fox, P., Buick, A., Kotronoulas, G., Miller, M., . . . Maguire, R. (2019). Adaptation and implementation of a mobile phone-based remote symptom monitoring system for people with cancer in Europe. *JMIR Cancer, 5*(1), e10813. doi:10.2196/10813

Gagnier, J. J., & Johnston, B. C. (2019). Poor quality patient reported outcome measures bias effect estimates in orthopaedic randomized studies. *J Clin Epidemiol, 116,* 36-38. https://doi.org/10.1016/j.jclinepi.2019.07.012

Green, M. J., Schubart, J. R., Whitehead, M. M., Farace, E., Lehman, E., & Levi, B. H. (2015). Advance care planning does not adversely affect hope or anxiety among patients with advanced cancer. *Journal of Pain and Symptom Management, 49*(6), 1088-1096. https://doi.org/10.1016/j.jpainsymman.2014.11.293

Hearn, J., & Higginson, I. (1999). Development and validation of a core outcome measure for palliative care: The palliative care outcome scale. *Palliative Care Core Audit Project Advisory Group. BMJ Quality & Safety, 8*(4), 219-227. https://doi.org/10.1136/qshc.8.4.219

Hopkinson, J. B., & Richardson, A. (2015). A mixed-methods qualitative research study to develop a complex intervention for weight loss and anorexia in advanced cancer: The family approach to weight and eating. *Palliative Medicine, 29*(2), 164-176. https://doi.org/10.1177/0269216314556924

Indonesia National Health Insurance Agency (BPJS Kesehatan). (2019). BPJS for health: Financial management report and financial report 2018 (Audit). Jakarta: Indonesia National Health Insurance Agency (BPJS Kesehatan).

Iskandarsyah, A., de Klerk, C., Suardi, D. R., Soemitro, M. P., Sadarjoen, S. S., & Passchier, J. (2013). Satisfaction with information and its association with illness perception and quality of life in Indonesian breast cancer patients. *Support Care Cancer, 21*(11), 2999-3007. https://doi.org/10.1007/s00520-013-1877-5

Iskandarsyah, A., de Klerk, C., Suardi, D. R., Soemitro, M. P., Sadarjoen, S. S., & Passchier, J. (2014). Psychosocial and cultural reasons for delay in seeking help and nonadherence to treatment in Indonesian women with breast cancer: A qualitative study. *Health Psychol, 33*(3), 214-221. https://doi.org/10.1037/a0031060

Johnston, B., Flemming, K., Narayanasamy, M. J., Coole, C., & Hardy, B. (2017). Patient reported outcome measures for measuring dignity in palliative and end of life care: A scoping review. *BMC Health Services Research, 17*(1), 574. https://doi.org/10.1186/s12913-017-2450-6

Johnston, B., Larkin, P., Connolly, M., Barry, C., Narayanasamy, M., Östlund, U., & McIlfatrick, S. (2015). Dignity-conserving care in palliative care settings: An integrative review. *Journal of clinical nursing, 24*(13-14), 1743-1772. https://doi.org/10.1111/jocn.12791

Johnston, B. C., Miller, P. A., Agarwal, A., Mulla, S., Khokhar, R., De Oliveira, K., . . . Guyatt, G. H. (2016). Limited responsiveness related to the minimal important difference of patient-reported outcomes in rare diseases. *Journal of Clinical Epidemiology, 79*, 10-21. https://doi.org/10.1016/j.jclinepi.2016.06.010

Johnston, B. M., McCauley, R., Rabbitte, M., McQuillan, R., Honohan, C., Mockler, D., . . . May, P. (2021). Evidence on the effectiveness and cost-effectiveness of out-of-hours palliative care. *Palliative Medicine, 35*(2), 367-368. https:doi.org/10.1177/0269216320969555

Johnston, K., Walker, D., & Lakzadeh, P. (2019). Characterizing the health-related quality of life burden of overactive bladder using disease-specific patient-reported outcome measures: A systematic literature review. *Advances in therapy PMC, 36,* 14. https://doi.org/10.1007/s12325-019-0880-8

Kane, P. M., Ellis-Smith, C. I., Daveson, B. A., Ryan, K., Mahon, N. G., McAdam, B., . . . Koffman, J. (2018). Understanding how a palliative-specific patient-reported outcome intervention works to facilitate patient-centred care in advanced heart failure: A qualitative study.

Palliative Medicine, 32(1), 143-155. https://doi.org/10.1177/0269216317738161

Knaul, F., Farmer, P., Krakauer, E., De Lima, L., Bhadelia, A., Kwete, X., . . . Rajagopal, M. (2017). Alleviating the access abyss in palliative care and pain relief—an imperative of universal health coverage: The lancet commission report. *The Lancet Commissions, 391*(10128), 63. https://doi.org/10.1016/S0140-6736(17)32513-8

Knaul, F. M. (2017). Health system responses to women's cancers in the Americas: Closing divides to achieve universal health coverage. Cancer Research. *Conference: San Antonio Breast Cancer Symposium, SABCS, 78*(4 Supplement 1).

Kotronoulas, G. (2021). Benefits, challenges, and opportunities of integrating patient-reported outcome measures in geriatric oncology to advance patient screening for functional fitness for treatment. *Seminars in Oncology Nursing, 37*(6), 151230. https://doi.org/10.1016/j.soncn.2021.151230

Kotronoulas, G., Connaghan, J., Grenfell, J., Gupta, G., Smith, L., Simpson, M., & Maguire, R. (2017). Employing patient-reported outcome (PRO) measures to support newly diagnosed patients with melanoma: Feasibility and acceptability of a holistic needs assessment intervention. *European Journal of Oncology Nursing, 31*, 59-68. https://doi.org/10.1016/j.ejon.2017.10.002

Kotronoulas, G., Cooper, M., & Johnston, B. (2019). Core patient-reported outcomes (PROs) and PRO measures (PROMs) for polypharmacy medicines reviews: A sequential mixed-methods study. *Patient Prefer Adherence, 13,* 2071-2087. https://doi.org/10.2147/ppa.S236122

Kotronoulas, G., Maguire, R., Papadopoulou, C., Eileen, F., Patricia, F., Ream, E., . . . Nora, K. (2016). Enabling symptom self-management via use of an electronic patient-reported outcomes (ePRO) system to increase self-efficacy of patients with cancer receiving active chemotherapy treatment. *Frontiers, 4*. Retrieved from: https://www.frontiersin.org/10.3389/conf.fpubh.2016.01.00077/event_abstract

Kotronoulas, G., Papadopoulou, C., Burns-Cunningham, K., Simpson, M., & Maguire, R. (2017). A systematic review of the supportive care needs of people living with and beyond cancer of the colon and/or rectum. *Eur J Oncol Nurs, 29,* 60-70. https:doi.org/10.1016/j.ejon.2017.05.004

Li, Q., Lin, Y., Zhou, H., Xu, Y., Yang, L., & Xu, Y. (2018). Factors moderating the mutual impact of benefit finding between Chinese patients with cancer and their family caregivers: A cross-sectional study. *Psycho-Oncology, 27*(10), 2363-2373. https://doi.org/10.1002/pon.4833

Lind, S., Wallin, L., Fürst, C. J., & Beck, I. (2019). The integrated palliative care outcome scale for patients with palliative care needs: Factors related to and experiences of the use in acute care settings. *Palliative and Supportive Care, 17*(5), 561-568. https://doi.org/10.1017/S1478951518001104

Mahendradhata, Y., Trisnantoro, L., Listyadewi, S., Soewondo, P., Marthias, T., Harimurti, P., & Prawira, J. (2017). The Republic of Indonesia health system review. *Health Systems in Transition, 7*(1). Retrieved from https://apps.who.int/iris/handle/10665/254716

Matias, M., Baciarello, G., Neji, M., Michiels, S., Partridge, A. H., Bendiane, M. K., . . . Luis, I. M. V. D. (2017). Fatigue and health behaviors in cancer survivors: A cross-sectional population based study. *Journal of Clinical Oncology, 35*(15_suppl), 10069-10069. https://doi.org/10.1200/JCO.2017.35.15_suppl.10069

McCormack, B. (2020). The person-centred nursing and person-centred practice frameworks: From conceptual development to programmatic impact. *Nursing Standard, 35*(10), 86-89. https://doi.org/10.7748/ns.35.10.86.s40

McCormack, B., & McCance, T. (2017). Person-centred practice in nursing and health care: Theory and practice: John Wiley & sons, Ltd.

Ministry of Health of the Republic of Indonesia. (2019). Indonesia Health Profile. Retrieved from https://kemkes.go.id/eng/profil-kesehatan-indonesia-2019

Ministry of Health of the Republic of Indonesia. (2023). Indonesia health survey 2023. Jakarta: Ministry of Health of the Republic of Indonesia.

Munoz, A. R., Salsman, J. M., Stein, K. D., & Cella, D. (2015). Reference values of the functional assessment of chronic illness therapy-spiritual well-being: A report from the American Cancer Society's studies of cancer survivors. *Cancer, 121*(11), 1838-1844. https://doi.org/10.1002/cncr.29286

Nasution, L. A., & Afiyanti, Y. (2024). Self-care among breast cancer survivors: A concept analysis. *Jurnal Keperawatan Padjadjaran, 12* (2), 12. https://doi.org/10.24198/jkp.v12i2.2504

Neeman, E., Gresham, G., Ovasapians, N., Hendifar, A., Tuli, R., Figlin, R., & Shinde, A. (2019). Comparing physician and nurse eastern cooperative oncology group performance status (ECOG-PS) ratings as predictors of clinical outcomes in patients with cancer. *Oncologist, 24*(12), e1460-e1466. https://doi.org/10.1634/theoncologist.2018-0882

Newcomb, R. A., Nipp, R. D., Waldman, L. P., Greer, J. A., Lage, D. E., Hochberg, E. P., . . . El-Jawahri, A. R. (2020). Symptom burden in patients with cancer who are experiencing unplanned hospitalization. *Cancer, 126*(12), 2924-2933. https://doi.org/10.1002/cncr.32833

Nguyen, T. Q., Do, T. M., & Pham, T. A. (2021).

Screening for psychological distress in vietnamese cancer patients: An evaluation of the distress thermometer. *Cancer Medicine, 10*(21), 7793-7803. https://doi.org/10.1002/cam4.4298

Nipp, R. D., El-Jawahri, A., Moran, S. M., D'Arpino, S. M., Johnson, P. C., Lage, D. E., . . . Temel, J. S. (2017). The relationship between physical and psychological symptoms and health care utilization in hospitalized patients with advanced cancer. *Cancer, 123*(23), 4720-4727. https://doi.org/10.1002/cncr.30912

Piderman, K. M., Radecki Breitkopf, C., Jenkins, S. M., Lapid, M. I., Kwete, G. M., Sytsma, T. T., . . . Jatoi, A. (2017). The impact of a spiritual legacy intervention in patients with brain cancers and other neurologic illnesses and their support persons. *Psycho-Oncology, 26*(3), 346-353. https://doi.org/10.1002/pon.4031

Pirri, C., Bayliss, E., Trotter, J., Olver, I. N., Katris, P., Drummond, P., & Bennett, R. (2013). Nausea still the poor relation in antiemetic therapy? The impact on cancer patients' quality of life and psychological adjustment of nausea, vomiting and appetite loss, individually and concurrently as part of a symptom cluster. *Supportive Care in Cancer, 21*, 735-748. https://doi.org/10.1007/s00520-012-1574-9

Pitman, A., Suleman, S., Hyde, N., & Hodgkiss, A. (2018). Depression and anxiety in patients with cancer. *BMJ, 361,* k1415. https:doi.org/0.1136/bmj.k1415

Poort, H., Kaal, S. E. J., Knoop, H., Jansen, R., Prins, J. B., Manten-Horst, E., & Servaes, P. (2017). Prevalence and impact of severe fatigue in adolescent and young adult cancer patients in comparison with population-based controls. *Supportive Care in Cancer, 25,* 2911-2918. https://doi.org/10.1007/s00520-017-3746-0

Purba, C., Johnston, B., & Kotronoulas, G. (2022). An exploration of family caregivers' health care needs when caring for patients with cancer in the resource-challenged context of West Java, Indonesia. *Seminars in Oncology Nursing, 39*(3), 151369. https://doi.org/10.1016/j.soncn.2022.151369

Purba, C., Johnston, B., & Kotronoulas, G. (2025). Developing a nurse-led palliative care intervention for adults with cancer and their family caregivers in the resource-challenged context of Indonesia. University of Glasgow, Glasgow. Retrieved from https://theses.gla.ac.uk/id/eprint/85010Developing (glathesis:2025-85010)

Ross, L., & Austin, J. (2015). Spiritual needs and spiritual support preferences of people with end-stage heart failure and their carers: implications for nurse managers. *Journal of Nursing Management, 23*(1), 87-95. https://doi.org/10.1111/jonm.12087

Sakurai, H., Miyashita, M., Morita, T., Naito, A. S., Miyamoto, S., Otani, H., . . . Matsushima, E. (2021). Comparison between patient-reported and clinician-reported outcomes: Validation of the Japanese version of the integrated palliative care outcome scale for staff. *Palliative and Supportive Care,* 1-7. https://doi.org/10.1017/S1478951521000018

Scheffold, K., Philipp, R., Koranyi, S., Engelmann, D., Schulz-Kindermann, F., Härter, M., & Mehnert, A. (2018). Insecure attachment predicts depression and death anxiety in advanced cancer patients. *Palliative and Supportive Care, 16*(3), 308-316. https://doi.org/10.1017/S1478951517000281

SchrÖDer-Butterfill, E., & Fithry, T. S. (2014). Care dependence in old age: preferences, practices and implications in two Indonesian communities. *Ageing and Society, 34*(3), 361-387. https://doi.org/10.1017/S0144686X12001006

Schröders, J., Wall, S., Hakimi, M., Dewi, F. S. T., Weinehall, L., Nichter, M., . . . Ng, N. (2017). How is Indonesia coping with its epidemic of chronic noncommunicable diseases? A systematic review with meta-analysis. *PLoS One, 12*(6), e0179186. https://doi.org/10.1371/journal.pone.0179186

Setiabudy, R., Irawan, C., & Sudoyo, A. (2015). Opioid use in cancer pain management in Indonesia: A call for attention. *Acta medica Indonesiana, 47*(3), 244-250. Retrieved from http://www.actamedindones.org/index.php/ijim/article/view/39

Silvoniemi, M., Vasankari, T., Vahlberg, T., Vuorinen, E., Clemens, K. E., & Salminen, E. (2012). Physicians' self-assessment of cancer pain treatment skills--more training required. *Support Care Cancer, 20*(11), 2747-2753. https://doi.org/10.1007/s00520-012-1396-9

Subandi, M., Praptomojati, A., Marchira, C. R., DelVecchio Good, M.-J., & Good, B. J. (2021). Cultural explanations of psychotic illness and care-seeking of family caregivers in Java, Indonesia. *Transcultural Psychiatry, 58*(1), 3-13. https://doi.org/10.1177/1363461520916290

Taherdoost, H. (2017). Determining sample size; How to calculate survey sample size. *International Journal of Economics and Management Systems, 2*. Retrieved from http://www.iaras.org/iaras/journals/ijems

Testoni, I., Sansonetto, G., Ronconi, L., Rodelli, M., Baracco, G., & Grassi, L. (2018). Meaning of life, representation of death, and their association with psychological distress. *Palliative and Supportive Care, 16*(5), 511-519. https://doi.org/10.1017/S1478951517000669

Tong, H., Zhu, Y., & Liu, Y. (2019). Incidence and risk of fatigue in cancer patients treated with MET inhibitors. *Medicine, e15522., 98*. https://doi.org/10.1097/MD.0000000000015522

Tractenberg, R. E., Garver, A., Ljungberg, I. H., Schladen, M. M., & Groah, S. L. (2017). Maintaining primacy of the patient perspective in the development of patient-centered patient reported outcomes. *PLOS ONE, 12*(3), e0171114. https://doi.org/10.1371/journal.pone.0171114

Wessner, P. B. (2018). Last chance to care: An autoethnography of end-of-life care in Indonesia. *The Qualitative Report, 23*(9), 12. https://doi.org/10.1111/jep.12725

Winarti, E., Prasetyanti, D., K., A. M., & Said, R. M. (2021). Determining behavior to uptake and its predictors toward cervical cancer screening among women: A case-control multistage study. *Jurnal Keperawatan Padjadjaran, 9*(3), 9. https://doi.org/10.24198/jkp.v9i3.1691

Yennu, S., Balachandran, D., Pedraza, S. L., Berg, E. A., Chisholm, G. B., Reddy, A. S., . . . Bruera, E. (2014). Frequency and characteristics of cancer-related drowsiness (CRD or excessive daytime sleepiness) in patients with advanced cancer: Results of a prospective survey at a tertiary cancer center. *Journal of Clinical Oncology, 32*(31_suppl), 131-131. https://doi.org/10.1200/jco.2014.32.31_suppl.131

Zou, Y., Wang, L., Zheng, D., Li, H., Sun, R., & Zhang, Z. (2024). Exploration of undergraduate nursing students' perspectives on conducting specialized nursing education during internship: A phenomenological research study. *Nurse education in practice, 80,* 104103. https://doi.org/10.1016/j.nepr.2024.104103