

## ORIGINAL RESEARCH

# PATIENTS' AND NURSES' PERCEPTIONS OF PALLIATIVE CARE OUTCOMES: A COMPARATIVE STUDY

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## Abstract

**Background:** Patients with advanced cancer require treatment and the fulfillment of their needs, based on the results of assessments regarding their physical symptoms, psychological and spiritual needs. Palliative care should be delivered with a person-centered care approach. It is important to consider the patients' reports of their carings' outcomes. Comparisons between the patients' and nurses' perceptions of palliative care outcomes can be used to improve the quality of palliative care.

**Objective:** The purpose of this study is to compare the patients' and nurses' perceptions of palliative care outcomes during the patients' hospitalization.

**Methods:** This is a comparative descriptive study with a cross-sectional design. Data were collected from May to June 2018 from a total of 106 patients with advanced cancer, and 61 nurses. The versions of the Palliative care Outcome Scale (POS) for patients and nurses were used to measure the palliative care outcomes of the patients' and nurses' perceptions.

**Result:** The study found a significant difference between the perceptions of the patients and nurses for the palliative care outcomes, particularly in the information availability domain ( $p = 0.001$ ), the other symptoms domain ( $p = 0.029$ ), and the anxiety feelings domain ( $p = 0.030$ ), while the other seven domains had no significant differences between both groups ( $p > 0.05$ ).

**Conclusion:** The anxiety feelings, other symptoms and information availability domains are the aspects of palliative care which need more attention from health care providers, especially nurses, when caring for patients with advanced cancer.

## KEYWORDS

palliative care outcome scale; patients; nurses; advanced cancer; Indonesia

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## INTRODUCTION

The prevalence of patients with advanced stages of cancer is increasing every year. Advanced cancer requires palliative care along with cancer treatment ([American Cancer Society, 2017](#); [Ministry of Health, 2007](#)). In 2011 palliative cases reached 20.4 million cases, of which 94% are adult patient palliative cases ([World Health Organization, 2017](#)). Cancer patients with the palliative condition need assessing to fulfill their physical, socio psychological, and spiritual needs ([Thomas et al., 2010](#); [Wang et al., 2008](#)). The assessment of these needs, conducted by the patients themselves, is occasionally different from the

review results made by nurses. ([Horton, 2002](#)). Quality care studies frequently only focus on the perspective and standards of professionals. This refers to the patients' conditions or the condition effect of pain suffered by patients ([Horton, 2002](#)). Moreover, the review conducted by nurses, without involving the patients, does not reflect the real needs of the patients ([Hearn & Higginson, 1997](#)). One of the instruments that can review the patients' conditions from the perspective of both patients and nurses is the Palliative care Outcome Scale (POS). The POS may be considered as the gold standard tool in the

context of palliative care. It is a tool to measure patients' physical symptoms, psychological, emotional and spiritual, and information and support needs ([Higginson et al., 2018](#)). The purpose of the study was to compare the perceptions of patients and nurses of palliative care outcomes experienced by patients with advanced cancer during hospitalization.

## METHODS

### Study Design

This was a comparative study with a cross-sectional design, which involved 106 patients with advanced cancer who were selected using consecutive sampling, and 61 nurses selected using a total sampling technique. This study was conducted in the academic hospital in Yogyakarta and a public hospital in Central Java. Data were collected from May to June 2018.

### Sample

The inclusion criteria for patients were: a) being patients with advanced cancer; b) >18 years old; c) the score of Eastern Cooperative Oncology Group (ECOG) > 2; d) willing to become a respondent by signing an informed consent form, and e) being hospitalized for at least 3 days. The exclusion criteria were being unconscious with Glasgow Coma Scale (GCS) scores < 13. The inclusion criteria for nurses were: a) willing to become a respondent by signing an informed consent form, b) experience in caring for palliative patients, and c) having at least one year's clinical experience.

### Instruments

This study used a patient and a nurse version of palliative care outcome scale (POS). The POS version of patient was used to assess a patient's perceptions of palliative care outcome scale. The version of POS for nurses was used to assess a nurse's perceptions of palliative care outcome scale that experienced by patients.

The palliative care outcome scale consists of ten questions, and the first question examines pain. *Pain* is the first domain in a palliative care assessment ([Higginson et al., 2018](#)). Pain is an experience that is often experienced by patients with palliative conditions, caused by tumors that suppress bones, nerves or other organs, and besides that pain is also caused by the chemotherapy treatment that the patients undergo ([Cancer Research United Kingdom, 2017](#)). Pain was measured using the Visual Analogue Scale (VAS) instruments. The second question in the POS instrument is *other symptoms*. Other symptoms are complaints such as coughing, nausea, vomiting, and shortness of breath that appear in patients with palliative conditions, and affect their quality of life ([Ministry of Health, 2007](#)). The other symptoms were measured using POS. *Anxiety* is the third question in the POS instrument. Anxiety is an unpleasant subjective experience, related to perceptions of threats that are real or imaginary ([Kumar & Parashar, 2015](#)). Anxiety was measured using POS. The fourth question is *family anxiety*. Family anxiety is the anxiety felt by the family due to their fear of losing family members who have cancer ([American Cancer Society, 2017](#)). Family anxiety was measured using

POS. The *availability of information* and *family support* are the fifth and sixth question in the POS. Information is something which is necessary for patients and families who receive a service related to their illness ([Page & Adler, 2008](#)). Family support is the actions, attitudes and behavior that are shown by family members to patients with cancer ([Borneman et al., 2010](#)). Availability of information and family support were measured using POS. The seventh question in the POS instrument is the *feeling of worth*, which was measured using the POS ([Higginson et al., 2018](#)). A feeling of worth is a balanced response between an awareness and self-acceptance of uncomfortable emotions, showing calmness when faced with unpleasant experiences, and accepting the conditions that occur ([Neef & Knox, 2017](#)). The eighth question is about *feeling good or not being depressed*, measured by using POS. Feeling good or not feeling depressed can be seen and observed through the attitude shown by the patients during treatment ([Religioni et al., 2015](#)). The ninth question is about the *feeling of wasted time when undergoing treatment*, which is the patients feeling that the treatment took a long time ([Higginson et al., 2018](#)), which was measured using POS. *Other problems arising in patients with cancer* is the tenth question in POS, and includes the financial problems caused by treatment and the changing roles and income of patients and family members ([Effendy et al., 2015](#)).

The researcher tested the validity and reliability of the POS in one of the hospitals in Yogyakarta with 65 patient respondents and 65 nurse respondents. The results of the validity of the versions of POS for the patients and the nurses showed that all ten questions in the POS instrument were valid. The  $r_{\text{tabel}}$  value obtained from the number of respondents (n) is reduced by the number of item questions (k), so that the value of  $r_{\text{tabel}}$  was 0.294 ([Nugroho, 2005](#)). The reliability test for the POS version of the patients' version showed a Cronbach's alpha value of 0.782, while the nurses' version had a Cronbach's alpha value of 0.639. Therefore, both the patients' and nurses' versions of the POS instruments were declared reliable.

### Ethical Consideration

This study was approved by the Ethics Commission of the Faculty of Medicine, Public Health and Nursing UGM No.KE/FK/0521/EC/2018, and by the committee ethics of RSUD Prof. Dr. Margono Soekardjo Purwokerto (420/05378a/IV/2018)

### Data Analysis

Categorical data were presented in a table of frequency distribution (f) and percentage (%), while the numerical data were presented in the form of the means and standard of deviation. The results of the normality test using Kolmogorov-Smirnov (n = 106) showed that the data were not normally distributed (p < 0.05). The results of the comparison of mean, median and Standard Deviation (SD) also showed that the data were not normally distributed. Statistical tests on the comparison of the POS instruments' results between patients and nurses used the Mann Whitney statistical test, with a significance value of p < 0.05

## RESULTS

## Demographic Characteristics of Nurses

**Table 1** shows the majority of the nurse respondents were female (62.3%), and 91.8% of the respondents are married.

Just over half (55.7%) of the respondents are aged between 20-40 years old. Most of them had a diploma degree (68.9%) and more than 3 years working experience (91.8%). In addition, most of the nurses had attended a palliative training seminar more than one time (82%).

**Table 1** Demographic Characteristics of Nurses

Characteristics of Respondents	Frequency (f)	%	Mean±SD
Gender			
Male	23	37.7	
Female	38	62.3	
Marital status			
Single	5	8.2	
Married	56	91.8	
Nurses' education level			
Diploma	42	68.9	
Bachelor	19	31.1	
Age			
20-40 years	34	55.7	39.41±8.55
41-60 years	27	44.3	
Work experience			
≤3 year	5	8.2	
>3 year	56	91.8	
Palliative training / seminar ever attended			
1	11	18	
> 1	50	82	

Frequency (f), Percentage (%), Standard of Deviation (SD)

**Table 2** shows that the majority of patients were female (65.1%), most patients were married (87.7%), and have an primary and high school education level (76.4%). Most of the respondents' income level was ≤ Rp. 1.572.200 (67%). The most commonly used insurance providers were JKN PBI and

ASKES (78.3%), and the most frequent stage of cancer was stage III (67.9%). The reproductive system cancer was the most dominant (37.7%), and chemotherapy was the most frequent treatment (55.6%).

**Table 2** Demographic Characteristics of Patients

Characteristics of Respondents	Frequency (f)	%	Mean±SD
Gender			
Male	37	34.9	
Female	69	65.1	
Marital status			
Not married / widowed / widower	13	13.3	
Married	93	87.7	
Age			
20 – 40 years	27	25.5	48.33±11.69
41-60 years	65	61.3	
≥61years	14	13.2	
Level of education			
Primary and High School	81	76.4	
Undergraduate School	25	23.6	
Income level*			
≤Rp. 1.572.200	71	67	
>Rp. 1.572.200	35	33	
Health care provider			
JKN PBI/Health Insurances	83	78.3	
JKN Non PBI	23	21.7	

**Table 2** *continued*

Cancer stage			
Stage III	72	67.9	
Stage IV	34	32.1	
Type of Cancer			
Reproductive system cancer	40	37.7	
Lung cancer	6	5.7	
Head & neck cancer	13	12.3	
Colorectal cancer	19	17.9	
Breast cancer	12	11.3	
Urinary system cancer	6	5.7	
Others (NHL, Skin, Pancreas, Leukemia & Bone)	10	9.4	
Duration of illness			
≤ 6 months	30	28.3	15.35±11.81
> 6 months	76	71.7	
Type of treatment			
Radiotherapy	10	9.4	
Chemotherapy	59	55.6	
Surgery & chemotherapy	22	20.8	
Surgery	15	14.2	

Frequency (f), Percentage (%), Standard of Deviation (SD) \*minimum wage of Central Java province

### The differences perceptions in palliative care outcomes between patients and nurses

The comparative analysis on the outcome of palliative care between patients and nurses can be seen in **Table 3**. From the ten domains in the POS, there were only three domains that showed differences in the palliative care outcomes between patients and nurses, which were the domains for: other

symptoms (nausea, coughing and constipation)  $p=0.029$ , feelings of anxiety  $p=0.030$ , and information availability  $p=0.001$ ; while the other seven domains (pain, family anxiety, the existence of support, self worth (feelings of worth to oneself), feeling good or not depressed, time wasted and practical problems) showed no difference between the outcomes for patients and nurses.

**Table 3** Patients' and Nurses' perception in Palliative Care Outcomes\*\*

Item palliative care outcome	Patients Median (min- max)	Nurses Median (min- max)	p value
Pain	3(1-4)	3(1-4)	0.205
Other symptoms	3(1-4)	2(1-4)	0.029*
Feelings of anxiety	3(1-4)	3(2-4)	0.030*
Family anxiety	4(1-4)	4(1-4)	0.056
Information availability	2(1-4)	2(0-4)	0.001*
Existence of support	3(0-4)	3(0-4)	0.082
Self worth (feelings of worth to one self)	3(1-4)	3(1-4)	0.241
Feeling good or not depressed	4(2-4)	4(2-4)	0.305
Time wasted	4(0-4)	4(0-4)	0.740
Practical problems	4(2-4)	4(2-4)	0.449

Significance value \* ( $p < 0.05$ ) | \*\*([Dewiyuliana, 2018](#))

### Analysis of differences in palliative care outcome scale based on respondents' characteristics

Table 4 shows the characteristics of the respondents in the study consist of their gender, marital status, age, level of education, income level, health care provider, cancer stage, type of cancer, duration of illness and type of treatment. The difference in POS, based on the nurses' characteristics, can be seen in Table 5. The characteristics for the nurses consist of their gender, marital status, nursing education level, age, work experience and the number of times they attended palliative training or a seminar.

This study found that only the education affected the perception of POS scores for the anxiety domain. There were no other factors affecting the POS scores of patients. On the other hand, the results of the POS analysis, based on the characteristics of the nurses, were influenced by the nurses' education for the domains of other symptoms, family support and self worth. The number of palliative training/seminars followed by nurses affected the domains of pain, other symptoms, anxiety, family support, self-worth and time wasted, while the age of the nurse influenced the practical problems domain.

Table 4 Palliative care Outcomes based on the Characteristics of patients

Characteristics of Respondents	Item Palliative Care Outcomes Scale(POS)													
	Pain		Other symptoms		Feelings of anxiety		Family anxiety		Information availability		Existence of support		Self Worth	
	Median (min-max)	P	Median (min-max)	P	Median (min-max)	P	Median (min-max)	P	Median (min-max)	P	Median (min-max)	P	Median (min-max)	P
<b>Gender</b>														
Male	3(1-4)	0.660	3(1-4)	0.769	4(2-4)	0.103	4(2-4)	0.791	2(2-4)	0.300	3(1-4)	0.838	3(1-4)	0.656
Female	3(1-4)		3(1-4)		3(1-4)		4(1-4)		2(1-4)		3(1-4)		3(1-4)	
<b>Marital status</b>														
(-) Not Married	3(2-4)	0.677	4(2-4)	0.841	3(1-4)	0.693	4(3-4)	0.298	2(2-4)	0.476	3(2-4)	0.148	3(2-4)	0.915
(+) Married	3(1-4)		3(1-4)		3(1-4)		4(1-4)		2(1-4)		3(1-4)		3(1-4)	
<b>Age</b>														
18-40years	3(1-4)		3(1-4)		4(1-4)		4(1-4)		2(1-4)		3(1-4)	0.452	3(3-4)	0.638
41-60 years	3(1-4)	0.791	3(1-4)	0.987	3(1-4)	0.402	4(2-4)	0.512	2(1-4)	0.947	3(1-4)		3(1-4)	
≥61 years	3(1-4)		3.5(1-4)		3.5(2-4)		4(3-4)		2.5(1-3)		3(1-4)		3(1-4)	
<b>Level of education</b>														
Primary-High school	3(1-4)	0.282	3(1-4)	0.075	3.5(1-4)	0.017	4(2-4)	0.562	2(2-3)	0.492	3(1-4)	0.744	3(1-4)	0.382
Undergraduate school	2(2-4)		3(2-4)		2(2-4)		4(2-4)		3(2-3)		3(1-4)		3(1-4)	
<b>Income level</b>														
≤UMR	3(1-4)	0.398	4(1-4)	0.291	4(1-4)	0.118	4(2-4)	0.878	2(1-4)	0.603	3(1-4)	0.332	3(1-4)	0.538
>UMR	3(1-4)		3(1-4)		3(1-4)		4(1-4)		2(1-4)		3(1-4)		3(1-4)	
<b>Health care provider</b>														
JKN PBI	3(1-4)	0.498	3(1-4)	0.682	3(1-4)	0.916	4(1-4)	0.737	2(1-4)	0.182	3(1-4)	0.186	3(1-4)	0.460
JKN non PBI	3(1-4)		4(1-4)		3(1-4)		4(2-4)		2(1-4)		3(2-4)		3(2-4)	
<b>Cancer stage</b>														
Stage III	3(1-4)	0.825	3(1-4)	0.954	3(1-4)	0.321	4(1-4)	0.756	2(1-4)	0.465	3(1-4)	0.431	3(1-4)	0.439
Stage IV	3(1-4)		3.5(1-4)		3(1-4)		4(2-4)		2(1-4)		3(1-4)		3(1-4)	
<b>Type of cancer</b>														
Reproductive system cancer	3(1-4)		3(1-4)		3(1-4)		4(1-4)		2(1-4)		3(1-4)		3(2-4)	
Lung cancer	4(2-4)		4(1-4)		4(1-4)		4(2-4)		2.5(2-3)		3(1-4)		3(3-4)	
Head & neck cancer	2(1-4)	0.270	2(1-4)	0.164	4(2-4)	0.822	4(2-4)	0.287	2(2-4)	0.372	3(3-4)	0.886	3(1-4)	0.250
Colorectal cancer	3(1-4)		4(1-4)		3(2-4)		4(2-4)		2(2-4)		3(1-4)		3(1-4)	
Breast cancer	3(1-4)		3(1-4)		3(2-4)		4(3-4)		2(1-4)		3(0-4)		3(2-4)	
Urinary system cancer	3(2-4)		4(3-4)		3.5(2-4)		4(3-4)		3(2-4)		3(3-4)		3(3-4)	
Others cancer	3(2-4)		3.5(2-4)		3(1-4)		4(2-4)		2(2-4)		3(2-4)		3(1-4)	
<b>Duration of illness</b>														
≤6 months	3(1-4)	0.624	3(1-4)	0.949	3(1-4)	0.223	3(1-4)	0.508	4(1-4)	0.389	2(1-4)	0.656	3(1-4)	0.595
>6months	3(1-4)		3(1-4)		3(1-4)		3(1-4)		4(2-4)		2(1-4)		3(1-4)	
<b>Type of treatment</b>														
Radiotherapy	4(2-4)		2.5(1-4)		3.5(1-4)		4(2-4)		3(1-4)		3.5(1-4)		3(3-4)	
Chemotherapy	3(1-4)		4(1-4)		3(1-4)		4(1-4)		2(1-4)		3(1-4)		3(1-4)	
Surgery & chemotherapy	3.5(1-4)	0.120	3(1-4)	0.738	3(2-4)	0.596	4(2-4)	0.665	2(1-4)	0.556	3(1-4)	0.075	3(3-4)	0.289
Surgery	2(1-4)		3(1-4)		3(2-4)		4(2-4)		2(1-4)		3(0-4)		3(1-4)	

Significance value \* ( $p < 0.05$ )

Table 5 Palliative care Outcomes based on the Characteristics of Nurses

Characteristic of Respondents	Item Palliative Care Outcomes Scale													
	Pain		Other symptoms		Feelings of anxiety		Family anxiety		Information availability		Existence of support		Self Worth	
	Median (min-max)	P	Median (min-max)	P	Median (min-max)	P	Median (min-max)	P	Median (min-max)	P	Median (min-max)	P	Median (min-max)	P
Gender														
Male	3(1-4)	0.432	3(1-4)	0.28	3(1-4)	0.492	4(2-4)	0.060	2(1-3)	0.644	3(1-4)	0.769	3(1-4)	0.65
Female	2.5(1-4)		2(1-4)	9	3(1-4)		4(1-4)		2(0-4)		3(0-4)		3(1-4)	6
Marital status														
(-) Not Married	2(1-4)	0.864	2(2-4)	0.13	3(2-4)	0.838	4(1-4)	0.548	2(1-4)	0.914	3(2-4)	0.942	4(3-4)	0.39
(+) Married	3(1-4)		3(1-4)	9	3(1-4)		4(2-4)		2(0-4)		3(0-4)		3(1-4)	5
Age														
20-40 years	2(1-4)	0.320	2(1-4)	0.73	3(1-4)	0.024	4(1-4)	0.336	2(1-4)	0.599	3(1-4)	0.088	3(2-4)	0.98
41-60 years	3(1-4)		3(1-4)	8	3(1-4)		4(2-4)		2(0-4)		3(0-4)		3(1-4)	9
Level of education														
Diploma	3(1-4)	0.117	3(1-4)	0.02	3(1-4)	0.123	4(2-4)	0.210	2(1-4)	0.794	3(0-4)	0.035*	3(1-4)	0.01
Bachelor	2(2-4)		2(2-4)	5	3(1-4)		4(1-4)		2(0-3)		4(1-4)		3(1-4)	3
Palliative training/ seminar ever attended														
once	2(1-4)	0.005*	2(1-4)	0.00	2(1-4)	0.029	4(1-4)	0.363	2(1-3)	0.647	3(1-4)	0.046*	4(2-4)	0.00
>1	3(1-4)		3(1-4)	2	3(1-4)		4(2-4)		2(0-4)		3(0-4)		3(1-4)	7
Significance value * ( $p < 0.05$ )														
Time wasted	Median (min-max)	P	Median (min-max)	P	Median (min-max)	P	Median (min-max)	P	Median (min-max)	P	Median (min-max)	P	Median (min-max)	P
Feeling good	Median (min-max)	P	Median (min-max)	P	Median (min-max)	P	Median (min-max)	P	Median (min-max)	P	Median (min-max)	P	Median (min-max)	P
Practical problems	Median (min-max)	P	Median (min-max)	P	Median (min-max)	P	Median (min-max)	P	Median (min-max)	P	Median (min-max)	P	Median (min-max)	P
0.058	4(2-4)	0.530	4(0-4)	0.69	4(2-4)	0.7	4(2-4)	0.15	4(0-4)	0.421	4(2-4)	0.078	4(2-4)	0.270
0.410	4(2-4)	0.421	4(0-4)	0.69	4(2-4)	0.7	4(2-4)	0.15	4(0-4)	0.421	4(2-4)	0.078	4(2-4)	0.270
0.026	4(2-4)	0.853	4(2-4)	0.14	4(2-4)	0.1	4(2-4)	0.08	4(0-4)	0.047	4(2-4)	0.047	4(2-4)	0.047
0.119	4(2-4)	0.078	4(0-4)	0.08	4(2-4)	0.09	4(2-4)	0.08	4(0-4)	0.047	4(2-4)	0.047	4(2-4)	0.047

## DISCUSSION

## Comparison of the palliative care outcomes between patients and nurses

There were similar perceptions in POS between patients and nurses for the domains of pain, family anxiety, existence of support, self worth (feelings of worth to oneself), feeling good or not depressed, time wasted and practical problems. The similar perceptions between patients and nurses in the pain domain were because pain is the most frequently reported symptom by patients with cancer (Hökkä et al., 2014). The patients pain could be seen and observed through various indicators, such as sleep disturbance, decreased daily activities, reduced motivation for treatment and reduced interaction between the patients and their families (Borneman et al., 2010; Swarm et al., 2007). This finding was in line with previous research results (Dequeker et al., 2018; Fabbian et al., 2014) that found there were similar perceptions between advanced cancer patients and the nurses who treated patients regarding pain intensity, pain scale and estimated pain that emerged using numeric rating scale instruments.

A similarity between patients and nurses was also found in the family anxiety domain. This was because while the patients were undergoing treatment, the patients and nurses could see and observe the anxiety of the family members who accompanied the patients. Patients and nurses could observe a family's anxiety through their behavior, such as crying and worrying when the patient has difficulty breathing. Emotional reactions shown by the families who have members with cancer include anxiety, anger, hatred, and feelings of guilt, crying and seeking information about the patient's illness (Woźniak & Iżycki, 2014). This perception between patients and nurses about family anxiety was in line with previous research (Modanloo et al., 2010) and showed that there were similarities in the reported perceptions between patients with chronic diseases treated in wards and their health workers.

It was also found that there was a similar perception between patients and nurses in the family support domain, which was because patients and nurses may have the same culture regarding the way they view the role of the family toward sick family members. The patients experienced the family support and it could be seen and observed by the nurses. The nurses also aware that families always accompany patients for 24 hours/day and contribute for the caring of the patients during hospitalization (Effendy et al., 2015). Families can also provide support to cancer patients in the form of care, treatment and decision-making support (Shin et al., 2013; Yi et al., 2016). Similar research results revealed by Akin & Durna regarding the perception of the similarities in the equality between cancer patients and nurses about family support (Akin & Durna, 2013).

Another domain that was similar for both patients and nurses was the self worth domain (a feeling of worth to oneself). This was due to the attitude and behavior shown by the patients during their treatment program that the nurses observed. The patients adhered to and followed all the treatment programs planned by the health team, to speed up the healing process,

interacted with their families to improve their self worth and reduce feelings of disappointment toward themselves. The patients have a highly valuable feeling of self esteem when taking the treatment if they received detail information about the medication and treatment programs ([Leite et al., 2015](#)). In addition, patients with advanced stage of cancer can increase their self worth by spending time with their families and with people who can raise their spirits, and avoiding self-assessment that can cause them emotional distress. Self worth can also be increased by reducing their guilt about themselves or feeling disappointed in themselves, and increasing their spirit and life expectancy ([National Comprehensive Cancer Network, 2018](#)).

The domain of feeling good or not depressed also showed no differences between patients and nurses, which was due to the behavior, attitude and actions shown by the patients during their treatment and medication. A stable or non-depressed emotional state was the attitude shown by the patients when they accept their diagnosis of advanced stage cancer and cancer treatments ([Religioni et al., 2015](#)). Patients could accept the symptoms they experienced, the changes to their quality of life, the limitations to their independence, and changes to their role in their family and community ([Mccracken & Velleman, 2010](#)). On the other hand, similar perceptions between patients and nurses also exist in the time in vain domain. This was because the patient and nurse assessed the patient's health condition, which showed no improvement/change in their health, due to the stage of cancer in the patient. The treatment that the patient received was only to provide comfort but could not cure him/her, so that was a waste of time having the treatment. The feeling of time being wasted by the cancer patients was due to the treatment and medication process that showed no improvement, as well as the repetitive cancer treatments, queuing and long waiting times to receive treatment ([American Cancer Society, 2017](#)).

This study found that the practical problems domain had no differences between patients and nurses, which was related to treatments' financing problems and long waiting times. Patients and nurses perceived no practical problems related to financing because all the patients have health insurance. Higginson et al (2018) found that the practical problems that arise in patients with advanced cancer are financing their treatment, and difficulties in transportation to health service providers ([Higginson et al., 2018](#)). A survey by the Association of Oncology Social Work reports that, by residing far away from medical services, the associated transportation difficulties and time discrepancies in taking drugs can cause practical problems for the patients.

There were differences in the perceptions of patients and nurses for the domain of other symptoms (nausea, coughing and constipation), feelings of anxiety and the information availability domain. In the other symptoms domain, the patients perceived nausea, coughing and constipation as symptoms that greatly affected their condition, so that other symptoms were categorized as very severe for patients. This was due to the presence of other symptoms that further worsen their condition. But the nurses perceived the other symptoms such as nausea,

coughing and constipation as normal reactions due to the development and growth of the cancer. Besides, those symptoms are caused by side effects of the treatment, such as radiotherapy, chemotherapy, and surgery. Similar results related to the differences in the perceptions between patients and nurses about other symptoms were also revealed by previous studies ([Cirillo et al., 2009](#); [Strömngren et al., 2001](#)), which showed differences in the results obtained between patients and nurses regarding the symptoms of vomiting, nausea and constipation. Patients perceived the symptoms of nausea, vomiting and constipation as being severe, while nurses perceived the other symptoms that the patient felt as being mild. The differences in the perceptions between patients and nurses were also found in the domain of anxiety. This was because anxiety is a subjective experience and cannot be observed directly. The difference in perception between patients and nurses in the anxiety domain was in line with the previous research ([Bahrami, 2010](#)) using the World Health Organization Quality of Life BREF (WHOQoL-BREF) instrument.

In addition, there were also differences in the domain of information availability. This was because the hospital did not have a guide or information map about cancer with palliative conditions and palliative care. So, the nurses and patients had different perceptions about the information needed by patients and nurses. A comprehensive information map provides complete information according to the needs of the health team and cancer patients. The absence of such an information map causes the health personnel to have difficulties in conveying the information needed by the patients ([Page & Adler, 2008](#)). Additionally, cultural factors also influence the differences in perception for the information availability domain, such as requests from the patients or families to avoid, delay, and discuss the estimation of the prognosis and life expectancy of the cancer patients ([Russell & Ward, 2011](#)). Health workers only provide information to patients based on family consent ([Michiels et al., 2009](#)).

#### **Comparison of palliative care outcome scale based on demographic characteristics**

The results of this study shows the differences in the perceptions of patients and nurses in POS, based on their demographic characteristics. Differences in the perceptions of patients were influenced by the education of the respondents in the anxiety domain, while differences in the perceptions of nurses were influenced by their age in the practical problems domain, education in the domain of other symptoms, while family support and self worth and training affected the nurses' perceptions for the domains of pain, other symptoms, family support, self worth and time in vain.

The low educational level of the respondents affected the patients' perceptions for the anxiety domain. Patients would find it difficult to perceive how worried they felt since they did not know the signs and symptoms of cancer, the disease's prognosis, and the actions and efforts that could be taken to make them more relaxed. Their education level was also related to the ease with which they could understand information. A study in the Netherlands indicated that education influences

people's awareness and knowledge about cancer, and affects the assessment of a patient's anxiety (Osse et al., 2005). Educational levels also relate to the acceptance and understanding related to the reduction of anxiety experienced by patients (Garcia, 2014).

Differences in the perceptions of the nurses were influenced by their age when assessing the practical problems experienced by patients with cancer. The literature stated that nurses in early adulthood have sensitivity and show concern when conducting an assessment of the practical problems experienced by advanced cancer patients. Age also affects the behavior, attitude, role and responsibilities of nurses towards patients (Zheng et al., 2015). Young adult nurses are more accepting of their role when collaborating with new teams compared to older nurses, when providing interventions related to the practical problems experienced by patients (Malfait et al., 2017).

On the other hand, the nurses' educational factors also influenced their differences in perception for the domains of other symptom, family support and self worth. The higher the education, the more knowledge they have about assessing other symptoms (nausea, coughing and constipation) in patients, family support and assessments, and how to improve the self worth of cancer patients. Nurses with a high level of education have a great deal of self-confidence in providing nursing services, based on their role and the family's support. Nurses' education can also improve the relationships between fellow health service teams when collaborating in improving services (Wiechula et al., 2016). Education is also one of the factors that influence the nurses' perception in understanding a patient's self worth. Education influences nurses to provide information in accordance with the self worth problems experienced by patients, so they are able to create a conducive atmosphere and can encourage patients to participate in improving their self worth (Opiyo, 2012).

Nurses' perceptions were also influenced by training/seminars that nurses had followed for the domains of pain, other symptoms, anxiety, family support, self worth and time in vain. Nurses who attended training in palliative care had the potential to do assessments that are appropriate to what the patient feels, related to their pain and other symptoms, such as nausea, coughing and constipation (Unroe et al., 2015). The knowledge and training/seminars on palliative care are needed by nurses to improve the treatment given to cancer patients (Bhatnagar & Patel, 2018).

Training in palliative care could also influence the nurses' knowledge about the assessment of anxiety experienced by their patients. Nurses could better understand the level of anxiety felt by patients (Gouveia et al., 2015). Nurses need training in assessing the necessary family support toward patients with palliative disease and such training could improve the nurses' abilities to obtain the information needed by the family (Landeiro et al., 2016). Training is also needed to successfully providing services to patients, based on the results of a self worth assessment and the practical problems experienced by the patients. The training provides an

understanding of the responses that can be given, based on the problems that are observed (Chaghari et al., 2017; El-Nagar & Lawend, 2013).

## CONCLUSION

There were seven perceptual equations in the domains of: pain, family anxiety, existence of support, self worth, feeling good or not depressed, wasting time, and also practical problems between the perceptions of advanced cancer patients and nurses in palliative care outcomes. However, there were three different perceptions in the domains of: other symptoms, feelings of anxiety and information availability. With these differences, it is expected that nurses should pay more attention to the assessment of the domains of other symptom, feelings of anxiety and the availability of information by using various approaches, and communicating in a manner that can be understood by the patients to obtain accurate information and fully explain about the symptoms and side effects which arise from the cancer treatments.

## Declaration of Conflicting Interest

None declared.

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## Authorship Contributions

DY: collected, analyzed the data and developed the draft of the manuscript.

CE: contributed to the data's analysis and drafted the manuscript.

SW: contributed to the data's analysis and drafted the manuscript.

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## References

- Akin, S., & Durna, Z. (2013). A comparative descriptive study examining the perceptions of cancer patients, family caregivers, and nurses on patient symptom severity in Turkey. *European Journal of Oncology Nursing*, 17(1), 30-37. <https://doi.org/10.1016/j.ejon.2012.02.002>
- American Cancer Society. (2017). Signs and symptoms of cancer. Retrieved from <https://www.cancer.org/cancer/cancer-basics/signs-and-symptoms-of-cancer.html>
- Bahrami, M. (2010). Do nurses provide holistic care to cancer patients? *Iranian Journal of Nursing and Midwifery Research*, 15(4), 245.
- Bhatnagar, S., & Patel, A. (2018). Effectiveness of the certificate course in essentials of palliative care program on the knowledge in palliative care among the participants: A cross-sectional interventional study. *Indian Journal of Palliative Care*, 24(1), 86.
- Borneman, T., Koczywas, M., Sun, V. C.-Y., Piper, B. F., Uman, G., & Ferrell, B. (2010). Reducing patient barriers to pain and fatigue management. *Journal of Pain and*

- Symptom Management*, 39(3), 486-501. <https://doi.org/10.1016/j.jpainsymman.2009.08.007>
- Cancer Research United Kingdom. (2017). Type of cancer. Retrieved from <http://www.cancerresearchuk.org/what-is-cancer/how-cancer-starts/types-of-cancer>
- Chaghari, M., Saffari, M., Ebadi, A., & Ameryoun, A. (2017). Empowering education: A new model for in-service training of nursing staff. *Journal of Advances in Medical Education & Professionalism*, 5(1), 26.
- Cirillo, M., Venturini, M., Ciccirelli, L., Coati, F., Bortolami, O., & Verlato, G. (2009). Clinician versus nurse symptom reporting using the National Cancer Institute—Common Terminology Criteria for Adverse Events during chemotherapy: results of a comparison based on patient's self-reported questionnaire. *Annals of Oncology*, 20(12), 1929-1935. <https://doi.org/10.1093/annonc/mdp287>
- Dequeker, S., Van Lancker, A., & Van Hecke, A. (2018). Hospitalized patients' vs. nurses' assessments of pain intensity and barriers to pain management. *Journal of Advanced Nursing*, 74(1), 160-171. <https://doi.org/10.1111/jan.13395>
- Dewiyuliana. (2018). *Perbandingan hasil pengkajian Palliative care Outcome Scale (POS) antara pasien kanker stadium lanjut dan perawat*. (Thesis), Faculty of Medicine, Public Health and Nursing, Universitas Gadjah Mada Yogyakarta, Indonesia. Retrieved from [http://lib.ugm.ac.id/ind/?page\\_id=248](http://lib.ugm.ac.id/ind/?page_id=248)
- Effendy, C., Vissers, K., Tejawinata, S., Vernooij-Dassen, M., & Engels, Y. (2015). Dealing with symptoms and issues of hospitalized patients with cancer in Indonesia: the role of families, nurses, and physicians. *Pain Practice*, 15(5), 441-446. <https://doi.org/10.1111/papr.12203>
- El-Nagar, S., & Lawend, J. (2013). Impact of palliative care education on nurses' knowledge, attitude and experience regarding care of chronically ill children. *Journal of Natural Sciences Research*, 3, 94-103.
- Fabbian, F., De Giorgi, A., Pala, M., Mallozzi Menegatti, A., Gallerani, M., & Manfredini, R. (2014). Pain prevalence and management in an internal medicine setting in Italy. *Pain Research and Treatment*, 2014. <https://doi.org/10.1155/2014/628284>
- Garcia, S. (2014). The effects of education on anxiety levels in patients receiving chemotherapy for the first time: an integrative review. *Clinical Journal of Oncology Nursing*, 18(5), 516-521. <https://doi.org/10.1188/14.cjon.18-05ap>
- Gouveia, L., Leloirain, S., Brédart, A., Dolbeault, S., Bonnaud-Antignac, A., Cousson-Gélie, F., & Sultan, S. (2015). Oncologists' perception of depressive symptoms in patients with advanced cancer: accuracy and relational correlates. *BMC Psychology*, 3(1), 6. <https://doi.org/10.1186/s40359-015-0063-6>
- Hearn, J., & Higginson, I. J. (1997). Outcome measures in palliative care for advanced cancer patients: A review. *Journal of Public Health*, 19(2), 193-199. <https://doi.org/10.1093/oxfordjournals.pubmed.a024608>
- Higginson, I. J., Harding, R., Murtagh, F., Bausewein, C., Benalia, H., Ramsenthaler, C., . . . Guo, P. (2018). What is POS. Retrieved from <https://pos-pal.org/maix/what-is-pos.php>
- Hökkä, M., Kaakinen, P., & Pölkki, T. (2014). A systematic review: non-pharmacological interventions in treating pain in patients with advanced cancer. *Journal of Advanced Nursing*, 70(9), 1954-1969. <https://doi.org/10.1111/jan.12424>
- Horton, R. (2002). Differences in assessment of symptoms and quality of life between patients with advanced cancer and their specialist palliative care nurses in a home care setting. *Palliative Medicine*, 16(6), 488-494. <https://doi.org/10.1191/0269216302pm588oa>
- Kumar, C. S., & Parashar, N. (2015). Death anxiety, coping and spirituality among cancer patients. *Indian Journal of Positive Psychology*, 6(3), 291.
- Landeiro, M. J. L., Martins, T. V., & Peres, H. H. C. (2016). Nurses' perception on the difficulties and information needs of family members caring for a dependent person. *Texto & Contexto-Enfermagem*, 25(1). <https://doi.org/10.1590/0104-070720160000430015>
- Leite, M. A. C., Nogueira, D. A., & Terra, F. d. S. (2015). Evaluation of self-esteem in cancer patients undergoing chemotherapy treatment. *Revista Latino-Americana de Enfermagem*, 23(6), 1082-1089. <https://doi.org/10.1590/0104-1169.0575.2652>
- Malfait, S., Eeckloo, K., & Hecke, A. (2017). The influence of nurses' demographics on patient participation in hospitals: A cross - sectional study. *Worldviews on Evidence-Based Nursing*, 14(6), 455-462. <https://doi.org/10.1111/wvn.12254>
- McCracken, L. M., & Velleman, S. C. (2010). Psychological flexibility in adults with chronic pain: a study of acceptance, mindfulness, and values-based action in primary care. *Pain*, 148(1), 141-147. <https://doi.org/10.1016/j.pain.2009.10.034>
- Michiels, E., Deschepper, R., Bilsen, J., Mortier, F., & Deliens, L. (2009). Information disclosure to terminally ill patients and their relatives: self-reported practice of Belgian clinical specialists and general practitioners. *Palliative Medicine*, 23(4), 345-353. <https://doi.org/10.1177/0269216308102043>
- Ministry of Health. (2007). Palliative care policy: Decree of the Ministry of Health of the Republic of Indonesia No: 812/Menkes/SK/VII/2007. Jakarta: Ministry of Health of the Republic of Indonesia.
- Modanloo, M., Sayed Fatemi, N., Bastani, F., Peyrovi, H., Behnampour, N., & Hesam, M. (2010). Comparison of pain assessment by patients and triage nurses. *Iranian Journal of Critical Care Nursing*, 4(1), 23-28.
- National Comprehensive Cancer Network. (2018). Patient and caregiver resource. Retrieved from <https://www.nccn.org/patients/>
- Neef, K. D., & Knox, M. (2017). Self-Compassion. In V. Zeigler-Hill & T. Shackelford (Eds.), *Encyclopedia of personality and Individual Differences*. New York: Springer.
- Nugroho, B. A. (2005). *Strategi jitu memilih metode statistik penelitian dengan SPSS [The exact strategy to chose the statistical research method with SPSS]*. Yogyakarta: Andi Offset.
- Opiyo, E. (2012). *Nurses perception of their knowledge and expertise in breast cancer care*. (Thesis), Central Ostrobothnia University of Applied Sciences, Finland.
- Osse, B. H., Vernooij-Dassen, M. J., Schadé, E., & Grol, R. P. (2005). The problems experienced by patients with cancer and their needs for palliative care. *Supportive Care in Cancer*, 13(9), 722-732. <https://doi.org/10.1007/s00520-004-0771-6>
- Page, A. E., & Adler, N. E. (2008). *Cancer care for the whole patient: Meeting psychosocial health needs*. Washington DC: National Academies Press.
- Religioni, U., Czerw, A., & DEPTAŁA, A. (2015). Acceptance of cancer in patients diagnosed with lung, breast, colorectal and prostate carcinoma. *Iranian Journal of Public Health*, 44(8), 1135.

- Russell, B. J., & Ward, A. M. (2011). Deciding what information is necessary: do patients with advanced cancer want to know all the details? *Cancer management and research*, 3, 191. <https://doi.org/10.2147/cmr.s12998>
- Shin, D. W., Cho, J., Roter, D. L., Kim, S. Y., Sohn, S. K., Yoon, M. S., . . . Park, J. H. (2013). Preferences for and experiences of family involvement in cancer treatment decision-making: patient–caregiver dyads study. *Psycho-Oncology*, 22(11), 2624-2631. <https://doi.org/10.1002/pon.3339>
- Strömberg, A., Grønvold, M., Sorensen, A., & Andersen, L. (2001). Symptom recognition in advanced cancer. A comparison of nursing records against patient self-rating. *Acta Anaesthesiologica Scandinavica*, 45(9), 1080-1085. <https://doi.org/10.1034/j.1399-6576.2001.450905.x>
- Swarm, R., Anghelescu, D. L., Benedetti, C., Boston, B., Cleeland, C., Coyle, N., . . . Ferrell, B. (2007). Adult cancer pain: Clinical Practice Guidelines in Oncology™. *JNCCN Journal of the National Comprehensive Cancer Network*, 5(8), 726-751.
- Thomas, D. M., Albritton, K. H., & Ferrari, A. (2010). Adolescent and young adult oncology: an emerging field. *Journal of Clinical Oncology*, 28(32), 4781-4782.
- Unroe, K. T., Cagle, J. G., Lane, K. A., Callahan, C. M., & Miller, S. C. (2015). Nursing home staff palliative care knowledge and practices: results of a large survey of frontline workers. *Journal of Pain and Symptom Management*, 50(5), 622-629. <https://doi.org/10.1016/j.jpainsymman.2015.06.006>
- Wang, S.-Y., Tsai, C.-M., Chen, B.-C., Lin, C.-H., & Lin, C.-C. (2008). Symptom clusters and relationships to symptom interference with daily life in Taiwanese lung cancer patients. *Journal of Pain and Symptom Management*, 35(3), 258-266. <https://doi.org/10.1016/j.jpainsymman.2007.03.017>
- Wiechula, R., Conroy, T., Kitson, A. L., Marshall, R. J., Whitaker, N., & Rasmussen, P. (2016). Umbrella review of the evidence: what factors influence the caring relationship between a nurse and patient? *Journal of Advanced Nursing*, 72(4), 723-734. <https://doi.org/10.1111/jan.12862>
- World Health Organization. (2017). Cancer key facts. Retrieved from <http://www.who.int/mediacentre/factsheets/fs297/en/>
- Woźniak, K., & Iżycki, D. (2014). Cancer: a family at risk. *Przegląd menopauzalny= Menopause review*, 13(4), 253.
- Yi, T.-w., Deng, Y.-t., Chen, H.-p., Zhang, J., Liu, J., Huang, B.-y., . . . Jiang, Y. (2016). The discordance of information needs between cancer patients and their families in China. *Patient Education and Counseling*, 99(5), 863-869.
- Zheng, R.-S., Guo, Q.-H., Dong, F.-Q., & Owens, R. G. (2015). Chinese oncology nurses' experience on caring for dying patients who are on their final days: A qualitative study. *International Journal of Nursing Studies*, 52(1), 288-296. <https://doi.org/10.1016/j.ijnurstu.2014.09.009>

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