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Perception of nurses about palliative care: Experience from a private hospital in west Indonesia

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Abstract

Background: Palliative care is a method for patients and their families facing life-threatening conditions to improve their quality of life. Nurses have a critical role on the palliative care team, and as such, they must have an accurate perception of palliative care.

Purpose: To identify nurses' perceptions about palliative care: from a private hospital in west Indonesia

Method: This research is a descriptive research conducted with a cross sectional design. Participants were recruited using a purposive sampling technique from a private hospital in West Indonesia, with a population of 238 nurses from all wards. All nurses who had worked for at least two years and agreed to participate in the study were included. Slovin's algorithm was used to determine the sample size, which resulted in 149 nurses. However, only 105 nurses answered the questionnaire and completed it.

Results: The results indicated that the majority of nurses were female in their early twenties. The study demonstrated that nurses had an exceptional grasp of the definition and philosophy of palliative care, albeit certain concerns remained unanswered.

Conclusion: In conclusion, providing palliative care training will improve nurses' knowledge as well as their practice in palliative care.

Keywords: Nurses; Perception; Palliative care; Experience

INTRODUCTION

Palliative care has increased in popularity throughout the world as a result of the growing variety of diseases that can benefit from palliative care. Palliative care is more likely to be in high demand as the prevalence of chronic diseases increases and mortality from long-term illnesses increases. Approximately 20.4 million people in low- and middle-income countries require palliative care (Alliance, & World Health Organization, 2014). Other studies project that by 2040, the need for palliative care will increase for people over the age of 85 and for those with chronic conditions (Etkind, Bone, Gomes, Lovell, Evans, Higginson, & Murtagh, 2017). Palliative care

aims to improve patients' and families' quality of life by relieving suffering and treating pain and other symptoms (World Health Organization, 2020). However, not all health care providers, particularly nurses, provide adequate palliative care, as nurses' awareness of palliative care remains limited.

Many nurses and other health care workers continue to lack knowledge and information about palliative care; Also, there are several different points of view on palliative care. As shown in one study, despite the fact that these countries have implemented palliative care services, nurses' understanding of palliative care has not been tested (Onyeka,

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Velijanashvili, Abdissa, Manase, & Kordzaia, 2013). Nurses with experience in general wards have a better understanding of palliative care than nurses with experience in intensive care units (Kim, Lee, Kim, 2020). As the need for palliative care becomes clearer, nurses must be prepared with palliative care knowledge and skills, as nurses are an important component of patient care and spend most of their time with patients and their families. This is because nurses are people who build relationships with patients and are familiar with their lives (Salmond, & Echevarria, 2017). Nonetheless, collaboration across health care disciplines such as doctors, nurses, psychologists, and religious leaders who may be members of the palliative care team is essential in providing palliative care. In addition, health care services must adapt to meet the needs of these groups.

Palliative care units have been developed in only a few care facilities in Indonesia. A palliative care unit and a palliative team have not been developed at this private hospital in West Indonesia. Additionally, no study has been conducted on nurses' perceptions of palliative care; thus, the purpose of this study is to examine nurses' attitudes regarding palliative care in a single private hospital.

RESEARCH METHOD

This was a descriptive study conducted using a cross-sectional design. The participants were recruited using a purposive sampling technique from a private hospital in West Indonesia, with a total population of 238 nurses from all wards. All nurses who had worked for at least two years and agreed to participate in the study were included. The Slovin algorithm was used to determine the sample size, which resulted in 149

nurses. However, only 105 nurses responded to the questionnaire and completed it. We examined the characteristics of nurses in this study, including their age, gender, educational background, job experience, and whether they had received palliative care training.

Additionally, we assessed nurses' perceptions with a questionnaire adapted from a prior study conducted in Nigeria (Fadare, Obimakinde, Olaogun, Afolayan, Olatunya, & Ogundipe, 2014). The questionnaire had 41 items and aimed to elicit information about the definition and philosophy of palliative care. The questionnaire was translated into Bahasa Indonesia and the English language expert read it back. The questionnaire's validity and reliability were evaluated on 30 nurses, with $r_{tabel}=0.36$. Four questions were found to be invalid, and so were removed from the study, leaving only 37 questions. Between March and May 2020, data collection was carried out among nursing staff at a private hospital in Western Indonesia. Participants were given a questionnaire through the head of the unit. In addition, nurses were informed of their willingness to participate in the study. In addition, confidentiality is also guaranteed. The number of nurses as many as 149 people, but who filled out the questionnaire only 105 people. Descriptive statistics were used to determine the general characteristics of the study participants and nurses' perceptions of palliative care. Respondents who filled out and submitted the questionnaire were deemed to agree. This research has received ethical approval from hospitals and institutions prior to initiation with the number (No.084/KEP-FON/III/2020) issued by the Ethics Committee of the Faculty of Nursing, Pelita Harapan University.

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RESULTS**Table 1. Distribution of Demographic Characteristics of Respondents (N=105)**

Variable	Results
Age(Mean±SD)(Range)(Year)	(23.86±2.525)(21-30)
Age (n/%)	
21-25	83/79.1
26-30	22/20.9
Gender (n/%)	
Male	31/29.5
Female	74/70.5
Education Background (n/%)	
Diploma III	9/8.6
Ners	96/91.4
Work Experience (n/%)	
0-5 years	99/94.3
6-10 Years	5/4.8
>10 years	1/0.9
Palliative Care Training(n/%)	
Yes	53/50.5
No	52/49.5

The characteristics of the participants can be seen in table 1. Most of the nurses (70.5%) were women, aged between 21-25 years. 91.4% of nurses have a bachelor's degree and most nurses have work experience between 0-5 years (94.3%). However, only 50.5% of nurses had palliative training.

Table 2. Nurses Perception of Palliative Care (N=105)

Variable	Agree (n/%)	Disagree (n/%)
What is palliative care?		
Pain Medicine	62/59	43/41
Geriatric medicine	29/27.6	76/72.4
Rehabilitation Medicine	28/26.7	77/73.3
Active care of the dying	89/84.8	16/15.2

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Philosophy of Palliative Care		
Affirms Life	101/96.2	4/3.8
Recognizes dying as a normal process	92/87.6	13/12.4
Hastens death	8/7.6	97/92.4
Prolongs life	50/47.6	55/52.4
Palliative care is needed for		
All dying patients	89/84.8	16/15.2
Metastatic cancer with uncontrolled pain	100/95.2	5/4.8
End stage heart failure	95/90.5	10/9.5
Debilitating illness like rheumatoid arthritis	44/41.9	61/58.1
Common non pain symptoms encountered in palliative care		
Constipation	74/70.5	31/29.5
Vomitting	78/74.3	22/25.7
Breathlessness	83/79	22/21
Communication prognosis		
Prognosis should always be communicated to the patient	83/79	22/21
Prognosis should only be told to family members	50/47.6	55/52.4
Not communicating prognosis could be led to lack of trust	80/76.2	25/23.8
Patients' wishes and choices should be clearly communicated	104/99	1/1
Palliative Care multi-disciplinary comprised of		
Medical social worker	65/61.9	40/38.1
Nurse	103/98.1	2/1.9
Medical Doctor	100/95.2	5/4.8
Pharmacist	86/81.9	19/18.2
Clergy	103/98.1	2/1.9
Advanced Medical Directives is		
A document through which the patient states his preferences about future medical decision/interventions	101/93.2	4/3.8
Appoints a person to make such decisions for them	95/90.5	10/9.5
Morphine		
Causes death in all dying patients	13/12.4	92/87.6
Improves quality of life	42/40	63/60
Relieve all kinds of pain	83/79	22/21
Relieves breathlessness in heart failure	75/71.4	30/28.6
Pentazocine		
Causes death in all dying patients	21/20	84/80
Relieves all kinds of pain	53/50.5	52/49.5
Relieve breathlessness in heart failure	32/30.5	73/69.5

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Components of good death include		
Pain and symptoms management	90/85.7	15/14.3
Clear decision making	101/96.2	4/3.8
Preparation for death	104/99	1/1

Table 2 summarizes nurses' perceptions of palliative care. This indicates that nurses' perceptions of palliative care are more focused on active death care (84.4 percent), with almost all nurses agreeing that the philosophy of palliative care is to affirm life (96.2 percent). More than 70% of nurses believe that the most common symptoms of palliative care are constipation, vomiting, and shortness of breath. Ninety-nine percent of nurses are aware that the prognosis must be clearly communicated to patients. 96.2 percent believe follow-up care directives are documents in which patients can express their wants and needs, and 99 percent of nurses believe that a good death is one that is prepared (99 percent).

DISCUSSION

This study was conducted to assess nurses' perceptions of palliative care in a private hospital. The general trend of the gender distribution among the study population is that there are more female nurses. Nurses' perceptions of the definition and philosophy of palliative care are very good considering that Indonesia is still relatively new in palliative care and this hospital has not yet implemented palliative care. Most nurses know that palliative care is active care at death (84.4 percent). Although this score is lower than the 90.2 percent found in other studies (Fadare, Obimakinde, Olaogun, Afolayan, Olatunya, & Ogundipe, 2014). It can be concluded that nurses understand the definition of palliative care.

One of the goals of palliative care is to affirm life while recognizing death as a natural process (World Health Organization, 2020). In this survey, 96.2 percent of nurses were aware of the goals of palliative care. Although 47.6 percent of nurses believed that palliative care was used to prolong the patient's life. Based on the philosophy of palliative care, this treatment is given to reduce pain, improve the quality of life of patients and their families, and control symptoms, not to delay or hasten death (Palliativecare,

2017; He, Geng, & Johnson, 2021). In terms of the need for palliative care, it should be noted that 84.7 percent of nurses believed that people who needed palliative care were dying. This finding is consistent with previous research (Mahon and McAuley, 2010; White, & Coyne, 2011). In comparison, a poll conducted in Palestine found that 63.5 percent of nurses disagreed with the statement (Ayed, Sayej, Harazneh, Fashafsheh, & Eqtaït, 2015). Typically, the palliative care team is contacted when the patient is actually nearing death (O'Shea, 2014). That is why the majority of nurses believe that palliative care is provided for terminally ill patients. While it is true that palliative care should be started as soon as a diagnosis is made (Alliance, & World Health Organization, 2014).

In addition, the findings indicate that nurses' understanding of the prognosis of communication is good. Ninety-nine percent of nurses prefer to communicate patient wishes and preferences. However, 47.6 percent of nurses agreed that family members should be informed about the patient's prognosis. Certain patients may withhold information about their prognosis from their families. Thus, prognostic communication should be an open and honest exchange with the patient (O'Shea 2014). Communicating with healthcare workers, especially nurses, can be difficult. Prognosis communication should be initiated early in the course of the disease and should be continued throughout treatment of the disease (O'Shea 2014; Wallerstedt, Benzein, Schildmeijer, & Sandgren, 2019).

The Advanced Care Directive (ACD) is a document that contains all the expressions and wishes of patients in their treatment if they are unable to communicate (Shatri, Faisal, Putranto, & Sampurna, 2020). This study found that nurses' perceptions of follow-up care directions were quite confusing. In comparison, nurses have a strong awareness of the mortality component (85 percent-99 percent). The

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majority of nurses agreed that follow-up care instructions were documents in which patients could express their preferences (96.2 percent). However, they agreed that ACD should appoint someone else to make patient care decisions (90.5 percent). As can be observed, their knowledge of ACD is limited. Although these talks are necessary to promote the patient's needs and wants, it is possible that discussing ACD is taboo in Indonesian culture. Discussing ACD in Arabic is also discouraged (Baharoon, Alzahrani, Alsafi, Layqah, Al-Jahdali and Ahmed, 2019). ACD is a component of viable mortality (Meier, Gallegos, Thomas, Depp, Irwin, & Jeste, 2016). Consequently, nurses' awareness of ACD is critical, as current research finds that nurses' perceptions of ACD remain unclear.

It is vital to establish nurses' baseline knowledge in order to design an effective educational program. Promoting nurses' knowledge of palliative care is critical in preparing nurses to provide the best nursing care possible in this setting. Additionally, evaluating nurses' expertise would imply the importance of attitude and behavior (Ayed et al. 2015). Nonetheless, nurses who have received education and certification in palliative care perform better on a palliative care quiz (Choi, Lee, Kim, Kim, & Kim, 2012; Kim, Kim, Yu, Kim, Park, Choi, & Jung, 2011). However, we did not investigate the association between nurses' degree of knowledge about palliative care and the amount of palliative care training received by nurses in this study.

CONCLUSION

The study's findings indicated that the majority of nurses in a private hospital were knowledgeable with palliative care. As can be seen, their comprehension of both the definition and philosophy of palliative care is quite outstanding. However, certain aspects of palliative care require development. Thus, expanding awareness of palliative care through training and seminars is still necessary to increase nurses' comprehension.

LIMITATION

Apart from the findings, this study has limitations. To begin, the findings of this study cannot be

generalized because they were limited to nurses with at least two years of work experience. As a result, additional large-scale studies may be required to generalize this finding. Second, four out of 37 questions were eliminated due to their invalidity at the time of the validity and reliability tests, which may have influenced the results. As a result, these questions could be adjusted to incorporate the complete questionnaire.

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