Jurnal Keperawatan Global
Vol. 7, No. 2, December 2022
https://doi.org/10.37341/jkg.v0i0.486

Original Research

Nurse's Obstacles In Delivering End Of Life Care

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ABSTRACT

Background: *Death can occur in any situation at any time, and each hospital setting has different difficulties in providing high-quality end-of-life care. The hospital's Islamic culture might offer new experiences to nurses when providing EOLC and be related to the challenges they face. This study identified the difficulties nurses encounter when providing end-of-life care in an Islamic-based hospital.*

Methods: *A descriptive cross-sectional survey was applied to this study. A questionnaire that was adapted from the Nursing Survey Questionnaire Regarding End-of-Life Care on Medical-Surgical Units was used to collect the data. The translation and back-translation processes were carried out in the Indonesian version. All questionnaire items were declared valid with a validity value range of 0.820 to 0.950 (r table = 0.312), and the reliability test results obtained an alpha coefficient value of 0.977 (very reliable). The consecutive sampling method was applied. The data were analyzed using univariate analysis. At an Islamic hospital in Semarang, 97 surgical and medical nurses in total participated in the survey.*

Results: *The findings indicate that the three main obstacles to nurses delivering end-of-life care are knowledge gaps (x = 2.53), a lack of education or training (x = 2.34), and health professionals' avoidance of dying patients (x = 2.30). Other major impediments include a lack of family acceptance and uncooperative family attitudes.*

Conclusion: *Nurses and family factors are the biggest obstacles for nurses in caring for dying patients.*

ARTICLE HISTORY
Received: June 8th, 2022
Accepted: December 17th, 2022

KEYWORDS
death, palliative care, terminal care;

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Cite this as: Utami, R. S., & Putri, A. K. (2022). Nurse's Obstacles In Delivering End Of Life Care. *(JKG) Jurnal Keperawatan Global*, 95–107. https://doi.org/10.37341/jkg.v0i0.486

INTRODUCTION

Hospitals continue to be the main site of death for patients with serious illnesses. Statistical data in Canada in 2019 showed 58.9% of deaths occurred in hospitals (Statistics Canada, 2020), while data from the Central Java Provincial Health Office in 2019 reported a total gross death rate in hospitals of 28,8% and the patient mortality rate after being hospitalized for more than 48 hours by 14,1% (Dinas Kesehatan Provinsi Jawa Tengah, 2020). Thus, it is very possible for nurses to care for patients at the end of life.

Nurses play a crucial role in delivering end-of-life care for patients and their families. The phrase "end-of-life care" (EOLC) refers to the treatment given to patients

who are no longer responding to curative interventions (Sadler, 2015). The goal of treatment is to alleviate the patient's pain and enhance their quality of life while honoring their last wishes. NICE, (2019) addresses the physical, psychological, social, and spiritual aspects of care.

End-of-life care has been implemented in several hospitals in Indonesia, but its implementation is still not optimal. According to a study conducted in the RSUP dr. Sardjito Yogyakarta's intensive care unit (ICU), the quality of end-of-life care in the ICU was rated at 55.29 out of 100 (Purnamaningrum & Setyarini, 2013). Another study in the emergency department found that nurses only focused on supportive care and were lacking in providing spiritual care for end-of-life patients. This is due to the busy environment and the nurses’ priorities for other patients (Ose et al., 2016).

The provision of high-quality EOLC by nurses is challenging (Dunning & Martin, 2018) (Searight, 2019) (Woo et al., 2006). The challenges encountered when giving EOLC in a hospital context, including the ICU Attia et al., (2013); Brooks et al., (2016); Crump et al., (2010); Iglesias et al., (2013); Permatasari & Utami, (2018), emergency room Ariyanti et al., (2019); Beckstrand et al., (2008); Ka & Ho, (2016), neonate intensive care unit Beckstrand et al., (2019), pediatrics Beckstrand et al., (2010), medical surgical Dufour, (2018) and oncology Beckstrand et al., (2009); Blaževičienė et al., (2017). Patients, families, nurses, doctors, and organizations' health service providers can all be sources of these obstacles (Ozga et al., 2020) (Rohmah et al., 2019).

Critical care nurses reported that the family presents the biggest challenge when giving EOLC. Family rejection of the patient's bad prognosis, family apathy in decision-making, emotional attitudes in the family, and a lack of family information and understanding are a few of the challenges. The attitude of doctors who still insist on aggressive treatment is also a barrier, thereby prolonging the suffering of the patient and preventing the patient from dying with dignity (Iglesias et al., 2013).

In the meanwhile, nurses' barriers to EOLC include a lack of knowledge and training, apathy, worry, and fear, as well as a lack of time and competing responsibilities. Another barrier is the lack of support staff and specialized facilities for patients nearing the end of their lives (Beckstrand et al., 2010) (Blaževičienė et al., 2017); (Brooks et al., 2016); (Dufour, 2018); (Harasym et al., 2020); (Ose et al., 2016). Although there has been some research on the challenges faced by nurses in administering EOLC in other nations, there hasn't been much done in Indonesia.

According to a thorough review by Chakraborty et al., (2017), a nation's cultural traditions and legislative framework significantly influence its citizens' attitudes around death and dying. The end-of-life decisions made by individuals and healthcare professionals are also influenced by religious teachings and beliefs. Roemani Muhammadiyah Hospital Semarang is one of the hospitals affiliated with the religion of Islam. Islamic values are the basis for hospitals providing services (Profile Rumah Sakit Roemani Muhammadiyah, n.d.).

The hospital's Islamic culture may be able to offer nurses a new experience when delivering EOLC and in relation to the challenges they encounter. Each hospital context poses different difficulties in delivering high-quality EOLC (McCourt et al., 2013). A medical-surgical ward is a ward in the hospital that has patients with various diagnoses and interventions. Some patients may have more than one chronic disease, while others are preparing for or recovering from surgery. Based on this phenomenon, this study aims to identify the barriers that nurses in the medical-surgical ward of Roemani Muhammadiyah Hospital Semarang have in providing care for end-of-life patients.

MATERIALS AND METHOD

This study uses a cross-sectional survey-based quantitative descriptive methodology. The study was carried out at Roemani Muhammadiyah Hospital in Semarang from July to August 2019. The population of the study was medical-surgical nurses, totaling 117 nurses. The inclusion criteria were nurses who had experience caring for end-of-life patients. Nurse managers and nurses who were absent (due to illness, childbirth, or study) were not eligible for this study.

A researcher asked initial questions to prospective respondents about their experience caring for end-of-life patients before distributing informed consent and a questionnaire. Using the consecutive sampling technique, samples were collected, yielding a total of 97 respondents. Four respondents dropped out of this study due to incomplete answers, and sixteen nurses were excluded because they did not meet the requirements.

Data were collected using a questionnaire consisting of two parts. The first section identifies the characteristics of the respondents, and the second section identifies the obstacles that nurses face when delivering EOLC. The Nursing Survey Questionnaire Regarding End-of-Life Care in Medical-Surgical Units was used (Dufour, 2018).

This questionnaire consists of 12 closed questions and 1 open question. There are 3 answer choices for closed questions, namely "not a barrier", "small obstacle" and "big obstacle". The scoring used in this questionnaire uses a Likert scale. Using their experiences, nurses were questioned in an open-ended manner to determine what they believed to be the main barrier to providing high-quality end-of-life care. Respondents answered the open-ended question in the questionnaire by writing down their answers on the sheet provided.

The researcher carried out the translation and back-translation process of the questionnaire with linguists. The questionnaire's reliability and validity were then tested on 40 medical-surgical nurses at RSI Sultan Agung Semarang. All 12 statement items passed the validity test, which had validity values ranging from 0.820 to 0.950 (r table = 0.312), and the reliability test yielded an alpha coefficient value of 0.977 (very reliable). Furthermore, paper-based questionnaires were distributed to respondents who met the requirements directly by the researcher. The questionnaires were collected five days later.

The data obtained were analyzed using univariate analysis and data processing using SPPS. The characteristics of respondents were presented as a frequency distribution table, while the obstacles of nurses in delivering EOLC were presented as a central tendency (mean). Moreover, the answers to open-ended questions were grouped, and the frequency was calculated. Then, the data is presented as a frequency distribution table. With reference number 42/B/RSI-SA/VII/2019, the RSI Sultan Agung Semarang ethics committee has approved this study's ethical clearance.

RESULTS

Table 1 shows that most of the respondents have worked less than five years on average, are female, are in early adulthood, and have a diploma in nursing. The majority of respondents chose PK 1 (junior) as their career path, with only an 8.3% difference between the number of nurses in PK 2 (medior). The number of nurses who do not have an EOLC training certificate is still quite high (43.3%).

Table 1. Characteristics of Research Respondents (n= 97)

Variable	Frequency (f)	Percentage (%)
Length of working		
0-5 years	59	60.8
6-10 years	20	20.6
11-15 years	5	5.2
16-20 years	7	7.2
>20 years	6	6.2
Gender		
Male	32	33.0
Female	65	67.0
Age		
21-39 years	82	84.5
40-60 years	15	15.5
Level of Education		
Diploma (D3)	84	86.6
S1/Ners	13	13.4
Level of Nursing Credentials		
PK 1	51	52.6
PK 2	43	44.3
PK 3	3	3.1
Training on EOLC		
Yes	55	56.7
No	42	43.3

Table 2 lists the variables that prevent nurses from providing EOLC in descending order of importance. Health personnel were responsible for the three main challenges, which were a lack of understanding of their role, avoiding dying patients, and a lack of EOLC education or training. The smallest impediment communicated by the nurse is the patient's or family's concern about the possibility of drug addiction from being administered drugs.

Table 2. Factors Inhibiting Nurses in Providing EOLC (n=97)

Inhibiting Factors	$\bar{x}$
Lack of knowledge of health workers	2,53
Lack of training on EOLC	2,34
Avoidance of dying patients by health workers	2,30
Lack of time	2,16
Lack of continuity of care across unit	2,13
Cultural factors influencing EOLC	2,12
Inadequate staff ratio	2,10
Death avoidance by family members	2,07
Health workers fear that they will become addicted to painkillers	2,01
Personal discomfort of health workers about death	1,99
Patient avoidance of death	1,92
Patient/family fear of addiction (painkillers)	1,76

Based on the responses to the open-ended questions asked of research respondents regarding the other major impediments to EOLC that nurses experienced, it was found that the major obstacle faced by nurses came from the nurses themselves (28.8%), followed by the patient's family factors (22.1%), other health team factors (10.5%), and management factors (9.6%). The remaining 26.9% of respondents did not convey any other obstacles. In detail, this can be seen in table 3.

Table 3. Other Inhibitory Factors Faced by Nurses in Providing EOLC Based on Open Questions (n=97)

Inhibiting Factors	Frequency (f)	Percentage (%)
Family		
Having high hope	1	0.9
Unacceptance	6	5.7
Uncooperative	7	6.7
Unpreparedness	1	0.9
Distrust	2	1.9
Death avoidance	2	1.9
Knowledge	2	1.9
Not understanding	1	0.9
Number of family members present	1	0.9
Total	**23**	**22.1**
Patient		
Unacceptance	1	0,9
Uncooperative	1	0.9
Total	**2**	**1.9**
Nurse		
Bad communication	5	4.8
Lack of time	3	2.8
Lack of knowledge and training	19	18.2
Lack of spiritual support	2	1.9
Feel of dread	1	0.9
Total	**30**	**28.8**
Management		
Ward management	1	0.9
Lack of staff	5	4.8
Culture	2	1.9
Service management	1	0.9
Unclear treatment goals	1	0.9
Total	**10**	**9.6**
Other health teams		
Performance	10	9.6
Lack of collaboration	1	0.9
Total	**11**	**10.5**
No obstacles		
Total	**28**	**26.9**

DISCUSSION

The results showed that most of the respondents were clinical nurses, had less than 5 years of working experience, were female, were in early adulthood, and had a

diploma in education. Clinical nurse 1 is a level of clinical nurse whose competence is limited to carrying out basic nursing care, which emphasizes technical nursing skills under guidance (Kementerian Kesehatan Republik Indonesia, 2017). In order to deliver effective EOLC, nurses at this level need assistance in developing their knowledge, clinical skills, and coping mechanisms. They require knowledgeable partners, educational resources, and ongoing education to minimize barriers to delivering EOLC (Caton & Klemm, 2006).

According to a study, healthcare professionals' attitudes toward EOLC are greatly impacted by the length of their employment (Shi et al., 2019). With an average length of employment of less than five years, it can be claimed that the majority of the respondents in this study are still relatively inexperienced workers. According to research by Gedamu et al., (2019), nurses with more than 5 years of experience were more knowledgeable about palliative care than those with less experience. Another study by Feudtner et al., (2007) shows that respondents with more experience also tend to feel more at ease caring for patients who are dying and their families.

In this study, female respondents made up the majority. Female nurses frequently display a fear of death when caring for patients who are dying. Additionally, nurses aged 20–29 rated higher on the dread of dying (Hasheesh et al., 2013). Nurses who experience death anxiety find it difficult to discuss death with patients and their families (Deffner & Bell, 2005). This concern may make it difficult to deliver care, which would lower the standard of EOLC offered (Peters et al., 2013).

Education can affect a person's learning process. The higher the education taken by a person, the more that person will tend to have access to more information (Rosseter, 2019). According to Abate et al., (2019), nurses with a bachelor's degree or above have a higher level of understanding of EOLC than nurses with only a diploma.

The higher a person's education, the more competencies he has, yet these competencies are not usually acquired through formal education. Participation in training related to EOLC can also have a positive impact on a nurse’s competence. Research demonstrates that nurses who participate in training have greater knowledge, abilities, and confidence in giving EOLC than nurses who do not (Anstey et al., 2016).

According to the findings of this study, the most significant barrier to nurses providing EOLC is a lack of knowledge about providing EOLC. Furthermore, the lack of EOLC education or training and health professionals' avoidance of dying patients are the second and third biggest obstacles. So, it can be concluded that health professionals are the biggest barrier to providing EOLC.

This conclusion was also reinforced by the responses of nurses to the open-ended question, in which the biggest obstacles came from the nurse (28.8%). This result is different from the results of research conducted in the pediatric intensive care unit at Sardjito Hospital Yogyakarta (Rohmah et al., 2019) and the intensive care unit at four hospitals in Central Java (Permatasari & Utami, 2018). In the two prior investigations, family issues posed the biggest challenge to delivering EOLC.

Previous studies Beckstrand et al., (2010); Blaževičienė et al., (2017); Brooks et al., (2016); Dufour, (2018); Iglesias et al., (2013) have identified a lack of knowledge and education as a barrier to EOLC. Hospital nurses in Korea were found to have little awareness of end-of-life care, according to research (Kim et al., 2020). Additionally, a literature review in 2020 revealed that the majority of hospital nurses in Asia had no experience with EOLC (Diana, 2020).

The lack of end-of-life content in the nursing education curriculum is one of the factors contributing to nurses' lack of understanding regarding EOLC. This is consistent with Robinson, (2004) research findings that 62 percent of nurses do not receive sufficient EOLC materials. Ranse et al., (2014) stated that knowledge is one of the characteristics that affect how well nurses provide EOLC. Nurse knowledge is significantly related to nurses' behavior and confidence in providing care (Kim et al., 2020).

The research results of Choi et al., (2012) demonstrated that nurses who participated in end-of-life education had more knowledge than those who did not. A significant improvement in knowledge and behavior linked to the end of life is shown in nurses who take part in the End-of-Life Nursing Education Consortium (ELNEC) Core Curriculum education program (O'Shea & Mager, 2019). Communication, pain management, symptom management, and ethics are among the topics covered in the ELNEC Core Curriculum.

The need to fill the nursing staff's knowledge and ability gaps makes continuing education programs on end-of-life care crucial. In accordance with the recommendations made by the Association of Indonesian Nurses Educational Institutions in 2015, EOLC materials have started to be incorporated into the basic curriculum for nursing education in Indonesia (Asosiasi Institusi Pendidikan Ners Indonesia, 2016). This policy is a wise move in the direction of enhancing nursing graduates' EOLC competence. However, in order to meet the needed competency standards, educators must constantly innovate to provide relevant and engaging learning techniques.

The respondents to this study also mentioned that they had not received any EOLC training. Other research also revealed this. Lack of training among nurses causes them to feel unqualified to provide EOLC (Iglesias et al., 2013). As a result, nurses expressed a desire for education in providing care for those who are dying. According to a survey by Crump et al., (2010), the top three subjects needed by nurses were culture, ethical issues, and communication.

Communication is one of the issues that often becomes a complaint. So, it is crucial to implement therapeutic communication training to boost nurses' self-assurance and enhance the standard of EOLC offered. The third major deterrent in this study was health professionals' avoidance of dying patients. The previous study demonstrated that doctors shy away from discussing diagnoses and prognoses with patients and their families (Blaževičienė et al., 2017).

Whereas, doctors should explain everything asked by patients and families to avoid inaccurate information Beckstrand et al., (2009), because patient prognosis information is outside the scope of nurses (Iglesias et al., 2013). This might be one of the reasons that nurses also avoid dying patients. One more obstacle to nurses performing EOLC is family. Family-related obstacles include uncooperative families, a refusal to accept the client's poor prognosis, mistrust of nurses, a lack of knowledge and understanding among the family, a lack of preparedness among the family, and the presence of numerous families in the room.

The study by Utami et al., (2021) yielded similar findings to this investigation. In this study, nurses reported difficulties communicating with the families of dying patients, particularly those who were still in the denial phase. Previous research by Enggune also stated that it is difficult to make families accept a poor patient's prognosis (Enggune et al., 2014). The family does not accept the poor prognosis and fully hopes

that the patient will recover (Beckstrand et al., 2009). The family also wants to avoid the patient's death and wants to keep the patient alive, even though the patient has agreed and signed not to request the treatment (Beckstrand & Kirchhoff, 2005).

Research in East Asia reports that families are reluctant to talk about end-of-life issues due to cultural norms. They believe that bad things or bad luck will happen if they talk about it loudly (Cheng et al., 2015). People from outside the United States and other Western countries often hide serious diagnoses from patients because sharing bad news is disrespectful and can put the patient at risk. On the other hand, Western culture places great emphasis on patient autonomy and "truth-telling" in the delivery of care (Searight, 2019). This principle was adopted to create the EOLC's quality standards (National Institute for Health and Care Excellence, 2013).

Families are frequently unaware that the interventions they make can worsen the patient's suffering (Reinke et al., 2010). This will increase the burden on nurses when caring for patients because it limits nurses' ability to provide high-quality EOLC (Beckstrand & Kirchhoff, 2005). Having a representative who can speak with medical personnel and teach families how to engage in patient care can improve the quality of care (Attia et al., 2013).

CONCLUSION

Nurses provide the biggest challenge to EOLC provision. Lack of understanding, inadequate training on EOLC, and medical professionals' avoidance of dying patients are the three largest barriers for nurses. The patient's family can be a major challenge for nurses, particularly if they refuse to acknowledge the patient's condition and are disobedient when it comes to patient care.

ACKNOWLEDGEMENT

We gratefully thank the Roemani Muhammadiyah Hospital for assisting with the process of data collection.

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