



WHEN, HOW, AND BARRIERS OF PALLIATIVE CARE IN INTENSIVE CARE UNIT: A SCOPING REVIEW

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ABSTRACT

Palliative and near-death conditions in critical ill patients may occur, either predictable prognosis or acute conditions. Nurses are often unprepared for these care needs, resulting in suboptimal patient care. This study aims to review empirical evidence over the past 10 years regarding when to start, how to apply, and constraints during applying palliative care and end of life (EoL) care in intensive care. This review was conducted using journal database CINAHL, PubMed, Scopus, and WOS and selected article by PRISMA. The findings show EoL care begins when the medical team has assessed and approved by the patient and family including using the referral checklist format from intensive care to EoL care including the resources needed. In addition, during the upbringing process counselling and consultation with the family for any decision-making medical measures, nursing rounds, emotional and spiritual support and touches and hugs for the patient and family, including support for the entire medical team. However, there are also obstacles in the right communication time to families, discussions about death, and improving the competence of nurses through EoL education and training.

Keywords: barrier; critical; end of life; intensif care unit; palliative

How to cite (in APA style)

Frisca, S., Koerniawan, D., Suryani, K., & Surani, V. (2024). When, How, and Barriers of Palliative Care in Intensive Care Unit: A Scoping Review. *Indonesian Journal of Global Health Research*, 7(1), 323-336. <https://doi.org/10.37287/ijghr.v7i1.4258>.

INTRODUCTION

The Intensive Care Unit or ICU is a part of the hospital service that specifically serves patients in critical condition. ICU services are divided into three categories, viz. primary, secondary and tertiary services. This category is determined based on human resources, facilities and infrastructure, and service competency (Kemenkes RI, 2010). The ability to care for emergency and critical patients affects the quality of care, which increases mortality rates. Curtis found that the average age of patients treated in the ICU was 71.1 years and the majority were male (53.67%) (Curtis et al., 2011). Causes of death in ICU patients include trauma and cancer (Curtis et al., 2011), septic shock, chronic heart failure and myocardial infarction, hormonal diseases, infections and circulatory disorders (Megawati, Dewi, Nurohmat, & Muliani, 2020). Approximately 1 in 5 deaths in the United States occur while patients are in the ICU or shortly after entering the ICU. This is what results in a higher number of deaths occurring in the ICU compared to other treatment rooms in the hospital (Angus et al., 2004). More than 80,000 people in Australia are treated in intensive care units each year for serious illness and although around 92% survive in critical condition, some continue to die (Bagshaw et al., 2009). Palliative care can improve the quality of life for patients and their families when facing a life-threatening illness. The treatment offered focuses on symptom and pain management through physical, emotional, psychosocial and spiritual measures. Based on data from the Centers for Disease Control and Prevention (CDC), 70% of deaths each year are caused by serious chronic illnesses, underscoring the important role of palliative care (CDC, 2015). Many of these deaths occur in acute care,

namely intensive care units. End-of-life care in critical care is an important issue affecting patients, families, and critical care staff. Fatalities and deaths can occur due to a sudden deterioration in the patient's condition or the disconnection of life support intended to prevent death. ICU patient deaths have been found to have significantly different effects on families compared to other units or areas of the hospital which may occur due to increased anxiety related to the ICU environment (Warren, 2020) or high recovery rates due to more intensive care equipment (Puri, 2003).

Interventions to maintain comfort and support for patients, families and even health care teams are important in the dying process. Medical guidelines such as “do not resuscitate” sometimes require further clarification to avoid mismanagement and misunderstandings in patient care. Maintaining patient comfort by facilitating a “good death” in the ICU (Gaeta & Price, 2010) helps manage symptoms such as agitation, pain, and shortness of breath and is critical to safeguarding patients, families, and caregivers in the dying process. Although this may seem trivial, related research shows that this is not always achieved, namely 78% of more than 900 ICU nurses in North America understand that patients in the ICU do not receive adequate pain medication with a response of “sometimes” or “often” (Puntillo et al., 2001). Collaboration and early involvement of the palliative care team is one way to integrate end-of-life care (EoL) for patients who remain in critical care areas or are transferred to other units. Withdrawal from mechanical ventilation support requires appropriate care to manage the potential for agitation, pain and hypoxia (Mularski et al., 2009). Use of opioids and benzodiazepines should be considered to prevent agitation and pain. The choice of bolus or infusion should be based on patient comfort. Continued oxygen therapy in the most appropriate form, and an oral airway can improve patient comfort and facilitate airway. Atropine and scopolamine have been reported to successfully reduce excessive oral secretions and improve well-being (O’Mahony, McHugh, Zallman, & Selwyn, 2003).

Although some patients die in peace and comfort, others die in difficult conditions and even severe suffering. Nurses in acute care settings are increasingly concerned about how the patients they care for will die. Nurses now realize that death may be inevitable and that the use of technology to prevent death is limited. Critical care nurses are in an excellent position to help patients and families during this difficult transition. Accompanying patients and families to “be there for them” and “do something for” them allows critical care nurses to provide the holistic care that is central to nursing. Intensive care nurses are part of the interdisciplinary team and provide an important role in discussions of palliative nursing care. However, distance nurses receive formal education in this subspecialty, resulting in a lack of skills and confidence when providing palliative nursing care in acute and dying conditions (Ashley & Fasolino, 2016). Skar stated how nurses are very valuable members of the palliative care team because they integrate the physical, social, functional and spiritual dimensions of patient care. now also notes the importance of factors that influence the success of providing palliative care, namely knowledge, attitudes, beliefs and experience of health workers and also influence their behavior during intervention and evaluation (Skår, 2010).

Palliative care and EoL care are not widespread in Indonesia, which is reflected in the limited number of published studies directly related to EoL. Several articles were found that did not specifically discuss the application of EoL in the ICU for patients with chronic and critical illnesses in general. Therefore, the aim of this study was to determine how nurses implement or implement EoL for seriously ill patients and families in the intensive care unit.

METHOD

This research uses a scoping review design with a selection stage using a literature search strategy (Table 1) and PRISMA (Diagram 1) which is then extracted and presented in tabulation. Data extracted by lead author and reviewed by all author and emphasized in summary format. Information about component of articles and focus on key terms “When to initiate EoL Care”, “How to implement EoL Care”, and “Barriers to implement EoL Care”.

Table 1
Literature searching strategy

	Key Word	CINAHL	WoS	Scopus	PubMed
#1	“critically care patient” OR “severe illness” OR “advance illness” OR “critical illness” OR “terminal Illness”	2.969	43.405	2.850	6.243
#2	“ <i>end of life</i> care” OR “palliative care” OR “supportive care” OR “terminal care” OR “care of the dying” OR “bereavement care” OR “care after death”	12.083	41.276	11.071	3.047
#3	ICU OR GICU OR HCU OR HDU OR ICCU	7.057	60.743	4.346	4.530
#4	("critical patient" OR "severe illness" OR "advance illness" OR "critical illness" OR "terminal Illness") AND ("end of life care" OR "palliative care" OR "supportive care" OR "terminal care" OR "care of the dying" OR "bereavement care" OR "care after death") AND (ICU OR GICU OR HCU OR HDU OR ICCU)	13	15	37	24

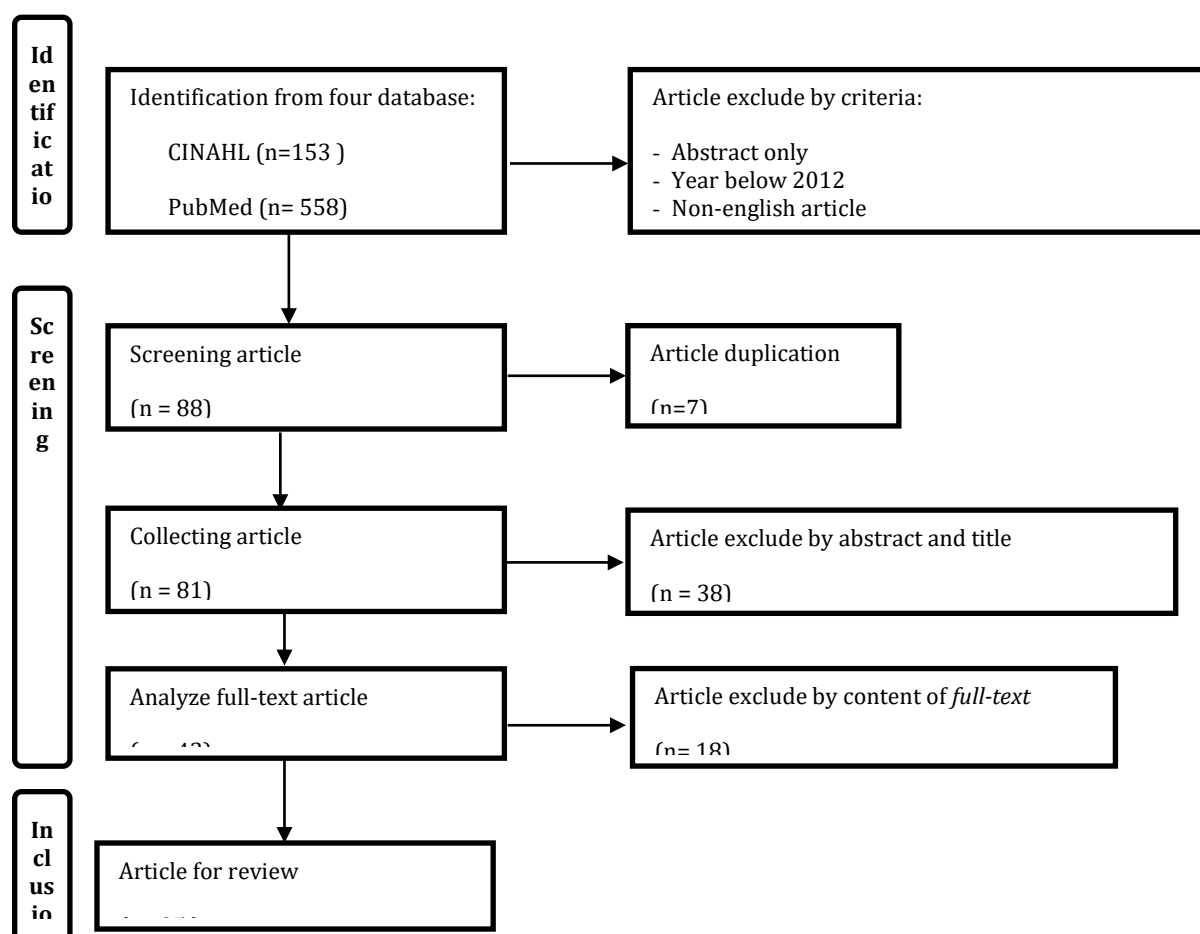
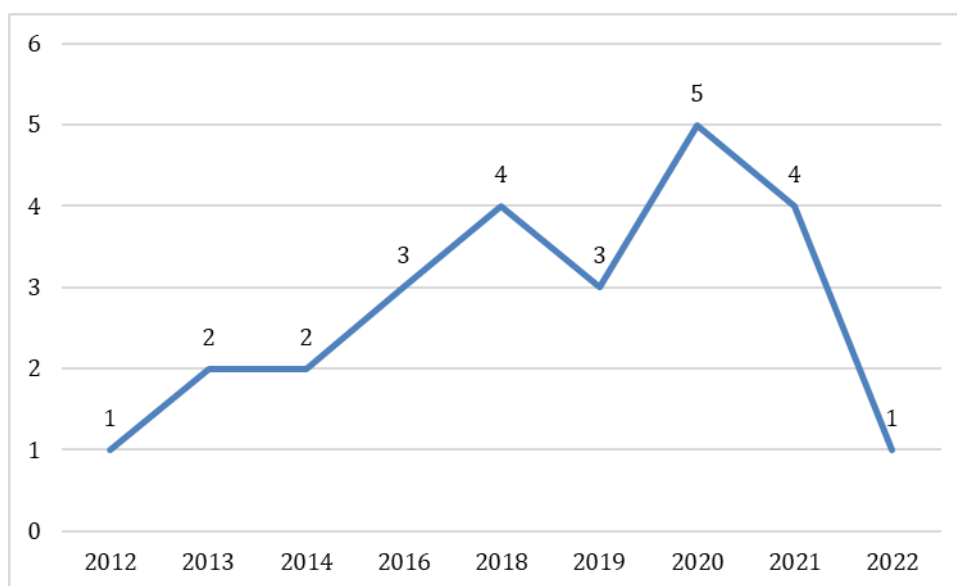


Diagram 1
Flowchart PRISMA

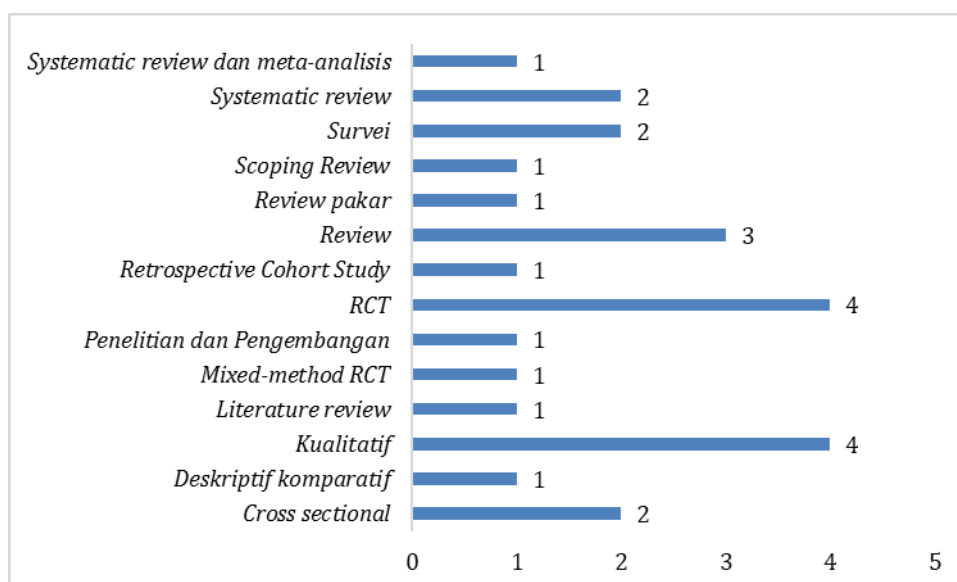
RESULTS

The results of the review of 25 articles are presented in descriptive form from aspects of year, research design, and tabulation of the three themes found, namely when to start end of life (EoL) care, how to implement EoL care, and barriers to EoL application.



Graph 1
Article Frequency Distribution based on Year

Graph 1 shows that most of the articles published in the last 10 years in the 2012–2022 range reviewed were published in 2018 (4 articles), 2020 (5 articles), and 2021 (4 articles). Meanwhile, from Graph 2, the majority of articles used a randomized control trial (RCT) and qualitative design (4 articles each).



Graph 2
Article Frequency Distribution based on Research Design

Table 2
Synthesis matrix of theme 1: When to initiate EoL care

No	Penulis	Tahun	Desain	Hasil
1.	Rao, et.al.	2021	Research and development	Development of a palliative care referral screening checklist in the ICU, referral checklist, and care resources checklist
2.	Bibas, et.al	2019	Systematic review dan meta-analisis	Decision making about care in critical settings depends on the companion or person responsible for the patient.
3.	Mercadante, Gregoretti & Cortegiani	2018	Review	It must be started as early as possible from the initial assessment when admitted to the ICU and whenever typical problems arise, especially during the palliative care evaluation process, carried out continuously in the ICU, identifying problems early and proactively, making decisions involving the family from the start, collaborative care involving a medical team and other health workers, especially a team of doctors who are experts in palliative care.

EoL care begins as early as possible when the patient is admitted to the ICU or whenever palliative or dying problems arise, including proactive and continuous follow-up of the patient's progress (Mercadante, Gregoretti, & Cortegiani, 2018). Assessment of referrals from intensive care to EoL can be done by developing a referral checklist instrument indicating EoL care and resource needs in EoL care (Rao, Belanger, Egan, Leblanc, & Olszewski, 2021). Final decision making involves an interdisciplinary team of scientists and the family or companion who is responsible for the patient (family or companion) (Bibas et al., 2019; Mercadante et al., 2018). The EoL care team requires health workers such as doctors and nurses who have competence in EoL care (Mercadante et al., 2018).

Table 3
Synthesis matrix of theme 2: How to implement EoL care

No	Penulis	Tahun	Desain	Hasil
1.	Aslakson, et.al.	2014	Systematic review	Intervention in the form of integrated consultations (comprehensive care team meetings with families, consultations, ICU rounds with families, booklets and education)
2.	Chacko, et.al.	2014	Comparative descriptive	Support in emotional and social dimensions, physical dimensions and spiritual dimensions
3.	Cox, et.al	2020	Mixed-method RCT	The application of connecting families with health workers as a form of reporting related to the palliative services provided is proven to be able to help families determine priority actions for patients.
4.	Davidson, et.al	2016	Systematic review	Recommendations for family-centered ICU care: family presence in the ICU, family support, communication with family members, specific consultation with the ICU team, as well as operational and environmental issues
5.	dos Anjos, et.al.	2019	Cross sectional	The approach through spiritual beliefs is more widely used as an influencing factor on PC
6.	Endacott, et.al.	2016	Qualitative	Appropriate time to communicate, accommodating individual behavior, appropriate care environment, and momentum towards death
7.	Lee, et.al	2021	Scoping Review	Touching and hugging are necessary in intensive care to increase comfort
8.	Ma, et.al	2019	RCT	Palliative counseling from the start of ICU admission can reduce the possibility of DNR/DNI and reduce the cost of ICU care
9.	McCurry, et.al.	2021	Qualitative	Pastoral Care (chaplin) provides comfort (support) to patients and families in facing conditions near death, prayer support for various purposes (prayer to ask for strength, prayer as a way to reflect, prayer for healing, prayer to express grief, prayer to express gratitude), helps support family members through complex medical decision making, and provides support

No	Penulis	Tahun	Desain	Hasil
				(facilitates) needs for various resources (religious leaders, religious ritual activities)
10.	Rothschild & Derrington	2020	Review	Care integration model for palliative patients in the PICU consisting of primary and secondary levels of palliative care
11.	Short & Thienprayoon	2018	Review	The treatment method that can be used is by implementing an interdisciplinary consultation process with health workers and integrative care involving the family
12.	White, et.al	2018	Randomized trial	Providing support to families through special programs from hospitals shows that satisfaction with patient care is higher than ordinary care.
13.	Bateman, et.al	2020	RCT	Casual conversations about death can reduce burnout in ICU nurses which has the effect of increasing the quality of care for patients.
14.	Halpern, et.al	2020	RCT	Providing advance directives to patients through home care supervised by professionals increases patient comfort and reduces inpatient costs.
15.	Lewis-Newby, et.al.	2020	Survey	Communication between health workers and patients during the last period of communicating next to the patient will provide a more comfortable feeling for PICU patients

Dying care is integrated care that is not only interdisciplinary but also involves non-medical teams such as pastoral care as a spiritual support service (Aslakson, Randall Curtis, & Nelson, 2014; McCurry, Jennett, Oh, White, & Delisser, 2021; Rothschild & Derrington, 2020; Short & Thienprayoon, 2018). Family-centered care is an important principle because every medical decision making and informed consent will often occur, especially at the beginning of deciding whether the patient will continue to undergo therapy or life-supporting procedures or not (Cox et al., 2020; Davidson et al., 2017; Ma et al., 2019). The EoL team needs to create a care planning strategy that can accommodate patient and family behavior, facilitating an appropriate care environment including before and during the moment of death (Endacott et al., 2016). Involving the family in rounds with the team in the ICU and opening consultations that can be accessed by the family at any time, as well as the presence of the family in care will enable the family to make decisions regarding priority actions for the patient (Aslakson et al., 2014; Cox et al., 2020; Davidson et al., 2017; White et al., 2018). This can also be done in home care conditions (Halpern et al., 2020).

Apart from physical support by supporting the patient's physiological function which is still good with therapy or medical procedures, nurses also need to provide emotional and social support, even spiritual support is one of the factors that influence the quality of EoL care including support for the family (Chacko, Anand, Rajan, John, & Jeyaseelan, 2014; dos Anjos et al., 2020; McCurry et al., 2021; White et al., 2018). Communication at the right time as well as touch and hugs helps patients and families through difficult times (Lee et al., 2021; Lewis-Newby et al., 2020). In addition, discussions about death and dying with nurses can reduce nurse burnout. so that it can improve the quality of care (Bateman et al., 2020).

Table 4.
Synthesis matrix of theme 3: Barriers on implementing EoL care

No	Penulis	Tahun	Desain	Hasil
1.	Anderson, et.al.	2016	Survey	Frequency of involvement and self-confidence are barriers for nurses in palliative care
2.	Aslakson, et.al.	2012	Qualitative	Barriers for nurses in carrying out effective communication in optimizing EoL care: physical barriers, discomfort discussing the patient's prognosis with the family, lack of skills and training, fear of conflict, cultural differences regarding care for the dying.

No	Penulis	Tahun	Desain	Hasil
3.	Barnato et al	2018	Retrospective Cohort Study	The existence of end of life care standards (ICU ratio, supporting care system and hospital expectations) which is higher for black patients than white patients, thus having an impact on the implementation of patient care which causes black patients to be treated less intensively than white patients.
4.	Burman et al	2021	Cross-Sectional Study	There is still low awareness and knowledge of caregivers regarding the importance of end of life and palliative care, only 26% were found to know about palliative care
5.	dos Anjos, et.al.	2019	Cross sectional	Doctors' knowledge regarding PC is still considered, communication is the biggest difficulty in carrying out PC
6.	Ito, et.al	2022	Expert REview	Health care providers are not aware of the need for palliative care in the ICU, think palliative care is close to death, and have difficulty communicating with patients at the right time. Inadequate training and training time and costs. Misconceptions of palliative care in patients and families.
7.	Mak, et.al.	2013	Interpretative Descriptive Qualitative	The lack of readiness of nurses in dealing with patient death, caring for patients in dying conditions reflects the role of nursing, reflecting on the meaning of death and the experience of being involved in dying care is a personal experience.
8.	Short & Thienprayoon	2018	Review	Barriers that arise in care consist of barriers from service providers and concerns of staff/health workers, systems that run in the ICU environment, barriers from families, and communication processes.
9.	Wang & Kearny	2013	Literature review	Culture can influence treatment, parental behavior in treatment; communication patterns; the influence of gender in the care and upbringing process

Barriers found in implementing EoL care arise from aspects of nurses, doctors, families and the norm system. Lack of frequency of nurse involvement in providing EoL care, self-confidence, effective communication, discomfort discussing the patient's prognosis with the family, fear of conflict, and lack of skills and training in EoL care are obstacles for nurses in providing EoL care (Anderson et al., 2016; Aslakson et al., 2012; Barnato, Chang, Lave, & Angus, 2018; Ito et al., 2022; Mak, Chiang, & Chui, 2013; Short & Thienprayoon, 2018). Other health workers such as doctors also experience a lack of knowledge in EoL care (dos Anjos et al., 2020). Barriers that arise from families occur due to low awareness and knowledge about EoL care (Burman et al., 2021; Short & Thienprayoon, 2018). Cultural issues, communication patterns, and gender are also inhibiting factors in EoL care (Aslakson et al., 2012; Barnato et al., 2018; Wang & Kearney, 2013).

DISCUSSION

Palliative nursing care seeks to support patients and families in improving the quality of life focusing on the management of pain and disease symptoms as a component or important in accordance with patient-centered care. Palliative nursing care is the coordination of an interdisciplinary team in meeting the needs and providing support for team members, patients and families. Intensive unit nurses are often involved in changing roles as providers of intensive care to palliative care and even nursing care towards death. Palliative nursing care is currently developing and is increasingly being felt to be a necessity in patient care in intensive care so that nurses need to reflect on the importance of understanding and having competence in quality dying care. This is an important concern because intensive and critical unit nurses have an important role in providing care for the dying. Effective integration of palliative and dying nursing care has the potential to accompany and guide patients and families and prepare them to face challenges and difficulties during care. Therefore, it is important for nurses to know and understand the scope of palliative and dying nursing care regarding when to start it, how to apply it, and what obstacles can be encountered while providing care.

When to initiate EoL care?

EoL care often begins in a critical or palliative condition that progresses to a worsening prognosis so that ultimately a decision is made to continue life-sustaining treatment or stop it and some of them experience do not resuscitate (DNR) status. Therefore, nurses need to proactively carry out ongoing assessment and evaluation (ongoing assessment) in providing care to patients who are in critical or palliative conditions (Strautmann, Allers, Fassmer, & Hoffmann, 2020). Continuing care is discussed in an interdisciplinary team to discuss the development of the patient's prognosis and the possibility of the emergence of near-death conditions. Nurses are also important in involving family participation from the beginning of care, including making decisions about further care plans whether to proceed to intensive, palliative or dying care. Interdisciplinary teams have a variety of backgrounds and expertise, but not all members are specialized in EoL. One of the team's understandings regarding decisions or suggestions for making EoL care is based on knowledge obtained from various training and experiences. An interdisciplinary team that has a better understanding will provide more appropriate advice to the team and the family. In addition, the communication built into the decision-making process becomes more meaningful, reduces anxiety, and makes it easier for families to understand the medical conditions of family members (Fang et al., 2022; Sun, Hsu, Ko, & Huang, 2020).

After decision making by the interdisciplinary team and family, EoL care will begin. Care planning must begin as early as possible after entering the intensive care unit based on the results of the initial assessment. Various methods can be used to make it easier for the team to provide nursing care, one of which is by having an appropriate assessment format so that it can be filled in quickly and displays information on the patient's EoL needs. The checklist form helps identify various things such as indications of changing intensive care to palliative care for dying, the resources needed such as the interdisciplinary team involved, actions taken and not taken during dying care, medical equipment installed, as well as assistance or support and counseling in aspects transcultural and spiritual for patients and families. The results of filling in the checklist format will make it easier to analyze and discuss within the interdisciplinary team, so that EoL nursing care decisions can be taken quickly and precisely.

How to implement EoL care?

Decision making on EoL care for patients will continue with the application of care in a hospital setting. Just like the care application decision-making process will also involve the interdisciplinary team and family. It should be noted that in the application of team and family care, the patient's condition will be affected, making them vulnerable to stress and fatigue, especially in direct care providers, whether nurses or family. Initial interventions that can be carried out are counseling and consultation as well as education for families (Eng, Hewitt, & Kekalih, 2022) using media such as booklets. This activity aims to increase the family's knowledge of nursing care for the dying and all aspects and planning programs that may be chosen for their member who is being cared for, including if care is ultimately carried out at home. Consultations can be provided by an interdisciplinary team and reinforced by nurses who provide 24-hour care. In this process, the terms used are often difficult to understand and are considered taboo by some people, such as the words death/dying. Caregivers sometimes replace diction with words that have the same meaning so that they are more polite when delivered. The use of the right choice of words is obtained through interaction and learning, either through training or sharing between interdisciplinary teams.

Furthermore, in providing care, family understanding is also supported by good communication when delivering it to the family. Clear and precise communication will make

it easier for the family to understand the patient's condition, making it easier to apply procedures to the patient. Nurses also need to continuously communicate the patient's progress to the family to reduce anxiety about the uncertainty of the patient's condition. Likewise, if the patient is not in a condition to be visited, various communication technologies can be used to support patient-nurse-family interactions. Apart from that, therapeutic touch and hugs are needed to provide energy support for patients and families in facing and going through difficult times (McParlin, Cerritelli, Manzotti, Friston, & Esteves, 2023) especially when making difficult decisions such as stopping all medical procedures taken to support the patient's life. A spiritual approach has been proven to be an effective way to support patients and families in facing the process of approaching death (Putu, Sasmita Sutarta, Ketut, & Ariani, 2022). Communication and being next to the patient and family can reduce feelings of grief and increase a sense of comfort.

Furthermore, involving families in providing direct care is important. Families need time together with patients and are involved in daily activities both in the hospital and at home. Through this process, the family's understanding of the patient's condition increases and makes decisions easier if there is a change in condition, especially one that is life threatening. Family involvement also makes it easier for nurses to provide education if the family decides to carry out the EoL process at home. Providing EoL by nurses can have an impact on stress and fatigue, so apart from patients and families, it turns out that counseling and communication for nurses is also important. In-depth and light discussions about the death process and the experience of caring for patients in the dying process can reduce nurses' stress and burnout (J. Peterson et al., 2013). Nurses need to convey the emotions they feel when providing care to patients and understand certain conditions that require help from other parties. When providing care, nurses need energy to accompany patients and families and even transfer positive energy to recharge the energy of patients and families during difficult times, as in the application of Roger's homeodynamic concept in the Science of Unitary Human Being (SUHB) theory (Alligood, 2014; S. J. Peterson & Bredow, 2013). Through this, nurses can improve the quality of care for patients.

The gap between clinical needs and the integration of palliative care during nursing education is the basis for improving and developing nurses' competence in palliative and dying care so that they have high self-confidence to provide nursing care to patients with palliative conditions. Continuing nursing education for palliative and dying care specialties can be an educational program for nurses in clinical settings. The palliative team design consisting of an interdisciplinary health team carries out activities in the form of team meetings in pain management and palliative care, nursing and medical rounds, and searching for literature sources and empirical evidence from research results related to pain management and signs of symptoms in patients with palliative conditions and near death.

Barriers on implementing EoL care

The competency of the medical team, especially nurses and doctors, is often inadequate due to a lack of EoL care training. In addition, the lack of frequency of involvement and confidence in providing care for the dying is an obstacle (Eng et al., 2022; Ho, Liu, Joo, Lee, & Liu, 2022). Doubts and fears in communicating the patient's prognosis, possible conflicts that may arise, unpreparedness in facing the dying process, result in inaccurate timing in conveying the patient's condition and poor communication with the family. The standards set by the hospital are also no less important factors related to the ratio of intensive rooms in terms of the number of beds to nursing staff, supporting systems of care and medical procedures, as well as the hospital's expectations in support of the EoL program, including support for nurses or other

medical teams. in maintaining psychological stability during the process of providing care because nurses also need support and counseling in the process of facing death. Providing nursing care to patients who are nearing death is a learning experience in itself. Death is not a bad event that can happen and be experienced by someone. Nurses feel uncomfortable talking about or discussing death with someone who is near death (Ho et al., 2022). Nursing care for the patient's family must be carried out continuously through periods of grief and loss. Some nurses do not want to be assigned to provide care services to patients who are near death. Some feel that nurses are not the ones who should discuss death with dying patients.

The length of time required to provide nursing care towards death is frustrating and stressful. Some find it difficult to build close relationships with the families of dying patients. There have been several incidents when patients in the final stages of their lives accepted their death willingly, but there were also patients who finally gave up hope. When a patient asks whether he will die, nurses often change the topic of conversation to a more pleasant one to reduce the patient's despair, the family must be involved in care, especially the daily needs or basic needs of patients who are just approaching. Nurses often hope that the patients they care for do not die during their time on duty. The family needs emotional support to accept changes in the behavior of the patient who is nearing death. The low level of awareness and knowledge of families as caregivers and those responsible for patients is also an obstacle to the importance of EoL care and related aspects, so that misconceptions about dying care often occur. Cultural issues and values that exist in the family are also factors that influence family decision making in EoL care.

CONCLUSION

End of life nursing care needs to start as early as possible, starting from the initial assessment when entering the intensive care unit to evaluating the results of ongoing assessments and can be made easier by using a referral checklist form. Communication and consultation are critical in the transition and throughout the EoL program. Family-centered care by accommodating cultural issues and spiritual support are the central points. In addition, support for provision in the form of training and increased involvement of nurses in EoL care as well as early education on EoL care for patients and families can reduce obstacles faced at the beginning and during the process of providing EoL care

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