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Review Article

Barriers and Challenges of End-of-Life Care Implementation in the Intensive Care Unit: Literature Review

Rizky Meilando[1*] | Cecep Eli Kosasih[2] | Etika Emaliyawati[3]

[1]Magister Student, Faculty of Nursing, University of Padjadjaran, Bandung, Jawa Barat - Indonesia

[2,3]Department of Critical Care Nursing, Faculty of Nursing, University of Padjadjaran, Bandung, Jawa Barat – Indonesia

***contact**

riskimeildo4462gmil.com

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Abstract

Aims: End-of-life care in ICU involves a wide range of staff from every discipline including nurses, who have a lot of interaction time with patients. Most of the patients in the intensive care room have unconscious characteristics and family acts as the holder of autonomy in decision making, so nurses must have competence and experience in caring for patients in the end-of-life phase. However, nurses feel many barriers and challenges in facing the end-of- life in the intensive care environment. This study aimed to identify barriers and challenges of end-of-life care implementation in the ICU

Designs: This study used literature review that analyzes articles from five reputable databases such as Pubmed, Proquest, CINAHL, Science Direct, and Google Scholar with the publication year between 2010 - 2021. The keywords used are 'critical care', 'critical care nursing', 'intensive care unit', 'end-of-life care', 'barriers', and 'challenges' with the help of bolean operators 'OR' and 'AND', articles were selected in stages using PRISMA. From the results of 2,186 articles, only 11 articles were identified that met the inclusion and exclusion criteria.

Results: The results of the review showed that some barriers of end-of-life care implementation in the ICU are lack of communication, lack of knowledge and training about end of life care, differences in religious and cultural backgrounds, medical team work in the ICU, patient and family factors, and environmental factors. Meanwhile, the challenges of end-of-life care in ICU are communication and decision making in end-of-life care and unrealistic family expectations.

Conclusions: There are still many barriers and challenges identified on implementation of end-of-life care in intensive care units, mostly due to lack of knowledge and communication during end-of-life care. As a recommendation in improving end-of-life care services in the ICU, health service agencies need to increase knowledge and training of health workers about communication and end-of-life care in critical patients.

Keywords :
Barriers, Challenges, End-of-Life Care, Intensive Care Unit

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INTRODUCTION

The Intensive Care Unit (ICU) is a part of a hospital equipped with specialized personnel and special equipment to observe, care and treat patients with potentially life-threatening diseases, injuries and complications. Usually, patients with certain conditions are admitted to the ICU room, like critical patients who suffer from one or more organ system failures (1). The complexity of the cases experienced by patients in the ICU makes its management involve the collaboration of professionals from various disciplines and supported by the cutting-edge technology with the presence of various life support tools, aggressive curative therapy and close monitoring for 24 hours (2). Even though, it involves professionals, drugs, sophisticated tools and equipment as well as intensive observation, in reality, patient deaths in the ICU still occur. The deaths from critical to chronic illnesses in the world increased by 1.1-7.4 million people and there were 9.8-24.6% of critical patients admitted to the ICU with 100,000 population (3). The critical illnesses, which are generally non-communicable are still cause 73% deaths in Indonesia. This increase is related to unhealthy lifestyle (4).

The health services including intensive care should prepare patients to face death with peace and dignity. Although all critical patients should receive aggressive care, the goal of aggressive end-of-life care should emphasize how to prepare for a peaceful death (5). Thus, services in the ICU is not only focus to maintain the patient's life, must also provide the best service in end-of-life care (6).

End-of-life care (EOLC) is treatment of patients with terminally ill progressive, incurable and potentially death-leading diseases, this treatment requires the support of nurses and families to identify the final phase of life, including pain and symptom management, psychosocial problems and spiritual support (7). The goal of end-of-life care makes a patient feel free from pain, comfortable, valued, respected and in peace and quiet and feel close to the person who cares for him (8), and to improve the quality of life and ensure that patients receive satisfactory comfort for the rest of their lives (9).

The need of end-of-life care is increasing along with technological developments and advances which are expected to improve the quality of care to prolong life (10). Currently in the worldwide patients who need EOLC reaches more than 20 million people with 69% of them are elderly who are dominated by men. The majority of patients requiring services died cause cardiovascular disease (38.5%) and cancer (34%), chronic respiratory disease (10.3%), HIV/AIDS (5.7%) and diabetes (4.5%).). 78% of adult patients requiring EOLC are low-middle income countries (11). Thus, the chronic non-communicable diseases EOLC will be increasingly needed until 2040 (12).

Patients who die in intensive care will go three stages of the end-of-life trajectory, admission with hope of recovery, transition from intervention to EOLC, and controlled death. The transition from intervention to EOLC is reported to be most problematic and ambiguous stage in the end-of-life trajectory (13). The end- of-life care in the ICU involves variety of staff from every discipline especially nurses, who have a lot of interaction time with patients. The role of nurses in carrying out critical nursing care is very important, nurses must have competence and experience in caring for patients in the end-of-life phase (14).

However, in the clinical practice , end-of-life care in intensive care unit often barriers and challenges (15). Based on research conducted by Zoomordi & Lyn (2010)

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stated that end-of-life care services in the ICU are not optimal, nurses feel many obstacles and challenges in facing end of life (EOL) in the intensive care environment (16). It happened because most of ICU nurses do not receive formal training in the end-of-life care (17), which raises questions about the level of knowledge and competence of nurses (18). The role of end-of-life care in the intensive care unit is appropriate, because it is not clear and the ICU nurses' perceptions of "good EOLC practice" and 'good death' are mostly unclear (19,20). In addition, Carvajal., et al (2019) stated that ICU nurses have limited education and training regarding end-of-life care both in their undergraduate and postgraduate studies on the philosophy of palliative care/end-of-life care which discusses about physical, psychological, social and spiritual aspects (21).

According to Velarde Garcia., et al (2016) stated that the problem of carrying out quality end- of-life care caused by family factors who cannot accept the communication given by nurses about the patient's prognosis. Lack of resources and interdisciplinary ability of health professionals to determine goals for critical patient care is also a problem (22). Therefore, research is needs to explore the current evidence regarding the barriers and challenges experienced by ICU nurses when providing end-of-life care. It is hoped that understanding the problems found will produce input for improving end-of-life care in the intensive care room.

Based on the above problems regard about increasing number of critical patients every year, the increasing need for end-of-life care in critical patients, the important role of nurses in optimizing end-of-life care, and there are still barriers and challenges based on the results of previous studies both caused by nurses, patients' families, and other interdisciplinary health professionals who have not been clearly identified. This study aimed to identify barriers and challenges of end-of-life care implementation in the ICU.

METHODS

This research includes scientific literature review research with techniques for finding references to theories and journals related to the major theme. The results of the search for journals related to major theme is basic for conducting a literature review. Sources of data used in this study are results of research that has been carried out and published in international reputable databases. In conducting this study, researchers searched for research journals published in the ProQuest, PubMed, CINAHL, Science Direct and Google Schoolar databases. Searching for informational articles used keywords and bolean operators (AND, OR, and NOT) that are adapted to the Medical Subject Heading (MeSH Term) (23). The keywords used in this study are as follows:

Table 1.
Keywords

PICO Format	Keywords	Mesh Term
P (Population)	Critical Care, Intensive Care	Critical Care, Critical Care Nursing, Intensive Care Unit
I (Intervention)	End-Of-Life Care	-
C (Comparison)	-	-
O (Outcome)	Barriers, Challenges	-

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The data collection process was carried out by filtering based on the inclusion and exclusion criteria determined by the authors of each journal taken. The inclusion and exclusion criteria for article collection are as follows:

Table 2. Inclusion and Exclusion Criteria

Inclusion Criteria	Exclusion Criteria
1. The year of the literature source taken is from 2010 to 2021. 2. The language used in the article is English and Indonesian 3. The subjects or samples of the study were nurses in the intensive care unit. 4. The articles used are full text in PDF format. 5. The research theme is barries and challenges of end-of-life care implementation in the ICU.	1. Articles are only in the form of abstracts. 2. Proceeding articles. 3. Paid articles.

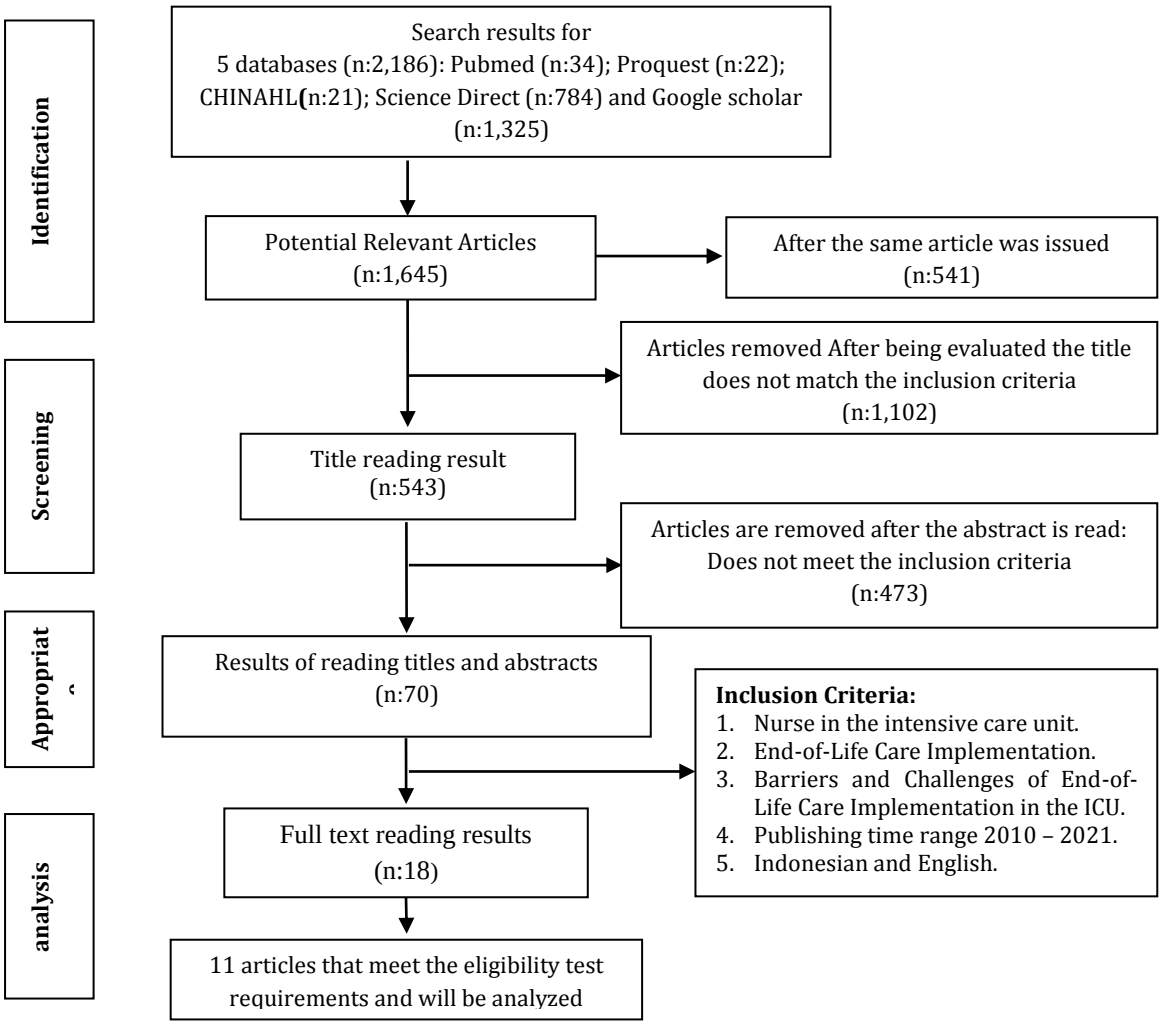

Figure 1. PRISMA

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After searching for articles based on keywords from 5 databases, the articles identified were 2,186 articles, which were then issued with the same articles in several databases as many as 541 articles. Furthermore, the researchers screened articles based on reading titles and abstracts as many as 543 articles, then articles with inappropriate titles and abstracts were removed. Furthermore, the researchers screened through selection based on inclusion criteria so that the number of articles that were estimated to be relevant were 70 articles. Furthermore, the articles that have been selected based on the inclusion criteria are carried out a eligibility test in the form of reading text as 18 articles, and finally the number of articles that are relevant and will be analyzed are 11 articles.

RESULTS

Based on the search results in five databases, 11 articles were found that discussed the barriers and challenges of end-of-life care implementation in the ICU. The 11 articles determined consisted of 1 article with a mix method study design, 4 articles with a qualitative design, and 6 articles with a quantitative design. Data extraction was carried out by analyzing the data based on the author's name, year of publication and country, purpose, research design, research sample and findings in the article. The results of data extraction showed that the dominant barriers of end-of-life care implementation in the ICU was caused by a lack of communication, lack of knowledge and training on end-of-life care, differences in religious and cultural backgrounds, medical team work in ICU, patient and family factors, and environmental factors. Meanwhile, the challenge of end-of-life care implementation in the ICU was communication and end-of-life care decision making, and unrealistic family expectations. The results of data extraction can be seen in the table 3.

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Table 3.
The result of data extraction

No	Author and Country	Aim	Research design	Research Sample	Findings
1.	(24) Saudi Arabia	To explore nurses' perceptions about barriers to intensive end-of-life care (EoLC) implementation in the care unit (ICU) of Saudi Arabia.	This study used a quantitative design with a cross-sectional approach	The sample in this study were 140 intensive nurses.	Cultural and religious differences are the 3 biggest challenges for ICU nurses in providing end-of-life care. The majority of patients in Saudi Arabia are Muslim, with restrictions on visits to the ICU very contrary to the belief that critically ill patients need assistance from their families, in Islam, visiting sick people is a sunnah that is prioritized. In addition, there are many aspects of legal and ethical issues involved in EOLC related to cultural and religious differences.
2.	(25) Australia	To explore experiences and perspectives nurses and doctors when starting end-of-life care in the intensive care unit.	This study used a qualitative design with in-depth interviews.	The sample in this study consisted of 17 nurses and 11 doctors.	Nurses and doctors experience the biggest obstacle in determining effective communication time to determine the need for end-of-life care to critically ill patients. Nurses and doctors stated that this communication must be done immediately before the patient's condition worsens, this communication related to end-of- life care can be started in the ER before the patient enters the intensive room so that the patient and family understand the prognosis of the disease experienced. Inappropriate communication time will have an impact on reducing the family's trust in nurses and doctors.
3.	(13) English	To identify challenges for health care professionals when moving	The design in this study was qualitative with a semi-structured	The sample in this study consisted of 13 medical staff and 13 nurses as	Patients who die in intensive care will pass through three stages of the end-of-life trajectory : enter with the hope of recovery; transition from intervention to EOLC; controlled death. Transition from intervention to EOLC reported

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		from recovery trajectory to the end-of-life phase in intensive care.	approach.	research informants.	as the most problematic and ambiguous stage in life's final trajectory, potential conflicts between medical teams, and also doctors and nurses.
4.	(26) Australia	The aim of this study was to explore the perspectives and experiences of doctors and nurses who provide EOL care in the ICU. In particular, the perceived barriers, supports and challenges to providing EOLC.	This study used a qualitative design with in-depth interviews.	The sample in this study consisted of 28 nurses and doctors who served in the ICU.	Some barriers to implementation of EOLC are conflicts between ICU doctors and external medical teams, availability of education and training, and environmental limitations. Supporting the implementation of EOLC is collaboration and leadership during the care transition. And challenges of EOLC are communication and decision making, and family expectations.
5	(27) United States of America	To describe the nurse surgeon's perspective on palliative and end-of-life care for patients with Stage IV CRCs	The research design was a mixed method study.	The sample in this study were 131 nurses.	Some barriers to palliative and end-of-life care: (1) knowledge and training, (2) communication challenges (3) difficulty with prognostication, (4) patient and family factors that include unrealistic expectations and discordant preferences; and (5) systemic problems including culture and lack of documentation and compliance resource.
6.	(28) United States of America	To explore barriers to optimal communication and end-of-life care in	This study used a qualitative design with focus group discussion.	The sample in this study were 32 SICU nurses.	Some barriers to optimal communication are summarized into four domains, namely: logistics, discomfort with in-house doctors discuss prognosis, inadequate skills and training, and fear of conflict. Optimal EOLC resistance results in four domains, namely: logistics, inability to recognize end-of-life situations, inadequate skills and training, and cultural differences related to end-of-life

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		SICU perceived by nurses.			care.
7.	(29) Iran	To determine the perception of pediatric nurses about the intensity, frequency of occurrence, and score magnitude in barriers to providing pediatric end-of-life (EOL) care	This study used a descriptive cross-sectional study design that examines Pediatric nurses' perceptions of the intensity and frequency of events barriers in caring for end-of-life children.	The sample in this study consisted of 151 NICUs.	The biggest barriers score were family did not accept the child's poor prognosis (5.04). The higher barriers that nurses feel are problems related to family. One of the possible causes is the lack of palliative care (PC) education in Iran. Thus, developing EOL/PC education can improve knowledge/skills of nurses to meet the challenges of EOL care.
8.	(30) United States of America	To identify perceived barriers, support and changes needed to improve end-of-life care (EOLC) in intensive care unit (ICU) and to compare physician perceptions with nurse	This study used a quantitative design with a cross-sectional approach to doctors and nurses in the ICU.	The sample in this study consisted of 50 doctors and 332 nurses.	The biggest barriers in implementing end-of-life care in the ICU is the lack of family communication. The optimal reinforcing factor for EOLC is nurses, and it is necessary to increase effective communication in providing optimal EOLC.

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9.	(31) Egyp	To identify critical care nurses' perceptions of barriers and supportive behaviors in providing end-of-life care (EOL) for dying patients and their families.	This study used a quantitative design with a cross-sectional approach	The sample in this study were 70 nurses in the intensive care room.	Some barriers to providing EOL care are intensive care environment, family members, knowledge and skills of nurses, attitude of doctors and rules of treatment procedures. Possible assistance to provide EOL care involves nurses supporting each other, patient and family centered care, and family support.
10.	(32) China	To assess nurses' perceptions of what can optimize end-of-life care (EOL) in hospitals and evaluate nurses' perceived barriers to the delivery of EOL care.	This study used a quantitative design with a cross-sectional approach.	The sample in this study were 175 nurses who worked in the ICU.	The top five barriers are “doctors are too busy”; "nurse too busy"; “insufficient personal space”; “nurses have limited training in EOL”; and “families have unrealistic expectations about patient prognosis.” Multivariate regression analysis identified that nurses have not experience in caring for dying patients reported significantly higher number of perceived barriers to EOL . treatment (p = 0.012). Those with postgraduate degree training reported significantly less perception resistance (p = 0.007).
11	(33) Korea	This study aims to determine the facilitators and perceived barriers by nurses to end-of-life care (EOL) in a clinical setting.	This research used an exploratory-descriptive study.	The sample of this study consisted of 400 nurses who worked in the ward unit, ICU, and oncology unit.	The top two perceived barriers were 'the family didn't accept what was' doctors inform them of the patient's prognosis' and 'deal with angry family members'.

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DISCUSSION

1. Barriers of End-of-Life Care Implementation in the ICU

a. Lack of Communication.

The term communication comes from the Latin *communicare* - *communicatio* and *communicatus* means a tool related to the system of delivering and receiving news, such as telephone, telegraph, radio, and others. In simple terms, communication can be defined as a process of exchanging, delivering, and receiving news, ideas, or informating from one person to another. Communication is very important role in patient healing, is related to the collaboration of nurses and other healthcare, and affects patient and family satisfaction (34).

Within the scope of intensive care, communication problems are still barrier and challenge for nurses, especially when dealing with patients' families. The condition of critical patients who are not aware of making family as the holder of autonomy in decision-making treatment action. This situation makes nurses always have to communicate with the patient's family and often have difficulty in assisting the family to accept condition of critical patients, complicated care and treatment procedures in the ICU, and misunderstandings between nurse-patient and family. Nurses should choose communication techniques that suit family characteristics such as speaking slowly, using simple and repetitive language. In shortly, Age factors and family education of patients in the ICU affect communication techniques who use nurses with them. Nurses choose to communicate slowly to families of elderly patients. When communicating with families with low levels of education, nurses use simple language and must repeat information (35).

The results of research conducted by Festic., et al (2010) stated that the biggest barriers during implementation of end-of-life care is the lack of communication to families, thus improving communication between the health team and paying attention to the consistency of messages to patients and their families is a must to improve EOLC (30). This is supported research from Brooks., et al (2017) stated that effective communication in initiating end-of-life care in intensive care is very important and requires multidisciplinary implementation. Nurses and doctors experience the biggest barriers in determining effective communication time to determine need for end-of-life care to critically patients. Nurses and doctors stated that this communication must be done immediately before the patient's condition worsens, this communication related to end-of-life care can be started in the emergency room before patient enters in the intensive room so that the patient and family understand the prognosis of the disease experienced. Communication time will have an impact on reducing the family's trust of nurses and doctors (26).

b. Lack of Knowledge and Training about End-of-Life Care.

Knowledge is a result of curiosity through sensory processes, especially in the eyes and ears of certain objects. Knowledge is an important domain in the formation of open behavior (36). While education is the process of transferring knowledge systematically from one person to another according to the standards

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set by experts. With the transfer of knowledge, it is expected to change attitudes, behavior, thinking maturity and personality maturity into formal education and informal education (37). Nurses' knowledge and education about end-of-life care is a barrier for optimal implementation.

According to Brooks, et al (2017) stated that education and training are essential in achieving optimal EOLC care and communication. Lack of knowledge and education about end-of-life care is still a challenge for ICU nurses (26). Furthermore, Suwanabol., et al (2018) stated that seventy-six percent of ICU nurses reported no formal training in end-of-life care. And forty-three percent of ICU nurses reported that the end-of-life care training they received was inadequate (27).

In addition, Aslakson., et al (2012) stated that the inadequate skills and training of nurses on end-of-life care caused nurses to not understand how EOLC should be carried out, nurses did not know what to say to the family when the patient had died (28). The research supported by Attia., et al (2013) stated that critical nurses need to be trained on how to discuss a topic of death with patient's family, how to manage pain in the end- of-life phase, and to gain a better understanding about care in the end-of-life phase (31).

Nurses' knowledge and education about end-of-life care needs to be improved. The research result by Chan., et al (2020) stated that nurses who had attended EOLC training experienced fewer barriers to implementing EOLC than nurses who had not attended training (32). In addition, Iranmanesh., et al (2016) stated that developing EOL/PC education can improve nurses' knowledge/skills to face the challenges of EOL care. Therefore, to support nurses, it was identified that education and training on EOL care should be available (29).

c. Differences in Religious and Cultural Background.
Humans are unique and holistic creatures, nurses must view patients as bio-psycho-socio-cultural and spiritual beings who respond holistically and uniquely to health changes. Nursing care provided by nurses cannot be separated from the cultural aspect which is an integral part of the nurse-patient interaction (38). Cross-religious and cultural care included in current issue in the nursing development, especially end-of-life care (39).

The research conducted by Aslakson, et al (2012) stated that cultural and religious background barriers in the implementation of end-of-life care can occur both nurses and families (28). They feel uncomfortable with the end-of-life care given because it is not in accordance with their religion and culture. In addition, Mani & Ibrahim (2017) stated that cultural and religious differences are 3 biggest challenges for ICU nurses in providing end-of-life care. The majority of patients in Saudi Arabia are Muslim, with restrictions on visits to the ICU very contrary to the belief that critical patients need assistance from their families, in Islam, visiting sick people is a preferred sunnah. In addition, there are many aspects of legal and ethical issues involved EOLC related to cultural and religious differences (40).

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d. Medical Team Work in Intensive Care Unit
The end-of-life care is inseparable from working relationship between medical professions, the better collaboration of the medical team in the ICU thus care provided will be better. The medical team performance that became barrier in the implementation of EOLC like conditions of the medical team's coping strategies, teamwork, and conflicts between medical team.

According to Brooks, et al (2017) stated that a common barrier that occurs in the implementation of end-of-life care in the ICU is conflict between intensive care doctors and the external medical team. This conflict is largely due of diffeerent views of the multidisciplinary team about the goals of patient care. Nurses and doctors pointed out that conflict between ICU team and external medical team was due to disagreements about patient management, concerns about acknowledgment of death, and the existence of unrealistic expectations (26). In addition, Chan, et al (2020) stated that busy doctors and nurses are barrier in implementing optimal end-of-life care (32).

e. Patient and Family Factors.
Patient and family factors related with wrong understanding of death, difficulty in prognosticating the patient's illness, and unrealistic family expectations for end-of-life care. The results of the study by Iranmanesh, et al (2016) stated that the barriers that nurses felt were higher were problems related to the patient's family (29). In addition, Chan, et al (2020) stated that unrealistic family expectations of patient prognosis are one of the highest barriers to end-of-life care (32). According to Lee, et al (2013) stated the top two barriers felt by nurses were 'families don't accept what doctors say about the patient's prognosis' and 'dealing with angry family members'(33). In addition, Attia, et al (2013) stated that critical care perceived that families who constantly called nurses to ask for the latest information about the patient's condition were severe barriers to providing EOL care. Although providing information about the patient's condition is an important part of patient care, frequent interruptions by the patient's relatives create a further burden on the nurse providing care (31).

f. Treatment Environmental Factors.
Barriers related to environmental factors for end-of-life patient care consist of human resources, and treatment room facilities. The results of the research by Attia, et al (2013) stated that Intensive care environment has a heavy workload where number of nurses is not proportional with number of patients, this will certainly reduce time between patients and nurses which has an impact on EOLC, in addition to poor ICU design that does not allow privacy for end-of-life patients or the bereavement of family members. perceived as the second most powerful barrier to providing EOL care. The ICU is designed to treat acutely ill patients, not dying patients and their families (31). In addition, Brooks, et al (2017) stated that intensive care environment was identified as a bottleneck in optimal EOL due to lack of privacy in the open ICU space, and noise from monitors and

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ventilators(26). According to Aslakson's et al (2012), There is no EOLC consultation facilities for patients, there is no EOLC standard operating precedure and maximum dose in drug administration in the ICU are logisyic barriers in the ICU(28).

2. Challenges of End-of-Life Care Implementation in the Intensive Care Unit

a. Communication and End-of-Life Care Decision Making

Critical patients who will go through intensive care stage to EOLC treatment begin with awareness of nurses and medical teams about the patient's condition that is not improving. There must be special communication between nurses, medical teams, patients, and families to determine a decision about the next therapeutic action(13). Communication between nurses, healthcare, and families is a challenge that must be considered in end-of-life care, good communication will greatly impact on good decision making (27). Nurses stated that they experienced difficulties in communication and decision making at the end-of-life, such as language barriers, poor communication and doctors' experiences in having difficult conversations. Nurses also feel pressured with timing of end-of-life care decisions, this indicates that discussions about decision-making occur too late. Nurses and physicians state that patients should be involved in decisions about EOL care. This view becomes a barrier in the ICU as some patients may not discuss with their families about EOL care, and often unable to make decisions about their care because of the severity of their illness (25).

b. Unrealistic Family Expectations

The nurse considers family to have challenges in accepting the patient's prognosis, difficulty in obtaining a consensual view of the family about treatment options, and fear of the unknown in undergoing the end-of-life care. Nurses describe having difficulty transitioning to end-of-life care when families have not reached consensus. The nurse stated that the actions of the health professional could contribute to unrealistic family expectations. This could be due to poor end-of-life discussion times, different communication styles, difference views of health professionals, and ineffective leadership (25).

CONCLUSIONS

Based on the description of the results and discussion from 11 articles about barriers and challenges of end-of-life care implementation in the ICU, it was found that barriers of end of life care implementation were lack of communication, lack of knowledge and training about end-of-life care, differences in religious and social backgrounds. culture, the work of the medical team in the ICU, patient and family factors, and environmental factors. Meanwhile, challenges of end-of-life care in ICU are communication and decision making in end-of-life care and unrealistic family expectations. As a recommendation in improving end-of-life care services in the ICU, health service agencies need to increase knowledge and training of healthcare about communication and end-of-life care in critical patients.

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