

NURSES' EXPERIENCE OF ETHICAL DILEMMA AT THE END-OF-LIFE CARE IN THE INTENSIVE CARE UNIT

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ABSTRACT

One of the aims of the care service in the Intensive Care Unit (ICU) is to prepare patients in end-of-life conditions to die in a dignified manner. This can be challenging due to decision-making problems and result in a dilemma. Therefore, this study explores the ethical dilemmas experienced by nurses that provide end-of-life care in the ICU. The qualitative phenomenological methodology was used to describe the ethical dilemmas nurses face during these conditions. The data were collected through in-depth interviews and were analyzed using Colaizzi. Purposive sampling was used to select a total of eight participants, i.e., ICU nurses, who have treated end-of-life patients. Four themes were obtained from this study, namely, "the dilemma between the family's decisions and continuing care", "patient's life expectancy and the family's hope", "DNR decisions and the nurse's confidence", and "the family's understanding of the information provided". This study recommends that the assessment of end-of-life status in critical care areas, especially the ICU, should be conducted as soon as possible to have a clearer purpose for the care provided.

Keywords: End of life; ethical dilemma; ICU; nursing



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INTRODUCTION

The Intensive Care Unit (ICU) handles critical patients due to illness, trauma, or other disease complications. The unit focuses on life or organ support that often requires intensive monitoring (Jones & Griffiths, 2014). It also aims to provide the best services to maintain the patient's life and for dying care (Fernandes & Moreira, 2012). The ICU ward is very complex because it is a life-saving area that requires health workers to apply ethics in situations that need quick decision-making (Park et al., 2015). The decision-making process could be very difficult when the patient or their family needs to decide things related to the lifesaving aspect of the patients (Span-Sluyter et al., 2018). This situation creates an ethical dilemma situation for health workers, especially nurses.

Ethical dilemmas can occur when nurses know the required actions to save the patients, but they are unable to do so due to various considerations, one of which is the socio-cultural problem of the patient's family (Holt & Convey, 2012). Moreover, the decisions taken could also conflict with the

moral beliefs of the health team (Santiago & Abdool, 2011). The ethical dilemmas that often occur in the ICU ward are related to end of life care (Sorta-Bilajac et al., 2011).

End-of-life care is part of palliative care for end-of-life patients (Krau, 2016). This care service aims to improve the patient's quality of life and to prepare them to die in a dignified state (Servillo & Striano, 2008). End-of-life care for patients who have experienced critical conditions, especially for patients in the ICU room, has improved due to developments and technological advances (Vanderspank-Wright et al., 2011). Nevertheless, end-of-life care in ICU services is challenging because the ethical dilemmas faced by nurses and doctors make it difficult for them to make medical decisions (Sorta-Bilajac et al., 2011). The aspects that contribute to this condition include religious factors, beliefs, education, and language factors related to the communication used. Unfortunately, the difficulties in making these decisions also have negative effects on patients and their families (Curtis & Vincent, 2010).

The long-standing ethical dilemmas faced by nurses will also be a factor that causes mental fatigue and can interfere with their professional practice, thereby leading to suboptimal care (McAndrew et al., 2011). Moreover, issues due to ethical dilemmas can increase patient suffering and the cost of care (Wiegand et al., 2015). Therefore, this study aims to explore the ethical dilemmas experienced by nurses providing end-of-life care in the ICU.

METHOD

Study design

This is qualitative research with a phenomenological approach. Phenomenology is the study of how individuals understand their life experiences so that they can reflect on them psychologically (van Manen, 2016). This approach aims to explain the structure or essence of the life experience of someone who experienced a phenomenon by identifying the meaning and accurately describing their life experience (Maxwell & Reibold, 2015).

Participants

The participants involved in this study were eight ICU nurses who were selected by using the purposive sampling method. The sample selection was assisted by the head nurse of the ICU with the following inclusion criteria: nurses with more than two years of work experience in the ICU, a minimum education of Diploma III in nursing, can communicate and work well, and have experience caring for end-of-life patients at least twice in the last two years. After discussing the selection of participants with the ICU head nurse, the researchers made a time contract.

Data collection

The data was collected using an in-depth interview approach, and the interviews were conducted in the ICU headroom. Before conducting the interview, the researchers met the respondents to explain the plan and purpose of the research. After they agreed to participate in the interviews, the researchers made a contract of where and when the interviews will be held. The interview was conducted for approximately 40-60 minutes. The research instrument included interview guidelines and voice recording devices.

The interview began with introduction, signing of the informed consent form, and asking research questions regarding the ethical dilemmas experienced by nurses when providing end-of-life care in the ICU. The interview process was done 1-2 times for each participant, in which the first meeting explored the nurses' experiences related to the ethical dilemmas they felt when providing end-of-life care in the ICU. Meanwhile, the second meeting clarified the data that were obtained, and the participants were asked again if there were other things that they would like to add or convey. At the final stage of the study, the researchers informed the participants about the findings and conclusions. The interview and participant recruitment stopped after 8 interviews to the point of data saturation.

Data analysis

Data analysis was performed with the Colaizzi method approach. Each interview recording was transcribed. The transcriptions were then returned to the participants to be validated if there is information that the participant wants to add or remove if it does not reflect their experience. All participants agreed with each transcription. Furthermore, the encryption is read repeatedly by the researcher to find the essence of the participant's expressions and determine important statements that follow the objectives of this study.

The important statements were then formulated into more general meanings and then formulated into a theme group.

Trustworthiness

In maintaining the rigor of the research and ensuring the credibility of the findings, the researchers used member checks. Reliability was achieved by maintaining the consistency of the same main questions in data collection per interview guidelines. Conformity was achieved by writing down what the participants expressed and then writing direct quotations from the transcribed data. Lastly, the researcher provided a detailed description of the research process and setting. This allows anyone interested in transferring data findings to determine whether or not such a transfer is possible (Lincoln & Guba, 1985).

Ethical considerations

This study went through several ethical consideration processes including obtaining ethical approval from the ethics committee of the Faculty of Medicine, Padjadjaran University with the ethical clearance number 201 / UN6.KEP / LC / 2019, regarding informed consent, anonymity, confidentiality, beneficence, and justice.

RESULTS

Based on the results of data analysis using the Colaizzi method approach, 4 themes were identified in this study.

The dilemma between the family's decisions and continuing care

The first theme found in this study is the existence of an ethical dilemma between the sustainability of care and family decisions. Almost all participants revealed that when a patient was treated for their end-of-life condition, families often experience dilemmas. They wish to continue the treatment, but it is constrained by the cost of care. The following is a relevant statement from a participant:

"Perhaps the most common thing here is, for example, families have objections in funding, but actually the patient still has hope, actually in my heart it feels like something is up in my mind ..." (P 1.4)

Other participants also revealed that the family's decision will affect the continuity of further care, as shown in the following statement:

"... but in terms of family members, they have decided to turn it off, so what we have done so far, and what we will do in the future is not optimal, ..." (P 3.2)

Other participants also expressed a similar statement:

"... On the one hand, we know that this patient is still able to survive, and the patient's life expectancy is still there, but on the other hand the family took the decision to take the opposite action" (P.4.22)

Patient's life expectancy and their family's hope

Some participants expressed experiencing a dilemma when faced with conditions when the family no longer had any expectations regarding care for the patient, even though the patient still had a high life expectancy.

"When it comes to making decisions, even though the patient's life expectancy is still there, the family would sometimes state to DNR (Do Not Resuscitate). So, even though we have explained the patient's progress, we will still respect the family's decision ..." (P.4.18)

Other participants also revealed that sometimes feelings of a dilemma arise when the expectations of the family differ from the life expectancy of the patient. An example would be when the patient has a low life expectancy, but the family has high expectations, as stated by a participant:

"... for example, BSD (Brain Stem Death) patients want to maximize their family life, but the life expectancy is gone, so we like to pity the patient, so it is like we are obstructing the patient ... it's like we are torturing the patient" (P 6.16)

DNR decisions and the nurse's confidence

The next theme that emerged in this study is when nurses' beliefs conflict with the termination of care. Most participants expressed that a common dilemma that they face is related to their contrasting beliefs regarding the decision to terminate care, as expressed by one participant:

"...On the one hand, we know that if, for example, this patient is given this procedure, he can still survive and the patient's life expectancy is still there, but on the other hand, the family makes the decision to end the treatment." (P 4.32)

Other participants also expressed a similar statement:

"...well, we will bring that to reality. Sometimes there are families of patients who receive the term. They want their family to recover, so whatever I do, even though if you look at it medically, the patient's quality of life is low" (P 5.10)

The family's understanding of the information obtained

Several participants revealed that they would experience an ethical dilemma when explaining information related to the patient's development to their families. The information conveyed by health workers, doctors, and nurses tends to be poorly understood by the families. The participants stated their experiences in the following statements:

"What frequently occurs is that after the patient's condition has been explained to the family by the medical team, the family will decide on the subsequent course of treatment. However, when that treatment is administered, the family frequently inquires once more to the nurse about the reason for the subsequent treatment and the procedure administered. Occasionally, after being given a further explanation, the family would refuse the action to be taken (P 7.3).

Another participant also revealed the following statement.

"..., due to the family's lack of understanding of the information provided, sometimes when an immediate decision is needed, the family seems confused on how to behave and hamper the care provided" (P 8.4)

DISCUSSION

The dilemma between the family's decisions and continuing care

The patient's family plays the role of an advocate for their ill family members (Kydonaki et al., 2014). They also act as a guarantor of the rights of critical patients and assume responsibility for decisions related to their care and treatment (Padilla Fortunatti, 2014). The problems that arise would be related to making treatment decisions, as sometimes nurses cannot predict when the family will decide on the next treatment and how long they would need to wait until the

family has made their decision (Hidayat et al., 2021). This study also found that most participants revealed that the decisions taken by the family will affect the continuity of care in patients and whether nursing actions will be continued or stopped.

In end-of-life care, the medical team sometimes has difficulty predicting the patients' length of treatment. This will in turn affect the cost of care that must be issued by the family (Selph et al., 2008). Other studies have also revealed that family decisions related to moral issues that occur in the family can sometimes help or complicate nurses in the process of further treatment follow-up (Chaves & Massarollo, 2009).

Patient's life expectancy and their family's hope

The decision-making process for DNR by the medical team could sometimes be rejected by the patient's family. This is influenced by the family's high expectations of the patient's recovery, in which the family expresses the desire that the patient can still receive maximum therapy, including CPR at the time of cardiac arrest (Amestiasih et al., 2015). The medical team must still respect all family's decisions or rejections (General Medical Council, 2014). Statements from this study's participants also revealed similar results, in which the family refused the DNR labeling despite the patient's low life expectancy.

It is often difficult for family members to make decisions on behalf of their loved ones as they may worry that their family member has suffered or that they give up too quickly, and they often harbor feelings of doubt, regret, and guilt (Adams et al., 2014). Family members who become responsible for the patient's decisions tend to also experience emotional distress related to their extended family's approval regarding the patient's death or any changes in their functional status and quality of life (Majesko et al., 2012).

DNR decisions and the nurse's confidence

The next theme is the decision to interrupt a treatment that is contrary to the nurses' beliefs. This ethical dilemma occurs when nurses face obstacles that prevent them from taking actions that are contrary to their moral beliefs (Santiago & Abdool, 2011). Such conditions could occur due to moral pressure, which could also lead the actions taken to be sub-optimal (Arianto et al., 2018). This condition is also often found when there is a treatment interruption process after the DNR decision-making process (Brizzi et al., 2012).

Caring for DNR patients is not easy, giving the DNR labels to patients can create a dilemma for nurses (Lingard et al., 2008). The dilemma can be influenced by the nurses' personal experience. It is more likely to occur in those who encounter DNR patients who eventually die during treatment. This dilemma is often felt by nurses who lack experience, knowledge, and information related to DNR. The limitations and inadequacy of DNR information affect the effectiveness of the delivery of dignified care (Piers et al., 2010).

Nurses must respect all decisions made by the family. They must act as an advocate for the patient or their family, provide correct and relevant information, and provide the best nursing care before the death process (Kon et al., 2016). The end-of-life care provided must also uphold the dignity and respect of the patient (Rosser & Walsh, 2014).

The family's understanding of the information provided

The communication dilemma felt by nurses is not only related to the attitude displayed by patients' families when dealing with them, but also to the nurses' psychological and physical

conditions. This is because when they are tired or are facing personal problems, nurses could often forget their appearance when communicating with patients' families (Arumsari et al., 2017). This condition can cause miscommunication.

Miscommunication between the family and the medical team also results in a misunderstanding of the decision-making process and consequently, the care provided to the patients (Flannery et al., 2016). Inadequate sources of information can affect the ineffectiveness of providing dignified care (National Institute for Health and Care Excellence, 2013). Communication problems in providing information related to the patient's prognosis to the family will influence the decision-making in the continuation of care. Moreover, misunderstandings occurring between the medical team and the doctor will result in treatment inconsistencies (Shorideh et al., 2012).

The limitation of this study is that during the interview the respondents could not leave the ICU ward. Hence, during the interview, they were sometimes disturbed by the activities of other nurses in the room.

CONCLUSION AND RECOMMENDATION

This study showed that there were four themes of ethical dilemmas felt by nurses working in end-of-life care in the ICU. These predicaments include the dilemma between the family's decisions and continuing care, the patient's life expectancy and their family's hope, DNR decisions and the nurse's confidence, and the family's understanding of the information provided. Each theme is interrelated as the dilemma is felt when family and medical decisions on patient care do not align with the nurses' applicable ethical values. This in turn results in the nurses' experience of moral distress. The results of this study also showed that nurses, especially those in the critical care area, experienced moral suffering because they had to take actions that do not follow their moral judgment. This results in an ethical dilemma that affects the quality of end-of-life care services provided.

Therefore, it is recommended for the hospital to form a special team to handle end-of-life cases to ensure the goals of care are achieved and ultimately improve the quality of care provided to end-of-life patients.

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