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Research article

Exploring nurses' end-of-life care for dying patients in the ICU using focus group interviews

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ABSTRACT

Purpose: The aim of this study is to illuminate how nurses working in an intensive care unit perceive their professional duties regarding end-of-life care based on their end-of-life care experience.
Design and methods: A qualitative research design utilising focus-group interviews was employed. Two focus groups with twelve nurses were recruited, one consisting of nurses with less than five years of clinical experience in intensive care units and the other with more than five years of experience.
Findings: An analysis of the nurses' explorations of end-of-life care in an intensive care unit for patients facing impending death revealed three main themes: (1) facing an extreme change in human existence, (2) being in the presence of the patient's transition and (3) being prepared as an intensive care unit nurse. These three themes covered a total of 16 subthemes.
Conclusion: The findings of this study outline how intensive care unit nurses perceive dying patients and how they manage end-of-life care. It also illustrates how patients and their families can be included in the process, and this should be a component of nurses' education regarding end-of-life care.

Implications for clinical practice

- A mentor system needs to be introduced for nurses in order to guarantee the quality of end-of-life care in intensive care units. Guidelines for end-of-life management that are specific to intensive care units should be developed based on the input of experienced nurses
- How intensive care unit nurses perceive dying patients, how they manage patients' end of life, and how patients and their families can be included in this process all need to be included in nursing training regarding end-of-life care in intensive care units.

Introduction

Critical care has become an increasingly important task for modern hospitals. In general, patients are admitted to the intensive care unit (ICU) of a hospital to aggressively treat their disease or injury; however, not all patients admitted to the ICU will recover (Abdalrahim and Zeilani, 2014; Kurian et al., 2014). Therefore, nurses are tasked with acknowledging the subtle transition from possible recovery to the understanding that further aggressive efforts may be futile in prolonging a patient's life (Coombs et al., 2012). End-of-life care (EoLC) in the ICU is becoming a recognised component of an ICU nurse's role and this needs to be made more explicit (Fontes and da Cruz, 2013; Fridh, 2014).

EoLC is currently a significant topic of debate in intensive care settings (Borhani et al., 2014). Research on EoLC in ICUs has primarily focused on the decision-making process involving medical staff and the patient's family related to initiating this form of care (Coombs et al., 2012), the provision of comfort to a dying patient and meeting spiritual needs in the last moments of life (Noome et al., 2017), dealing with the emotional distress of a dying patient's family (Kisorio and Langley, 2016a; Noome et al., 2016a) and the medical staff's need to prepare for EoLC in the ICU (Fenwick and Brayne, 2011; Mazzarino-Willett, 2010; Curtis, 2012; Kisorio and Langley, 2016b).

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The literature clearly indicates that the role of ICU nurses in terms of EoLC is care for the patient, family and environment. A large volume of information is available on what care should be provided, but it remains unclear how nurses do this in EoLC (Noome et al., 2016b; Haugh, 2015; Choi et al., 2015). In order to reduce the lack of clarity regarding the provision of EoLC in an ICU and to provide high-quality services, practical guidelines that can be applied in practice are required considering the diverse cultural background of the patient and the degree of expertise of the practitioner, yet few have been developed (Efstathiou and Walker, 2014; Ramasamy Venkatasalu et al., 2015; Reid et al., 2015).

Previous studies have found that people are afraid of dying alone and that they also need EoLC to deal with spiritual issues (Fountain and Kellehear, 2012; Fenwick and Brayne, 2011; Mazzarino-Willett, 2010). However, the literature suggests that ICU nurses are not prepared to adequately deal with spiritual matters (Fontes and da Cruz, 2013). Care of patients dying in an ICU often requires a dramatic shift from rescue mode to approaches that recognize death's inevitability (Silva et al., 2011). Death in an ICU is neither straightforward nor natural; the process can be messy, noisy and complicated (de Boer et al., 2012). However, there is a need to focus on the transition from curative intervention to EoLC so that effective and timely decision-making underpins the care of dying patients (Coombs et al., 2012).

ICU nurses are increasingly the frontline providers of EoLC when life-sustaining measures have become futile (Haugh, 2015). Death in the ICU can be especially stressful for nurses, who must constantly care for a patient while other health care providers visit for short periods and then leave to perform other duties (Abdalrahim and Zeilani, 2014; de Boer et al., 2012). Despite this added stress, the provision by nurses of a warm, family-friendly environment and spiritual support has been presented as a key element of compassionate EoLC in an ICU (DeSanto-Madeya and Safizadeh, 2017). Therefore, the quality of EoLC in an ICU depends on nurses' perception of dying patients and how they choose to provide EoLC. Despite this, few studies have documented what ICU nurses consider to be suitable EoLC (Endacott et al., 2016). The aim of this study is thus to investigate how nurses working in an ICU perceive their professional tasks regarding EoLC based on their professional experience.

Methods

To explore ICU nurses' in-depth thoughts on end-of-life care (EoLC) in an ICU, qualitative research utilising focus-group interviews was conducted. Focus groups can provide information about the range of ideas and feelings held by individuals on certain issues, as well as illuminating the differences in perspectives between groups of individuals. The advantage of using focus-group interviews is that, in the interview process, one participant can stimulate another to add his or her perspective (Morgan et al., 2004; Dilshad and Latif, 2013).

Participants

A purposive sample of nurses working in an ICU at a university hospital in South Korea who volunteered for this study was used to explore their personal thoughts and feelings. ICU nurses from the target hospital were informed of the purpose of this study and volunteers were recruited to participate. It is assumed that only nurses who were willing to discuss issues regarding death and dying would decide to take part in this study. Two focus groups were then created based on ICU experience: one consisting of nurses with less than five years of clinical ICU experience, and the other with more than five years of experience. Participants were recruited until each group contained six nurses, meaning 12 in total took part in the research. Five years of clinical experience was set as the criterion for dividing the two groups based on preliminary interviews conducted with ICU nurses. When opinions were sought on related topics during these interviews, the nurses' answers started to exhibit differences at the five-year mark. The characteristics of the participants are presented in Table 1.

Data collection

The data collection period was from December 2015 to February 2016. Each group was interviewed twice, with a more open discussion about EoLC held in the first interview followed by a more direct approach in the second based on an analysis of the first interview. Because the two groups differed in their length of clinical ICU experience, the differences in perception regarding EoLC were compared between the groups and these findings were shared with the groups to explore the perception of EoLC.

The interviews were conducted in a quiet, noise-free ICU nursing facility. EoLC in an ICU encompasses different aspects of care, such as personal care, the support of the patient and their family, and dealing with existential questions about life and death (Noome et al., 2016a). We created the interview questions in consideration of these elements of EoLC.

After each question was discussed, the researcher checked whether their understanding of the participants' opinions on EoLC given in the interview truly reflected the participant's experiences. The interviews were recorded, field notes were taken and each tape-recorded interview was immediately transcribed verbatim.

Ethical considerations

The study was approved by the Institutional Review Board of the associated university (IRB No: 1040548-KU-IRB-15-178-A-2). The researchers explained the purpose of the study to all

Table 1
Characteristics of the participants.

Group	ID	Gender	Age	Years of experience	Religion	Education
Focus Group 1:	F1, P 1	F	24	3 years 7 months	Protestant	BSN
Nurses with	F1, P 2	F	24	2 years 6 months	Atheist	BSN
<five years of experience	F1, P 3	F	25	1 year 10 months	Atheist	BSN
	F1, P 4	F	24	1 year 3 months	Buddhist	BSN
	F1, P 5	F	25	2 years 9 months	Protestant	BSN
	F1, P 6	F	30	3 years 3 months	Roman Catholic	BSN
Focus Group 2:	F2, P 7	F	35	9 years 10 months	Protestant	BSN
Nurses with	F2, P 8	F	39	15 years 9 months	Protestant	MSN
>five years of experience	F2, P 9	F	29	6 years 9 months	Buddhist	BSN
	F2, P 10	F	29	6 years 3 months	Buddhist	BSN
	F2, P 11	F	30	7 years 10 months	Atheist	BSN
	F2, P 12	F	29	6 years 5 months	Roman Catholic	BSN

participants and, after confirming that the participants were participating voluntarily, the researchers distributed a study consent form to each participant that explained the purpose and process of the study. The researchers informed the participants that they did not need to participate if they did not want to do so during the interview process. This study was conducted only with those participants who submitted the written consent form and agreed to participate.

Data analysis

Thematic analysis was used to gain an understanding of the nurses' perception of EoLC in an ICU (Braun and Clarke, 2006). First, we familiarised ourselves with the data, generating initial codes and searching for themes. We then reviewed these themes by defining and naming them. The analysis continued until a convincing story using the data could be formulated. To ensure the consistency and reliability of the data analysis, all of the data was analysed by two researchers.

Findings

The thematic analysis of the participating nurses' exploration of end-of-life care (EoLC) in an ICU for patients facing impending death revealed three main themes consisting of 16 subthemes. The three main themes were (1) facing an extreme change in human existence, (2) being in the presence of the patient's transition, and (3) being prepared as an ICU nurse (Table 2).

Facing an extreme change in human existence

Recognising the inevitability of death

All of the participants had experienced a patient's death during clinical practice and had witnessed the death process firsthand. When the participants observed a patient's death, they established their own philosophical values with regards to life and death and learned about the true meaning of life and death. They recognised that the death of a human is a phenomenon that must be managed throughout life, rather than being an event that suddenly approaches one day.

> "*If I did not have a job as an intensive care nurse, I would have lived without thinking deeply about death. In the ICU, when I look at the people who are dying and their families, I think I am a little more thoughtful about human death and I feel that someday I will die. Human death is a fate that can't be avoided*". (F2, P8)

Table 2
Themes and Sub-Themes in ICU Nurses' Perception of End-of-Life Care.

Themes	Sub-Themes
Facing an extreme change in human existence	Recognising the inevitability of death Unfamiliar with dealing with the process Following the process of change The end of life as a critical time that needs to be managed using active care End of life as entering biological death End of life as a critical moment in spiritual care
Being in the presence of the patient's transition	Letting the patient know that they are not alone Mediating between the patient and their family Providing time and space to say goodbye Treating the patient as if they were conscious Being together during the painful process of transition Taking care of the patient's affairs Recognising a patient as a being experiencing physical death Accepting a patient as a spiritual being accepting death
Being prepared as a ICU nurse	Necessity of learning end-of-life care as a novice Necessity of ICU-specific end-of-life care systems

Unfamiliar with dealing with the process

The less-experienced participants tended to describe the strong memory of their first experience with a patient's death in the ICU and were inclined to perceive human death as cold, dark and scary.

> "*I have been working in the intensive care unit for just one year and I am a little afraid when I see a patient who is dead. I'm afraid when I see a patient who is already dead and hard like a mannequin. I'm scared of death and I'm afraid that I will disappear*". (F1, P4)

Following the process of change

The more-experienced participants tended to recognise death as a natural part of life that everyone experiences, rather than holding a negative view of death. They tended to see death as a change on the continuum of life and suggested that they would participate in the process of change.

> "*I do not think death is the end of life. I think that life is like the driving force and death is something that everyone must experience without any exception, so death is also an extension of life in the end. . .*" (F2, P12)

The end of life as a critical time that needs to be managed using active care

The participants emphasised that they should try to understand the loneliness of a dying patient isolated from their family and the fears of patients who are dying in an unfamiliar place. They believed that the patient should be treated as a human rather than as a patient until the last moment of their life. In addition, the participants explained that a patient should have the opportunity to organise the final stages of their life without regrets before dying and they understood that a patient's death was a process that needed to be managed by the patient's caregivers.

They also recognised that the final stage in EoLC would be postmortem care, emphasising the need to preserve the dignity of the deceased as much as possible.

> "*The ICU is a lonely space for dying patients. Rather than thinking that life is ending when treating a dying patient, I think as a human being and if there is a way for things to end comfortably and with dignity in the process of finishing a patient's life, I should help as much as possible*". (F2, P8)

> "*It is not very pretty when the patients are intubated just before death and tubes are plugged into their whole body. Postmortem care should be done in a courteous manner to protect the rights of the deceased patient*". (F1, P1)

End of life as entering biological death

The less-experienced participants were familiar with the definition of biological and medical death, which states that death occurs when the heart, respiration and brain functions have stopped. However, after encountering various death situations in the ICU, they were beginning to recognise that there was a need to define death in a broader sense than mere clinical death.

"*Is it right for the patient to experience an unnecessary procedure every time one is added in the situation where he is waiting for death? In the intensive care unit, [which is] familiar with biological death, I think it is more necessary to define a patient's death, but it is difficult to decide how it should be defined*". (F1, P1)

End of life as a critical moment in spiritual care

However, the more-experienced nurses tended to view death as the last moment of life and an important spiritual experience. They saw the patient as a spiritual being and recognised the role of the nurse in dealing with a dying patient's need for spiritual care.

"*If we regard human death as merely stopping the heart and breathing, what does a man's life mean? I assume that human death can be the beginning of another spiritual phase*. . ." (F1, P1)

Being in the presence of the patient's transition

The final hours before death may be the most momentous for dying patients. Generally, the greatest fear for many people is to die alone. The participants stated that the end-of-life experience of a patient is accompanied by a rapid change, not only physically but also spiritually, and the nurse should take care of this process. EoLC includes considerations of the patient not feeling lonely, the painless management of the physical process and accompanying the patient during any spiritual changes.

Letting the patient know that they are not alone

The more experienced participants emphasized that it is important for nurses to communicate warmth and tenderness when a dying patient is aware of and/or fears their death and to allow the patient to interact with their family as much as possible so that they don't feel they are alone as death approachess

"*In the ICU setting, I assume the dying patient will be more scared and lonely because their family is not there. So I think the patients are more reliant on the nurse. The nurse may give empathic understanding to the dying patient and try to provide warm contact to overcome the fear and loneliness of death*" (F2, P2).

Mediating between the patient and their family

The more-experienced participants emphasised that it was important that the medical staff fully explain the imminence of the patient's death and any accompanying medical treatment so that the family members can accept and prepare for the death of their loved one.

"*If I was a family member of an ICU patient, it would be best for the nurse or doctor to come to me first and explain the patient's condition--what kind of treatment was being given, what the present condition was, and what treatments were planned. Actually, even when it is time for the family to prepare for death, busy doctors sometimes can't take the time to explain everything to the family*". (F2, P10)

Providing time and space to say goodbye

Additionally, because the ICU is a controlled and closed space, participants recognised that dying patients and their families needed space and time to conduct their own farewell ceremony.

In the ICU, when a patient is dying, there are patients who are unconscious from the beginning, but there are cases where the consciousness of the patient is clear and the treatment is proceeding. I think there should be space and time for them to be able to spend with their precious family so that the patient can have a more peaceful and meaningful end. (F1, P1)

Treating the patient as if they were conscious

The less-experienced participants stated that ICU staff should not say anything that could hurt the patient even if the patient is unconscious and unresponsive.

"*The patient can listen when the medical staff speaks. Even if the patient does not express it, the patient can be hurt by the words of the healthcare provider*". (F1, P6)

Being together during the painful process of transition

The participants stated that dying patients in the ICU expected nurses to listen to them, believe in them, and acknowledge them until the moment of their death. This care includes managing the extreme pain that the dying patient experiences before death, faithfully attending to the basic needs of the patient.

"*Patients before dying will most likely want a nurse to help them so they are not in pain. It is very unfortunate for them to suffer pain until the end of their life*". (F1, P3)

Taking care of the patient's affairs

The less-experienced participants emphasised that a dying patient would not want to appear unsightly in front of their family after death and would want to have their final appearance taken care of. It was also suggested that the medical staff be honest and inform the dying patient that death is imminent, so that the patient has time to organise their affairs.

"*When the patient's death is expected, I would like the medical staff to inform the patient that their death is near so that the patient can decide what they want to do and what they want to say. I would like to give the patient an opportunity to prepare for the end and help them prepare well for their death*". (F1, P3)

Recognising a patient as a being experiencing physical death

In terms of the spiritual change of dying patients, all of the participants had direct or indirect experiences regarding the deathbed visions of dying patients. The less-experienced participants tended to interpret the deathbed visions of a dying patient as a phenomenon that can occur when the patient's organs are failing just before death or as a kind of delirium experienced in a physically and mentally weakened state just before death.

"*When a patient talks about his own deathbed vision, I honestly do not know how to accept it. I am a nurse, but I do not know how to react. I think that when the patient is approaching their death, the condition is getting worse overall. At that time, we think they are getting to the end*". (F1, P3)

Accepting a patient as a spiritual being accepting death

On the other hand, most of the more-experienced participants recognised that the deathbed visions of a dying patient are a unique experience which should not be neglected by the medical staff. They also recognised a dying patient's deathbed visions as a kind of coping mechanism, such as the belief that a dying patient has accepted death.

"*The patient I was nursing was an old woman and she met with her two daughters and she suddenly said "Mom." I asked, "What did you just say to me?" She told her two daughters that her mother had come to her, and her daughters laughed jokingly, saying, "Mom, why?", and then they went home. After an hour, she*

suddenly went into arrest. In the end, she passed away. But when she said she's looking at her mom, it's not really irritable. Is that delirium? She was really alert and comfortable when talking about her mom". (F2, P11)

Being prepared as an ICU nurse

The participants stated that nursing a dying patient in the ICU was a common task, but they were not sure how to go about it. Given that many patients are in the final stages of their life in an ICU, guidelines for nursing end-of-life patients that can be referred to by ICU nurses are needed, along with broader discussions about relevant nursing practices.

Necessity of learning end-of-life care as a novice

The participants emphasised the need for education in end-of-life care, especially how to provide spiritual care for dying patients and how to prepare patients for dying when unnecessary active treatment is halted, which they said was not considered important in the ICU. The participants experienced emotional exhaustion as a result of providing EoLC in the ICU, which they had not learned in their nursing courses, because they were embarrassed and guilty when they provided dying patients with unsatisfying EoLC.

"*I honestly do not know the spiritual concept of nursing, and I do not know which approach is right. It seems that education about spiritual nursing should be done before working in the ICU and that educating nurses about unfamiliar phenomena such as deathbed visions experienced by dying patients would be helpful for treating the dying patient with more attention*". (F1, P1)

Necessity of ICU specific end-of-life care systems

The participants emphasised that EoLC in the ICU, where the patient is hospitalised in a critical condition, is different from the approach to cancer patient-centered hospice care. The participants therefore emphasised that an EoLC system specific to the ICU should be incorporated as part of the formal care system in the ICU.

The participants emphasised the emotional exhaustion of ICU nurses performing EoLC. The participants also suggested that ICU nurses should develop ways to care for the family of dying patients and develop effective interventions for discomfort, including the pain experienced by dying patients and included them as formal nursing procedures. In addition, in situations where contact with religious people is not common, it was proposed to establish ICU-specific spiritual care to accommodate the spiritual needs of dying patients.

"*I often experience situations involving death while working in the intensive care unit, and the more I experience patients' deaths, the more I become numb to death and my feelings become exhausted. I would like to have a system that manages the emotional suffering of the ICU nurse*". (F2, P7)

"*I think the ICU nurse can be the person closest to the patient in the hospital. I think the nurse should be able to approach the patient first, rather than ignoring them when they are hesitating to say something*". (F2, P8)

Discussion

This study focuses on how ICU nurses, who witness many patient deaths, define end-of-life care (EoLC) in the ICU and explores their values and perceptions about that care. Nursing assumes that human beings are physical, psychological, social and spiritual beings and that spirituality emerges as a particularly important area of nursing when patients face death (Korhan et al., 2014; Pilger et al., 2014). Noome et al. (2017) suggested that during EoLC, ICU nurses have to anticipate and address questions and feelings about life and death, i.e., spiritual questions. However, while undergraduate nursing textbooks devote much space to physical nursing, spiritual nursing is not covered in most nursing curricula. The findings of this study confirm that, even for ICU nurses, the death of a patient is not a regular discussion topic in ICU settings. When interviewed in the focus groups for this study, the nurses confessed that they had never participated in this kind of discussion before, reflecting the fact that the mention of human death was a neglected area of routine clinical nursing, as well as of ICU nursing. The participants in this study recognised patients' EoLC needs, such as the need for friendly contact, having someone to listen to, and there being an active presence until their death. However, despite acknowledging the EoLC needs of patients and their family, nurses do not often provide EoLC. Studies have suggested that this situation is due to a lack of time and EoLC education (Endacott et al., 2016; Taylor, 2013). The participants in this study emphasised that EoLC should be instituted as part of systematic ICU nursing care rather than being considered an additional task and that it should be included in the education of inexperienced ICU nurses.

This study explores, from the perspective of nurses working in an ICU, human death and dying patients' deathbed behaviour and visions, neither of which are actively discussed in clinical practice, even among ICU nurses. By establishing two focus groups based on their length of experience in the ICU, the researchers were able to identify the characteristics of EoLC as illustrated by the practical experience of ICU nurses. Kisorio and Langley (2016a) suggested that, as a form of collegial support, experienced nurses should mentor junior nurses to improve EoLC. However, few studies have been conducted on the relationship between nursing expertise and the characteristics of EoLC in an ICU.

The two participant groups with different ICU experience levels shared their opinions on EoLC in the ICU and differences between these views were identified. The less-experienced group tended to present EoLC in general ICU practice, while the more-experienced group showed a tendency to consider EoLC in terms of the care of existential human phenomena. Several studies have emphasized the importance of ICU nurses' education in EoLC, especially spiritual nursing (Fridh, 2014; Noome et al., 2017; Ranse et al., 2016). ICU nurses are more likely to witness patient death compared to nurses in other hospital departments and to experience significant stress. The stress associated with an ICU patient's death is linked to the negative emotions arising from the concerns that they did not provide appropriate nursing care for the dying patient (Kisorio and Langley, 2016a).

The ICU should be a place where lives are saved, but peaceful deaths should also be accepted and supported, and ICU nurses need to be prepared to provide appropriate nursing care in this situation. In this study, we suggest that EoLC in an ICU should be linked systematically with curative care. To reflect the diverse range of ICU working environments, more research is required to improve the quality of EoLC in ICUs.

Limitations

The primary limitation of this study was the choice of subjects, who were recruited from the ICU of a single hospital. In addition, we suggested differences in perceptions of more experienced nurses and less experienced nurses on EoLC in ICU, but only through the findings discussed in two focus groups. Therefore, a more detailed discussion of this topic and differences in perception

of EoLC according to a nurse's clinical experience should be addressed in future studies.

Conclusions

This study investigates how ICU nurses perceive dying patients, how they can manage their patients' end of life while providing end-of-life care (EoLC), and how patients and their families can be included in EoLC. All three of these considerations should be included as part of nursing education in EoLC. In this study, it was emphasized that EoLC in ICUs should be considered a formal ICU service rather than merely an additional one.

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Conflict of interest

The authors have no conflicts of interest to declare.

Ethical statement

The study was approved by the institutional review board of Korea University (IRB No 1040548-KU-IRB-15-178-A-2).

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