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**END-OF-LIFE CARE IN THE INTENSIVE CARE SETTING: A DESCRIPTIVE EXPLORATORY
QUALITATIVE STUDY OF NURSES' BELIEFS AND PRACTICES**

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Contributions

Study design: KR, PY, FC
Data collection: KR
Data analysis: KR, PY, FC
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KEYWORDS

Nursing, Intensive Care, end-of-life care, practices

ABSTRACT

Background

End-of-life care is a significant component of work in intensive care. Limited research has been undertaken on the provision of end-of-life care by nurses in the intensive care setting. The purpose of this study was to explore the end-of-life care beliefs and practices of intensive care nurses.

Methods

A descriptive exploratory qualitative research approach was used to invite a convenience sample of five intensive care nurses from one hospital to participate in a semi-structured interview. Interview transcripts were analysed using an inductive coding approach.

Findings

Three major categories emerged from analysis of the interviews: Beliefs about end-of-life care, end-of-life care in the intensive care context and facilitating end-of-life care. The first two categories incorporated factors contributing to the end-of-life care experiences and practices of intensive care nurses. The third category captured the nurses' end-of-life care practices.

Conclusions

Despite the uncertainty and ambiguity surrounding end-of-life care in this practice context, the intensive care setting presents unique opportunities for nurses to facilitate positive end-of-life experiences and nurses valued their participation in the provision of end-of-life care. Care of the family was at the core of nurses' end-of-life care work and nurses play a pivotal role in supporting the patient and their family to have positive and meaningful experiences at the end-of-life. Variation in personal beliefs and organisational support may influence nurses' experiences and the care provided to patients and their families. Strategies to promote an organisational culture supportive of quality end-of-life care practices, and to mentor and support nurses in the provision of this care are needed.

INTRODUCTION

End-of-life care is a significant component of nursing work in the intensive care setting. Mortality rates of up to 20% of patients in intensive care have been reported in the literature.^{1,2} Although patient death in intensive care may occur suddenly, the majority of deaths occur following a decision to withdraw or withhold treatment.³ Patients and their families at this time are likely to have specific care needs that require appropriately targeted nursing responses.

Limited research has been undertaken on the provision of end-of-life care by nurses in the intensive care setting. The purpose of this study was to identify the beliefs and practices of intensive care nurses about end-of-life care.

BACKGROUND

Intensive care is a high intensity work environment and end-of-life care is an emotive area of practice. The practice context of intensive care is dominated by the medical model and the focus of care is typically directed towards curing the patient. The intensive care context is one that is characterised by uncertainty and ambiguity surrounding patient prognosis and treatment, and where tensions between curative and comfort only care may occur.⁴⁻⁶ In a curative culture where death may be perceived as failure,^{7,8} the provision of end-of-life care may lead to unmet patient and carer needs, and may contribute to stress and burnout amongst nurses. Previous research indicates a lack of formal support for nurses providing end-of-life care.⁷ Identification and development of strategies to support nurses in the provision of end-of-life care is required to ensure quality care and to minimise stress and eliminate burnout.⁴

Previous research in acute medical and cardiac wards has identified that such non-palliative care areas lack appropriate resources for dying patients.^{5,6} However, few studies have explored or described actual end-of-life care nursing practices and the factors influencing these practices in the intensive care context.

Two Australian studies have explored the lived experiences of Intensive Care Nurses in relation to withdrawing or withholding treatment.^{7,9} Jones and FitzGerald interviewed seven senior nurses and the findings of their study highlighted the importance of communication and debriefing in end-of-life care.⁹ Halcomb et al. identified five themes following interviews with 10 intensive care nurses: comfort and care, tension and conflict, do no harm, nurse-family relationships and invisibility of grief and suffering.⁷ In a study undertaken in the United States, intensive care nurses participating in focus groups described 'good' end-of-life care and difficulties experienced in the transition to end-of-life care in the intensive care context.¹⁰ Although the ability to generalise the findings beyond the settings of the studies is limited, these studies provide some insight into this area of practice.

Previous North American studies have identified positive and negative intensive care nurse behaviours in end-of-life care¹¹ and the domains and quality indicators of end-of-life care, and interventions and behaviours to address these indicators in intensive care.¹² In both studies, the sample was limited to participants considered clinical 'experts' and empirical testing and validation of behaviours identified with larger samples was not undertaken.

Other research of end-of-life care in intensive care has explored nurses' perceptions and role in decision making,¹³⁻¹⁶ nurse's experiences and perceptions of end-of-life care¹⁷⁻¹⁸ and the barriers and facilitators of end-of-life care.¹⁹⁻²²

In summary, the practice context of intensive care presents unique challenges and opportunities for the provision of end-of-life care. Studies to date have provided some insight into the provision of end-of-life care in intensive care. However, further research is necessary to gain greater understanding of end-of-life care in this context. The present study thus aims to add to this work in this field to date by obtaining in-depth accounts of the beliefs and practices of a group of Australian intensive care nurses with varying levels of experience in this field of practice. Such research is required to inform the development of strategies and interventions to support nurses in the provision of end-of-life care and inform future research to evaluate and improve end-of-life care for the patient and their family.

METHODS

This study used a descriptive exploratory qualitative research approach.²³ A descriptive exploratory qualitative approach is useful in summarising and understanding an area of interest,²³ and was appropriately selected for this study to describe and explore the end-of-life care beliefs and practices of intensive care nurses.

A convenience sampling technique was used to invite Registered Nurses (both junior and senior) employed in a 14-bed intensive care unit at an Australian tertiary teaching hospital to participate. Participants were recruited via a presentation at a nursing staff meeting and an advertisement posted on noticeboards within the unit.

Semi-structured interviews were used as a means of data collection.^{24,25} A semi-structured interview format provided participants an opportunity to openly share their personal experiences of end-of-life care in the intensive care unit. Participants were asked to describe a

recent or significant experience of caring for an adult patient at the end-of-life following a decision to withdraw or withhold treatment. The interviewer actively listened to the participant's narrative and clarified or explored participant responses as required.²⁵ Where necessary, additional open ended questions were asked of the participant such as: "What do you think is important in caring for patients at the end-of-life?" "What assists you to provide end-of-life care?" "What barriers or difficulties have you experienced when providing end-of-life care?"

Interviews ranged in length from 13 to 72 minutes (mean = 42 minutes). A digital voice recorder was used to record each interview and this recording was transcribed verbatim. Transcripts were analysed using an inductive coding approach.²⁶ Each transcript was read and reread and labels of one to two words were placed in the margin of the transcript to identify ideas and/or concepts of interest. Margin labels were reviewed and groups of similar ideas and concepts were collated. Each group was named using one to two words that captured the essence of the content. These groups formed the preliminary categories. The content of each preliminary category was reviewed to ensure 'best fit' of content.²⁶ Groups containing similar content were combined to create major categories and where appropriate, sub-categories were identified.

Check-coding, as described by Miles and Huberman,²⁶ during the initial coding of the transcripts was undertaken. Inter-coder agreement was achieved between the authors following comparison and discussion/debate of the categories. The findings were presented at a nursing in-service in the study setting to enable further verification of the study findings. Nurses present during this in-service agreed that the findings generally reflected their own experiences and practices of end-of-life care, providing further confirmation of the categories developed during data analysis.

Ethical approval to undertake this study was granted by the health service of the study setting and the university affiliated with the study.

FINDINGS

Five female registered nurses participated in this research (see Table 1). After five interviews, sufficient data had been obtained to achieve the study purpose of exploring the end-of-life care beliefs and practices of intensive care nurses, providing insight into this area of practice in the study setting.

Analysis of the interviews revealed three major categories: beliefs about end-of-life care; end-of-life care in the intensive care context; and facilitating end-of-life care (see Table 2).

Beliefs about end-of-life care

The value of participating in and the complexity of this area of practice was emphasised by participants. Participants used terms such as 'privilege' and 'honour' to describe how they felt about the opportunity to care for a patient at the end-of-life and their family. Although some participants believed that the provision of end-of-life care is an advanced practice skill, they did not elaborate on what was involved in the complexity of this care.

“I’ve seen it allocated to the junior nurses and it’s just, oh well you just extubate and then start the morphine...and it is so much more than that, *so much more*” (Participant 1)

Some participants felt that the value and the complexity of end-of-life care was not always recognised by their nursing colleagues. The allocation of junior nurses and higher nurse to

patient ratios were cited as evidence of both the lack of value and lack of understanding of the complexity involved in end-of-life care. In particular, the strong curative culture reflected a tension that exists with regard to the value placed on end-of-life care.

“...I think there’s a very strong part of the culture here in ICU that death is failure. Nurses don’t seem to like looking after dying people, not only perhaps because they don’t quite know how they feel about death themselves, but I think also because it’s considered that you don’t need skills to look after a dying person. I think that it’s quite the contrary.” (Participant 2)

End-of-life care in the intensive care context

Participants reported a practice context of emotional intensity and limited organisational supports relating to end-of-life care issues. The uncertainty and ambiguity surrounding end-of-life care practice in this context was also alluded to by some participants.

Emotional intensity

Caring for patients with traumatic injuries and critical illness on a daily basis exposes intensive care nurses to grief and human suffering not experienced in other workplaces. One participant highlighted this situation stating:

“...Your family doesn't understand, your partner doesn't understand, they don't get it. You say, I've had a really horrible day. Oh, mine too. Column A wouldn't add up to column B and that made column C all out of whack. No, someone's died. No-one gets it except for the people that are here.” (Participant 5)

Despite this frequent exposure to grief and suffering, some participants identified that as a nurse in intensive care, you were expected to cope with death and dying.

“It’s not okay here to say that you're not quite coping. You are looked down upon if you say I’m not really coping, I'm kind of struggling with this...We don’t have that support.” (Participant 5)

Participants in this study identified that emotional support for intensive care nurses providing end-of-life care was needed. Some participants acknowledged that although external support services existed, they were not accessed. Some participants identified that they rely on their collegial network for support and that this form of support may not be available for junior staff who may not have established these networks. One participant described how senior nurses ‘check in’ with each other after caring for a patient at the end-of-life. Although this support is offered, some participants’ perceived that support would not be required for experienced nurses.

“But a lot of times it’s just are you alright? They go yep. Because a lot of times we are, because we’ve done it so many times.” (Participant 4)

Organisational support

Some participants also perceived that organisational support in regard to end-of-life care was needed. Participants did not identify any specific policies or protocols that were available to guide end-of-life care. The guidance provided by nursing team leaders to junior nurses was sometimes described as being inadequate to address the complexity of end-of-life care. Moreover, following the decision to withdraw treatment, the medical team was sometimes perceived to withdraw from participating in the care of the patient resulting in some nurses feeling less supported:

“...the doctors don’t even go in except to pronounce the death. There would be nothing wrong with them popping in just to see how the family was going or – you know.” (Participant 4)

Uncertainty and ambiguity

Some participants alluded to the uncertainty and ambiguity surrounding patient prognosis and end-of-life decision making in this setting. This uncertainty and ambiguity appeared to continue even after decisions had been made to withdraw treatment. In a practical sense, participants reported that this would manifest in waiting for family members to arrive at the patient's bedside, resulting in a delay between when a decision was made to withdraw treatment and when this actually occurred.

“We can have a dying patient here for two days because – well, first of all, well the niece needs to come and she won't be here for 12 hours... then the second cousin, four times removed... I think a lot of times we give the family a lot of – maybe too much time to – before withdrawal of treatment... I think it's disrespectful to the person who's dying, to lie there, gasping sometimes, because they're waiting for someone to come...” (Participant 4)

Facilitating end-of-life care

The category facilitating end-of-life care incorporated the nurses' practices of caring for the patient at the end-of-life and their family.

Providing comfort care

Participants identified that end-of-life care consists of more than just the removal of treatment. One participant defined comfort care provided at the end-of-life by offering the following explanation:

“We had moved her to comfort care. If comfort is the criteria, then you're looking at emotional, physical, psychological comfort, not only of her but also of the extended family.” (Participant 2)

The actual nursing interventions undertaken in the provision of comfort care mentioned by participants included bathing, hair care, mouth care, pressure area care, spiritual care, and the administration of analgesics, sedatives and antimucolytics. However these interventions were not discussed in detail.

Modifying the environment

All participants described interventions undertaken to modify the bedside environment and create an intimate and peaceful setting for the patient and their family to experience end-of-life care. The use of a single room for the patient and a 'relative's room' separate to the visitor's waiting room, provided space and privacy, allowed more visitors at the bedside and permitted visitation of family outside visiting hours. The use of private rooms was also perceived to be beneficial to other patients and families to lessen their exposure to the dying patient and their family.

“Normally people go to a private room: one, to allow more visitors; secondly, it's just a quieter environment. Also, for other patients as well, to see people upset and crying is very disturbing for the other relatives because they think, 'there but for the grace of god go I'.” (Participant 2)

Removing clinical equipment, combined with modifications such as dimming the lighting, replacing the hospital linen with coloured sheets and quilts, putting up photographs and playing music assists in “removing the intensive out of intensive care” (Participant 2) creating an atmosphere that is less clinical and more homely. These interventions assisted in humanising the patient and shift the families focus to comfort care.

“... getting rid of the monitoring is a big thing for me...I don't want their last moments with their loved one to be watching a screen...You shouldn't be watching a monitor,

you should be watching your loved one and talking to your loved one and I think we're depriving them of that if we keep all this other stuff around." (Participant 5)

Facilitating the family's experience

A significant proportion of participant dialogue in each interview was dedicated to care of the patient's family. Some participants stated that they asked the family "what do you want?" (Participant 4) to try to ascertain the type of atmosphere the family wanted to create, the support required from the nurse and the degree to which family wanted to participate in the care of their relative. All participants identified that they explained what was happening to the patient and their family, answered questions and provided information. This was a practical and comfortable area of practice for nurses.

"I felt quite comfortable doing that, that was something I could do. Right, okay, comfort zone again, I can explain this." (Participant 5)

Some participants described how they asked the family about the patient to enable them to 'get to know' the patient. The process of the nurse 'getting to know' the patient also provided an opportunity for the family to talk about their relative and reflect on their lives together.

"I think you do find people wanting to share stories and that sort of stuff. So I think allowing them to do that and to let us, the stranger, sort of know them. Or I can just say I don't know your dad, because he's always just been attached to tubes. So what was he like?" (Participant 4)

All participants described their role in being there to support family members to be with their relative at the end-of-life. Being there included a physical presence by the nurse at the patient's bedside and encouraging the family to sit, talk to and touch the patient.

“I think she [the patient’s wife] wanted me to be there for a little bit...she just sort of held on to my arm... it was like it’s okay, sit down and I encouraged her to talk to him...So she sat down and held his hand and had a chat and then I left...” (Participant 5)

All participants in this study described actions that they undertook to assist in creating memories for the patient’s family. Memory making activities included taking the patient’s hand prints and collecting a lock of the patient’s hair and their identity bands for the family to keep. At an advanced level of practice, personalised meaningful experiences could be facilitated for the family. When this occurred, the nurse intuitively grasped the family situation, identified a meaningful moment and responded appropriately to assist in creating a positive experience. The importance of these experiences for the family was highlighted when the family acknowledged the nurse for their work. One example of this work is described by a participant:

“I wrote a book for this [child], for both of them. After hearing the discussion... I drew upon what I had heard the father talking to the [child] about...I just was really driven by concern for this [child], and also just the lack of vocabulary that this man had for explaining death. The book was created...Then I went to the funeral and he actually read that book out in lieu of a eulogy...I was struck by the significance of what the book became. Then he actually wrote a letter...about the care that his wife had got. I got a phone call from the CEO. That really blew me away.” (Participant 2)

Stories shared by some participants indicated that creating memories and positive experiences is a satisfying aspect of end-of-life care practice for intensive care nurses and is important in providing positive end-of-life experiences for families.

DISCUSSION

The practice context of the intensive care setting presents both unique challenges and important opportunities for nurses providing care to patients at the end-of-life and their family. Beliefs about the value and complexity of end-of-life care, emotional and organisational support and the actual practices undertaken by nurses in facilitating end-of-life care were aspects of end-of-life care that emerged from the interview data.

Although participants in this study reported that some of their colleagues held the view of death as failure, end-of-life care was considered to be a complex area of practice and highly valued by participants. Variation in the personal beliefs held by individual clinicians in regard to the value of end-of-life care and the complexity of this area of practice are factors that may influence clinicians' approach to end-of-life care and the care provided to patients and their families.

Nurses in this study described a need for emotional and organisational support when providing end-of-life care in this setting. This finding is consistent with a study by Halcomb *et al.* that identified lack of formal support and the emotional toll of end-of-life care on nurses.⁷ Other research has reported lack of debriefing²⁷ and the presence of informal support through collegial support networks^{9,11} similar to that identified in this research.

Insufficient emotional and organisational support may influence the care provided to patients and their families, and nurses' end-of-life care experiences, stress and coping. It is recommended that formalised support strategies be implemented such as a buddy network for new and junior staff and regular debriefing and critical reflection sessions facilitated by a social worker or external counsellor. Although some end-of-life care / palliative care policies and guidelines exist,²⁸⁻³⁰ nurses in this study were not aware of any organisational or unit

specific policies to guide end-of-life care. Therefore, the development of guidelines specific to the intensive care context may also assist nurses in the provision of end-of-life care.

Nurses' perceptions of reduced medical team participation following a decision to withdraw treatment has been identified in other studies.^{7,15} Similarly to the findings of Halcomb *et al.*, participants in this study did not articulate what the role of the medical team should include.⁷ Factors that may influence disengagement of medical staff include the curative culture, perception of death as failure and personal comfort with death and dying. Medical staff may commit energy and skills to those that can be saved potentially compromising the active clinical care that needs to be given to patients during the dying process and their relatives. Further evaluation of the perceptions and possible roles of the different members of the intensive care team may contribute to the provision of comprehensive holistic end-of-life care.

Uncertainty and ambiguity related to patient prognosis, the trajectory of critical illness and treatment decisions surround practice in intensive care.⁵ The findings of the current study suggest that this uncertainty and ambiguity continues even after a decision is made to withdraw treatment. This was reflected in tensions surrounding the timing of withdrawal of life sustaining treatment. The concept to timing in relation to withdrawal of treatment has been reported elsewhere.^{9,18} The findings of the current study suggest that although a clinical decision had been made in relation to withdrawing and withholding treatment, the patient's family may not always be ready for this decision to occur. Several factors may contribute to family readiness including the uncertainty and ambiguity surrounding the patient's prognosis and treatment in intensive care, the overwhelming experience of having a family member in intensive care and the experience of grief and loss. Such awareness may reflect attempts to individualise care. However, such uncertainty may also result in greater distress for the patient, their family and health professionals if it results in avoidance of efforts to deal with

eventually fatal conditions. The identification of strategies to ascertain family readiness in relation to withdrawal of treatment and providing adequate preparation and support to family members may smooth transitions between curative and comfort only care. In addition, further research into the experience of end-of-life care in intensive care from the perspective of family members may contribute to knowledge and practice in this area.

The intensive care setting presents unique opportunities for nurses to facilitate meaningful end-of-life experiences for patients and their families. Although some authors identify that non-palliative care areas may be inadequate for the provision of end-of-life care,^{5,6} participants in this study described how an intimate, peaceful setting in which to experience end-of-life care and death can be achieved through interventions aimed at modifying the environment.

Care of the family has been identified as important to quality end-of-life care in previous studies.^{7,19,27} Halcomb *et al.* found that the presence of family shifted the nurse's focus from the patient to the family.⁷ In the present study, a focus on caring for the patient's family and facilitating the family's experience of end-of-life care dominated the interview data. Nurses provided support to family members through their physical presence and the provision of information. Physical and emotional presence has also been reported in previous studies.^{9,31} For a nurse to 'be there' at the end-of-life for a patient and their family, they need to feel comfortable with being there themselves.³¹ In comparison, it is a 'second nature' aspect of nursing practice to explain and provide information and this is no different when caring for a patient at the end-of-life. Explaining and providing information was considered a 'safe' area as the information needs and questions from family were similar. This was a practical and comfortable area of practice for all nurses in the often confronting and emotional work of providing end-of-life care.

In this study, the role of the nurse was pivotal in supporting families to have meaningful experiences with their relative at the end-of-life. Few papers in the intensive care end-of-life care literature discuss nurses' role in the facilitation of creation of memories and positive experiences.³² Acknowledgement of this work by families provides some evidence of the importance of this work. Further research to describe the practices undertaken by nurses in supporting patients and their families to have positive and meaningful experiences at the end-of-life makes an important contribution to nursing knowledge and the development of nursing practice through dissemination of this knowledge.

Limitations

Practice is complex and multidimensional in nature, however, due to constraints of the spoken and written word, this account of patient care at the end-of-life at times, appears linear. The actual nursing interventions undertaken in the provision of comfort care to the patient were not discussed by participants in detail. Absence of discussion of tasks undertaken in the provision of comfort care may be taken for granted aspects of participant's practice.

Participants may also have felt that they did not need to describe these details of their practice due to the interviewer's experience and knowledge of intensive care work.

Although only a small sample from one intensive care unit was used in this study, the aim of this research was to gain insight into this area of practice. Thus the sample size and sampling strategy was deemed appropriate for the purpose of this study. Further research is needed to explore this area of practice and to identify the extent to which the findings apply to other intensive care contexts.

CONCLUSION

The practice context of intensive care is a high intensity work environment surrounded in uncertainty and ambiguity that may contribute to tensions between curative and comfort only care. Limited emotional and organisational support for nurses providing end-of-life care may influence the care provided to patients and their families and nurses' end-of-life experiences, stress and coping. Despite these challenges, nurses identify opportunities and play a pivotal role in facilitating end-of-life experiences for patients and their families. Variation in clinician's personal beliefs about the value and complexity of end-of-life care may influence their approach and the care provided to patients and their families.

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