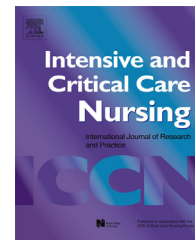




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ORIGINAL ARTICLE

# Exploring family experiences of nursing aspects of end-of-life care in the ICU: A qualitative study



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## KEYWORDS

Family;  
Nursing care;  
End-of-life care;  
Intensive care;  
Qualitative research

## Summary

**Objectives:** The aim of this study was to examine the experience(s) of family with the nursing aspects of End-of-life care in the intensive care unit after a decision to end life-sustaining treatment, and to describe what nursing care was most appreciated and what was lacking.

**Method:** A phenomenological approach including inductive thematic analysis was used. Twenty-six family members of deceased critically ill-patients were interviewed within two months after the patient's death about their experiences with nursing aspects of end-of-life care in the intensive care unit.

**Findings:** Most family members experienced nursing contribution to end-of-life care of the patient and themselves, especially supportive care. Families mentioned the following topics: Communication between intensive care nurses, critically ill patients and family; Nursing care for critically ill patients; Nursing care for families of critically ill patients; Pre-conditions. Families appreciated that intensive care nurses were available at any time and willing to answer questions. But care was lacking because families had for example, a sense of responsibility for obtaining information, they had problems to understand their role in the decision-making process, and were not invited by nurses to participate in the care.

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*Conclusions:* Most family appreciated the nursing EOLC they received, specifically the nursing care given to the patient and themselves. Some topics needed more attention, like information and support for the family.

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### Implications for Clinical Practice

- This paper adds insight into the experiences, needs and wants of family of deceased ICU patients, related to nursing care. Some omissions in nursing EOLC in the ICU were found, including the families' feeling of being responsible for obtaining information and understanding their role in the decision-making process, not being able to say goodbye, not inviting family to participate in the care for the patients, and the follow up meeting.
- Previous studies showed omissions in communication between ICU nurses and family, in contrast to the results in this study.
- ICU nurses can adapt their care to the needs and wants of family of dying ICU patients, which may improve the quality of care.

## Introduction

In the Netherlands, nearly 8% of all intensive care unit (ICU) patients die in the ICU (NICE, 2015). Because of the use of life-sustaining measures, approximately 85% of the deaths of ICU patients occur after withdrawal or withholding life-sustaining treatment (Kompanje et al., 2013). Withholding treatment can be defined as a planned medical decision not to order treatments that are otherwise warranted, whereas withdrawal of treatment means the discontinuation of life-sustaining treatment (Latour et al., 2009; Quenot et al., 2012; Valentin et al., 2008).

Because of the increasing number of critically ill patients, the number of decisions to withdraw or withhold life-sustaining treatment is expected to increase as well (Halcomb et al., 2004; Kompanje et al., 2013).

In the Netherlands three levels of ICUs exist. In Table 1 the differences between the levels of the ICUs are presented.

End-of-life care (EOLC) is defined as the care and supportive services that a serious ill patient and his family receive following the decision to end treatment(s) (Latour et al., 2009). Domains of quality of EOLC in the ICU are described including: (1) patient and family centered decision making, (2) communication with patients and family, (3) continuity of care, (4) emotional and practical support for patients and family, (5) symptom management and comfort care, (6) spiritual support and (7) emotional and organisational support for ICU professionals (Curtis and Engelberg, 2006).

During EOLC, not only ICU patients need nursing care, but also their family, including relatives and friends, need care and support. In the Netherlands, family members act as the legal representative of a patient who is unconscious or sedated. This means that the family have to be informed about the treatment and should represent the values and preferences of the patient. Family often discuss their ideas and thoughts about withdrawing treatment with the attending nurses. However, the decision for treatment is made by the physician and family do not decide on treatment for

the patient. However physicians strive for agreement on treatment decisions with the family (Gerritsen et al., 2009).

Nursing care is, among other things aimed at emotional and spiritual support for patient and family, because an ICU stay of a (beloved) person can cause anxiety, depression and even posttraumatic stress disorder (Davidson et al., 2012; Kirchhoff et al., 2004).

Family of ICU patients experienced the relationship with ICU nurses during the end-of-life (EOL) decision-making process as adequate regarding compassion and comfort, but they deemed the communication as vague and evasive (Lind et al., 2012). Besides, nurses did not always participate in family meetings thus family missed the support of nurses. These findings are in line with the results of Lloyd-Williams et al. (2009). In this study, family appreciated the physical care for the patients, but communication and delivery of bad news were a cause for concern. Also, the facilities in the ICU, such as lack of family rooms, little privacy at the patients' bedside or during farewell and lack of follow up meetings were mentioned.

Follow up meetings, support groups and family meetings with an attending nurse for family of deceased ICU patients are recommended as a way for professionals to communicate with family (Davidson et al., 2012). These authors describe the post-intensive care syndrome family, representing the response of family to EOLC and the death of ICU patients, including anxiety, acute stress disorder, posttraumatic stress, depression and complicated grief. Communication and involving family in care may affect long-term outcomes.

In the Netherlands, the ICU physician communicates with patients and family about treatments and sometimes the physician will ask the family what they think that should be done. However, the physician decides. The physician has to request informed consent of the patient about the treatment. When a patient is unconscious, sedated or incompetent, the legal representative of the patient has to be informed and should represent the values and preferences of the patient in decision-making (Gerritsen et al., 2009; NICE, 2015). The patient, if possible, and family are informed during family meetings. Regularly, the physician discusses

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