

# The nursing role during end-of-life care in the intensive care unit related to the interaction between patient, family and professional: an integrative review

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## The nursing role during end-of-life care in the intensive care unit related to the interaction between patient, family and professional: an integrative review

**Aim:** The aim of this study was to explore how intensive care unit (ICU) nurses describe their role during End-of-Life Care (EOLC) in the ICU, related to the interaction between patient, family and professionals (care triad).

**Method:** Three electronic databases, PubMed, CINAHL and EMBASE, and reference lists of included studies were searched for studies in English, Dutch or German between January 2002 and August 2015. Studies were included if they presented data about EOLC in the adult ICU, and the role of ICU nurses around EOLC. Quantitative and qualitative studies and opinion articles were extracted. Inductive content analysis was carried out to analyse and categorise the data.

**Results:** Twenty studies were included. Four categories emerged: care for the ICU patient, care for the family, environmental aspects of EOLC and organisational aspects of EOLC. Regarding the care triad, a gap exists

between theoretical models and the actual care provided by ICU nurses during EOLC. The relational aspect of care, like aimed with care triad, is absent.

**Conclusion:** The literature clearly indicates that the role of ICU nurses concerns care for the patient, family and environment. It described which care should be given, but it remains unclear *how* care should be given (attitude). Therefore, it is difficult for ICU nurses to provide this care. Further, it seems that care provided to family mainly consists of giving advice on how to care for the patient; care for family members themselves was only mentioned in a few studies. Therefore, it seems that family does not always receive adequate care yet, which may be helpful in preventing problems like depression, anxiety or post-traumatic stress disorder. It can be concluded that it is important for ICU nurses to be aware of the existing relationships; however, comparing the literature, care triad does not appear to be reached.

**Keywords:** review, intensive care units, end-of-life care, nursing care, care triad.

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## Introduction

In Europe, 6–27% of all intensive care unit (ICU) patients die in the ICU, and in the USA, this number varies 10–29% (1, 2). In the Netherlands, ICU mortality is

nearly 8% (3), where three Scandinavian countries (Sweden, Norway, Finland) have an overall ICU mortality of 9.1% (4). Over 85% of those deaths occur after withdrawal or withholding life-sustaining treatment (5). Since the number of critically ill patients will increase, the number of decisions to withdraw or withhold life-sustaining treatment will increase as well (6). During end-of-life care (EOLC), ICU patients are in need of nursing care, as well as their family members, next of kin, relatives or friends, hereafter referred to as family.

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Nursing care for family mostly consists of emotional support. Family members often discuss their ideas of and moral feelings on the decision to withdraw or withhold treatment with nurses. Due to the experienced stress, an ICU stay can cause anxiety, depression and post-traumatic stress disorder in family members (7, 8). Since the consequences for family members may be severe, it is reasonable that not only care is provided for patients, but nurses also care for families. This triangle, patient, family and professionals, is called a care triad.

During care for the patient and his family, nurses have to deal with the relationships that exist between the patient and his family, but also with the relationships the nurse herself has with the patient and his family.

Fortinsky (9) defined the relations between patients, professionals and family members as a care triad in which the interaction between patient, family and professional is known as a 3-way partnership to which all partners bring their unique socio-demographic, cultural, psychological and health-related characteristics. Likewise, Kongsuwan & Touhy (10) described a comparable theory as mentioned above, but with a focus on EOLC. They stated that a peaceful death requires interaction between patients, family and nurses. All three must be intimately engaged in the process. The study of Beneken genaamd Kolmer et al. (11) showed the importance of the relation between patient and family in caring situations. Supportive interventions of professionals should focus at the relationship between patients, family and nurses. Care professionals should respect and acknowledge their responsibility by, on the one hand, exploring possibilities of family participation, invite them to participate and leaving tasks to family whenever they want to perform these tasks themselves and, on the other hand, explore the limits of the care provided by the family together with the family, in order to keep them from becoming physically, psychologically or socially overburdened (11). The interaction between patient, family and professionals as mentioned above is also part of the study of Cannaerts et al. (12). They described a theory for palliative care in relation to the interaction between patient, family and professionals. They define palliative care as 'care for life', and not as providing comfort care and quality of life. Furthermore, the cross-sectional study of Moghaddasian et al. (13) mentioned the care triad related to empathy provided by nurses. This empathy leads to greater satisfaction with care in both patient and family. They found a significant connection between nurses' empathy and the needs of the patients' family ( $p < 0.001$ ). The authors stated that by increasing the nurses' empathic skills, care provided according to family needs would be improved.

The studies described above mention the existing role of a care triad in nursing care. The care triad seems to be important during EOLC in the ICU as well. However, the exact role of ICU nurses in the care triad during EOLC is

unknown. Because of the lack of clarity about the role of the ICU nurse, and the possible consequences for the family members, research is needed to clarify what kind of care should be provided to the patient and his family by the ICU nurse during EOLC.

Thus, the aim of this study was to explore how the role of ICU nurses during EOLC in the ICU is described in the interaction between patients, family and nurses.

To our knowledge, this is the first review on the role and tasks of ICU nurses during EOLC, with a focus on the relation between patients, family and nurses.

## Method

An integrative review was performed to gain insight into the roles and tasks of ICU nurses during EOLC in the ICU. Integrative review is a specific review method used in nursing science, which allows the assessment of diverse methodologies (14). Two researchers (MN and BD) performed the integrative review using a review protocol.

### *Search strategy*

PubMed (including MEDLINE), CINAHL and EMBASE were searched in August 2015. The search terms 'intensive care units', 'End-of-life', 'nursing care', 'nursing role' and 'family' (and related terms) were combined with MeSH terms and free text (see Table 1). Furthermore, reference lists were hand searched for relevant articles. All recent studies about the developments and research in EOLC in the ICU are included. Studies were restricted by year of publication ( $\geq 2002$ ).

### *Inclusion criteria*

Studies evaluating or describing the role of nurses during EOLC in the ICU published in peer-reviewed journals were included. All types of methodologies such as quantitative and qualitative studies, and opinion articles, which described the role of ICU nurses in EOLC in the ICU were included.

Only studies on adult ICU patients were considered for inclusion, since the paediatric and neonatal ICU differs very much from the adult ICU. Adult ICU patients are ICU patients with an age of 18 years or older. The final inclusion criterion was that studies were published in English, German or Dutch. The search was restricted to articles published as 'full paper'. Conference abstracts, editorials, personal communications or unpublished studies were excluded (see Table 2).

### *Study selection*

All articles were screened on title and abstract by two reviewers (MN and BD) and were included if the title or

**Table 1** Search strategy

Search strategy	Results
PubMed (‘Critical care’ [Mesh] OR ‘intensive care units’ [Mesh] OR critical care [tiab] OR intensive care[tiab] OR ICU[tiab]) AND (end of life[tiab] OR ‘palliative care’ [Mesh] OR ‘terminal care’ [Mesh] OR ‘withholding treatment’ [Mesh] OR ‘palliative care’ [tiab] OR ‘terminal care’ [tiab] OR ‘withholding treatment’ [tiab] OR withdrawing treatment[tiab] OR treatment cessation[tiab]) AND (‘nursing care’ [Mesh] OR ‘nursing care’ [tiab] OR ‘nursing’ [Mesh] OR ‘nursing’ [tiab] OR ‘nursing role’ [tiab] OR ‘nursing skill*’ [tiab] OR ‘nursing knowledge’ [tiab] OR ‘nursing task*’ [tiab]) AND (‘relatives’ [tiab] OR ‘family’ [tiab] OR ‘Family’[Mesh]) Adult: +19, English, German, Dutch, from 2002	162
CINAHL (MH ‘Critical Care+’ OR MH ‘Intensive Care Units+’ OR TI (critical care OR intensive care OR ICU) OR AB (critical care OR intensive care OR ICU)) AND (end of life OR palliative care OR terminal care OR withholding treatment OR palliative care OR terminal care OR withholding treatment OR with-drawing treatment OR treatment cessation) AND (nursing care OR critical care nursing OR nursing role OR nursing skill OR nursing knowledge OR nursing task) AND (family OR relatives OR MH relative OR MH family) All adults, English, German, Dutch, 2002–2015	100
EMBASE (exp intensive care/OR intensive care unit/OR critical care.ti,ab. OR intensive care.ti,ab. OR ICU.ti,ab.) AND (end of life.ti,ab. OR palliative care.mp OR terminal care.mp OR withholding treatment.mp OR palliative care.ti,ab. OR terminal care.ti,ab. OR withholding treatment.ti,ab. OR withdrawing treatment.ti,ab. OR treatment cessation.ti,ab.) AND (nursing care.mp OR nursing care.ti,ab. OR nursing.ti,ab. OR nursing role.ti,ab. OR nursing skill.ti,ab. OR nursing knowledge.ti,ab. OR nursing task.ti,ab.) AND (family.ti,ab. OR relatives.ti,ab. OR exp relative/OR exp family) Adults, English, German, Dutch, 2002 till present	180

**Table 2** Inclusion and exclusion criteria applied to the literature search

Inclusion criteria	Exclusion criteria
Adult ICU patients	Conference abstracts, editorials, personal communications or unpublished studies
Studies published in English, German or Dutch	
Published as ‘full paper’	
All methodologies	
Published ≥2002	

abstract described the role of ICU nurses around EOLC in the adult ICU. After the initial selection, remaining articles were screened full text by two reviewers (MN and BD) and were included if (i) EOLC and (ii) the role of ICU nurses were described. In case of differences of opinion, a third researcher (JS) was consulted and agreement was reached in all cases. This was only required in one case, in which it was not clear whether the aim of the study was about the tasks and roles of ICU nurses.

#### Data analysis and quality assessment

From each article, the description of the role of ICU nurses and their activities during EOLC were extracted. Study characteristics included study reference (including country and year), level of evidence, study design, target population, sample size, intervention or

recommendation, and findings. Two reviewers (MN, BD) independently extracted the data, as an assessment of reliability.

Methodological quality of the articles was assessed using standardised evaluation forms of the Dutch Institute of Healthcare Improvement CBO. Following this assessment, the studies were classified by level of evidence (15). According to this classification, a randomised double-blind clinical trial of good quality and adequate sample size receives level A1, whereas comparative studies not containing all characteristics of A2 (including cohort studies or case-control studies) are classified as level B. Observational and descriptive studies are classified as level C, and opinion articles are considered as level D.

For the study quality score and the classification of methodological quality of qualitative studies, the evaluation forms of the Critical Appraisal Skills Programme (CASP) were used. In this programme, a plausible meta-synthesis receives ++, a plausible study receives +, a study with limited plausibility receives ± and a study with little plausibility receives – (16). Two independent reviewers (MN and BD) assessed the quality of all included studies by using the standardised evaluation forms of the Dutch Institute of Healthcare Improvement CBO and CASP.

The categorisation of the quantitative and qualitative studies differs, but studies with a level of evidence of A1/A2 can be categorised as similar to level of evidence ++, level B as +, level C as ± and level D similar to –.

## Results

### Study selection

In total, 442 studies were identified. Following de-duplication, 90 were removed. A hand search of the reference lists of included studies identified another two studies meeting the inclusion criteria. At the end of the inclusion process based on title, abstract, inclusion criteria and methodology, 20 studies were included in this review (Fig. 1).

Exclusion was primarily based on studies about neonatal or paediatric ICU's, do-not-resuscitate (DNR) orders (timing of treatment decision, procedure around DNR, legal, ethical and financial considerations, relation between DNR and EOLC) DNR requests and physicians (studies only described EOLC only from a physicians' perspective).

### Study characteristics

The reported data were collected in the following countries: United States of America (USA) (n = 11) and one each from Australia, the United Kingdom (UK), Europe,

Sweden, Norway, Turkey, South Africa, Brazil and Canada. The included studies were 13 qualitative studies, three surveys, two cross-sectional studies, one post-test-only study and one opinion article. The quality assessment revealed 12 studies as level C or ±, and the others were level D or -. Table 3 shows a summary of the included studies.

### Main results

Results that answered the research question 'What is the role of ICU nurses during End-of-life care in the ICU, related to the interaction between patients, family and nurses?' were extracted. Four categories emerged while analysing the full text studies: care for the ICU patient, care for the family, environmental aspects of EOLC and organisational aspects of EOLC.

*Care for the ICU patient.* Care for the ICU patient was discussed in twelve studies. Providing optimal pain and symptom management for the comfort of the patient was considered an important nursing intervention, although pain and symptom management is solely described in terms of administering analgesics and sedatives (17–28).

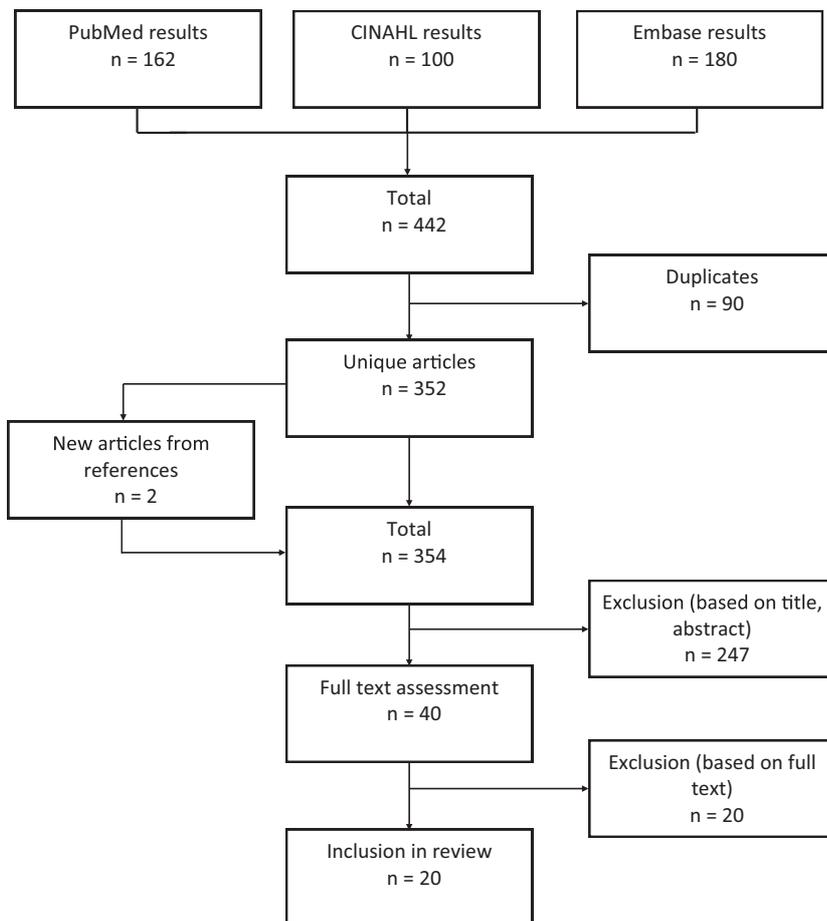


Figure 1 Flow chart integrative review.

**Table 3** Summary of included studies

Author (s), country	Purpose of the study	Sample	Study design	Data collection	Main results	Evaluation	Category
<b>Qualitative studies</b>							
Adams et al. (30), USA	To describe the behaviour of professionals and responses of family through the lens of adaptive leadership of a patient transitioning from curative to palliative care	One case of an ICU in a tertiary teaching hospital	Prospective case study	Observation of daily rounds, observation and audio recording 3 family meetings and an interview with family. Data was collected in July 2010	The adaptive leadership behaviours identified in the analysis include: Provide information: the challenge to provide information in a clear, honest and lay term way. Decision support: for example, explaining the prognosis, identifying risks. Support realistic hope: by assuring that the patient and family would continue to be cared for, foreshadowing, compassion, reframing hope, allowing time to process information. Address work avoidance. The authors described that adaptive work is often avoided, because it requires effort and might create fear and loss	±	Care for the family of the ICU patient
Adams et al. (29), USA	To explore how family of ICU patients at high risk of dying respond to nursing communication strategies	17 cases of two 16-bed adult ICUs in a tertiary care university hospital (11 patients died)	Prospective, qualitative descriptive study (17 cases study)	Observing interactions among professionals, family and patient, engaging in discussions, attending rounds and family meetings. Data was collected between October 2012 and February 2013	Five categories emerged from data analyses: Demonstrating concern: nurses demonstrated concern (or lack thereof) for physical, emotional, psychosocial and spiritual well-being of the patient and family. For example, ensuring that the patient is comfortable, express emotions. Building rapport: strengthen the therapeutic relation, which included holding family in high esteem, being approachable and affable. Examples are talking with family about themselves, making eye contact and sitting close. Demonstrating professionalism: this includes showing professional demeanour, respect for the patient and family and providing evidence that nurses were collaborating with other professionals. Providing factual information: nurses are seen as an important source of information about the ICU, the patients' treatment and situation. Supporting decision-making: nurses supported decision-making by remaining unbiased in the face of decision-making. The authors also described that due to nurses using eye contact, facing the family and coming to the phone when family called, the family had trust and confidence, helping the family to cope	±	Care for the family of the ICU patient

Table 3 (Continued)

Author (s), country	Purpose of the study	Sample	Study design	Data collection	Main results	Evaluation	Category
Abour et al. (17), USA	To understand the experiences of ICU nurses and to understand their perceptions of activities and roles that they performed while caring for patients and families during transition from aggressive life-saving care to palliative and EOLC	19 ICU nurses from a medical and surgical ICU of a tertiary care medical centre	Descriptive, phenomenological study	Interviews	Results can be divided into seven categories. Educating the family: depends on family needs, background, characteristics and emotional state. It includes information about withdrawal of treatment as well as spiritual and physical comfort. Advocating for the patient: For example, advocating appropriate pain management, or to document the wishes of the patient. Encouraging and supporting family presence: for example, no restriction on visiting hours. Managing symptoms Protecting families and creating positive memories: Nurses referred to going beyond the 'call of duty'. By protecting the memories of family by helping the patient look comfortable and clean. Also facilitating family involvement. Family support: providing necessary information, advocating for family, providing emotional support, encouragement and seeing that family wishes were honoured. Mentoring and teaching: teaching new ICU nurses. The authors also described facilitating a homelike atmosphere by playing music and removing all nonessential technology	±	Care for the ICU patient, Care for the family of ICU patient, Environmental aspects of EOLC
Bach et al. (36), Canada	To formulate a conceptual framework of the nursing role in EOLC decision-making in ICU's	14 nurses of an ICU and a CRCU in a large teaching hospital	Qualitative following the grounded theory approach	Semi-structured interviews	The results showed a main theme 'Supporting the journey', which can be divided into four major themes: being there, a voice to speak up, enable coming to terms and helping to let go. Important tasks of ICU nurses include being physically present, but also through letting family know you will be there for them, encouraging family to share their wishes during family meetings, and providing comfort	-	Care for the family of the ICU patient
Bratcher (20), USA	To explore and describe the characteristics of a good death	15 ICU nurses of a 12-bed medical surgical ICU at a Veteran's Administration (VA) hospital in a mid-sized urban city	Qualitative, exploratory study	Interviews. Data was collected from May 1, 2008, to May 31, 2008.	The themes mentioned mostly were the following: the patient does not die alone, the patient does not suffer and acceptance of death by the patient and family. The acceptance of death also included the idea that a patient and their family did not have any unresolved issues and that there was consensus with professionals about what was happening to the patient. Next to that, nurses wanted to create a serene environment, which could be achieved by playing music, and with a 'get to know me' card in the patients' room to help professionals see the patient as a person. Nurses also informed family about bereavement and about what to do after death. Besides, nurses could give families a beeper so they can leave the ICU to eat, sleep or pray while staying in touch with the ICU	±	Care for the ICU patient, Care for the family of the ICU patient, Environmental aspects of EOLC, Organisational aspects of EOLC

Table 3 (Continued)

Author (s), country	Purpose of the study	Sample	Study design	Data collection	Main results	Evaluation	Category
Calvin et al. (32), USA	To describe neuroscience ICU nurses' perceptions regarding their roles and responsibilities in the decision-making process during the change in intensity of care and EOLC for patients	12 Neuroscience ICU nurses employed at one hospital	Qualitative descriptive study	Interviews	Results are divided into three major themes: providing guidance (informing family, answering questions and guiding the family by pushing or urging them to move forward a decision), being in the middle of the communication process (facilitating communication between family and professionals, making sure everything is understood) and sensing the emotions of the patient and family	-	Care for the family of the ICU patient
Fridh et al. (21), Sweden	To explore nurses' experiences and perceptions of caring for dying patients in the ICU with focus on unaccompanied patients; the proximity of families and environmental aspects	9 ICU nurses employed at three ICUs	Qualitative study	Interviews	Results show one main category 'Doing one's utmost'. The results were divided into four categories and can be divided into fifteen subcategories. Table 4 shows the results of this study	±	Care for the ICU patient, Care for the family of the ICU patient, Environmental aspects of EOLC, Organisational aspects of EOLC
Hov et al. (28), Norway	To acquire a deepened understanding of what good nursing care is for these patients	14 ICU nurses of a nine-bed, adult, general ICU in a central hospital	Qualitative study, based on interpretative phenomenology	ICU nurses were divided into two groups, and group interviews were held four times	Three themes were described: general condition for good nursing care, good nursing care related to specific patient situations, and the essence of good nursing care to ICU patients on the edge of life. General condition for good nursing care is divided into continuity, cooperation, knowledge and competence. Nurses mentioned the need of family for support to cope with their own situation and the stress when they were at the patient's bedside. Good nursing care included protecting the patient against distressing impulses and sensory imbalance. Therefore, family members were encouraged to stay with the patient at the bedside. The essence of good nursing care is described as being open and nursed by safe and caring hands in a collaborative environment. Each patient should be seen as a unique person, which involved preserving his personality, acceptance, respectful treatment, and being nursed for his own interests	±	Care for the ICU patient, Care for the family of the ICU patient, Organisational aspects of EOLC

Table 3 (Continued)

Author (s), country	Purpose of the study	Sample	Study design	Data collection	Main results	Evaluation	Category
Long-Sutehall et al. (24), UK	To illustrate how differing dying trajectories impact on decision-making underpinning withdrawal of treatment processes, and what nurses do to shape withdrawal of treatment	13 ICU nurses from four clinical critical care units (ICU, CICU, NICU and RHC).	Qualitative study, based on grounded theory method	Interviews were held from September 2008–September 2009.	The key category was negotiated dying. The authors describe a model, which highlights what appear to be essential elements of nursing EOLC. It illustrates assessing (assessing the needs of the patient, family dynamics and processes), facilitating (facilitating communication between teams, family and patient, patient and teams, family and teams, facilitating care and processes), coordinating, operationalising (operationalising processes including rites and rituals, family contact and care) and negotiated dying. Nurses also identified the importance of the place of death, whether the family was present and aware of what was going to happen, and whether the patient was comfortable. They decreased supportive drugs, fluids, weaning ventilation, increased the administration of sedatives and analgesics and removed monitoring equipment, so that the patient is 'given back' to the family	–	Care for the ICU patient, Care for the family of the ICU patient
Popejoy et al. (35), USA	To elucidate the viewpoints of ICU nurses about caring for critically ill and dying patients in the ICU	22 ICU nurses of a private tertiary care hospital	Qualitative preliminary study, using the focus group method	Focus group interviews	Five major themes were described: 'helping the patient through', telling bad news, grieving as a process, family as the patient and the dying patient's effect on the nurse. 'Helping the patient through' is about supporting the patient and family by informing them about treatments, procedures, and prognosis, and managing the patients' comfort. Next to that, being personally involved was mentioned as giving support to the family. Nurses mentioned giving away control vs. allowing control to be taken by the family. Nurses gave some control away by actively involving the patient in his plan of care. Nurses worked closely with family and developed meaningful relationships	–	Care for the family of the ICU patient
Ranse et al. (26), Australia	To explore EOLC beliefs and practices of ICU nurses	5 ICU nurses employed in a 14-bed intensive care unit at a tertiary teaching hospital (all women)	Descriptive exploratory qualitative study	Semi-structured interviews	Three major categories were described: beliefs about EOLC, EOLC in the ICU context, and facilitating EOLC. The third category contains the nurses' practices of caring for the patient during EOLC and their family. The nursing interventions undertaken included bathing, hair care, mouth care, pressure area care, spiritual care and the administration of analgesics, sedatives and antimicrobials. A single room for the patient and a family room separate from the waiting room, and open visiting hours were also mentioned. Creating a less clinical and more homely environment was achieved by dimming the lighting, replacing the hospital linen with coloured sheets and quilts, placing photographs and playing music. Next to that, ICU nurses wanted to get to know the patient by talking with the family about the patient and reflect on their lives together. 'Being there' included a physical presence by the nurse at the patient's bedside and encouraging family to sit, talk to and touch the patient. At last, nurses made memories for families by taking the patients' hand prints and collecting a lock of hair and the identity band	–	Care for the ICU patient, Care for the family of the ICU patient, Environmental aspects of EOLC

Table 3 (Continued)

Author (s), country	Purpose of the study	Sample	Study design	Data collection	Main results	Evaluation	Category
Da Silva et al. (25), Brazil	To know the meaning of caring in nursing for a good death from the perspective of a team of intensive care nurses	10 ICU nurses of a teaching hospital	Qualitative study	Semi-structured interviews between April and July 2010.	The central category was promoting comfort. Which meant to relief physical discomfort like pain, social and emotional support to the patient and family, allowing family presence at any time, and ensuring the integrity of the patient. This category was divided into relief of physical discomforts (minimise pain and respiratory distress through analgesics and sedatives), social and emotional support (support for the patient and family by affection, attention, words of courage and strength and the use of relaxation and leisure strategies, like encouraging family to stay at the bedside, helping family to understand the inevitability of loss), and maintaining the health and body positioning (ensure the physical integrity, respect the body, preserving the good body image)	-	Care for the ICU patient, Care for the family of the ICU patient
Zomorodi & Lynn (27), USA	To explore nurses' definitions of quality EOLC and to describe the activities that promote quality EOLC in the ICU	9 ICU nurses employed at a burn unit, medical ICU, surgery/neurosurgery ICU, cardiothoracic ICU and coronary care units	Qualitative study	Semi-structured interviews	The results are divided into personal, environmental and relational factors. Environmental factors included reducing technology. Nurses who provide quality EOLC were described as someone who utilised resources for both the patient and family, provided a calm environment, communicated effectively to other nurses, patients, family and other professionals, was flexible and understood that a dying patient could not be placed in a protocol, set up the death scene appropriately, balanced time effectively and provided optimum pain and symptom management. Nurses described the process as 'taking a step back'	-	Care for the ICU patient, Environmental aspects of EOLC
Quantitative studies Badir et al. (18), Turkey	To investigate the views and experiences of Turkish ICU nurses related to EOLC in ICUs	626 ICU nurses of 32 second and third level ICUs of 19 hospitals (72.3% response rate)	Cross-sectional study	Questionnaire 'Views of European Nurses in Intensive Care on EOL Care (VENICE)'. Data was collected in March and April 2012.	Results showed that 87.2% agreed that the patient and family should perform their final religious and spiritual duties. 86% of the ICU nurses agreed to continue pressure sore prevention, effective pain relief (85.5%), endotracheal or oral aspiration (82.2%), nutritional support (77.6%), hydration (64.8%), passive range of motion exercises (64.3%), and removal of endotracheal tubes (61.3%). 57.5% of the ICU nurses stated that dying IC patients should be cared for in the ICU. Besides, 27% of ICU nurses supported a restriction of visits by family. The authors described that ICU nurses should focus on interventions as symptom management, withholding and withdrawing treatment, spiritual and psychological care, comfort care for the patient, and grief and bereavement interventions for family	C	Care of the ICU patient, Care of the family of the ICU patient, Environmental aspects of EOLC

Table 3 (Continued)

Author (s), country	Purpose of the study	Sample	Study design	Data collection	Main results	Evaluation	Category
Beckstrand et al. (19), USA	To collect suggestions from ICU nurses for improving EOLC in ICU's in the USA	861 members of the American Association of Critical-Care Nurses (61% response rate). They were employed as staff nurses (53%), charge nurses (36%), clinical nurse specialists (4%), or in other roles (6%)	Survey	Questionnaire	Providing a 'good death' was the major theme. Most mentioned barriers are lack of time (n = 72), physicians' behaviours (n = 47), seeing the death of the patient as personal failure (n = 24). Specific suggestions included making environmental changes to enable dying with dignity, not allowing patients to be alone, pain and symptom management (n = 43), and knowing and following the wishes of the patient (n = 39)	C	Care for the ICU patient, Environmental aspects of EOLC
Beckstrand & Kirchoff (31), USA	To measure ICU nurses' perceptions of the intensity and frequency of occurrence of obstacles to providing EOLC and supportive behaviours that help in providing EOLC in the ICU	864 members of the American Association of Critical-Care Nurses (61.3% response rate). 80% worked in the ICU/CCU	Experimental, post-test-only, control-group design	Questionnaire 'National Survey of Critical-Care Nurses Regarding End-of-Life Care'	The most intense obstacle for providing EOLC were having multiple physicians who differed in opinion about the direction of a patient's care (mean 4.03), family who continually called for an update (mean 4.02) and physicians who were evasive and avoided conversations with family (mean 4.00). The scoring items indicating supportive behaviour were: giving family members adequate time alone with the patient (mean 4.44), creating a peaceful and dignified bedside scene (mean 4.45), informing families how to act around the dying patient (mean 4.19), having enough time to prepare family for the patient's death (mean 4.28), letting the social worker or religious leader take primary care of the grieving family (mean 3.59), and asking family for physical help during care for the dying patient (mean 3.20)	C	Care for the family of the ICU patient, Environmental aspects of EOLC, Organisational aspects of EOLC
Kirchoff et al. (33), USA	To describe how ICU nurses prepare families for withdrawal from mechanical ventilation, followed by the death of the patient	31 ICU nurses of four ICUs located at one rural and two urban hospitals (48% response rate)	Survey	'Preparing Families for Withdrawal' Questionnaire	Results showed 43 themes ICU nurses informed families about, of which 67.5% were physical sensations and symptoms. Most nurses informed families about respiratory and skin items (respectively 71% and 74%). Besides information about the physical signs and symptoms of the dying process, 36% of the nurses were available for supporting families by offering emotional support, reassuring family about the patients' comfort and giving spiritual care	C	Care for the family of the ICU patient

Table 3 (Continued)

Author (s), country	Purpose of the study	Sample	Study design	Data collection	Main results	Evaluation	Category
Langley et al. (22), South Africa	To investigate South African ICU nurses' experiences and perceptions of EOLC	100 ICU nurses of four ICUs in two university-affiliated public hospitals (67% response rate)	Cross-sectional study	Questionnaire VENICE	Results showed that 93% strongly agreed that the patient and family should perform their final religious and spiritual duties. 62% agreed that the patient could breathe spontaneously, the endotracheal tube should be removed, 83% felt that oral or endotracheal suction should be continued to maintain airways, 85% should continue hydration, 89% should continue to perform pressure injury interventions, 84% agreed that the patient should be provided with effective pain relief. 68% of the nurses agreed that the care should be given by the same nurse, in a private room (73%), and permitted no restriction of family (70%)	C	Care for the ICU patient, Care of the family of the ICU patient, Environmental aspects of EOLC
Latour et al. (23), Europe	To investigate experiences and attitudes of European ICU nurses regarding EOLC	162 ICU nurse participants who attended the second European critical care nursing congress of EFCCNa (39.1% response rate)	Survey	Questionnaire VENICE. Data was collected in November 2005	73.4% reported active involvement in the decision-making process. The expected quality of life of the patient was ranked as very important from the patient's and family's perspective. Results showed that 96.9% agreed that the patient and family should perform their final religious and spiritual duties. 61% of the ICU nurses agreed to continue pressure sore prevention, effective pain relief (98.8%), endotracheal or oral aspiration (81.4%), nutritional support (41.6%), hydration (74.7%), passive range of motion exercises (36%) and removal of endotracheal tubes (74.4%). 54.2% of the ICU nurses stated that dying IC patients should be cared for in the ICU. Besides, 34.2% of ICU nurses supported a restriction of visits by family in general, views and experiences of EOLC were similar, the provision of nutrition and use of sedation showed most differing views	C	Care for the ICU patient, Environmental aspects of EOLC
Opinion article Nelson et al. (34) USA	To discuss the key role that nurses can and must continue to play in integrating palliative care in the ICU	Not applicable	Opinion article	Not applicable	Nurses have the important role of implementing a care plan and have the most intensive involvement with patients and family. ICU nurses help family to understand the condition and prognosis of the patient, and share their knowledge about the patient, his values and preferences. ICU nurses also have knowledge of the concerns and questions of the family, and give family emotional and practical support	D	Care for the family of the ICU patient

ICU nurses from Turkey (85.5%), 84% of South African and 98.8% of European ICU nurses agreed to effective pain relief, 86% Turkish, 89% South African and 61% European ICU nurses agreed to continue pressure sore prevention, nutritional support (77.6% Turkish, 84% South African, 41.6% European), hydration (64.8% Turkish, 85% South African, 74.7% European), passive range of motion exercises (64.3% Turkish, 74% South African, 36% European) and removal of endotracheal tubes (61.3% Turkish, 62% South African, 74.4% European) (18, 22, 23). Next to the pain and symptom management, nursing care, such as bathing, hair care, mouth care (prevention of), pressure area care, and spiritual care were mentioned. Studies described that every patient is unique and that it is important to understand that a dying patient cannot be defined by a protocol. Therefore, nurses have to adapt their care to the wishes of the patient, and nurse them with safe and caring hands in a collaborative environment (19, 26–28).

Three studies also stated that the patient should not be alone during the dying process (19–21). Long-Sutehall et al. (24) described that nurses decreased supportive drugs, fluids, and weaning ventilation and removed monitoring equipment, so that the patient is 'given back' to the family. Arbour et al. (17) stated that nurses advocated for the ICU patient.

*Care for the family of the ICU patient.* Seventeen studies dealt with nursing care for family of dying ICU patients. The main theme discussed in those studies concerns the support of the patient and his family. Support includes informing them about treatments, procedures and prognosis, but also how to act around the dying patient, and by offering emotional support and reassurance to the family that the patient is comfortable (17, 18, 21, 22, 24, 25, 29–35).

Good nursing care included protecting the patient against distressing impulses and sensory imbalance. Family members were encouraged to stay nearby, sit, talk to and touch the patient (21, 25, 26, 28, 36). Popejoy et al. (35) described how nurses gave away their control and allow the family to take over. Nurses gave some control away by actively involving the family in the patients' plan of care. Asking the family for physical help during the care for the dying patient was described by Beckstrand & Kirchhoff (31).

A meaningful relationship between nurses and family is needed to establish good nursing care. Working with the family includes getting to know the patient by talking with the family and to reflect on their lives together, while also by being physically present, as a nurse, at the patient's bedside (26, 34–36). Adams et al. (29) add that there is a need to strengthen the therapeutic relation between family and professionals, which included holding the family in high esteem, for example talking with

family about themselves, making eye contact and sitting close.

Beckstrand & Kirchhoff (31) also argued that it is important to give family sufficient time to be alone with the patient. Bratcher (20) stressed the importance of the acceptance of death by patient and family. The acceptance of death also includes according to him the idea that a patient and his family do not have any unresolved issues. Adams et al. (30) described that the family needs to be supported in realistic hope, for example by assuring that the patient and family would continue to be cared for, foreshadowing, compassion, reframing hope, and allowing time to process information during their stay in the ICU.

Good EOLC can also be achieved by nurses making memories for families by taking the patient's hand prints and collecting a lock of hair and the identity band, or organising follow-up meetings with the opportunity to meet the family again, answering questions about the care provided, requesting feedback on the care provided and handing over the dead patient's belongings (17, 21, 26).

*Environmental aspects of EOLC.* Ten studies described the environmental aspects of EOLC. Environmental factors included reducing technology, providing a calm environment, setting up the appropriate death scene by creating a peaceful, serene and dignified bedside. This can be achieved by playing music, dimming the light, replacing the hospital linen with coloured sheets and quilts, placing photographs and if desired, moving the patient to a single patient room (17, 19–21, 26, 27, 31).

Bratcher (20) also advised to use a 'get to know me' card in the patient room to help professionals see the patient as a person, the person he was before being admitted to the ICU. Ranse et al. (26) added a family room separate from the waiting room, and open visiting hours. The latter was also mentioned by Arbour et al. (17) Twenty-seven per cent of Turkish, 15% of South African and 34.2% of European ICU nurses supported a restriction of visits by family (18, 22, 23).

*Organisational aspects of EOLC.* The organisational aspects of EOLC were described in four studies. Beckstrand & Kirchhoff (31) and Fridh et al. (21) described the importance of having enough time to prepare the family for the patient's death (Table 4). Bratcher (20) described that nurses could give families a beeper so they can leave the ICU to eat, sleep or pray while staying in touch with the ICU. Beckstrand & Kirchhoff (31) advised to let the social worker or religious leader take primary care of the grieving family.

Next to that, Hov et al. (28) stated that the general condition for good nursing care is divided into continuity, cooperation, knowledge and competence.

**Table 4** Results of the study of Fridh et al. (21)

Category	Subcategory	Example
Ensuring the patient's dignity and comfort	Decreasing pain	Administering analgesics
	Management of symptoms which can cause discomfort	Administering sedatives
Caring for the unaccompanied patient	Acting as both professional and fellow human being	Never leave the patient alone
	Determining the moment of withdrawal of life-sustaining treatment 'The forgotten patient'	The death trajectory for patients with no family present is shorter The unaccompanied patient remained anonymous for nurses.
Caring for the family	Reassuring the family that the patient does not suffer	Family regularly asking assurance that their loved one did not suffer
	Informing family about the patient's condition	Family is informed, none of the nurses ever informed the patient
	Motivating family to come to the ICU, and helping them to feel comfortable and secure	
	Encouraging family to touch and talk to the patient	
	Removing medical devices Follow-up visits	Opportunity to meet family again, answering questions about the care, requesting for feedback of the given care, and handing over the dead patient's belongings
Environmental obstacles to doing one's utmost	Lack of private rooms and problems in creating privacy for the family	Preferences of nurses for single rooms or special EOLC rooms
Organisational obstacles to doing one's utmost	Lack of time and support	Sometimes there is insufficient time to care for the patient and family during the whole EOLC process

## Discussion

This integrative review explored the role of ICU nurses during end-of-life care (EOLC) related to the interaction between patients, family and nurses. Due to possible severe problems experienced by patients and family, it seems important to know the exact role of ICU nurses during EOLC in the ICU, related to the interaction of patients, family and nurses. The literature clearly indicates that the role of ICU nurses concerns care for the patient, family and environment. However, a clear description of realising the care triad is lacking.

The results were divided into four categories, but during the data abstraction another subdivision could be made. The results could be divided into: (i) *What* should be done (activities), and (ii) *How* this should be done (attitudes). Table 5 shows a summary of what should be done and how this should be done.

As shown in Table 5, most literature described *what* should be done during EOLC in the ICU, but little is written about *how* care should be given. *What* should be done is described in activities. The activities are mostly concrete, like bathing, hair care, mouth care, pressure area care, administration of analgesics and giving a beeper to family. It seems quite normal that the literature focuses on functional activities, which can be explained by the fact that the ICU is mostly seen as a technological care environment where ICU nurses perform highly complex care.

The few studies that described *how* to provide EOLC remained vague. Those studies used terms like 'respectful care', 'compassion', 'ensure physical integrity' and 'open attitude', but were not concretised. For example, Zomorodi & Lynn (27) described 'taking a step back', but do not define how this should be done. 'Taking a step back' can be explained in different ways, as literally taking a step back, but also, for example, using less communication, or being less present in the patient room. Another example comes from Beckstrand et al. (19) and Bach et al. (36). They mentioned 'being present' during EOLC. Bach et al. (36) describe 'being present' as physically being there and letting the family know 'you will be there' for them. Or, for example, 'ensuring physical integrity' as described by Da Silva et al. (25).

The descriptions mentioned above still remain indistinct and do not present concrete indications how to perform this care. Because of the different ways nurses could interpret the concepts, it is not clear what the authors actually meant. The translation from research to practice could lead to problems.

Besides the differences in *what* and *how* care should be given, the literature also shows a process in which there is a shift in nursing activities from care for the patient to care for the family, even more so when patients are unconscious. This shift is not explicitly mentioned in the literature, but all articles discuss nursing care for the patient and care for the family after that. It seems that ICU nurses should change their focus during EOLC from

**Table 5** Results divided into what is being done and how it is done

<i>What should be done/activities</i>	<i>How should this be done/attitude</i>
Provision of care for the patient Bathing, hair care, mouth care, pressure area care, spiritual care, administration of analgesics, sedatives and antimucolytics, investigating (cultural and religious) wishes and needs, not letting the patient alone (17–27) Advocating for the patient (17)	Each patient needs to be met openly as a unique person, which involves preservation of his personality, acceptance, respectful treatment, and being nursed for his own interests (28). A dignified, peaceful and respectful death (20). Ensure physical integrity, respect the body (25)
Provision of care for family Talking about the patient and reflecting on their lives together, supporting families, encouraging family to sit, talk to and touch the patient, informing about treatments and procedures, asking them to help in the care for the patient (17, 20, 21, 24–26, 28–36) Developing meaningful relationships with family and work very hard to help family find peace with the decision, and building an emotional relation with family members (29, 35) Providing guidance (32) Giving adequate time alone with the patient (31) Giving a beeper so they can leave the ICU to eat, sleep, exercise or pray while remaining in touch with the ICU (20) Making memories for family (17, 21, 26)	'Taking a step back' (27). Giving some control away by actively involving the family in his plan of care (35). Giving the patient back to the family (24). No unresolved issues between patient and family (20). Being physically present, but also by letting family know you will be there for them (36). Support realistic hope by assuring that the patient and family will continue to be cared for, foreshadowing, compassion, reframing hope, allowing time to process information (30). Using eye contact, facing the family and coming to the phone when family calls, offering the family trust and confidence, which helps the family to cope (29)
Environmental aspects of EOLC Single room for the patient and a family room separate from the visitor's waiting room, creating an atmosphere that is less clinical and more homely and serene by dimming the lighting, playing music and reducing technology (19–21, 24, 26, 27, 31)	
Organisational aspects of EOLC Open visiting hours, being there for the patient and family, balancing time effectively, coordinating care and communication, follow-up visits (23, 24, 27)	

patient to family care; however, ICU nurses mentioned that care is always patient-centred care, and stays this way during EOLC (37). This seems in contrast to the process mentioned above, where care is shifting towards family-centred care during EOLC, including patients and the social system.

Furthermore, some studies described nursing care activities for the family. But when analysing the literature, the care for the family is mostly about activities related to the patient. The nursing care for family exists of helping and advising the family how they can support or take care of the patient, and not explicitly about caring for the family members themselves. Only Arbour et al. (17), Adams et al. (30), Ranse et al. (26), Fridh et al. (21) and Treece (38) recommended some activities like making memories for the family, giving some time alone for the patient and family, asking for emotional and practical needs of family, organising follow-up meetings and open visiting hours.

The studies of Latour et al. (23), Langley et al. (22) and Badir et al. (18) showed that most of the ICU nurses from Europe, Turkey and South Africa (65.8%, 73% and

85% respectively) would like to have open visiting hours, like recommended as care for family. Therefore, it is questionable if even though the literature does not give many suggestions for care for the family, it might be desired by family or even practiced already by the ICU nurses.

Comparing the results of the studies of Latour et al. (23), Langley et al. (22) and Badir et al. (18), it showed several similarities indicating that ICU nurses have similar perspectives about EOLC. However, European ICU nurses would sooner end nutrition, passive range of motion exercise and pressure sore prevention than nurses in studies elsewhere. The European ICU nurses agreed more with effective pain relief and removal of endotracheal tubes in comparison with nurses from other continents. These differences could be explained by the different cultures and religions, but also due to law and regulations.

A clear role of ICU nurses during EOLC in interaction with the patient and family may be helpful in preventing stress, anxiety, depression and post-traumatic stress disorder in family members. Therefore, it is important to

know what the role of ICU nurses should be in the care triad during EOLC in the ICU. Comparing the literature, the interaction between patients, family and nurses, with the aim to find balance in the provided care by family and professionals (care triad) as described in the theory of Fortinsky (9), Kongsuwan & Touhy (10) and Beneken genaamd Kolmer et al. (11), does not appear to be reached. Adams et al. (29) does describe the importance of a therapeutic relation; however, this is not the balance meant in the theories, because the care triad should prevent the need of a therapeutic relation. Fridh et al. (21) even described that nurses in her study never informed patients about their condition during EOLC. It has to be said that many ICU patients are sedated or unconscious, but in similar studies it is stated that nurses have to encourage family to talk to the patient even when they are unconscious. For those patients, it seems important that the care provided is an expression of being human (12). Therefore, the care for conscious and unconscious persons should be the same: nurses should explain and inform the ICU patient.

It seems essential that ICU nurses understand how the historical relation between the patient and family was, and which motives for caring for the patient are important to the family (11). Besides that, it should become clear what the exact role of the ICU nurse should be in caring for patients *and* family. It remains questionable if all described care is the responsibility of ICU nurses during EOLC.

More research is needed to answer this question. It can be concluded that it is important for ICU nurses to be aware of the existing relationships mentioned in the theories, due to the possibility of causing stress for patients and family, and thus the relations that already exist and will develop during admission in the ICU.

#### *Methodological limitations*

Some limitations of this study must be conceded. A limitation we faced was the moderate quality of the included studies. A moderate quality incorporates a high risk of bias, but the similarities in the results support the results and decrease the bias. Next to that, only articles written in English, Dutch or German were included. Because of this, some relevant studies may have been missed. Though, with the use of three well known and widely used databases most relevant studies will have appeared.

#### **Conclusion**

This review provides an overview of the described role of ICU nurses during EOLC, related to the interaction

between patients, family and nurses. The data can be divided into four categories: care for the ICU patient, care for the family, environmental aspects of EOLC and organisational aspects of EOLC.

This review gives information about the interaction between patients, family and professionals, but the literature remains unclear and focuses on *what* ICU nurses should do (activities) and not on *how* this should be done (attitudes). Therefore, it is difficult for ICU nurses to provide this care. Further, it seems that care provided to family mainly consists of giving advice on how to care for the patient; care for family members themselves was only mentioned in a few studies. Therefore, it seems that family does not always receive adequate care yet, which may be helpful in preventing problems like depression, anxiety or post-traumatic stress disorder. It can be concluded that it is important for ICU nurses to be aware of the existing relationships; however, comparing the literature, care triad does not appear to be reached.

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#### **Author contributions**

The study method concerned a literature review performed by M. Noome, MSc, RN, and B.M. Dijkstra, MSc, CCRN, RN, under supervision of D.M. Beneken genaamd Kolmer PhD, E. van Leeuwen PhD, and L.C.M. Vloet PhD, RN. Additionally, we like to state that all authors have made substantial contributions to all of the following: (i) the conception and design of the study, or acquisition of data, or analysis and interpretation of data, (ii) drafting the article or revising it critically for important intellectual content and (iii) final approval of the submitted version.

#### **Ethical approval**

Ethical approval was not sought for, and was not needed.

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