Challenges and facilitators in providing effective end of life care in intensive care units

Elena Ivany and Leanne Aitken

Abstract
Caring for patients who are at the end of their lives is an essential aspect of practice in intensive care units (ICUs). While intensive care is one of the fastest-growing healthcare specialties as a result of technological and scientific advances, a significant proportion of patients admitted to an ICU in the UK will not survive their ICU stay. Therefore, it is important to examine ways to enhance practice in this area and the factors that might affect the care provided to patients and their families.

Aim: To identify the challenges and facilitators that members of the ICU multidisciplinary team encounter in the delivery of end of life care to dying patients in ICUs.

Method: A scoping literature review was undertaken. Cumulative Index to Nursing and Allied Health Literature (CINAHL) Plus with full text, MEDLINE Complete and the EBSCOhost E-Journals Database were searched electronically to identify literature from April 2007 to April 2017, alongside hand-searching. Critical appraisal tools were used and thematic analysis was undertaken to analyse the data and identify themes.

Findings: Ten articles were included in the literature review, which identified various challenges and facilitators in providing effective end of life care in ICUs. The main themes identified were: communication, family involvement, personal factors and the ICU environment.

Conclusion: All of the studies included in the literature review identified several important challenges related to communication, such as time constraints, disagreements among healthcare professionals, and a lack of knowledge among healthcare professionals about how to conduct challenging conversations with patients and families. Future developments in practice should consider the role of effective multidisciplinary team-working in end of life care.

Author details

Keywords
communication, critical care, death, end of life care, good death, intensive care, literature review, palliative care, patient-centred care, patients, person-centred care, research

Caring for patients who are at the end of their lives is an essential component of care in intensive care units (ICUs). Although technological and scientific advances have made intensive care one of the fastest-growing healthcare specialties, 15-25% of patients admitted to an ICU in the UK (Connolly et al 2016) and 15% of patients worldwide (Vincent and Creteur 2015) will not survive their ICU stay. There is an ongoing shift in critical care ideology in which increased emphasis is placed on patients’ quality of life rather than the idea that survival at all costs is the only acceptable goal (Vincent and Creteur 2015). However,
end of life care / research
evidence & practice

end of life care in ICU settings continues to vary and studies show that important aspects of end of life care, such as timely communication and patient involvement in decisions about their care, can be improved (Papadimos et al 2011, Aslakson et al 2014).

Aim
To identify the challenges and facilitators that members of the ICU multidisciplinary team encounter in the delivery of end of life care to dying patients in ICUs.

Method
A scoping literature review was undertaken. Considering the aim of the literature review was to identify the challenges and facilitators experienced by multidisciplinary team members in the delivery of end of life care in the ICU, it was felt that a framework specifically designed for qualitative research would be appropriate. Therefore, the PICo (population, interest, context) framework (Curtin University 2018) was used to identify the search terms (Table 1) and the research question, as follows:

Population – multidisciplinary team members. It was felt that broadening the question to the multidisciplinary team rather than solely focusing on nurses would result in a literature review that accurately reflects clinical practice, since nurses work alongside other healthcare professionals to deliver patient care.

Interest – challenges and facilitators in providing end of life care.

Context – end-of-life care for dying patients in the ICU.

The PICo framework resulted in the research question: ‘What do multidisciplinary team members identify as the challenges and facilitators in providing palliative care to patients dying in the ICU?’

The following databases were searched electronically for literature from April 2007 to April 2017 inclusive: Cumulative Index to Nursing and Allied Health Literature (CINAHL) Plus with full text, MEDLINE Complete and the EBSCOhost E-Journals Database. Where appropriate, relevant search terms were truncated using an asterisk to ensure possible variations were included (Table 1). The reference lists of the selected literature were hand-searched to identify any relevant articles that might have been missed. Inclusion and exclusion criteria were applied to the search to identify the most relevant literature (Box 1).

All of the studies included in the literature review were analysed using critical appraisal tools. For the qualitative studies, the Critical Appraisal Skills Programme (CASP) (2017) Qualitative Checklist was used, while the Center for Evidence-Based Management’s (2016) Critical Appraisal of a Survey tool was used to appraise the studies that used questionnaires. Inductive thematic analysis was used to synthesise the findings of the literature review and to identify themes.

Findings
A total of 5,931 articles were identified through the electronic database search and a further five articles were identified through hand-searching, giving a total of 5,936 articles. The inclusion and exclusion criteria were applied to the titles and abstracts, and then the full articles, which left ten articles that were included in the scoping literature review.

Seven of the studies used surveys as the data collection method. Sample ranges across all studies varied between nine participants and 509 participants. Nurses were the most represented profession across the studies – seven studies sampled the views of nurses only, two studies sampled the views of doctors alongside nurses, and one study sampled the views of social workers.

A summary of the articles analysed in the literature review is shown in Table 2. The main themes that emerged from the thematic analysis were: communication; family involvement; personal factors; and the ICU environment.

Communication
The challenges of communicating with patients in ICUs who are at the end of their lives were highlighted in the studies in this literature review, particularly in relation to patients in ICUs often being too unwell to engage in decision-making (McCormick et al 2007, Friedenberg et al 2012). Communication difficulties may lead to unanswered questions about patients’ wishes regarding their end of life care (Crump et al 2010, Zomorodi and Lynn 2010, Losa Iglesias et al 2013). In Friedenberg et al’s (2012) study, 67% of doctors stated that patients not being able to take part in discussions about end of life care was a significant barrier to the provision of effective care. Doctors sampled in another study

Table 1. Search terms used in the literature review

<table>
<thead>
<tr>
<th>Population</th>
<th>Interest</th>
<th>Context</th>
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<tbody>
<tr>
<td>Multidisciplinary</td>
<td>Barrier* Challenge*</td>
<td>Intensive care unit</td>
</tr>
<tr>
<td>team members*</td>
<td>Negative*</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Issue* Difficult</td>
<td>Critical care unit</td>
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<td></td>
<td>Problem*</td>
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<tr>
<td></td>
<td>Facilitator*</td>
<td>Adult critical care unit</td>
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<tr>
<td></td>
<td>Ease Help</td>
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<tr>
<td></td>
<td>Benefit* Palli$</td>
<td>ICU</td>
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<tr>
<td></td>
<td>Palliative care</td>
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<tr>
<td>End-of-life End of</td>
<td>ACCU</td>
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<td>life Dying</td>
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Box I. Inclusion and exclusion criteria for the literature review

Inclusion criteria
- Multidisciplinary team professionals
- Intensive care unit settings
- Primary research
- Challenges and facilitators to end of life care provision
- Adults aged 18 years and over
- Peer-reviewed publication in English
- Research design: qualitative, quantitative, mixed method

Exclusion criteria
- Patients’ and/or relatives’ experience
- Other acute care settings, such as emergency departments, coronary care units, acute admission units, anaesthetic recovery units
- Disease-specific research
- Editorials, case reviews, service evaluations and audits
- Research design: randomised control trials, pilot studies, feasibility studies, questionnaire development
stated that open and transparent discussions that address patients’ wishes can lead to enhanced end of life care (Brooks et al 2017).

Communicating with families was an important subtheme that emerged from this scoping literature review. Doctors and nurses in Brooks et al’s (2017) study identified that families often travel on ‘a journey of understanding’, which is different for every family. However, nurses and doctors in several studies identified that patients and families can have unrealistic expectations of the effectiveness of ICU care, with participants suggesting that families did not always understand the severity of the patient’s condition (Friedenberg et al 2012, Tirgari et al 2016, Brooks et al 2017). In Beckstrand et al’s (2017) survey study, nurses identified that ‘patients and families do not understand what the phrase “lifesaving measures” really means’ and this was the most significant challenge to providing effective end of life care, while nurse participants in Brooks et al’s (2017) study stated that clinicians sometimes hide the unpleasant elements of ICU care from families, for example by asking them to leave the bed space when a patient experiences seizures or dangerously low blood pressure. This might inhibit families’ understanding of how unwell the patient actually is.

Communication between doctors and other healthcare professionals was mentioned in all of the studies. Nurses stated that a lack of effective communication resulted in fragmentation of care (Zomorodi and Lynn 2010, Gélinas et al 2012), nurses feeling that their clinical opinion was not valued (Crump et al 2010, Attia et al 2013, Beckstrand et al 2017) and nurses feeling that they were not involved in decision-making (Gélinas et al 2012). The extent to which doctors rated communication between clinicians to be a challenge varied. For example, Friedenberg et al’s (2012) study reported that 9% of medical residents identified suboptimal multidisciplinary team communication as a challenge, but Brooks et al’s (2017) study reported that suboptimal communication between the ICU medical team and other medical teams was a barrier to providing effective end of life care.

Family involvement

Family involvement was identified as both a challenge and a support across several studies. Where families displayed behaviour perceived by healthcare professionals to be challenging – such as asking too many questions, insisting on curative treatment or challenging clinical decisions – participants in several studies rated such family involvement as a considerable barrier to delivering end of life care to patients in the ICU (McCormick et al 2007, Crump et al 2010, Attia et al 2013, Losa Iglesias et al 2013, Beckstrand et al 2017). Furthermore, patients’ families were at the centre of four of the ten most challenging barriers identified in one study (Beckstrand et al 2017). Practical issues, such as a language barrier or, for social workers, not having the time to engage with families, were also identified as barriers to delivering end of life care (McCormick et al 2007, Crump et al 2010, Friedenberg et al 2012).

Engaging with families was also among the supporters or facilitators identified by participants (McCormick et al 2007, Losa Iglesias et al 2013). Social workers were increasingly likely to be satisfied with their work if they had positively engaged with the patient’s family (McCormick et al 2007). In Losa Iglesias et al’s (2013) study, nurses strongly identified family presence at the bedside of the dying patient to be a supportive practice, and found it beneficial to educate families about how to behave around the dying patient.

Personal factors

Several nurses reported that the ethos of ICU, where the goal is successful life-saving treatment, did not lend itself well to caring for dying patients, thereby causing moral distress for the nurses (Gélinas et al 2012, Tirgari et al 2016). Some nurses also found it emotionally challenging to provide active care to patients who were not going to survive (Zomorodi and Lynn 2010). Other challenges identified by nurses included the belief that most patients who die in the ICU would not have chosen the critical care setting as their preferred place of death and the perceived belief that providing comfort care was of less value, or involved using fewer nursing skills, than the provision of active treatment (Gélinas et al 2012, Tirgari et al 2016). To counteract such feelings, nurses found it beneficial to receive encouragement, positive feedback and emotional support from fellow nurses and from patients’ families (Crump et al 2010, Attia et al 2013, Losa Iglesias et al 2013).

Lack of end of life care guidance meant that nurses were unsure whether the decisions they made were correct, and some nurses reported being fearful of legal responsibility for certain end of life care practices such as the administration of opiates and the withdrawal of treatment (Zomorodi and Lynn 2010, Friedenberg et al 2012)

Key points

- 15-25% of patients admitted to an intensive care unit (ICU) in the UK (Connolly et al 2016) and 15% of patients worldwide (Vincent and Creteur 2015) will not survive their ICU stay

- There is an ongoing shift in critical care ideology in which increased emphasis is placed on patients’ quality of life rather than the idea that survival at all costs is the only acceptable goal (Vincent and Creteur 2015)

- Lack of end of life care guidance meant that nurses were unsure whether the decisions they made were correct, and some nurses reported being fearful of legal responsibility for certain end of life care practices such as the administration of opiates and the withdrawal of treatment (Zomorodi and Lynn 2010, Friedenberg et al 2012)

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<table>
<thead>
<tr>
<th>Title and author</th>
<th>Study focus</th>
<th>Country</th>
<th>Intensive care unit (ICU) type*</th>
<th>Sample</th>
<th>Data collection</th>
<th>Findings</th>
<th>Strengths and weaknesses</th>
</tr>
</thead>
<tbody>
<tr>
<td>Critical care nurses’ perceptions of barriers and supportive behaviors in end-of-life care (Attila et al 2013)</td>
<td>Barriers and support</td>
<td>Egypt</td>
<td>Oncology, cardiac care unit, liver, surgical</td>
<td>70 nurses</td>
<td>Survey</td>
<td>Barriers to providing end of life care were related to: the ICU environment; family members’ attitudes; doctors’ attitudes; nurses’ knowledge and skills; and treatment policy. Facilitators included: nurses’ support of each other, families’ support; and patient and family-centred care</td>
<td>Strength: multicentre study; Weakness: original survey not piloted</td>
</tr>
<tr>
<td>Critical care nurses’ perceptions of obstacles, supports, and knowledge needed in providing quality end-of-life care (Crump et al 2010)</td>
<td>Barriers and support</td>
<td>US</td>
<td>Not specified</td>
<td>56 nurses</td>
<td>Survey with open-ended questions</td>
<td>Barriers included family attitudes, inadequate education for nurses, doctors’ attitudes. Facilitators included clear direction of care and providing a peaceful and dignified death</td>
<td>Strength: inclusion of open-ended questions; Weaknesses: self-selecting sample. Single-centre study</td>
</tr>
<tr>
<td>Critical care nurses’ values and behaviors with end-of-life care: perceptions and challenges (Zomorodi and Lynn 2010)</td>
<td>Barriers and facilitators</td>
<td>US</td>
<td>Burns, cardiac care unit, surgical, cardiothoracic</td>
<td>9 nurses</td>
<td>Interviews</td>
<td>Factors that can facilitate or hinder end of life care were categorised as personal, environmental and relational. Nurses used strategies such as balancing, trial and error, coaching the physicians and taking a step back to improve the quality of end of life care provided</td>
<td>Strength: field notes used; Weaknesses: self-selecting sample. Single-centre study</td>
</tr>
<tr>
<td>Obstacles and helpful behaviors in providing end-of-life care to dying patients in intensive care units (Losa Iglesias et al 2013)</td>
<td>Barriers and facilitators</td>
<td>Spain</td>
<td>Not specified (adult and paediatric)</td>
<td>266 nurses</td>
<td>Survey</td>
<td>One of the main barriers was evasive doctors. One facilitator was providing a peaceful environment for the patient and family</td>
<td>Strength: sample size; Weaknesses: questionnaire not piloted. Single-centre study</td>
</tr>
<tr>
<td>Social workers in palliative care: assessing activities and barriers in the intensive care unit (McCormick et al 2007)</td>
<td>Practice and barriers</td>
<td>US</td>
<td>Not specified</td>
<td>20 social workers</td>
<td>Survey</td>
<td>The most common practice activity undertaken by social workers was providing support to families. One of the main barriers was a high workload</td>
<td>Strength: 84% response rate; Weaknesses: questionnaire reviewed but not piloted. Participant data not anonymised</td>
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<tr>
<td>Stressors</td>
<td>Barriers</td>
<td>Barriers</td>
<td>Challenges</td>
<td>Barriers, enable</td>
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<td></td>
<td></td>
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<tr>
<td>Canada</td>
<td>US</td>
<td>US</td>
<td>Iran</td>
<td>s and challenges</td>
<td></td>
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</tr>
<tr>
<td>42 nurses</td>
<td>Survey</td>
<td>Survey</td>
<td>Survey</td>
<td>Focus groups</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Multicentre study</td>
<td>Strength: multicentre study</td>
<td>Strength: large sample. Some longitudinal analysis available</td>
<td>Strength: questionnaire validated</td>
<td>Strength: focus groups</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Weakness: participants recruited in groups</td>
<td>Weakness: uneven doctor and nurse samples</td>
<td>Weakness: No explanatory qualitative data</td>
<td>Weakness: face-to-face recruitment</td>
<td>Weaknesses: single-centre study. Self-selecting sample</td>
<td></td>
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</tbody>
</table>

<table>
<thead>
<tr>
<th>Barriers</th>
<th>US</th>
<th>Not specified</th>
<th>113 doctors and 53 nurses</th>
<th>For nurses, barriers such as language barriers and inadequate training in recognition of pain and anxiety, varied by hospital. For doctors, barriers vary by training. Insufficient medical resident training in end of life care was reported as a significant barrier</th>
</tr>
</thead>
<tbody>
<tr>
<td>Survey</td>
<td>Strength: focus groups. Multicentre study</td>
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</table>

<table>
<thead>
<tr>
<th>Barriers</th>
<th>Not specified</th>
<th>508 nurses</th>
<th>Four of the top ten barriers related to family, such as family not understanding the meaning of life-sustaining treatment. Three of the top ten barriers related to doctors, such as doctors being evasive and avoiding speaking to the patient’s family</th>
<th>Strengths: large sample. Some longitudinal analysis available</th>
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</thead>
<tbody>
<tr>
<td>Survey</td>
<td>Weakness: No explanatory qualitative data</td>
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</table>

<table>
<thead>
<tr>
<th>Challenges</th>
<th>Surgical, cardiothoracic, neurological, general</th>
<th>123 nurses</th>
<th>The main challenges identified by the nurses were in converting from active treatment to comfort care, and that life-sustaining treatment is often given excessively</th>
<th>Strength: questionnaire validated</th>
</tr>
</thead>
<tbody>
<tr>
<td>Survey</td>
<td>Weakness: face-to-face recruitment</td>
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<thead>
<tr>
<th>Barriers, enablers and challenges</th>
<th>Cardiothoracic, general, neurosurgical, medical</th>
<th>11 doctors and 17 nurses</th>
<th>Barriers included conflict between ICU physicians and external medical teams; lack of specialist education and training; and environmental limitations. Enablers included collaboration and leadership during transitions of care. Challenges included family expectations and communication, and decision-making</th>
<th>Strength: focus groups</th>
</tr>
</thead>
<tbody>
<tr>
<td>Focus groups</td>
<td>Weaknesses: single-centre study. Self-selecting sample</td>
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</table>
of litigation was more pronounced in nurses than in doctors. Some doctors and nurses reported that they receive most of their end of life care education ‘on the job’ because of a lack of practical guidance (Zomorodi and Lynn 2010, Brooks et al 2017). A lack of education about the specific challenges of communicating with patients and families about end of life care was identified in one study, with participants stating that some multidisciplinary team members avoided challenging conversations, for example concerning the transition from active treatment to comfort care, because of a lack of relevant training (Brooks et al 2017).

Intensive care unit environment

Challenges relating to the ICU environment were identified in all studies. Participants in several studies identified that ICUs lacked private space for communicating with the patient and family, and reported that the design of the ICU did not always enable family members to be physically close to the dying patient (McCormick et al 2007, Gélinas et al 2012, Attia et al 2013, Brooks et al 2017). Some nurses also identified that families seldom have a private space where they can rest (Attia et al 2013). Even when private rooms were available for the patient and their family, the presence of specialist equipment at the bedside and the proximity of other patients who are unwell were identified as barriers to enabling a peaceful death (Zomorodi and Lynn 2010, Gélinas et al 2012, Attia et al 2013, Brooks et al 2017). Nurses reported removing or switching off non-essential monitoring equipment to reduce noise at the bedside and to enable the family to spend time with the patient in a private, quiet setting (Gélinas et al 2012).

In McCormick et al’s (2007) study, lack of time and high workload were identified as environmental barriers, with social workers reporting that increases in workload negatively affected their ability to deliver effective care. In Losa Iglesias et al’s (2013) qualitative study, it was reported that a lack of staff resulted in one nurse having to care for a dying patient alongside other patients. Doctors also reported that conflicting demands on their time made providing end of life care in the ICU setting increasingly challenging (Friedenberg et al 2012).

Discussion

This scoping literature review has emphasised the importance of effective communication between members of the multidisciplinary team. While effective communication promotes effective decision-making, improved communication practices in the ICU can also alleviate the symptoms of burnout among nursing and medical staff (Embracio et al 2007). Several studies suggested that nurses feel excluded from the decision-making process, which can lead to feelings of frustration and uncertainty about patients’ prognoses and treatment plans. This finding is supported elsewhere in the literature, showing that supporting ICU nurses’ involvement in family meetings positively correlates with nurses’ job satisfaction (Van Bogaert et al 2013). Furthermore, effective nurse-doctor communication has been identified as a cornerstone of effective palliative care in ICU settings (Nelson et al 2009).

Many of the studies included in this literature review also addressed the role that patients’ families have in the delivery of high-quality end of life care (McCormick et al 2007, Crump et al 2010, Attia et al 2013, Losa Iglesias et al 2013, Tigrari et al 2016, Beckstrøm et al 2017, Brooks et al 2017). Although some of the findings identify families as a potential challenge, the presence of family at the bedside of a dying patient has also been identified as an aid to delivering effective end of life care. In the ICU setting, families can have an important role in providing emotional care and information. For patients who are at the end of their lives, family presence is frequently associated with psychological comfort (Loh et al 2016). There is also evidence that families themselves express a desire to be present at the bedside of dying patients (Loh et al 2016).

Nurses are generally sensitive to this desire, employing various methods to assist in reconnecting the dying patient with their family, such as de-medicalising the patient’s bed space (Gélinas et al 2012).

Families can also be an important source of information in ICU settings. Effective communication between the patient and members of the multidisciplinary team can be a barrier in the provision of end of life care in the ICU. In situations where patients are unable to communicate their wishes to the clinical team, families can adopt the role of patient spokesperson (Nelson et al 2009). Therefore, it is important that families have access to information that is open and transparent and easy to understand from early in the patient’s ICU admission, because it is often necessary for families to have an active role in the decision-making process (Crump et al 2010).

Limitations

The aim of this scoping literature review was to explore issues that affect the delivery of end of life care in ICU settings. While the literature review included the perspectives of nurses, doctors and social workers, most of the articles included in the literature review focused on nurses’ views only. This means that this scoping literature review could not effectively represent the challenges and facilitators experienced by the wider multidisciplinary team in the delivery of end of life care in the ICU. Similarly, direct comparison between the studies included is complicated by the fact that they were undertaken in different countries, which have different healthcare systems, and different cultural and ethical beliefs. Nonetheless, the main themes identified in this scoping literature review transcend these differences, and therefore confirm that some of the challenges and facilitators that healthcare professionals experience in the delivery of end of life care in the ICU are related to the ICU setting itself.

Future developments in practice

Future developments in practice should consider the role that effective multidisciplinary team-
working has in improving end of life care. Initiatives such as multidisciplinary ward rounds and multidisciplinary debrief sessions could contribute to effective communication practices. Joint training in end of life care might lead to improved team-working and address some of the uncertainties that healthcare professionals reported experiencing in this scoping literature review. It would be preferable if such training focused on themes specific to end of life care in the ICU setting, such as communicating with families of dying patients, limits of care and treatment withdrawal, as well as addressing the general principles of effective end of life care.

**Conclusion**

This scoping literature review identified that the challenges and facilitators experienced by healthcare professionals who care for dying patients in ICU settings are related to several interrelated issues, including: communication; healthcare professionals’ personal values; family involvement in patient care; and the ICU environment. Effective communication is at the core of effective end of life care across ICU settings; however, several challenges relating to this theme were identified in all of the studies included in this literature review, including time constraints, disagreements among healthcare professionals, and a lack of knowledge among healthcare professionals about how to conduct challenging conversations with patients and their families. Specialist end of life care education was identified as another important factor in the delivery of effective end of life care in ICU settings.

**IMPLICATIONS FOR PRACTICE**

- Effective communication between healthcare professionals is important in providing high quality, cohesive end of life care in ICU settings.
- Because families can be involved in making decisions about patient’s end of life care, it is important to provide families of dying patients with open and transparent and easy-to-understand information about the patient’s condition and likely prognosis.
- Specialist training and education about providing end of life care in ICU settings would enhance ICU nurses’ knowledge in this area.
- Providing active care to patients who are unlikely to survive can be emotionally challenging for ICU nurses. The provision of debriefing opportunities, as well as specialist communication training and education about end of life care, can be used to support nurses’ emotional needs.

**References**


