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The challenges and facilitators of delivering end-of-life care in the ICU: a scoping review.

Elena Ivany and Leanne Aitken

Abstract

Caring for patients who are at the end of their lives has always been, and will continue to be, an important component of care in the ICU. 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.

Aims: 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.

Methods: 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.

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.

Background

Caring for patients who are at the end of their lives has always been, and will continue to be, an important component of care in the ICU. Although technological and scientific advances have made intensive care one of the fastest growing health care specialties, 15-25% of patients admitted to an ICU in the UK will not survive their ICU stay (Connolly et al, 2016, Vincent and Creteur, 2015).

The ongoing shift in critical care ideology is placing increasing emphasis on patients' quality of life rather than the idea that survival at all costs is the only acceptable goal (Vincent and Creteur, 2015). Yet the practice of delivering end-of-life care in ICU settings continues to vary and studies show that key aspects of end-of-life care, such as timely communication and patient involvement, can be improved on (Aslakson et al, 2014; Papadimos et al, 2011).

Aim

The aim of this scoping literature review was to identify the barriers and facilitators that members of the ICU multidisciplinary team (MDT) encounter in the delivery of end-of-life care to patients dying in ICU.

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?

Table 1: PICo framework and search terms.

Population	**Interest**			**Context**
Multidisciplinary team members*	**Challenges and facilitators of providing palliative care**			**End-of-life patients in the intensive care unit**
	Barrier*	Challenge*	Negative*	Intensive care unit
	Issue*	Difficult	Problem*	Critical care unit
	Facilitator*	Ease	Help	Adult critical care unit
	Benefit*	Palli$	Palliative care	ICU
	End-of-life	End of life	Dying	ACCU

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 (Table 2).

Table 2: Literature review inclusion/exclusion criteria

Inclusion	Exclusion
MDT professionals	Patients' and/or relatives' experiences
ICU settings	Disease-specific research
Primary research	Other acute care settings: A&E, coronary care units, ward, anaesthetic recovery unit
Research design: qualitative, quantitative, mixed method	Editorials, case reviews, service evaluation, audits
Challenges and facilitators to end-of-life care provision	Research design: randomised control trials, pilot studies, feasibility studies, questionnaire development
Adults aged 18 years and over	
Peer reviewed publication in English	

For the qualitative studies, the Critical Appraisal Skills Programme's Qualitative Checklist was used (CASP, 2013), whilst the Centre for Evidence-Based Management's Critical Appraisal of a Survey tool was used to appraise the studies that utilised questionnaires (CEBMa, 2016). Inductive thematic analysis was used to synthesise the findings of the literature review.

Results

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 utilised survey as the data collection method. Samples ranges across all studies vary between nine and 246 participants. Nurses are 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 3. The key themes that emerged from the review were: communication, family involvement, personal factors and the ICU environment.

Communication

The challenges of communicating with ICU patients who are at the end of their life were highlighted, particularly because critically-ill ICU patients are often too sick to engage in decision-making (Friedenberg et al, 2012; McCormick et al, 2007). Communication problems lead to unanswered questions about patients' wishes regarding their end-of-life care (Losa Iglesias et al, 2013; Zomorodi and Lynn, 2010; Crump et al, 2010). Sixty-seven percent of doctors sampled in one study stated that patients not being able to take part in discussions about end-of-life care was a large barrier to good care (Friedenberg et al, 2012). Doctors sampled in another study stated that timely and honest discussions that address patients' wishes can lead to improved end-of-life care (Brooks et al, 2017).

Communicating with families was a key sub-theme that emerged. Doctors and nurses identified that families often travel on "a journey of understanding", which is different for every family (Brooks et al, 2017). However, nurses and doctors also identified that patients and families can have unrealistic expectations of the effectiveness of ICU care, with one study participant arguing that families did not always understand the severity of the patient's condition (Brooks et al, 2017; Tirgari et al, 2016; Friedenberg et al, 2012). In fact, nurses identified the statement "patients and families do not understand what the term 'lifesaving measures' really means" as the biggest challenge to providing end-of-life care (Beckstrand et al, 2017).

Communication between doctors and other health professionals was mentioned across all studies. Nurses stated that lack of effective communication resulted in fragmentation of care (Gelinas et al, 2012; Zomorodi and Lynn, 2010), nurses feeling that their clinical opinion was not valued (Beckstrand et al, 2017; Attia et al, 2012;

Table 3: Analysis of papers included in literature review

Author, Year	Theme	Country	ICU Type*	Sample	Data Collection	Results	Strengths/Weaknesses
Attia et al, 2013	Barriers & Support	Egypt	O, C, L, S	70 nurses	Survey	Barriers: ICU environment, family attitude, doctor attitude. Support: colleague support, supportive families.	Multi-centre study. Original survey not piloted.
Crump et al, 2010	Barriers & Support	USA	Not specified	56 nurses	Survey with open-ended questions	Barriers: family attitude, poor education, doctor attitude. Support: clear direction of care, dignified death.	Researcher reflexivity. Single-centre study.
Zomorodi & Lynn, 2010	Barriers & Facilitators	USA	B, C, S, CT	9 nurses	Interviews	Key factors: personal, environmental, communication.	Field notes used. Self-selecting sample. Single-centre study.
Losa Iglesias et al, 2013	Barriers & Facilitators	Spain	Not specified (adult & paediatric)	246 nurses	Survey	Key barrier: evasive doctors. Key support: dignified & peaceful death.	Questionnaire not piloted. Single-centre study.
McCormick et al, 2007	Practice & Barriers	USA	Not specified	20 social workers	Survey	Practice: supporting families. Barriers: workload, timing.	Questionnaire reviewed but not piloted. Participant data not anonymised.
Gelinas et al, 2012	Stressors	Canada	Not specified	42 nurses	Focus groups	Key factors: organisational, professional, personal.	Focus groups. Multi-centre study. Participants recruited in groups.
Friedenberg et al, 2012	Barriers	USA	Not specified	113 doctors & 53 nurses	Survey	For RN: barriers vary by hospital. For Drs: barrier vary by training.	Multi-centre study. Uneven Dr & RN samples.
Beckstrand et al, 2017	Barriers	USA	Not specified	509 nurses	Survey	4 of top 10 barriers linked to family. 3 of top 10 barriers linked to doctors.	Large sample. Some longitudinal analysis available.
Tirgari et al, 2016	Barriers	Iran	S, CT, N, G	129 nurses	Survey	Main barrier: converting from active treatment to comfort care.	Questionnaire validated. Face-to-face recruitment.
Brooks et al, 2017	Barriers & Enablers & Challenges	Australia	CT, G, N-S, M	11 doctors & 17 nurses	Focus groups	Barriers: conflict between teams, lack of specialist education. Enabler: collaboration Challenges: family expectations & communication.	Focus groups. Singe-centre study. Self-selecting sample.

*ICU Type: O = oncology; B = burns; C = cardiac care unit; L = liver; S = surgical; M = medical; G = general; CT = cardiothoracic; N = neurological

Crump et al, 2010) and nurses feeling that they were not involved in decision-making (Gelinas et al, 2012). The degree to which doctors rated communication between clinicians to be a challenge varied. One study reported that only 9% of residents identified poor MDT communication as a challenge but another study reported that poor communication between the ICU medical team and other medical teams was a barrier to good end-of-life care (Brooks et al, 2017; Friedenberg et al, 2012).

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, study respondents rated such family involvement as a considerable barrier to delivering end-of-life care to ICU patients (Beckstrand et al, 2017; Losa Iglesias et al, 2013; Attia et al, 2012; Crump et al, 2010; McCormick et al, 2007). In fact, patients' families were at the heart of four of the ten most challenging barriers identified by 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 (Friedenberg et al, 2012; Crumpt et al, 2010; McCormick et al, 2007).

On the other hand, engaging with families was amongst the key supports identified by participants. Social workers were more likely to be satisfied with their work if they had positively engaged with the patient's family (McCormick et al, 2007). Nurses strongly identified family presence at the bedside of the dying patient to be a supportive practice (Losa Iglesias et al, 2013). Nurses also found it helpful to

educate families about how to behave around the dying patient (Losa Iglesias et al, 2013).

Personal factors

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, thus causing moral distress for nursing staff (Tirgari et al, 2016; Gelinas et al, 2012). At the same time, nursing staff found it emotionally challenging to provide active care to patients who were not going to survive (Zomorodi and Lynn, 2010). Some nurses felt that few patients would choose ICU as their preferred place of death and the disconnect between reality and patients' perceived wishes was identified as a barrier (Tirgari et al, 2016). Nurses also struggled with the perceived idea that comfort care was inferior to, and of less value than, critical care (Gelinas et al, 2012). To counteract such feelings, nurses found it helpful to receive encouragement, positive feedback, and emotional support from fellow nurses and from patients' families (Losa Iglesias et al, 2013; Attia et al, 2012; Crump et al, 2010).

Lack of end-of-life care guidance and education were also identified as important barriers, with one study reporting that 60% of the 42 study participants identified lack of education as a severe barrier to the provision of competent end-of-life care (Attia et al, 2012). Lack of end-of-life guidance left nurses unsure of their decision-making 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 (Friedenberg et al, 2012; Zomorodi and Lynn, 2010). This fear of litigation was more pronounced in nurses than in doctors. Due to little practical guidance, both doctors and nurses reported that they receive most of their end-of-life care education 'on the

job' (Brooks et al, 2017; Zomorodi and Lynn, 2010). Lack of education about the specific challenges of communicating with patients and families about end-of-life care was identified by one study, with participants stating that some MDT members avoided difficult conversations due to lack of relevant training (Brooks et al, 2017).

The ICU environment

Challenges relating to the ICU environment were identified in all studies. Participants identified that ICUs lacked private space for communicating with the patient and family, and reported that the design of the ICU did not always allow for family to be physically close to the dying patient (Brooks et al, 2017; Gelinas et al, 2012; Attia et al, 2012; McCormick et al, 2007). Some nurses also identified that families seldom have private space where they can rest (Attia et al, 2012). 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 sick patients, were identified as a barrier to the provision of a peaceful death (Brooks et al, 2017; Gelinas et al, 2012; Attia et al, 2012; Zomorodi and Lynn, 2010). Nurses reported removing or switching off non-essential monitoring equipment in an attempt to calm the scene at the bedside (Gelinas et al, 2012).

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

Discussion

This scoping review has highlighted the importance of effective communication between members of the MDT. Not only does good communication promote more effective decision-making, but improved communication practices in the ICU can help alleviate the symptoms of burnout amongst both nursing and medical staff (Embriaco et al, 2007). Several studies argued that nurses feel excluded from the decision-making process, which leads to feelings of frustration and uncertainty amongst nurses. This finding is supported elsewhere in the literature, showing that supporting ICU nurse involvement in family meetings positively correlates with nurse job satisfaction (van Bogaert, 2013). Furthermore, effective nurse-doctor communication has been identified as a cornerstone of good palliative care in ICU settings (Nelson et al, 2009).

Many of the studies included in this review also addressed the role that patients' families play in the delivery of high-quality end-of-life care. Although some of the findings identify families as a source of challenges, the presence of family at the bedside of a dying patient has also been identified as an aid to delivering good end-of-life care. In the ICU setting, families can play the valuable roles of emotional care givers and information providers. For patients who are at the end of their life, family presence brings psychological comfort (Loh et al, 2015). There is also evidence that families themselves express a desire to be present at the bedside of dying patients (Loh et al, 2015). Nurses are generally sensitive to this wish, employing a variety of tools to help reconnect the dying patient with their family, such as de-medicalising the patient's bed space.

Families can also be key sources of information in ICU settings. Poor communication between the patient and members of the MDT 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 take on the role of patient spokesperson (Nelson et al, 2009). As well as highlighting specific wishes that can guide medical and nursing care, families can also help healthcare staff learn more about patients' personalities. In fact, participants in some of the studies included in this literature review stated that, by connecting with families, they were able to 'humanise' the patient they are caring for.

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 ought to consider the role that effective multidisciplinary team-working has on high-quality end-of-life care. Initiatives such as multidisciplinary ward rounds and multidisciplinary debrief sessions can all contribute to effective communication practices. Joint training in end-of-life care can also lead to improved team-working and address some of the uncertainties that were reported in the literature review. It would be preferable if such training tackled 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 more general concepts of good quality end-of-life care.

Conclusion

The challenges and facilitators identified by healthcare professionals who care for dying patients in ICU settings are related to several separate but closely connected issues – healthcare professionals' personal values, the ICU environment, family involvement in patient care and communication pathways. Effective communication is at the core of good end-of-life care across ICU settings, yet several important challenges relating to the theme of communication were identified in all studies. Specialist end-of-life care education was identified as another important factor in the delivery of good 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.

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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