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# End-of-life care guidelines and care plans in the intensive care unit

Alison Lockett

## ABSTRACT

The aim of this literature review was to examine end of life (EoL) care practice within the Intensive care unit (ICU). By exploring the literature, it is hoped to suggest how national guidance can be integrated into the ICU setting. Delivering high-quality, patient-centred EoL care is high priority on the UK health agenda. The highly technological environment within ICU can create barriers to recognising death and initiating EoL care planning. Despite recommendations in the literature for the integration of standardised guidance, implementation, compliance and evaluation are yet to be widely reported. This literature review highlights the need for ICU health professionals to embrace EoL guideline recommendations. Development of robust processes is vital to inform future practice.

**Key words:** Intensive care units ■ End of life care ■ Decision making ■ Documentations

Providing high-quality end-of-life (EoL) care within UK healthcare settings is a high priority identified in national and local guideline and policy documents. The Department of Health (DH) (2016) published a document of commitment following a review of choice at EoL, recognising the need for high-quality personalised care. This echoes many of the priorities put forward by The National Palliative and End of Life Care Partnership (2015) who published ambitions for EoL provision. These ambitions emphasised the need for individualised care, equality of access, maintaining comfort, coordination across service providers and the need for staff education and training. The National Institute of Health and Care Excellence (NICE) (2011 (updated in 2013)) quality standard for *End of Life care for Adults* lists several quality statements. Quality statement 3 considers the need for assessment and formation of individualised care plans for dying patients:

**'People approaching the end of life are offered comprehensive holistic assessments in response to their changing needs and preferences, with the opportunity to discuss, develop and review**

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**a personalised care plan for current and future support and treatment.'**

*NICE, 2011*

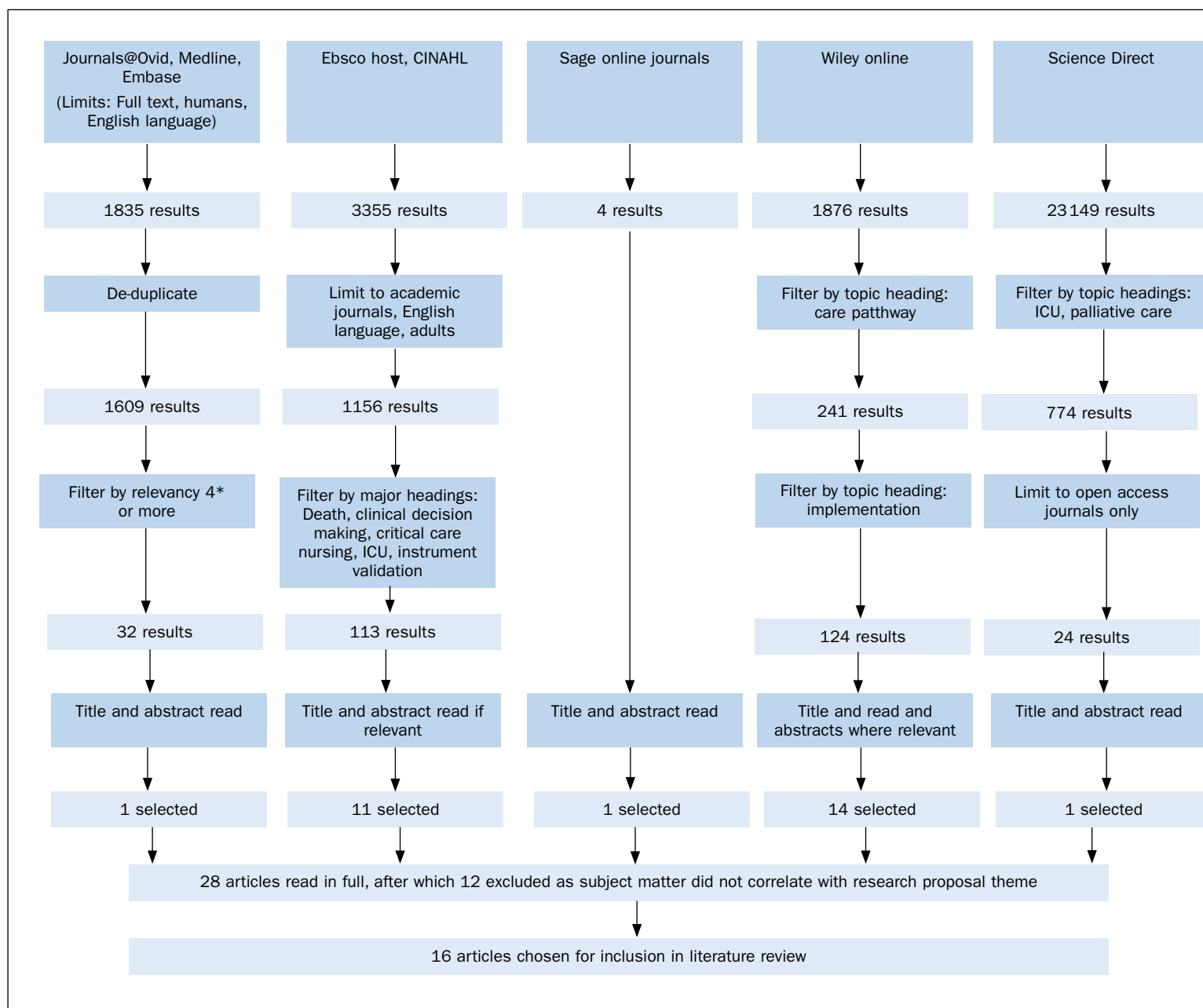
The Liverpool Care Pathway (LCP) was used as primary guidance for EoL care within the UK until July 2014 when following intense media scrutiny which sparked national review it was withdrawn (Compassion in Dying, 2015). Despite being widely used in community and ward settings in the UK and overseas, it was never designed specifically for ICU (Handy et al, 2013). Walker and Read (2010) found little evidence that the later adapted LCP for ICU had been widely adopted. It too was withdrawn concurrently with the general LCP in 2014.

## Background

Recommendations for high-quality EoL care from the Leadership Alliance for the Care of Dying People (LACDP) (2014) include timely recognition of dying, sensitive communication, the involvement of the patient and family in care decisions, supporting those involved and forming an individualised care plan to encompass compassionate care. These are broad generic terms and may leave too much room for interpretation when adopted in an ICU.

Prognostic uncertainty in critically ill patients often results in EoL decisions being made too late, preventing timely recognition and individualised care planning (Campbell, 2013; Nelson, 2006; Hamric and Blackhall, 2007). The adoption of advanced care planning for EoL is rare within ICU as most patients are haemodynamically unstable when they arrive and priority is given to restoring homeostasis, treatment and cure. Conversations with patients and their families or carers on admission often focus on treatment aims rather than discussion of EoL preferences should this be necessary.

The majority of deaths in the ICU occur after a decision to withdraw or withhold treatment once consensus has been reached agreeing the patient has no chance of survival (Morgan, 2008; Dean et al, 2010). Curtis et al (2010) highlight the increase in older patients presenting to ICU following cardiopulmonary resuscitation with pre-existing co-morbidities. These patients may be for limited interventions, with agreement for transition to EoL care if unsuccessful (Monkhouse 2013; Morgan et al, 2014). The use of targeted therapies where escalation of care is not recommended and more patients being transferred from ICU for EoL care requires ICU clinicians to initiate EoL care planning, adhering to policies and guidelines. Checkley et al (2014) found an annual ICU mortality rate of 10.9% over



**Figure 1. Search strategy flowchart**

69 centres in the US. Capuzzo et al (2014) found European mortality rates within ICU were 19.1% with a further 4.8% of post-ICU patients dying prior to discharge. Therefore recognising EoL care as a legitimate outcome within the ICU could ensure patient and family choices at EoL are discussed and achieved when possible.

### Aim

The aim of this international literature review was to gain understanding of EoL care practices in the ICU, to ascertain the guidelines in use and how care is documented. Sprung et al (2003) reported the multi-centre Ethicus study which found significant religious, cultural and procedural variation in European EoL practices. Since then EoL care and guidelines have changed. While this study examined practices it did not

specifically examine documentation used or guidelines followed. Ethicus II is currently being undertaken internationally to examine current practice with an aim to inform policy makers and assist in improving EoL care (Bassford, 2015).

### Methods

To understand the complex issues when planning care for dying patients in ICU a literature review was undertaken (Figure 1). The MeSH terms 'end of life', 'dying', 'intensive care' and 'care planning' have been used and Boolean operators 'and, or' were used. Publication years 2008 to 2015 were chosen as this period represents the emergence of EoL care as a priority within healthcare following the publication of the *End of Life Care Strategy* (DH, 2008). Multiple databases were searched, EBSCOhost, Ovid, Medline, CINAHL, in addition publishing

**Table 2. Literature search results**

Author/s (year of publication)	Study design/ country of origin	Key recommendations/conclusions	Strengths/limitations
Aslakson et al (2014)	Literature review USA	Using US national ICU guidelines can help to improve palliative care	None identified
Bjurling-Sjöberg et al (2015)	Mixed-method exploratory design. Survey & interviews Sweden	Implementation of care plans in ICU rely on multifaceted strategies, committed individuals and bottom-up approach	Mixed methods Limited dataset, retrospective data collection, risk of recall bias
Chan and Webster (2013)	Update of Cochrane systematic review Australia	Evidence supporting impact of EoL care plans is lacking. Audit and evaluation is required	None identified
Coombs and Long (2008)	Discussion paper UK	EoL care plans for ICU must be a blend of policy guidance and clinical process	None identified
Coombs et al (2012)	Qualitative semi-structured interviews UK	Adopting EoL care plans may be inhibited when the greatest challenge in ICU is diagnosing dying	Convenience sampling, study bias, poor transferability
Cox et al (2012)	Clinical practice review paper UK	EoL protocols specific to ICU can help provide excellent care	None identified
Efstathiou and Walker (2014)	Qualitative semi-structured interviews UK	Practice guidelines for EoL care in ICU are needed to reduce ambiguity	Single site self-selected interviewees could limit transferability
Glavan et al (2008)	Quantitative, multi-centre survey USA	Retrospective analysis of medical notes of dying patients provides quality markers for improving EoL care	Limited variables measured, single region, low response rate (41.2%), recall bias
Langley et al (2014)	Quantitative, cross-sectional survey South Africa	Use of formal guidelines and education recommended to improve EoL care and communication	Reasonable response rate (67%) Sample bias as self-selecting, poor generalisability
Morgan (2008)	Literature review UK	ICU nurses require educational support to implement EoL care guidance practice	None identified
Penrod et al (2012)	Quantitative, prospective multi-site observational study of palliative care processes USA	Use of a care and communication bundle approach was applied inconsistently and infrequently	Only three sites used retrospective medical record analysis relied on accurate documentation
Ranse et al (2015)	Qualitative, cross-sectional survey Australia	Identification of factors influencing EoL care provision in order to develop a standardised order for care	Convenience sampling, poor response rate (45%)
Ryan and Seymour (2013)	Literature review UK	Use of guidelines can help reduce emotional stress for ICU nurses caring for patients at EoL	None identified
Ramasamy Venkatasalu et al (2015)	Qualitative semi-structured interviews UK	Staff still require clear guidelines for EoL care in ICU despite the withdrawal of the LCP	First study to explore the issues following LCP withdrawal Small sample size limits transferability
Watts (2012)	Discussion paper UK	EoL care plans exist as a means of documentation but offer little help in complex decision making	None identified
Watts (2013)	Literature review UK	EoL care pathways in general should be welcomed as a means to enhance care	None identified

ICU: intensive care unit, EoL: end of life, LCP: Liverpool Care Pathway

websites were also searched including Wiley, ScienceDirect and Sage Journals online. Further limiters as shown in *Figure 1*, were used when appropriate depending on the search engine for each source. Choosing such broad search terms resulted in

a high volume of worldwide literature from which titles and key words were read to ascertain relevancy. Appropriate filters facilitated reduction of the results to a reasonable amount of abstracts to be read. A total of 28 articles were read in full and 12 excluded as their focus did not meet the aims of the research proposal. Reasons for exclusion of the articles involved those focusing on ethical decisions around withdrawal of treatment, relationship between EoL care planning and reduced length of stay and articles examining advanced care planning or quality of life scoring systems.

## Results

A total of 16 articles were deemed relevant and chosen for inclusion in the review (*Table 1*). The decision to take such a broad international literature search from multiple sources is drawn from previous experience of conducting a literature review concentrating on UK EoL practices in the ICU. The aim of the literature review was to explore if and how LACPD (2014) guidance could be adopted in ICU following the withdrawal of the LCP for dying patients. Restricting the review to UK sources only within the same publication years (2008–2015) yielded very low results, perhaps reflective of the lack of UK based research in EoL within ICU. No studies were found suggesting the new LACPD (2014) guidance had been adopted or detailing what care plans were in use. It may have been too early to evaluate the effects of the guidance as new care plans may still have been in development, or it may be that new guidelines had not been adopted within the specialist setting of ICU.

## Discussion

Review of the literature resulted in several themes emerging in relation to EoL practices in the ICU setting. These include difficulties with integration of national frameworks, decision making, care planning, implementation and compliance, and evaluation.

### Integration of national frameworks

Coombs and Long (2008) looked at whether national guidelines can assist in providing a good death within ICU. While it is acknowledged that they provide a broad overview of key areas, they fail to address the complexities of ICU care. Specific barriers within ICU are identified with regard to the decision to change the focus of care from curative to EoL. Therefore EoL care documents developed for ICU must be appropriate to setting and context.

Morgan (2008) stated that national EoL policy for the ICU is imprecise and integration of hospital wide EoL care is often absent from the ICU setting.

This absence of formal national guidelines being used in ICU areas is highlighted in qualitative research undertaken by Efstathiou and Walker (2014) and Venkatasalu et al (2015). Both articles reported on semi-structured interviews regarding provision of EoL care in the ICU. Although undertaken in different UK locations, none of the ICUs had any formal guidance or standardised care plans. Both articles recommended that the development of standardised guidelines within ICU at

EoL could help reduce ambiguity in relation to withdrawal of treatment processes and prompt discussion to facilitate patient and family choices.

The use of an EoL care plan as a vehicle to prompt dialogue for individual choice is further endorsed by Watts (2012) who suggested that conversations about EoL preferences should occur sooner in the dying trajectory. Aslakson et al (2014) supported early identification of EoL needs but reported that results from a randomised controlled cluster trial found that using standardised EoL care plans had no effect on quality care outcomes (Curtis et al, 2011)

In comparison, Chan and Webster (2013) published an update of a Cochrane systematic review concluding that recommendation to use EoL care plans could not be made, stating a lack of direct high-quality evidence supporting their effectiveness. They recommended that independent audits of care plans are required to build the evidence base. Since this Cochrane systematic review there has been another review (Chan et al, 2016). Although outside the limits of the literature review, the Chan et al (2016) concluded that there was limited evidence available to draw conclusions on the effectiveness of EoL care pathways.

### Identifying EoL and decision making

A significant barrier identified in the literature for EoL care in ICU centred on the difficulties in diagnosing when a patient is nearing EoL. Coombs et al (2012) undertook qualitative research through semi-structured interviews of ICU doctors and nurses. They identified the complex variables evident when diagnosing dying in ICU. Complex variables include prognostic uncertainty, defining futility, reaching a consensus in line with the values and beliefs of all stakeholders and managing transition to EoL care.

Differentiating between treatments prolonging death or enabling recovery is not straightforward (Ryan and Seymour, 2013). The biomedical culture of dying in hospital perceives death as a failure, favouring technological interventions as an avoidance tactic (Watts, 2012). This combined with a lack of knowledge on how clinicians diagnose dying inhibits timely EoL discussion. There are also inconsistencies of predictive tools developed for probability of dying in ICU, leading to diagnosis of dying being considered too late to initiate EoL care planning (Cox et al, 2012). Therefore it could be argued that because timely diagnosis of EoL is the first priority from LACPD (2014) guidance for high-quality EoL care, integrating this principle into the ICU setting is potentially flawed from the outset.

Once the decision has been reached to progress to EoL care, RamasamyVenkatasalu et al (2015) advocated that having specific EoL guidelines in ICU are vital to reduce inconsistencies in care. In their study RamasamyVenkatasalu et al (2015) looked at the effects following the withdrawal of the adapted LCP-ICU in two large acute hospitals in the UK. Interviews uncovered concerns that without this evidence-based guidance clinicians became unsure of the action to take, nurses became more reliant on doctors for treatment decisions and concerns rose that there was no robust documentation to safeguard practice.

## Personal distress

The effects of personal distress to clinicians experienced by lack of guidance are further explored by Coombs and Long (2008), Ryan and Seymour (2013) and Efsthathiou and Walker (2014). Coombs and Long (2008) discuss the difficulties arising between doctors and nurses when deciding the process of withdrawal of treatments. Differences in values, beliefs and opinion between the disciplines caused difficulties achieving consensus. They surmise that evidence based EoL guidelines developed from UK policy could help to reduce this (Coombs and Long, 2008). Ryan and Seymour (2013) specifically examined the emotional stress ICU nurses face when initiating EoL care. They found that once a doctor made the decision that active treatment should stop, nurses bear the responsibility for stopping them. The nurse is the main facilitator of treatment withdrawal (Ranse et al, 2014). A lack of clear guidance and consensus on the process can lead to increased distress for nurses. Efsthathiou and Walker (2014), conducted semi structured interviews of nurses providing EoL care in ICU at a single site UK hospital. The lack of standardised evidence-based EoL care guidelines in the setting was found to increase uncertainty, nurse dissatisfaction and inhibit effective communication.

## Documentation and processes

Several of the articles included in the review highlight the need for a clear documentation process owing to variations in EoL care and withdrawal of treatment decisions. Venkatasalu et al (2015) undertook a qualitative study of how the transfer to generic EoL guidance in ICU was affecting care. They found inconsistencies and communication difficulties were arising owing to adopting these care plans following the withdrawal of the LCP-ICU. It was no longer clear why care was either given or not given. Recommendations from the study include development of ICU-specific guidance to include shared decision making and staff education. Langley et al (2014) undertook a cross-sectional survey of South African ICU nurses' views and experiences of the process of withdrawing treatment. It was surmised that development of formal guidelines could improve inter-professional and family communication at EoL.

Cox et al (2012) stated that although treatment withdrawal decisions should be made on benefit versus burdens basis; owing to variations and differing interpretation of the decisions to stop specific therapies, robust documentation is vital. Although Ryan and Seymour (2013) highlighted the lack of research evidence supporting specific ICU EoL guidelines, they acknowledged their potential for standardising care and communication.

Coombs and Long (2008) suggested a lack of evidence behind decisions to limit or withdraw specific treatments for dying patients such as mechanical ventilation. Accurate ICU-specific EoL documentation could help build the evidence base for structured withdrawal of treatment processes.

While the argument for standardised and robust documentation is evident in the literature, evidence regarding its effectiveness is variable. Aslaskon et al (2014) cited a large multi-centre randomised controlled trial in the US where standardised EoL care protocols were used (rather than non-standardised ones) (Curtis et al, 2011). The study found no perceived improvement

in quality outcome measures of dying by nurses and families. ICU nurses rely more on experience to guide practice in delivering high-quality care at EoL than guidelines (Ryan and Seymour, 2013). Without standardised guidance junior nursing and medical staff in ICU will lack the knowledge to provide quality care (Ramasamy Venkatasalu, et al, 2015). Increased staff turnover and recruitment of junior nursing staff could be a significant factor within ICU settings in the UK.

## Implementation and compliance

Difficulties with implementation and compliance with standardised care plans is explored within the literature. Bjurling-Sjöberg et al (2015) undertook an exploratory mixed-methods study examining how standardised clinical care plans are used in Swedish ICUs. Multiple factors were identified, the format had to be user-friendly and have perceived benefits for staff and patients. Bottom-up initiatives were deemed to be more successful with repeated reminders to use the care plans required to help embed new working practices.

Lack of involvement by doctors was found to be a barrier with implementation and compliance. Without structured guidelines ICU nurses over-rely on doctors for decision making when caring for dying patients (Venkatasalu et al, 2015). Bjurling-Sjöberg et al (2015) suggested that a reason for doctor's reluctance to use standardised care plans is the perception that they lose control over decision making. Further research could identify other significant factors affecting implementation and compliance. Watts (2013) discussed challenges with implementation and sustainability when using EoL care plans, with transient workforce, organisational culture, role boundaries and concern about litigation as mitigating factors. In addition there are concerns around whether standardised care plans satisfy the recommendation for individualised patient care at EoL (Watt, 2013). Formulating an individualised plan of care is one of the five key recommendations within the revised LACDP (2014) guidance.

## Evaluation

Several articles examined the importance of evaluation. Penrod et al (2012) undertook a multisite observation study evaluating the performance of key EoL care processes in the ICU. The use of and compliance to a national EoL care bundle within the US was examined. They found that evidence-based care processes were frequently missed and the care plans not consistently followed. However one of the limitations of this study is that was a retrospective case analysis and there is potential for the care to have been given but not documented.

In comparison, Glavan et al (2008) suggest that retrospective case note analysis when evaluating EoL care provides valuable information to guide quality improvement. How the effect of a standardised care plan is evaluated can have a profound effect on its perceived usefulness (Bjurling-Sjöberg et al, 2015). Therefore when undertaking such research it is important to ensure robust methods and data analysis are adopted.

## Limitations

Limitations of the research presented in this literature review are that it is largely based on participant views or retrospective

case note analysis, rather than observation in practice (Penrod et al, 2012; Ramasamy Venkatasalu et al, 2015). Observation in practice poses moral and ethical challenges for researchers that are difficult to overcome in EoL situations. EoL care plans should be independently audited and their subsequent use evaluated despite the methodological challenges posed by research around EoL (Chan and Webster, 2013).

### Implications and recommendations

Despite an extensive international literature search, only 16 articles were found in relation to the use of standardised EoL care plans in the ICU. The inconsistencies and ambiguity regarding how EoL care is performed and documented is evident within the literature. Despite acknowledgement within the articles presented that the evidence base for the use of EoL care plans in ICU lacking, emphasis is placed on recommending the need for their development and evaluation. To date it would appear that nationally no research has taken place into ICU EoL care plans introduced under the new LACPD (2014) guidance. The effectiveness of individualised care planning and guideline development in assisting health professionals to manage EoL care within ICU requires further research.

### Conclusion

Recognising EoL in a timely manner may always be difficult for health professionals owing to the unpredictable clinical course of illnesses in ICU. Providing high-quality EoL care is an important skill that ICU nurses need to develop through training and collaborative working. The ICU patient experience could be improved if discussions about EoL took place promptly when required. This would allow forward planning to ensure that once EoL is recognised, individualised care plans can be formed. The formulation of clear guidance and care planning within ICU is necessary to ensure the transition towards EoL is efficient and effective. **BJN**

*Declaration of interest: none*

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### KEY POINTS

- A literature review looking at end-of-life (EoL) care in the intensive care unit (ICU) was undertaken
- Several themes emerged from the literature including difficulties with implementation and compliance, decision making and the integration of national frameworks
- There are methodological challenges with conducting research into EoL care
- The formulation of clear guidance is necessary to ensure high-quality EoL care in the ICU

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## CPD reflective questions

- What can be done in your area to improve end-of-life (EOL) care for patients and families?
- Does your organisation have standardised intensive care unit-specific EOL documents, and what do you think about the impact these have on the patient experience?
- Think about some of the methodological challenges to research in EOL care and how some of these might be overcome