

Practice Recommendations for End-of-Life Care in the Intensive Care Unit

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TOPIC A substantial number of patients die in the intensive care unit, so high-quality end-of-life care is an important part of intensive care unit work. However, end-of-life care varies because of lack of knowledge of best practices.

CLINICAL RELEVANCE Research shows that high-quality end-of-life care is possible in an intensive care unit. This article encourages nurses to be imaginative and take an individual approach to provide the best possible end-of-life care for patients and their family members.

PURPOSE OF PAPER To provide recommendations for high-quality end-of-life care for patients and family members.

CONTENT COVERED This article touches on the following domains: end-of-life decision-making, place to die, patient comfort, family presence in the intensive care unit, visiting children, family needs, preparing the family, staff presence, when the patient dies, after-death care of the family, and caring for staff. (*Critical Care Nurse*. 2020;40[3]:14-22)

The goal of intensive therapy is to help critically ill patients survive; however, approximately 10% to 30% of patients die in intensive care units (ICUs) worldwide,¹⁻³ with differences mainly due to patient mix. Of those who die, 35% to 95% die after life-sustaining therapy has been either withheld or withdrawn.^{4,5} Wide variations between and within countries are mainly due to cultural,⁶⁻⁸ religious,⁹ and personal factors.^{3,10} High-quality end-of-life care (EOLC) is therefore an important part of ICU work.¹¹

CE 1.0 hour, CERP B

This article has been designated for CE contact hour(s). The evaluation tests your knowledge of the following objectives:

1. Identify 2 reasons why intensive care unit nurses are important members in interprofessional discussions concerning life-sustaining therapy.
2. Describe 3 ways to promote family presence when a patient is dying in the intensive care unit.
3. Describe 3 reasons why after death care and bereavement follow up are important for family members.

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One proposed definition of EOLC is “to assist persons who are facing imminent or distant death to have best quality of life possible till the end of their life regardless of their medical diagnosis, health conditions, or ages.”¹² Death may occur in the ICU or after ICU discharge, but in either case the patient needs high-quality EOLC in the ICU.

The main focus of high-quality EOLC is the individual patient, but EOLC is also important for the family. Family members are likely to always remember events surrounding a loved one’s death.¹³ Death of a relative in the ICU may also be associated with complicated grief,¹⁴ posttraumatic stress disorder, anxiety, and depression.¹⁵

A growing body of ICU end-of-life literature includes various recommendations¹⁶ and guidelines for EOLC.^{8,11,17} These guidelines provide common goals for high-quality EOLC. However, EOLC is multifaceted, and sufficient knowledge about EOLC may be lacking.¹⁸ Furthermore, EOLC education and implementation still depend largely on services available at individual hospitals. Each patient and family situation is unique and no single model fits all.¹⁹ Nurses need to use their clinical and moral judgment, their imagination, and their own and other nurses’ previous experiences to meet the needs of individual patients and families.²⁰ Studies reveal that ICU nurses learn EOLC through experience and not via textbooks or guidelines, yet they provide this care competently and with compassion.²¹ However, studies also show that novice nurses and nurses without EOLC training can find this care challenging and difficult, potentially leading to reluctance to care for dying patients and their family members.²²⁻²⁴ Consequently, EOLC may differ from place to place, and approaches and thoughts regarding high-quality EOLC might be unknown outside individual ICUs. Updated guidelines, recommendations, and ideas

are needed to demonstrate the full scope of EOLC possibilities so that patients can be offered individualized care from the full range of EOLC practices, regardless of the ICU in which they die. The purpose of this article is to provide recommendations for high-quality EOLC for the patient and the family.

Methods

The article reviews the following domains identified in published literature^{11,19,25-30}: end-of-life decision-making, place to die, patient comfort, family presence in the ICU, visiting children, family needs, preparing the family, staff presence, when the patient dies, after-death care of family, and caring for staff. We conducted a literature search in CINAHL, PubMed, and EMBASE for each domain. The search terms were *critical care*, *intensive care*, *end-of-life care*, *palliative care*, *death*, and *dying*, used both as keywords and as Medical Subject Headings and combined for each domain by using the Boolean operators *or* and *and*.

Most of the articles we selected were published in the past 10 years, but we included older publications if they described subjects not available in more recent publications. We also included articles found in the reference lists of identified **High-quality end-of-life care is multifaceted and entails an individual approach.** articles if we judged them to be relevant. We excluded articles not written in English and those focusing solely on patients younger than 18 years of age.

Results

The following sections present aspects of and options for EOLC in the ICU according to domain.

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Table Recommendations for end-of-life care

Domain	Main recommendations
EOL decision-making	If possible, decisions to withhold or withdraw life-sustaining treatment should be made together with the patient, and the patient's wishes and values should be included. Families should be continuously involved in assessment of the patient's situation. Family involvement in decision-making depends on legal practice in each country. EOL decisions should include all members of the interprofessional team. EOL decisions should be documented. A do-not-resuscitate order does not automatically mean that other therapies should be withheld.
Place to die	If in any way possible, the patient should be allowed to die in the ICU. Single rooms are preferred. If discharging the patient from the ICU is necessary, information and reasons should be given as early as possible. It may be possible to let patients go home to die.
Patient comfort	When life-sustaining treatments are withdrawn, palliative care becomes the main goal. Patient comfort entails frequent assessment of needs and individually tailored use of medical and nonmedical methods. Comforting patients at the EOL is about being aware of and sensitive to factors at play in each different situation. Great effort should be made to identify and honor the patient's wishes regarding visits, catering, spiritual support, etc. For the patient without family, the nurse is an important substitute for relatives.
Family presence in the ICU	Free access throughout the day and night for close family and friends (if the patient wants it) is the ideal. Unnecessary waiting outside the room must be avoided.
Visiting children	Children should be allowed to visit and be told the truth about the patient's condition. Nurses should talk with the children before the first visit. The ICU should have places where the children can play.
Family needs	Apart from information, the family may need emotional, spiritual, and practical support.
Preparing the family	For some family members, being with a dying person is a new and potentially frightening experience, and they need information about symptoms and about what may happen. Generally, it is not possible to precisely predict how long the dying process will be for the individual patient. Families should be assured that patients' symptoms will be assessed and treated continuously.
Staff presence	Asking about the family's preferences regarding staff presence at the bedside is necessary. If the family prefers to be alone with the patient, the nurse should still go into the room frequently.
When the patient dies	After death of the patient, the family needs time to say goodbye. Family members can be involved in taking care of the dead patient.
After-death care of family	Some ICUs give mementoes such as handprints, locks of hair, and letters of condolence to give to the family. Follow-up practices such as telephone calls, a visit in the ICU, and follow-up cafés may improve outcomes for bereaved family members.
Caring for staff	It is helpful to talk with colleagues about one's experiences and ask others how they are and how they are coping after the death of a patient. EOL situations that have not been handled well may lead to burnout.

Abbreviations: EOL, end of life; ICU, intensive care unit.

The Table summarizes the main recommendations within each domain.

End-of-Life Decision-Making

If life-sustaining therapy does not succeed, decisions about withholding or withdrawing such therapy are often made in the ICU.^{5,26} These decisions should be made together with the patient if the patient is capable of making decisions.^{19,31,32} However, patients should not have this responsibility imposed upon them if they do not want it.³³ If the patient cannot participate, family members can contribute by providing knowledge about the patient's wishes and values.^{25,34} The patient's preferred proxy needs

to be identified because this person might not be a relative.²⁵ Different countries have different laws regarding family members' rights to make decisions on behalf of patients.⁶ However, regardless of whether family members are able to make decisions about withholding and withdrawing therapy, continuously involving them in the assessment of the patient's condition is important to ensure that they understand what is happening and that death may be the outcome.³⁵ Timely and honest communication concerning the loved one's prognosis and about the limitations of life-sustaining therapy may also help prevent complicated grief and posttraumatic stress among family members.^{15,36} Finding the right time and a suitable

quiet place for these difficult talks should be highlighted. Respecting family members' reactions and feelings is important; people show their feelings in different ways.¹⁹ Openness among health care professionals is also a prerequisite for excellent EOLC.¹⁴

Discussions and decisions about withholding and withdrawal should include all members of the interprofessional health care team.¹¹ Contributions from nurses are important. Through their care for the patient and communication with the patient and family, nurses often have the greatest knowledge about nontechnical patient issues such as wishes and values.³⁷⁻³⁹ Because end-of-life decision-making precedes the shift from lifesaving therapy to EOLC, nurses' involvement in end-of-life decisions is crucial for successful EOLC.^{40,41}

Decisions should be documented in the hospital record with precise orders specifying which therapies are being withheld or withdrawn and which are continuing.¹¹ A do-not-resuscitate (DNR) order, for example, does not automatically mean that other therapies should be withheld, and a DNR order should be reconsidered if the patient's condition changes.⁴² A shift in policy from DNR to goals of care has been proposed to prevent patients with DNR orders from receiving less-adequate treatment than patients without such orders.⁴³

Place to Die

If possible, the dying patient should stay in the ICU if death is imminent.⁴⁴ A single room is always preferred to ensure privacy and allow the dying patient and the family to express feelings.^{45,46} Transforming a high-technology environment into an ideal place to die is difficult, but all unnecessary equipment can be removed from the room and the room should be tidy. Monitoring can be basic or not conducted at all, perhaps with a black screen in the room and basic monitoring on the central screen, because the monitor may disturb family members' attention to the patient.¹⁹ A small, practical, very important detail is to make sure that the room has sufficient and comfortable chairs for family members.

With overcrowding or low capacity in the ICU, the patient may have to be transferred to a step-down unit or to the parent ward if the dying process is long or new patients need to be admitted. Such transfers may be painful for the patient and the family. The patient and family members should be informed of the necessity of the transfer as early as possible.⁴⁷ However, if the patient

has had a long stay in the parent ward before the ICU admission and only a short time in the ICU, the parent ward may be the best place for the patient to die. Considerations regarding the patient's and family members' best interests should be made explicit so that such decisions are not based on hectic priority considerations.⁴⁷

If the patient is awake and the patient and family members all strongly want this option, letting the patient go home to die may be possible.^{28,48,49} Patients and family members will need help from the home care or palliative care team to feel safe and secure. In some countries, transferring the patient to a hospice or palliative care unit in the hospital may also be possible.⁵⁰

Patient Comfort

Throughout the ICU stay, patient comfort through palliative care is one of the treatment goals, but when life-sustaining treatments are withdrawn, palliation and EOLC become the main goals.¹⁹ Palliative care demands frequent assessment and treatment tailored to the individual patient for symptoms such as thirst, pain, anxiety, breathlessness, nausea, and agitation.⁵¹ Faber-Langendoen and Lanken⁵² have given valuable practical advice on the use of medications. Nurses are responsible for assessing symptoms and ensuring that adequate treatment is provided.⁵³

A number of nonmedical methods, such as music and touch, can also be used to relieve symptoms.⁵⁴ An end-of-life protocol may help ensure adequate patient comfort.^{25,55} Family members are often a resource because of their

knowledge of how the patient reveals

Dying patients should be offered a quiet, family-friendly environment and palliative care tailored to the individual patient.

symptoms of stress and agony, and family members provide comfort by letting the patient feel safe, loved, and cared for by hearing their voices. Comforting patients at the end of life is about being aware of and sensitive to factors at play in each situation.⁴⁴ This type of care is achieved by using knowledge from relational care, evaluating this information, and acting in various situations with "the heart eye or the perceptive eye," as described by the Norwegian philosopher Kari Martinsen.⁵⁶

If the patient is awake, great effort should be made to identify and honor the patient's wishes¹⁹; for example, have specific people visit or, if they are far away or time is short, contact them by telephone or use technology

such as video chat. If the patient can eat, even if just a mouthful, his or her favorite food, such as wine or chocolate, can be procured. Efforts should be made to ensure that culturally appropriate food is available.⁵⁷ As a rule, no wish should be rejected on the grounds of it being impossible. With creativity and imagination, a lot can be done. The patient and/or accompanying family members may want a visit from a chaplain, an imam, or another spiritual leader. Health care chaplains are often key support agents for patients, family members, and staff during the dying process.⁴⁶ Chaplains often bring a Bible, a hymnal, or a collection of poems (or the ICU may have materials for a ceremony) if the patient or the family wants a ceremony.⁵⁸ A visit from a patient's beloved pet, especially if the patient has no relatives, can be arranged.⁵⁹ For unaccompanied patients, the nurse is an important substitute for relatives. By assuring patients that they are not alone, the nurse protects patients' integrity and privacy and thereby ensures them a dignified death.²¹

Family Presence in the ICU

When an ICU patient is dying, it is important for the patient and the family members to experience a humanized and personalized dying process the last days or hours they have together.⁶⁰ Therefore, free

access
throughout
the day and
night for close
family and
friends (if the

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patient wants it) is the ideal.^{19,25,61} Some ICUs have strict visiting policies that may clash with this ideal.⁶² Nevertheless, even if families are not generally allowed to visit ICU patients throughout the day and night, great efforts should be made to secure exceptions for dying patients and avoid unnecessary waiting outside the room.^{63,64} Identifying and honoring wishes can promote patient and family centeredness as a main aspect of palliative care.^{60,65}

Nurses also care for patients who do not have a DNR order but might die despite resuscitation efforts. A growing body of research describes how the presence of family members during resuscitation affects family members' psychological symptoms, their burden as caregivers, and their relationship and potential conflict with health care personnel. Davidson and colleagues²⁵ conducted a scoping

review and identified evidence for best practices for family-centered care in the ICU. Their guideline suggests that family members of critically ill patients be offered the option of being present during resuscitation efforts. They recommended that family members in these cases be supported by a staff member.²⁵

Visiting Children

The patient's critical illness affects all of the close family members, including children.⁶⁶ Adults often believe that children need protection from facts about their critically ill and dying relative.⁶⁷ However, children need to be included when critical illness hits the family.⁶⁶ Sweden and Norway have added appendices to their health legislation to ensure the recognition of children's rights to information, advice, and support when their parent or sibling is seriously ill. Published studies recommend that visiting restrictions for children be removed and that children be told the truth about their family member's condition.⁶⁸⁻⁷⁰ Children will often be thinking about the critically ill family member, and it is important for them to see the patient and witness the situation to be reassured and feel involved.⁶⁸ Research has shown that children's fantasies are often worse than the reality.^{66,68-70} Nurses should carefully prepare visiting children for what they might see and hear by using tools such as photographs of equipment, preferably with the patient connected, while they describe in a simple way what the equipment is and what it is used for. During children's visits, nurses can continue to communicate with them and help them start processing their impressions. The youngest children can continue this process by playing in the ICU with toys related to hospitals and accidents, such as ambulances and helicopters, as well as their usual toys. They should have opportunities for drawing, reading books, using computers, playing games, and other activities. The British organization ICUsteps has published a booklet, *Visiting the Intensive Care Unit*, that can help young children. The booklet is available online.⁷¹

Family Needs

In addition to information, family members may need emotional, spiritual, and practical support.^{25,72,73} Research findings suggest that nurses should assess the spiritual needs of family members. If wanted, nurses can help them contact a spiritual advisor.⁷⁴ Especially

if the dying process is long, family members will need food, drink, fresh air, exercise, rest, and sleep. If available, a bed (or at least a good chair) in the patient's room or close by in the hospital will make it easier for family members to get needed sleep.²⁵

Preparing the Family

Family members often express concerns about facing the reality of death, and being with a dying person is a new and potentially frightening experience for some family members.⁷⁵ Nurses need to assess family members' needs and prepare them with selected information by communicating clearly and considerately.^{72,76} They should inform family members of what might happen and what symptoms the patient might experience (discoloration of skin, coldness, death rattle, etc). Nurses should explain that precisely predicting how long the dying process will take for an individual patient is not generally possible but that the ICU staff will be present throughout the process and assess and treat symptoms continuously.¹⁹

Staff Presence

Family members have described nursing presence as a "comforting embrace," and the presence of nurses has sustained families before, during, and after a patient's death.^{64,77} Families appreciate signs that nurses respect the patient, such as holding their loved one's hand, talking to their dying family member, and calling the patient by name.²⁹ However, some families prefer a private sphere with a place for privacy and confidentiality when it is time to say goodbye.⁴⁶ The nurse needs to ask what each family prefers because one cannot be sure that one's guesses are correct. If the family prefers to be alone with the patient, the nurse should still go into the room frequently, primarily to assess the patient's condition and symptoms and administer medication accordingly but also to consider how the family is coping. Families who prefer to be alone with the patient still need assurance that they can get help swiftly if needed.⁶⁴

When the Patient Dies

Family members deeply appreciate that health care providers demonstrate respect and genuine care for their loved one and for the family when the patient dies.²⁹ After the loved one's death, family members may need time to realize what has happened. For some family members, being able to hold the patient's

body while it is still warm is important.⁶⁴ Some family members might want to help take care of the body, so asking them if they would like to help (while making it very clear that it is all right to decline) might be an option. Family members can also be involved in deciding which clothes the deceased patient should wear. Family members appreciate having the remaining equipment removed and, if necessary, additional chairs brought into the patient's room.²⁹

Saying goodbye is a process that takes time, and it takes longer for some families than for others, which can be a dilemma if the room is needed for a new patient or if the ICU is busy and the nurse is wanted elsewhere.²¹ However, death of a loved one is an experience the family has to live with in all of its dimensions, so care for the family in the hours after patient death should be highly prioritized. Research has shown that bereaved families may suffer considerably after ICU deaths⁷⁸ and that care that meets the family's need may have some benefit on outcomes for bereaved family members.⁷²

After-Death Care of the Family

Intensive care units use various practices after patients die. Music chosen according to the preferences of family members or the dead person could be played during the viewing to make that event special and memorable.⁷⁹ In some ICUs, volunteers make patchwork blankets for the family to take home as a memory of the patient. Some ICUs provide

other mementos, such as handprints or a lock of hair.⁸⁰ Sometimes nurses attend the wake or the

funeral, and staff members who took care of the patient might sign letters of condolence. Institutions can provide information leaflets about grief after losing a loved one and about practical issues such as funerals.⁸¹⁻⁸⁴ A patient diary kept during the loved one's stay in the ICU, if available, can act as a support during the post-ICU bereavement period.⁸⁵ Bereavement follow-up after a patient's death in the ICU has been found to reduce prolonged grief and risk of posttraumatic stress disorder in family members,⁸⁶ and many ICUs have a follow-up program in which families are invited to an appointment

Family-centered bereavement care includes preparing the family for the dying process and providing different kinds of after-death care to reduce prolonged grief and posttraumatic stress disorder in family members.

with ICU professionals after the death of their loved one. Some conduct ICU family cafés or have bereavement support groups for families.^{87,88} Family members highly appreciate returning to the ICU for a follow-up conversation, when this is offered. Such a meeting provides the opportunity to identify the events that led to the death of the loved one, which can help family members become reconciled to their loss.^{64,89}

Caring for Staff

End-of-life care is often intensive and demanding but can also be immensely beautiful and rewarding by providing the opportunity to walk a small part of the way with patients and their family members.^{21,89,90} If an end-of-life situation has had a more substantial impact, the staff member affected should talk it through with the manager and perhaps get professional help.⁹¹ End-of-life situations that have not been handed well may lead to burnout.³⁰ Likewise, moral distress may develop if health care professionals cannot fulfill what they consider to be their moral obligations to patients and families or act in the way they believe to be right because of factors out of their control.^{39,92,93}

Nurse Contributions

For all the domains, nurses play a crucial role in providing high-quality EOLC for the patient and the family. In ICUs that lack some of the recommended practices, such as open visiting hours and sufficient staff resources for EOLC, nurses can use the evidence to promote best practices through discussion within the ICU and at organizational and political levels.

Limitations

We included only articles in English, which may have introduced bias against end-of-life practices in countries in which the primary language is not English. The recommendations are based on available research, but because EOLC is relational and individual, not all care can be evidence based.

Conclusion

High-quality EOLC is possible in an ICU setting. We encourage nurses to be imaginative, to take an individual approach to providing the best possible EOLC for patient and their family members, and to share their experiences with others. [CCN](#)

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None reported.

See also

To learn more about end-of-life care in the critical care setting, read “Communication and Decision-Making About End-of-Life Care in the Intensive Care Unit” by Brooks et al in the *American Journal of Critical Care*, 2017;26(4):336-341. Available at www.ajconline.org.

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