End-of-life communication in the intensive care unit

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Abstract

Objective: Because one in five Americans die in the intensive care unit (ICU), the potential role of palliative care is considerable. End-of-life (EOL) communication is essential for the implementation of ICU palliative care. The objective of this review was to summarize current research and recommendations for ICU EOL communication.

Design: For this qualitative, critical review, we searched PubMed, Embase, Cochrane, Ovid Medline, Cinahl and Psychinfo databases for ICU EOL communication clinical trials, systematic reviews, consensus statements and expert opinions. We also hand searched pertinent bibliographies and cross-referenced known EOL ICU communication researchers.

Results: Family-centered communication is a key component of implementing EOL ICU palliative care. The main forum for this is the family meeting, which is an essential platform for implementing shared decision making, e.g., transitioning from curative to EOL palliative goals of care. Better communication can improve patient outcomes such as reducing psychological trauma symptoms, depression and anxiety; shortening ICU length of stay; and improving the quality of death and dying. Communication strategies for EOL discussions focus on addressing family emotions empathically and discussing death and dying in an open and meaningful way. Central to this is viewing ICU EOL palliative care and withdrawal of life-extending treatment as predictable and not an unexpected emergency.

Conclusions: Because the ICU is now a well-established site for death, ICU physicians should be trained with EOL communication skills so as to facilitate palliative care more hospitably in this challenging setting. Patient/family outcomes are important ways of measuring the quality of ICU palliative care and EOL communication.

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1. Introduction

Because approximately 22% of all deaths in the United States occur during or after an intensive care unit (ICU) admission [1], the potential role for palliative care communication is considerable. For example, the need for clinician–family communication about withholding or withdrawing life-supporting therapies is the norm when a person dies in the ICU, rather than the exception [2–6]. Nevertheless, a palliative care philosophy towards dying is often perceived to be incongruent with the lack of hospitality shown to dying patients and their families, the impersonal technology and the action-oriented ICU ethos [7–9].

Difficulties with ICU EOL communication are well documented. Fifty-four percent of family members may have a poor understanding of the patient’s diagnosis, treatment and prognosis; comprehension is particularly poor when physician–family meetings last for less than 10 min [10]. A recent study demonstrated that physicians tended to discuss EOL life-sustaining treatment in a scripted, depersonalized and procedure-focused manner, while surrogate decision makers showed a poor integration of the medical dilemma that was the goal of the decision-making discussion [11].

Another study showed that 40% of family members of ICU patients retrospectively perceived that conflict had occurred with ICU staff and 31% cited unprofessional
behavior [12]. Examples included the physicians saying that another patient needed the dying patient’s bed, talking to a sister-in-law who was a nurse while ignoring the primary caregiver and having a do-not-resuscitate (DNR) discussion at the bedside of a ventilated patient where the family members were uncertain whether he could hear or not. Curtis et al. [13] described frequent missed communication opportunities in EOL family meetings, such as addressing family emotions, affirming nonabandonment of the family and discussing palliative care or ethics. Even clear, signed advance directives and well-intentioned, competent physicians do not mitigate the intrinsic complexity of EOL communication [14] and the potential to cause iatrogenic emotional harm [15].

This concise review aims to consider barriers to better ICU EOL communication, approaches to counteracting these barriers and evidence that better communication and communication skills training might improve patient outcomes. This is followed by a practical overview of EOL ICU communication strategies.

### 1.1. Family-centric ICU EOL communication

The first step in implementing EOL palliative care is usually family communication-reorienting goals of care from hope of cure to palliation [16,17]. Delirium and use of sedatives and analgesia result in the majority of critically ill patients unable to make their own treatment decisions, even after extubation [18,19]. The family therefore links the patient to the ICU team. American College of Critical Care consensus statements support the importance of family-centered EOL communication [20,21].

One problem in this regard is that doctor–family communication is not taught in most medical schools or critical care programs. Another problem is that there are considerable barriers to better ICU family communication, which is multifaceted rather than linear, and these are considered below.

### 2. Barriers to better ICU EOL communication

#### 2.1. Emotional barriers to EOL ICU communication

ICU physicians must be able to deal effectively with strong and chaotic emotions, as well as promote consensus among family and staff. When emotions, communication or deciding what is best for the patient cannot be managed within the ICU or the hospital (ethics committees, psychiatric consultations), external court intervention becomes necessary (e.g., Quinlan, Cruzan and Schiavo cases) with dramatic and long-lasting consequences [22–25].

There are many inter-related reasons for high emotions in the ICU. The blurred boundary between curative and palliative goals of care is vulnerable to misperception and disagreement [12,17,26,27]. In fact, the ICU admission is often initiated as a therapeutic trial. Only when it fails are curative goals of care reassessed [21]. Conflicting values, culture, religion and prognostic challenges can amplify emotions [17,28–31]. Some 73% of family members of ICU patients have significant levels of anxiety; 35% have depression symptoms [32]. Distress therefore is a predictable feature of the ICU family meeting.

A core strategy for managing overwhelming family emotions is to respond empathically, but in one study of 51 ICU EOL family meetings, there were no empathic responses at all in one third of these meetings [33]. Empathic statements are significantly associated with greater satisfaction with ICU care [33,34]. Conversely, lack of empathy increases patient dissatisfaction and the malpractice risk [35]. Patients who perceive their physicians as reassuring and willing to discuss feelings at time of cancer diagnosis report less anxiety 1 year later [36].

Empathy is not necessarily an innate quality. Empathic strategies can be taught in communication training programs [37–40]. Larson and Yao [41] even propose a model for teaching empathy based on principles of acting. Table 1 lists common empathic communication techniques, both verbal and nonverbal, used in teaching ICU clinicians at Memorial Sloan Kettering Cancer Center’s Comskil Lab [42]. Nonverbal empathic expressions (e.g., posture) predict patient satisfaction independently of their assessment of the physician’s technical expertise [43]. Powerful empathic skills include an awareness of another’s discomfort and suffering [44] and recognition of the human stories that accompany illness [45].

Empathy and emotional engagement lie at the heart of trust [46–48]. Without trust, the ICU physician has no foundation for EOL communication and decision making with families. Why should a family believe that the best course of action is to discontinue life-extending treatments if

<table>
<thead>
<tr>
<th>Strategies</th>
<th>Suggested dialogues and notes</th>
</tr>
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<tbody>
<tr>
<td>1. Normalizing/validating</td>
<td>“It is normal to be upset at such a difficult moment...”</td>
</tr>
<tr>
<td></td>
<td>“Your anger is understandable...”</td>
</tr>
<tr>
<td>2. Name or acknowledge the emotion</td>
<td>“You seem sad...”</td>
</tr>
<tr>
<td>3. Gesture or touch</td>
<td>“I can see that you are upset...”</td>
</tr>
<tr>
<td>4. Encourage expression</td>
<td>Offering tissues, a drink or gentle touch (if culturally appropriate) may promote empathy or trust.</td>
</tr>
<tr>
<td>5. Paraphrase and repeat back</td>
<td>“Tell me more about how you are feeling...”</td>
</tr>
<tr>
<td>6. Apologize</td>
<td>“If I understand you correctly, you are angry because the oncologist said that chemotherapy could be restarted after the ICU had treated the pneumonia.”</td>
</tr>
<tr>
<td>7. Praise/affirm adaptive coping</td>
<td>“I am sorry that things have not worked out as we might have wished...”</td>
</tr>
<tr>
<td>8. Silence</td>
<td>“This takes great courage...”</td>
</tr>
</tbody>
</table>

Silence reflects listening, acknowledging and sharing suffering.
they lack trust in their physicians or the institution that stands behind them?

Family satisfaction can be used as a barometer of communication and, indeed, communication successes and failures generate more gratitude and complaints than any other aspect of care [12,49]. Satisfaction is associated with being given the opportunity to ask questions; articulate personal values; express painful emotions; and discuss concerns, feelings or guilt [50,51]. The Family-Satisfaction-in-the-Intensive-Care Unit survey differentiates between satisfaction with care and satisfaction with decision making [52,53]. It also correlates highly with the quality of ICU dying and death [54–57].

2.2. Prognostic barriers to ICU EOL communication: anticipating death vs. death as an unexpected emergency

Approximately 90% of ICU deaths occur after decisions to forgo or limit treatment [2,3,5,58]. Thus, the need to talk about EOL goals of care and decision making is predictable in the vast majority of patients who die in the ICU. Viewing death as unpredictable turns it into an emergency. Anticipation allows for setting standards of care, education of staff and mobilization of resources. There is a large movement advocating standard protocols for withdrawal of life-extending treatments, which are available online [16,59]. Similarly, Nelson et al. [60] have developed a family meeting “toolbox” to help ICU staff plan for the meeting, assist the family to set their agenda and document outcomes, including a template with checkboxes to satisfy billing or quality improvement requirements. The toolbox also contains a prognostic schema to determine the likelihood of an ICU admission longer than 5 days. Other prognostic systems can also be used to generate more objective data supporting the likelihood of death [61], albeit not without controversy [62]. Prognostic information should be presented so as to aid comprehension and retention, such as citing naturalistic frequencies rather than probabilities [63]. To illustrate, it is easier to understand when a clinician says that, in a group of 100 similar patients, 80 will die and 20 will be alive at discharge, rather than saying there is a 20% survival to discharge rate.

In summary, the more predictable the death, the easier it is to plan and devote resources to its management. A key element of this is communicating the anticipated prognosis to the family. The often cited recommendation of a routine family meeting within 72 h of ICU admission [64] is somewhat dated because many deaths occur within this timeframe — the goal of a family meeting within 24 h of admission seems more clinically pertinent.

2.3. Ethical barriers to ICU EOL communication

It is essential that ICU physicians appreciate the ethical principles underlying ICU EOL communication. For instance, clinicians must appreciate the importance of respecting and maximizing patient autonomy, even when the patient is incapacitated or ventilated and cannot verbally express his or her wishes. Thus, decision making should be patient centered, reflecting palliative care principles [16,17,59,65].

One way that this is done is via substituted judgment. This is used when a patient is incapacitated and has not left written EOL advance directives to guide treatment; the surrogate decision-maker is supposed to make medical decisions as if she/he was in the patient’s shoes [66]. To illustrate, when a surrogate states that he could not imagine life without the patient and declines withdrawal of life-extending care, this is not substituted decision making. This is an example of a decision based on the surrogate’s own values. Substituted judgment is saying, “My Dad always said that everyone’s time comes and he would be ready for that moment,” because here the son is imagining what he might say if he was his father.

Another ethical principle is making decisions in the patient’s best interests. This is determined by considering the patient’s condition, prognosis, the benefits/burdens of treatment options and the patient’s prior views. Making decisions based on knowing what the patient might have wanted is preferable to making a decision based on the perceived best interests of that person.

Making an EOL decision based on the need for an ICU bed by another sick person reflects the principle of distributive justice or resource allocation and this should be avoided [67].

2.4. Barriers to joint decision making

Joint decision making also informs ICU EOL communication. This collaborative process involves educating and reflecting on the patient’s illness/prognosis, the benefits and burdens of the treatment alternatives and the patient’s values and beliefs. Shared decision making has been associated with a higher family satisfaction with communication [68]. American, European and Australian critical care societies advocate this approach [69,70].

Shared decision making can be more difficult within the ICU, where families do not have a preexisting relationship with critical care physicians. Furthermore, many patients have not discussed their wishes with their families and, even when their wishes are known, family members often prove ambivalent about planning for the dying process, even when carrying out the patient’s wishes. The physician needs to be sensitive to the not uncommon circumstance of families who cannot bear the burden of a shared decision to withdraw treatment. In such cases, it is appropriate for the clinician to bear responsibility for the medical decision. This is supported by studies on patient preferences. For example, one study of patients with a terminal diagnosis found that 52% would prefer shared decision making, 34% would prefer to make their own decisions and 15% would defer to their physicians. However, if they lacked capacity, 39% would defer to their physicians [71]. This highlights the importance of the personal qualities of physicians to make...
ethically appropriate and wise decisions [72]. A physician’s knowledge and prior experience in treating similar EOL cases are invaluable in guiding the family.

Part of the process of shared decision making is education and provision of medical information, but one study found that 35% of surrogates did not understand the physician’s explanation about the diagnosis and care options [73]. In another, surrogates perceived the communication from the physician to be insufficient [74], highlighting the difficulty of processing medical data at times of crisis suggests that communication skills training techniques such as “checking family’s understanding of the illness and treatments” and “frequent summarizing” are helpful [75]. An educational brochure about what to expect from the dying process is also a well-established approach [76].

EOL decision making should not be hasty, nor is it appropriate to unilaterally withdraw treatment in the midst of family protest. At the same time, futile treatment is not in the patient’s best interests. One strategy to find the balance between clinical realism and family optimism is to propose a time-limited, empirical trial of treatment, with an agreement that, if there is no improvement in clinical parameters, treatment goals will be revised with a view to withdrawing futile life-extending treatments [77].

Stuttering withdrawal of life-extending treatment, as a consequence of avoidant EOL communication, is undesirable. A recent study, however, paradoxically reported higher family satisfaction when the withdrawal of life-extending care took time. Here, the prolonged ICU admission was seen to facilitate more certainty in decision making [8]. Ideally, better EOL communication should replace the need for tempered withdrawal of treatment as a vehicle for accepting the inevitability of death. Communication should also aim to prepare the family for bereavement [76]. The bottom line is that all parties should be certain that the decision is reasonable, given the circumstances.

2.5. Do-not-resuscitate directives as a barrier to ICU EOL communication

Semantics and choice of words are important in communication. The term “DNR,” for example, may have authoritarian connotations, focusing on the negative, on what will not be provided. It does not reflect, in itself, palliative goals of care. A relatively new synonym is “allow natural death” (AND), which is used alongside DNR in New York State’s Medical-Orders-for-Life-Sustaining Treatment (MOLST) program [78]. The advantage of using the term “AND directives” is that it facilitates discussion of the palliative goals of care in the EOL discussion. “AND” emphasizes a natural death; by extrapolation, cardiopulmonary resuscitation (CPR) is incongruent with this palliative goal.

Is the AND/DNR discussion poorly implemented? There is evidence that AND/DNR directives are often implemented very late in the dying trajectory, often on the day of death [79]. This delay may reflect physician discomfort or avoidance with this discussion. Low health literacy is another barrier and researchers such as Volandes et al. [80] suggest that a narrative description of comfort care or resuscitation is inadequate. Visual images of palliative care or CPR may be more helpful in aiding understanding [80].

2.6. Physician unconscious barriers to EOL communication

The physician’s unconscious reaction to EOL communication can also present a barrier to communication. The physician is unaware of these subtle emotional undertones, although they might be quite apparent to others. For example, a physician may think, “There is nothing that I can offer this patient”; feel a failure; and experience sadness. The nurse may wonder why the physician has not yet met with the family.

Delaying EOL conversations, communicating euphemistically (discussed below) or giving overly optimistic prognoses [15,81,82] may all be symptoms of the physician’s unconscious emotional reaction to the clinical interaction. Kelly et al. [83] provide a thoughtful overview of how transference, countertransference and boundaries interact with EOL ethics. For instance, less experienced physicians may be more likely to agree with physician-assisted suicide, pointing to a skill deficit influencing decisions when they have difficulty tolerating helplessness [83]. Kelly et al. [84] elegantly demonstrated how physicians’ unconscious attitudes may influence the desire to hasten death: physicians’ subjective perception of reduced patient optimism and more emotional suffering (as well as less training in counseling) were factors predicting agreement with hastened death, a far cry from the objective factors that we would prefer to see considered in these deliberations. The concept of demoralization by Kissane et al. [85] is another example of a factor that might be unwittingly influencing EOL decision making. Might a demoralized physician be unconsciously more willing to push for withdrawal of life-extending care?

Although emotional and organizational support for ICU physicians is an American College of Critical Care consensus recommendation [21], addressing unconscious attitudes in communication skills training can be challenging. Certainly, the more meaningful and personal satisfaction a physician gains from his or her work, the greater the potential for personal growth [86,87].

2.7. Patients too sick for the ICU: EOL triaging by ICU physicians

Patients triaged and deemed too sick to benefit from ICU admission invariably forego life-sustaining therapy. However, these cases often display communication deficits such as less discussion with patients/families or even rejection over the phone, without an ICU physician actually seeing the patient [88–90]. Anecdotally, EOL communication is a
source of frustration for critical care physicians on triage duty who are asked to evaluate dying patients, prima facie, because the primary physician has avoided discussing EOL goals of care. There is relatively little research to guide this interaction.

2.8. Can communication skills training improve patient outcomes?

Critical care training might change significantly if there were convincing data demonstrating better patient/family institutional outcomes as a result of communication skills training [91].

To illustrate, consider the traumatic effect of an ICU death on next-of-kin as an outcome of communication training. Ninety days after an ICU death, significant posttraumatic stress symptoms are seen in 50% of next-of-kin, but when the next-of-kin actually participated in EOL decisions, this number jumps to 81.8% [74]. A recent New England Journal of Medicine publication reported on a prospective randomized controlled trial in 22 French ICUs using an intervention that consisted of five printed objectives for the EOL conference, presented to the physician before the meeting, and a family brochure about what to expect from the dying process [76]. Ninety days postmortem, the Impact of Events scale was lower in the intervention group (P=.02), indicating that 45% of the intervention group and 69% of the control group were at risk for posttraumatic stress disorder. Anxiety and depression were also lower (11 vs. 17, control group were at risk for posttraumatic stress disorder. Phrases such as "the cancer is advancing," "salvage chemotherapy" (salvaging and recycling are good), "prognosis is guarded" (stiff upper lip), "if your heart stopped beating..." (heart is treated as an isolated component), "aggressive EOL care is associated with worse patient quality of life and more depression among the bereaved [95]."

Roter, a communication expert, in a three-arm randomized controlled study, demonstrated that 8 h of training in either problem solving or addressing emotions significantly improved problem defining and handling emotions, without making consultations longer [96]. This, and the variety of interventional studies above, emphasizes that multiple strategies may be helpful in improving patient outcomes from organizational, to educational, to purer communication skills training approaches.

2.9. Talking openly about death and dying

Many communication clashes in the ICU occur because clinicians and families are not, sometimes literally and sometimes metaphorically, speaking the same language [97]. Families who report that clinicians give them mixed messages in the ICU are significantly more likely to have symptoms of anxiety and depression [98]. Phrases such as "the cancer is advancing" (advancement is usually positive), "salvage chemotherapy" (salvaging and recycling are good), "prognosis is guarded" (stiff upper lip), "if your heart stopped beating..." (heart is treated as an isolated component failure) are euphemisms that reflect avoidance of talking directly about dying. When physicians are more confident using words such as death and dying rather than euphemisms, the conversation is more authentic; communication skills training can be used to practice integrating the words death and dying into EOL conversations [42].

2.10. Interdisciplinary and spiritual communication strategies

Discrepant perceptions about EOL care between doctors and nurses are well described and often a source of frustration, especially when nurses conclude before the physician that the patient is unlikely to survive [99–101]. Implementing spiritual care, an important component of quality EOL care and another marker for family satisfaction...
in ICU [102,103], requires a high degree of interdisciplinary communication. It should be individualized and culturally sensitive, aiming to make the final moments gentler, more personal and consistent with the patient’s lived values [104].

Broadening involvement in the dying process has the advantage of de-medicalizing death, placing responsibility on society at large. Here death is viewed from the palliative perspective as a natural consequence of living rather than as a medical failure. This perspective can be enormously liberating to the ICU clinician. The American College of Critical Care’s guidelines even recommend allowing pets into the ICU to facilitate the goal of a more family-oriented death [20].

2.11. Specific strategies for ICU EOL communication

Table 2 contains a communication algorithm for ICU EOL family meetings, based on the communication skills training approach of the Comskil Laboratory at Memorial Sloan Kettering Cancer Center. It is not dissimilar to other expert recommendations [26,105–108]).

First and foremost, the algorithm emphasizes the importance of addressing emotions empathically. Emotional expression by the family is a cue that requires the clinician’s response [109], before moving ahead with EOL decision making/problem solving. However, even in the absence of a cue, it is appropriate to empathize with the patient’s and family’s difficult plight. It is difficult to build trust or promote rational decision making without first discussing emotions. Listening is one effective technique for addressing emotions. One study found that ICU physicians spoke for 70% and families for 30% of the time during family meetings, but satisfaction with quality of care was associated with more opportunity to speak [110]. A private location for these intimate discussions is an important element in facilitating trust, and the absence of such a room is associated with greater family anxiety [98]. Thus, elements of the setting facilitate the empathic tone.

Another communication skills training emphasis is on discussing death and dying fruitfully. Gathering information about death and dying preferences is a task that most ICU physicians find uncomfortable. One strategy is simply to ask directly. Especially in the setting of chronic illness, the patient may have already articulated these wishes and families are grateful to reflect on these further:

Physician: “Did your father ever discuss the prospect of death and dying?”

Family: “He said that he was ready to go! He said he had lived a full life and that he did not want to linger [tears].”

Education is a useful follow-up if the meaning of palliative care is not entirely appreciated. Thus,

Physician: “What is your understanding of comfort care?” [Physician listens carefully to family’s understanding of these terms so that misperceptions can be corrected]

A second strategy is asking about past experiences with death and dying. Most families have prior experiences with death approaches.

**Physician:** “... palliative care is our medical approach when the cancer cannot be cured, infection is overwhelming and the heart and kidneys are shutting down. This is unfortunately happening with your father at the moment. The aim of our treatment now focuses on reducing suffering and promoting comfort, so he can pass away peacefully and naturally ... [empathic silence]. Sometimes we doctors use too many technical terms... how was my explanation?” [checks understanding]

A comforting, past experience with hospice may be reassuring; negative experiences, such as a painful death, can inform ways of improving EOL ICU care.
The third strategy is substituted judgment. Where a patient lacks capacity, family can be invited to reflect on “who the patient is as a person” and what their EOL wishes might be “if they could speak to us right now.”

After discussing EOL care options, a clear physician recommendation should guide the family, avoiding both the extremes of paternalism and “dumping” the decision on the family. Thus, the decision-making burden is truly shared. This avoids the misperception that, e.g., “we killed grandma.”

In making EOL recommendations, specific clinician statements are associated with greater family satisfaction: assurance that the patient will not be abandoned; assurance that staff will do everything to maximize patient comfort and minimize suffering and clinician support for the family’s decision to withdraw life-sustaining treatment [111].

**Physician:** “This is a difficult situation. We will do our best to help you through it. I think that we are making the most reasonable decision, given the options…” [the “we” statement reflects shared decision-making and support for the family]

Expressing admiration for the patient’s and family’s strengths and praising their courage promote the family’s cohesiveness. “Go around” questioning is a technique that can be used to reinforce consensus by inviting each family member to contribute their thoughts.

**Physician:** “John, what are your thoughts about letting your dad die peacefully, as we have discussed?” [Listens] “Sally, what about you…?”

Physicians should be alert to barriers blocking adaptive decision making, e.g., where a patient expresses contradictory wishes, such as both wanting to fight and desiring a peaceful death [112]. Here a useful strategy is to encourage planning for the best but also the worst possible outcome in parallel, rather than viewing them as serial events.

### 3. Conclusions

The ICU has become an increasingly frequent site for the implementation of EOL care and therefore critical care physicians need to be competent in family-centered EOL communication. They should be able to manage a family meeting so as to promote consensus and discuss the transition from curative to palliative goals of care, and/or DNR directives, withdrawal of life-extending treatment and the dying process.

The need for palliative care in the ICU setting is predictable when viewed from a macro perspective. If a large percentage of ICU patients receive balloon pumps, clinicians are trained to use these devices. If 15-20% of ICU patients die, clinicians need to be trained to deal with this outcome. Here there is great opportunity for communication training, reproducible algorithms and standards that reflect multidisciplinary approaches to facilitate ICU palliative care and support the family. Finally, emerging evidence suggests that better EOL communication may impact on patient outcomes such as the quality of the death, bereavement, length of ICU admissions and cost of EOL care.

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