

# Communication at the End-of-Life in the Intensive Care Unit: A Review of Evidence-Based Best Practices

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## ABSTRACT

This article summarizes current data and recommendations regarding the care of patients in an intensive care unit (ICU) at the end of life. Through analysis of recent literature and society guidelines, we identified three areas of focus for practitioners in order to deliver compassionate care to patients and their families at this critical time – family communication, caregiver support, and palliative care involvement. Attention to these topics during critical illness may reduce stress-related disorders in both patients and family members, as well as increase satisfaction with the care delivered.

**KEYWORDS:** end-of-life, family support, goals of care

## INTRODUCTION

For patients who are hospitalized in an intensive care unit (ICU), there is an average mortality of 10–29% depending on age and medical condition prompting ICU admission.<sup>1</sup> In comparison, overall mortality for hospitalized patients not in an intensive care unit was 2% in 2010.<sup>1</sup> Navigating a patient’s end-of-life (EOL), and addressing family needs and concerns, is a crucial component of care in the ICU. A growing body of literature seeks to address how clinicians can best address these issues in a way that supports the patient’s wishes as well as the needs of their loved ones.

We will examine three primary areas of focus surrounding care around EOL - communicating with families, supporting family members/caregivers of patients and reducing distress, and involving palliative care.

## COMMUNICATION WITH FAMILIES

Having a critically ill loved one in an ICU is an immensely stressful experience for families. Numerous studies have demonstrated significant residual trauma and emotional distress for caregivers following admission to the ICU, regardless of patient outcome.<sup>2</sup> In order to best support families during an ICU admission, existing data supports the early and frequent use of interdisciplinary teams.<sup>3</sup> While current data regarding the emotional impact of interdisciplinary team use is equivocal, there is a significant positive impact on family perceptions of care.<sup>3</sup>

**Figure 1.** VALUE mnemonic to guide family communication – This mnemonic is presented by SCCM as a guide to help clinicians in communicating with families during end-of-life and difficult conversations.

<b>V.A.L.U.E.</b>
<b>A 5-step mnemonic to improve ICU clinician communication with families</b>
<b>V</b> = Value comments made by the family
<b>A</b> = Acknowledge family emotions
<b>L</b> = Listen
<b>U</b> = Understand the patient as a person
<b>E</b> = Elicit family questions

“VALUE” developed by University of Washington End-of-Life Care Research Program at Harborview Medical Center

Regular communication with caregivers is the cornerstone of caring for patients at the end-of-life. Several studies have demonstrated the potential impact of structured discussions regarding care for critically ill patients. There should be particular emphasis on spending time addressing specific concerns and understanding the patient as an individual, including their goals and values. The Society for Critical Care Medicine (SCCM) 2017 guidelines recommend the use of the VALUE mnemonic (**Figure 1**) to guide discussions with families of critically ill patients.<sup>2</sup> Data regarding the implementation of structured VALUE mnemonic has demonstrated decreased rates of PTSD, anxiety, and depression scores amongst family members.<sup>4</sup> VALUE can help providers address family concerns appropriately and empathically.

Interestingly, the use of standardized patients to facilitate better communication skills among physicians does not appear to impact families in a positive manner, bringing into question how young physicians in training can best be prepared to discuss end-of-life care with families.<sup>5</sup> Designated nurse facilitators to help ensure that communication runs smoothly and that families feel their concerns are addressed may be one way of addressing potential gaps in communication. The use and inclusion of nurse facilitators in family meetings has been associated with increased satisfaction with care.<sup>6</sup>

In conducting a family meeting for a patient who is critically ill approaching end-of-life there are several important considerations. It is necessary to address both family and

patient needs. Potential areas of miscommunication or conflicting goals should also be addressed. When meeting with families, the clinician should be mindful of the amount of time spent sharing information, as compared to families being allowed to express concerns and hopes. A demonstrable decrease in stress symptoms and an increase in family satisfaction has been shown to be directly proportional to the amount of time a family is able to speak during family meetings, as compared to time spent in which the clinician is directing communications.<sup>4,7</sup>

For critically ill and dying patients, current recommendations on addressing redirection of care encourage the family to focus on what the patient would want. However, the issue of what a patient would want does not sufficiently ground the family in the reality of the situation. For example, a family may say that their loved one would want further therapy (i.e., hemodialysis) that may not be an option. Instead, experts suggest eliciting from the family what the patient would think of their current situation, or how they would respond given their situation.<sup>8</sup> This helps to focus a family's attention and thought on the reality of their loved one's illness.

**Table 1.** Suggestions for Family Meeting discussions – As referenced, this table is adapted from several references as suggestions for possible verbiage during end-of-life and difficult conversations.

Word Choice for Family Discussions	
Commonly Used Phrases	Suggestions for Rephrasing
Withdrawing care	Redirecting focus of care
Do Not Resuscitate	Allow natural death
What do you think we should do next? OR: What do you want to do?	What would your [loved one] think if they were sitting here?
What would [loved one] want?	You've told me (or, you can tell me) about what [loved one] would think so I can help you best respect their values
Your [loved one] is very sick. This is what's happening...	What is your understanding about what's happening with your loved one? OR: What do you think is going on with your loved one?
I'm not sure what's going to happen	I wish I could tell you that [loved one] will improve.
General Principles for Family Meetings	
<ol style="list-style-type: none"> <li>1. Use 'wish' statements when conveying concern and helping family come to terms with unrealistic goals.</li> <li>2. Approach family meetings with mentality of "Hope for the best, prepare for the worst."</li> <li>3. Try to foreshadow possible outcomes and give the family an idea of what clinicians are looking for in their loved one's course.</li> <li>4. Normalize common reactions.</li> <li>5. Frequently pause to assess family understanding and reactions</li> <li>6. Focus discussion around what family believes the patient's goals are</li> </ol>	

Attention to word choice extends to descriptions of medical interventions and changing the focus of a patient's care. Careful attention to how messages are conveyed can help to support families and their decision-making during a stressful time, while minimizing conflict with the medical team due to lack of understanding (Table 1).

While successful communication with families should be the goal of all ICU clinicians, there are often occasions in which the clinicians' perspective of patient care conflicts with family hopes or goals. In these situations, an ethics consultation, if available, has been shown to be helpful on multiple levels. One particular study demonstrated reduced hospital stay and life-sustaining treatments without a change in patient mortality. Perhaps more significantly, this study also demonstrated that the majority of physicians, nurses, and surrogates found the consultation to be helpful in resolving conflict as well as distress.<sup>9</sup>

**FAMILY SUPPORT & REDUCING DISTRESS**

In addition to communication, the ability of family members to be present at the bedside is crucial. The 2017 SCCM guidelines recommend that families be allowed at the bedside on an open and flexible basis, including at bedside rounds and even during resuscitation if the family so chooses.<sup>2</sup> One study of families who witnessed CPR demonstrated reduced anxiety and depression symptoms than in those who were unable to witness CPR being performed on their loved ones.<sup>10</sup> In keeping with these guidelines, the Rhode Island Hospital and Miriam Hospital Medical Intensive Care Units allow patients' families to have unrestricted visitation with their loved ones.

Among pediatric and neonatal populations, family involvement in care has been consistently demonstrated to improve parent comfort and reduce distress. However, assessments of family needs without a concomitant change in provider approach has been associated with increased distress, indicating the need for providers to actively respond to family needs instead of merely elucidating them.<sup>11</sup> Additionally, narrative writing is becoming an increasingly recognized tool for emotional support during times of stress. Among both pediatric and adult populations, there is some data to suggest that the use of regular journaling may be a useful tool for families while dealing with the stress of ICU admission.<sup>12</sup> Data thus far seems to indicate a potential impact on both family satisfaction and stress scale measurements but limited utility amongst patients themselves for prevention of PTSD.<sup>13,14</sup>

There is a growing body of literature focused on mitigating the high prevalence of delirium in patients during and after being hospitalized in the intensive care unit, as well as PTSD following ICU/hospital discharge.<sup>2,15</sup> In addition to the impact on patients, recent studies have looked at the likelihood of anxiety, depression, and PTSD symptoms

amongst family members after a patient's ICU stay, regardless of the patient's ultimate outcome.<sup>15,16</sup> There is some data that families of patients who are chronically ill, as well as patients who remain unresponsive on mechanical ventilation after 10 days, are at higher risk of developing PTSD.<sup>15</sup> Recent work has shown flexible visitation hours in the ICU does not significantly impact patient outcomes, but have a positive impact on anxiety and depression symptoms in family members.<sup>16</sup>

A key tenant of distress reduction focuses on sharing information in a way that is meaningful to families. A communication facilitator may be a helpful way of ensuring that families understand their loved ones' care and clinicians' concerns.<sup>6</sup> Programs which focus on sharing information about the ICU and the individual patient's illness, and also follow-up with families after leaving the ICU or after discharge, can also help to smooth the transition and reduce family trauma.<sup>2</sup>

While there are ways to reduce distress while an individual is in the ICU, many recent studies have focused on interventions after a patient is discharged. For patients who survive to hospital discharge, post-ICU specific rehabilitation and follow-up clinic may help to alleviate their distress and likelihood of describing post-traumatic symptoms. There is some data to suggest that these clinics may also be helpful for families.<sup>17</sup> In addition, support groups may be beneficial as a means of coping and processing. In an age of increased accessibility and frequent smartphone use, the use of mindfulness programs via self-directed application use may offer an interesting new approach for healthy coping on an individual basis.<sup>18</sup>

The care team in the ICU can help to reduce family distress through careful communication that follows families after patients leave the intensive care unit. Efforts to support patients' families, particularly if there is a traumatic outcome, after their ICU stay may be beneficial in reducing longer term distress as well.

## PALLIATIVE CARE

Palliative care is an often-overlooked component to responsible and patient-centered care at the end-of-life in an ICU. Current data regarding palliative care involvement has demonstrated unclear benefit of palliative care consultations in ICU patients.<sup>19</sup> However, the integration of palliative principles can significantly lessen distress of both patients and families in the ICU.<sup>2,20</sup>

Within the ICU, individual physicians may have varying levels of comfort with palliative-based care. A specific palliative care consult may not be necessary for individual cases in which symptoms are easily managed, but this should be

determined on a case-by-case basis. One recent review distinguishes between two main models for the integration of palliative care in the ICU.<sup>20</sup> In the first model, described as the 'consultative model,' the focus is primarily on engaging palliative care consultants for help with symptom management, family and patient-centered care, and clear communication with the team. This may be particularly helpful with issues such as withdrawal of care and transitioning out of the ICU for patients who are at the end of life. Current SCCM guidelines recommend the early consideration of palliative care as a potential means of decreasing cost of care and length of ICU stay, although this recommendation is based on low quality evidence.<sup>2</sup>

The second model, advocated by many critical care societies as a core competency for ICU physicians, is an 'integrative model'.<sup>20</sup> With this approach, palliative care is a focus, rather than a consulting service. Many societies advocate for, and provide for, professional training of ICU providers in basic tenets of palliative care, and there is a small but growing subpopulation of critical care physicians who receive additional training in palliative care.

Most successful integrations of intensive and palliative care ultimately rely on both consultative and integrative models for palliative care. Clinicians who are competent and comfortable with principles of palliative care are well-positioned to effectively and empathetically communicate with families of critically ill patients as well as guide dying individuals and their families through difficult symptoms that arise. These clinicians may also be better able to recognize opportunities for further palliative care assistance through consultation, which can work synergistically with the primary team's efforts towards palliation.

## CONCLUSION

A hospitalization in an intensive care unit, particularly at the end-of-life, carries with it a high burden of patient symptoms, family distress, and difficult decisions that can manifest for many family members in the form of PTSD and depressive symptoms. These symptoms can continue months after the individual is discharged from the ICU. Three main principles for limiting distress and providing the highest quality care for those at the end of life can help guide ICU care. A focus on supporting families, limiting distress as much as possible, and appropriately directing efforts towards palliative care are crucial considerations for critically ill patients and their loved ones. Following these principles, providers can help to mitigate some of the difficulty and trauma of a stressful time and help people to feel supported and listened to during their time in the ICU.

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