

GOALS OF CARE AND END OF LIFE IN THE ICU

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Summary: Critical illness is traumatic for patients and their families and caregivers. Unrealistic expectations and mistaken assumptions about patients' goals of care often drive burdensome and unwanted treatment of those with serious illness or at the end of life. Compassionately delivering accurate and honest prognostic information inclusive of functional, cognitive, and psychosocial outcomes is crucial for helping patients and families understand what to expect from an ICU stay. Interdisciplinary strategies to develop a shared understanding of patient values and priorities as related to potential future health states and available therapeutic options help ensure that chosen treatments in the ICU are aligned with realistic and attainable patient goals. Focusing critical care efforts broadly on the well-being of the patient and family unit through optimal symptom management and attention to psychosocial and spiritual needs is important for easing physical and nonphysical suffering in the ICU and beyond. Attention to these 3 domains of care for critically ill patients and their caregivers helps ensure the best possible outcomes, independent of survival.

Keywords: Goals of care, Shared decision making, ICU, Functional and cognitive outcome, End-of-life care, Palliative care, Communication

Key Points

- The trauma and long-term sequelae of critical illness affect not only patients but also their families and caregivers.

- Unrealistic expectations and erroneous assumptions about the outcomes acceptable to patients are important drivers of misguided and goal-discordant medical treatment.
- Compassionately delivering accurate and honest prognostic information inclusive of functional, cognitive, and psychosocial outcomes is crucial for helping patients and families understand what to expect from an episode of surgical critical illness.
- Skilled communication and shared decision-making strategies ensure that treatments provided in the ICU are aligned with realistic and attainable patient goals.
- Attentive management of physical and nonphysical symptoms, including the psychosocial and spiritual needs of families and caregivers, eases suffering in the ICU and beyond.

Introduction

There is little doubt that the past half-century has seen tremendous advances in surgical critical care. The advent of lung-protective ventilation in the management of acute respiratory distress syndrome (ARDS), the evolution of balanced resuscitation strategies for the reduction of abdominal compartment syndrome, and the aggressive deployment of prevention and treatment strategies against the systemic inflammatory response syndrome and sepsis, along with many other technological innovations, have markedly reduced the morbidity and mortality associated with critical illness and multi-organ system failure.

Nevertheless, at times even the most aggressive measures fail to rescue patients from death or from life states that they would find unacceptable. It is an important role of the surgical intensivist to recognize when these situations might occur, to elicit patient values and identify appropriate goals of treatment of

critically ill patients with poor or uncertain prognoses, to relieve the physical and nonphysical symptoms and family/caregiver distress that often accompany the end of life and the sequelae of critical illness, and to skillfully shepherd patients and families through appropriate transitions of care in the final weeks, days, and hours. This review addresses core principles and incorporates recent literature adding to the evidence base for improving the care of critically ill surgical patients at or near the end of life. The principles and evidence presented are not only relevant in the care of primarily surgical patients by surgical intensivists but also of critically ill patients with primarily medical diagnoses who develop surgical problems and require the attention of surgeons equipped to meet the challenges of prognostication, communication, and decision making in this population.

A few caveats deserve mention at the outset. First, end-of-life care is often falsely equated with palliative care. This is understandable in the context of the history and evolution of palliative medicine, which originated as an offshoot of the hospice movement focused on relief of suffering for the terminally ill. It is paramount, however, to recognize the distinctions between the two. Present-day palliative care is specialized medical care dedicated to improving the quality of life of patients with serious or life-limiting illness and their families.¹ Although relieving burdensome physical and nonphysical symptoms at the end of life is a component of palliative care, the expansion of the field of palliative medicine has resulted in a shift in focus from improving the quality of death and dying to helping patients live as best as they can for as long as they can -regardless of their stage of illness. Second, all too often, the phrase "goals of care" is narrowly invoked to imply a conversation regarding resuscitation preferences or withdrawal of life-sustaining treatment (WLST). However, establishing clear and realistic treatment goals and promoting care strategies concordant with those goals are important aims of both palliative and critical care, regardless of the specific

treatment decision in question or a patient's prognosis for survival. With that in mind, this review is focused on the optimal care of critically ill surgical patients with serious underlying illness or at the end of life, and should by no means be construed as a comprehensive primer for palliative care or goal setting, broadly speaking, in the surgical ICU.

Prognostication: helping critically ill patients and their caregivers understand what to expect

Unrealistic expectations and erroneous assumptions about the outcomes acceptable to patients have been identified as important drivers of misguided and goal-discordant medical treatment in serious illness and at the end of life. The landmark Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments (SUPPORT) found that almost half of ICU patients experienced unwanted medical treatment, more than half were undertreated for pain, and many failed to have their therapeutic preferences identified or heeded by their treatment teams.² Thus, recognizing and avoiding overtreatment and undertreatment at the end of life is an important aspect of surgical critical care. Appropriate goal setting and decision making in surgical critical care require consideration of the respective likelihoods of a range of outcomes and a clear sense of which of those outcomes are acceptable to a patient and which are not. The relevant outcomes include not only hospital and short-term survivals but also long-term survival (extending beyond the customary 30 days to 6 months or 1 year or more), functional and cognitive status, health-related quality of life, and psychosocial outcomes for both patients and caregivers.

Multiple scoring systems are available to predict short-term mortality and some-times ICU length of stay for critically ill patients. Based on degree of derangement in physiologic, clinical, and laboratory parameters, these scoring

systems include the Acute Physiology and Chronic Health Evaluation scoring system, Sequential (Sepsis-related) Organ Failure Assessment instrument, the Simplified Acute Physiologic Score, and the Mortality Prediction Model. However, these scoring systems are not designed to forecast outcomes for single individuals but rather large populations of critically ill patients, limiting their utility for decision making on a case-by-case basis. In addition, mortality estimates based on 30-day or in-hospital outcomes often paint an incomplete picture of the health care trajectory for seriously ill surgical patients. For example, in a large retrospective cohort study of Medicare recipients, two-thirds of older patients who received prolonged mechanical ventilation after high-risk surgery were dead within the year; 30-day survivors had a 47% 1-year mortality rate and a 90% risk of discharge to dependent care.³

Because predictors of mortality are imperfect for individual patients and because patients and their caregivers care deeply about outcomes other than short-term mortality alone,⁴ it is problematic to strategically offer or limit aggressive life-saving or life-sustaining critical care based on probabilistic life-or-death outcomes. Rather than focusing exclusively on survival, every effort should be made to accurately and honestly prognosticate about the nature of the future clinical course and the expected resulting health states, so that patients and their surrogates can make well-informed decisions about treatment options and their sequelae. Forecasting functional outcomes in particular is crucial for patients and caregivers and also has important impacts on clinician behavior. For instance, specifically documenting a patient's functional prognosis has been shown in a scenario-based randomized controlled trial to have significant bearing on the likelihood of a clinician subsequently broaching the subject of WLST.⁵ In addition, acknowledging and anticipating expected functional outcomes affords

clinical teams the opportunity to prospectively minimize and mitigate adverse sequelae of critical illness through targeted survivorship strategies.

ICU survival is no guarantee of a good outcome. Not only do mortality risks remain elevated for months after ICU discharge but also functional and cognitive deficits linger, and ongoing pain and other physical symptoms are unfortunately common among ICU survivors. These features characterize the syndrome of persistent infection and immunosuppression, neuropathy, myopathy, endocrinopathy, and cognitive dysfunction now recognized as chronic critical illness.⁶ In a landmark 2004 study of patients with prolonged respiratory failure, Nelson and colleagues⁷ reported prevalence rates of 50% to 95% for a range of chronic critical illness symptoms affecting survivors, including nausea, dyspnea, insomnia, and anxiety. In a large prospective cohort study of adults over 65 who spent greater than 24 hours in an ICU, including surgical ICUs, more than one-third of patients were dead at 6 months; health-related quality of life declined during the follow-up period for most older patients (86 years and older), whereas it tended to improve for younger patients (age 65-69).⁸ In a follow-up to SUPPORT, investigators found that approximately half of survivors of severe acute respiratory failure needed help with at least 1 activity of daily living, and more than one-quarter rated their quality of life as poor or fair 5 years after ICU discharge.⁹ Choi and colleagues¹⁰ found that the vast majority of ICU survivors (89%-97%) self-reported at least 1 symptom, most commonly sleep disturbance, fatigue, weakness, and pain, across all time-points in a 4-month follow-up study. Additional investigators have documented significant persistent long-term functional disability as measured by impaired performance on 6-minute walk test, along with decreased physical quality of life and increased costs and use of health care services, in ARDS survivors 2 years to 5 years after discharge from the ICU.^{11,12} Because duration of bed rest in the ICU is directly related to weakness

over the course of 2-year follow-up, it is possible that interventions to reduce the duration of bed rest during critical illness may prove beneficial for reducing the prevalence and severity of chronic impairment among ICU survivors¹² (Fig. 1).

Diminished quality of life and functional impairment are closely tied to cognitive and psychosocial outcomes. In a retrospective cohort study of trauma patients admitted to the surgical ICU, of whom 50% had severe traumatic brain injuries, fewer than half of survivors who completed follow-up were able to return to work or school within 2 years to 5 years.¹³ In a prospective cohort study, global cognitive deficits and impaired executive function comparable to moderate traumatic brain injury or mild Alzheimer disease were found in up to one-third of ICU survivors of shock or respiratory failure 1 year after discharge, despite a baseline cognitive impairment prevalence of only 6%.¹⁴ The prospective longitudinal cohort study Bringing to light the Risk factors And Incidence of Neuropsychological dysfunction in ICU survivors (BRAIN-ICU) demonstrated that one-quarter of ICU survivors face deficits in both basic and instrumental activities of daily living up to 1 year postdischarge.¹⁵ Approximately one-third of ICU survivors suffer from depression 1 year after discharge, and the prevalence of posttraumatic stress disorder (PTSD) is as high as 20% 6 months to 12 months after ICU discharge.¹⁵⁻¹⁷ The pooled prevalence of cognitive impairment, mood disorders, and PTSDs has been measured at 20% among 5-year survivors of ARDS¹⁸ (see Fig. 1).

Finally, outcomes among patient caregivers, including friends and family, must also be considered. The experience of having a loved one in the ICU is highly traumatic.

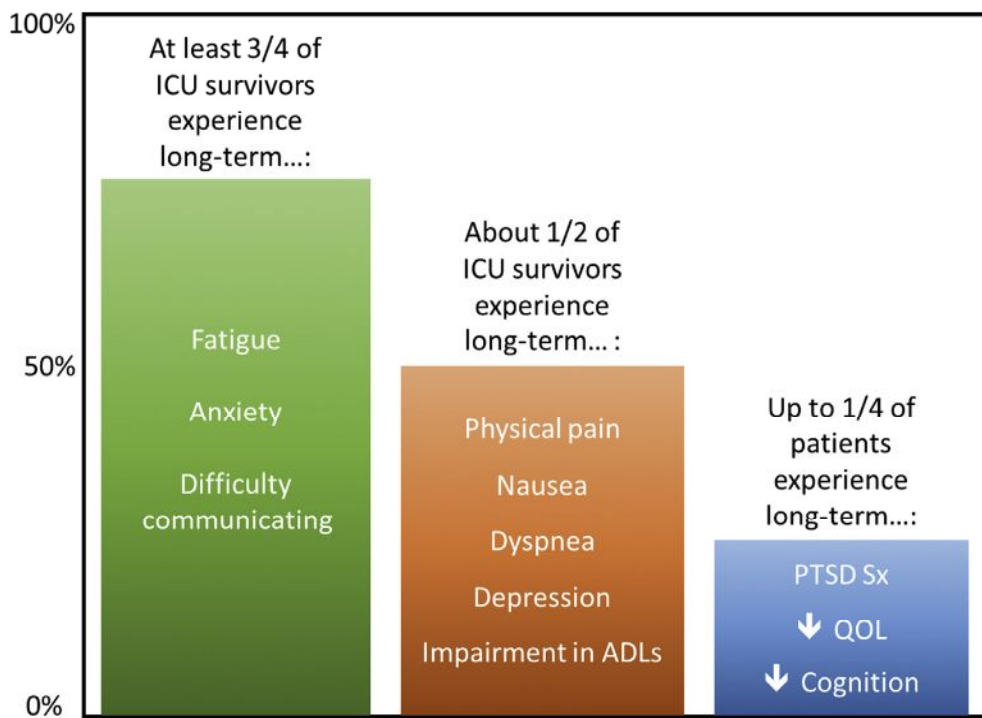


Fig. 1. Estimated prevalence of chronic symptoms in survivors of critical illness. ADLs, activities of daily living; Sx, symptom; QOL, quality of life. (Data from Refs.6,8,9,13-16)

This trauma is compounded by grief and bereavement for the loved ones of decedents and ongoing distress for loved ones of survivors suffering from chronic critical illness and other post-ICU impairments. High rates of depressive symptoms, with a prevalence of up to 23% to 50% at 1 year, have been observed among caregivers of mechanically ventilated ICU survivors- exceeding the burden of depression seen among caregivers of patients with dementia. In addition, 3 months after discharge, symptoms suggesting a moderate to major risk of PTSD were found in one-third of family members of ICU patients overall and in more than 80% of family members who had shared in end-of-life decisions for an ICU decedent.^{19,20} Caregiver-reported findings suggest that some of these burdens can

be mitigated by increased contact and communication with physicians, improved counseling about what to expect, greater emotional support, and better symptom management for their loved ones in the ICU.²¹

Communication and decision making: working with critically ill patients and their caregivers to choose the best treatments for them

In the face of uncertainty about ICU outcomes, communication and decision-making skills become paramount for ensuring that patients receive treatments that are medically appropriate and concordant with their values, goals, and priorities. Structured communication interventions have been shown to improve end-of-life care for critically ill patients,^{22,23} and shared decision making (SDM) has been established now for decades as a standard of patient-centered care in the ICU and is applicable for all treatment decisions that hinge on personal values and preferences.^{24,25} Nevertheless, confusion persists as to the nature and optimal implementation of SDM. Too often, SDM is interpreted merely as shared burden of responsibility on the part of physician and patient for choosing from among a set of treatment options. This, however, can leave some patients and their surrogate decision makers feeling abandoned by their physician, who has abdicated an important professional responsibility in the name of patient autonomy that may not be desired. A more ethically and scientifically grounded interpretation of SDM is one in which the physician and the patient/surrogate share different roles and spheres of deliberation in the decision-making process, which is mediated by the physician or another trusted and invested member of the clinical care team. In general, patients and surrogates are best poised to contribute knowledge and information about what is important to them, whereas clinicians should contribute their knowledge of treatment options and their likely outcomes in the context of a patient's overall illness and articulate an interpretation of how

each treatment option supports or undermines the values and priorities expressed by the patient and/or surrogate.²⁶

The tenets of communication and SDM in the ICU involve timing, setting, core content, and key steps. First, especially when patients are unable to participate in discussions about their care, every effort should be made to reach out to family members, caregivers, and surrogates (herein referred to as "family") as early as possible in the ICU stay. Studies of family satisfaction and outcomes have noted improvements when family meetings are scheduled within 72 hours of admission to the ICU, and 5 days is now considered a minimum standard.^{22,27-29} Among other benefits, meeting early helps avoid the pitfall of not having met until an acute life-threatening situation develops, forcing the encounter to take place suboptimally in the midst of a pressured crisis. Additional triggers for family meetings are discussed subsequently in this section and include changes in medical status, uncertainty or disagreements between or among family members and clinicians regarding the therapeutic goals and whether/how these can be achieved, and family requests (see Table 2).

Setting-including the location, individuals involved, and their expectations-plays an important role in the success of a communication intervention. Privacy, quiet, freedom from distractions, and ample seating options should be ensured. The patient should be included as much as possible but often is not able to participate due to the nature of critical illness. Decisional capacity should be objectively assessed and documented, and, when found lacking, the appropriate surrogate(s) or proxy(ies) - assuming they exist- need to be called on. Staff should be interspersed among the family, and those in attendance should reflect the makeup of the interdisciplinary team, including the physicians (intensivists, surgeons, and palliative care clinicians), nurse, social worker, chaplain, translator, and others involved in the patient's care as appropriate. Individuals should

identify themselves clearly and understand each other's roles and the purpose of the meeting. Clinicians should prebrief with each other prior to the meeting to ensure that they all have a clear command of the relevant medical facts, to establish consensus as to the unified messages that will be conveyed to the family, to openly address and resolve their own biases or conflicts with respect to the appropriateness of various potential therapeutic options, and to agree on an appointed facilitator for the meeting.³⁰ Similarly, family meeting guides are available as printed hand-outs to help family members prepare for meetings with ICU clinicians and to facilitate comprehension, maximize efficiency, and ensure that feelings and concerns are appropriately addressed.³¹

Opening a family meeting or discussion of goals of care can feel awkward and intimidating to clinicians, but it is important to remember that the family members gathered may feel the same way. Beginning the meeting with an expression of gratitude for the participants time and an open-ended question is an excellent way to set a relaxed and inviting tone and to gather clues about the family's emotional state and assess their informational and decision-making preferences- because not all patients want to share equally in SDM or any of its domains³². Throughout the meeting, clinicians should resist the temptation to dominate the meeting or to seek intellectual refuge from strong emotions by providing lengthy clinical explanations, using medical jargon, and focusing on procedures. Instead, clinicians should not only encourage family members to contribute their perspectives and participate in determining the flow of the conversation but also allow time and space for silence and the nonverbal expression of emotion, which should be actively explored and validated throughout the conversation by members of the clinical team. Empathic statements-including expressions of naming, understanding, respecting,

supporting, and exploring emotion (NURSE statements)-have been associated with greater family satisfaction in communication interventions.^{33,34}

The next task in the conversation is to discuss prognosis. First, clinicians must elicit a patient's/family's understanding of the nature and expected course of the acute problem and any contributing underlying conditions. Again, open-ended questions are especially helpful. Then, the clinical team must compassionately and effectively communicate the prognostic assessment to the patient/family, explicitly addressing the life-threatening and life-altering nature of critical illness, and contextualizing this in terms of the overall health trajectory and functional status.

The 6-step Set-up, Patient's Perception, Invitation, Knowledge, Emotions and Empathy, Strategy and Summary (SPIKES) protocol³⁵ has long been advocated as a strategy for breaking bad news, but recent investigators have emphasized the lack of evidence, in particular patient and caregiver-reported outcomes, in rigorously evaluating the effectiveness of this methodology. Nevertheless, it remains an important tool whose value may be enhanced through adaptation to individual patient preferences, clinician style, and cultural contexts.³⁶ Providing ranges of expected outcomes (eg, best case and worst case), acknowledging uncertainty, and emphasizing the rapidly evolving nature of critical illness can help prepare caregivers for the emotional trauma of a loved one's stay in the ICU. In addition, clinicians must deliver honest, consistent messages and avoid the common pitfall of mitigating the emotional impact of unwelcome news by providing false reassurances or encouraging unrealistic hopes. By anticipating and tracking nuanced characteristics of the strong emotions that are often triggered by the delivery of poor prognostic information, clinicians can be prepared to respond effectively using empathic strategies tailored to individuals' unique needs.³⁷

After establishing a shared understanding of prognosis, clinicians should next seek to formulate a comprehensive mutual understanding of a patient's values and preferences. Exploratory questions should be used to elicit the patient's goals, values, and priorities as well as fears and worries. Furthermore, clinicians should explore what tradeoffs the patient would or would not be willing to make for the chance of a given outcome. The patient dignity question, "What do I need to know about [you/your loved one] as a person to take the best care of [you/him/her] that I can?" has shown promise for promoting patient-centeredness in the care of seriously ill patients across multiple settings, including acute hospitalization.^{38,39} Exploration of goals should include an understanding of treatments that the patient wishes to avoid (eg, tracheostomy) or states that would be unacceptable to him or her (eg, severe communication impairment).

The final steps in the goals of care conversation include outlining the therapeutic options, making a recommendation for treatment that is aligned with a patient's goals (including consideration of a time-limited trial, when appropriate [discussed later]), affirming that the clinical team is committed to caring for the patient and family regardless of the treatment course, and adjourning the meeting. Before proceeding, however, it is wise to assess the patient/caregiver for readiness to continue. It may be necessary to tailor the agenda of each meeting to the clinical context and situational needs. For example, delivering poor prognostic information or breaking bad news may dominate the initial meeting after a traumatic injury. In these instances, formulating a shared understanding of the patient's prognosis, establishing therapeutic rapport, providing emotional support, and probing for patient preferences may be the most important goals of the encounter; although families may initially be too overwhelmed to address specific treatment goals and participate in decision making about therapeutic options, a

clear and specific follow-up interval should be agreed on at which point to continue the conversation.

Therapeutic options to be considered in the context of critical illness may include invasive procedures, such as bronchoscopy, tracheostomy, gastrostomy, or surgical interventions; continuing treatment, withholding treatment, or WLST (mechanical ventilation, renal replacement therapy, artificial nutrition and hydration, use of cardiac assistive technology); introduction, escalation, or withdrawal of therapeutic measures, such as vasopressors or antibiotics; and resuscitation status. The role of concurrent palliative or comfort-directed care should be stressed, and patients/caregivers should be reassured that aggressive symptom management will be pursued to the fullest extent allowed by the overarching therapeutic strategy. Treatments that cannot effectively meet the therapeutic goals should not be offered. Because preferences vary for patient/caregiver engagement in the decisional domain of SDM, clinicians should obtain an invitation to make a treatment recommendation if they believe they have the clinical certainty and sufficient data about a patient's preferences to do so. In making a recommendation, clinicians should emphasize how the recommended treatment aligns with what the patient's values and goals in the context of both the acute problem and premorbid health trajectory.

The time-limited trial is a practical and effective strategy for facilitating goal-oriented critical care in the context of uncertain prognoses. With demonstrated applicability to the surgical patient population, time-limited trials help mutualize expectations among clinicians and families, permit the initiation of treatment without a protracted commitment in the event of clinical failure, and provide a safe platform from which to fully explore the possibilities offered by life-saving and life-prolonging technology.^{40,41} In a time-limited trial, clinicians and family/caregivers outline objective measures of improvement or deterioration-

based on a patient's predetermined goals-to be assessed after a defined period of initial therapy (eg, 48 hours or 1 week). At the agreed-on interval, outcomes are evaluated and, depending on a patient's progress toward the desired goals, the intervention is either continued or discontinued, as previously decided. Regardless of whether a time-limited trial is pursued, closure of the meeting involves checking for shared understanding among all participants, actively encouraging family/caregivers to raise any lingering questions or concerns, and settling on a mutually convenient time for a subsequent encounter.

Finally, family meetings should be promptly and clearly documented in the medical chart or electronic health record. Such notes should be clearly identified so that other members of the treatment team can readily access important information about the goals of care and patient and family preferences. Structured note templates not only facilitate documentation but also may help prompt clinicians to address the important content areas. Such a template for an ICU family meeting should include the following core elements³¹:

- Location
- Patient participation
- Family/caregiver participants and their contact information
- Clinical team participants
- Preexisting advance directives or health care proxy documents identified
- The patient's/family's/surrogate's understanding of the prognosis
- Patient identity and values; patient/family hopes and worries/fears
- Specific therapeutic goals identified
- Plan/recommendations made
- Other content of meeting (such as emotional or spiritual support provided)
- Time involved in meeting

Note headers containing key search words or phrases, including "family meeting", "goals of care", or "palliative care," help distinguish documentation of important conversations from standard progress notes and may facilitate not only clinical care but also quality improvement and research endeavors.

When, how, and by whom should communication interventions and other more comprehensive palliative care services be deployed in the surgical ICU? Triggers for structured serious illness communication interventions and palliative care assessment are continually being developed and defined, largely based on prognostic criteria that ideally include not only mortality risk but also the potential for future distress and functional or cognitive impairment.⁴²⁻⁴⁵ Various service delivery models have also been described, including consultative, integrative, and mixed models. Mosenthal and colleagues²⁷ and Lambda and colleagues²⁸ described an integrative model for changing the culture around end-of-life care in the surgical ICU for both trauma and liver transplant patients; in both populations, a program, including family support and assessment of prognosis and preferences at admission, along with an interdisciplinary family meeting within 72 hours, was successful in achieving earlier consensus on goals of care as well as decreasing length of stay for patients who died without affecting overall mortality.^{27,28}

In addition, debate has stirred over the role of palliative care specialists versus generalist clinicians in performing communication interventions and palliative care assessments for critically ill patients. All physicians and health care professionals should be expected to have a command of basic palliative care skills, including routine prognostication, communication, and symptom management. Some especially complex or vulnerable patients, however, may require clinicians with specialized expertise in these areas.⁴⁶ Although the supply of palliative care specialists is increasing to meet rising demand, the triggers for specialist palliative care involvement must currently be titrated to the availability

of clinicians to provide those services, and the remainder of the system's need must at this time be met by generalists (or continue unaddressed). Simply deploying palliative care specialists for one-off interventions likely is ineffective in supporting patients with serious illness and their caregivers. A recent randomized controlled trial showed that palliative care specialist-led family meetings for patients requiring greater than 7 days of mechanical ventilation failed to reduce anxiety and depression symptoms among caregivers and may have increased symptoms of PTSD. These meetings were highly scripted for the delivery of prognostic information as the primary communication goal and generally did not involve an ICU physician or other members of the ICU clinical team.⁴⁷ Thus, who performs the communication interventions may be secondary to how these interventions are carried out. These findings highlight the shortcomings of a blanket strategy reliant on specialized consultative services divested from the longitudinal relationships and therapeutic alliances that should be fostered between ICU clinicians and family caregivers and emphasizes the importance of equipping primary providers with the inter-personal and communication skills required to meet the basic needs of most patients.

Surgeons with palliative care expertise may be uniquely poised to facilitate SDM for critically ill surgical patients perioperatively.⁴⁸

Symptom management: easing physical and nonphysical suffering in the ICU and beyond

The goals of symptom management in the ICU include not only relieving suffering in the present and providing a quality end-of-life experience for decedents and their families but also minimizing future burdens for survivors. Pain should be aggressively managed and controlled for all patients. Although opioids remain the mainstay, non-opioid adjuncts-including local anesthetics,

nonsteroidal anti-inflammatory drugs, acetaminophen, ketamine, and other neuropathic drugs-also may be considered as appropriate. Dyspnea is also treated with opioids, in addition to addressing underlying correctable factors and providing humidified oxygen. Delirium should be carefully assessed, and contributing factors, including sleep and circadian rhythm disturbance, should be mitigated. Hypoactive delirium is best managed with reorienting stimuli and reassurance (for both patient and family/caregivers), whereas patients with hyperactive delirium and unmanageable agitation are treated with antipsychotics. Benzodiazepines, which can worsen disorientation and further disinhibit patients, and restraints, which can worsen agitation, should generally be avoided.⁴⁹

Most patients who die in the ICU do so only after withholding life-sustaining treatment WLST.⁵⁰ Ideally, this decision is reached through the communication and SDM strategy outlined previously. Because the transition from curative to comfort—oriented treatment can be difficult for patients and loved ones, extra emotional and spiritual support should be available at this time. In addition, it should be recognized that organ donation can help soothe the grief of family and caregivers, especially when this act represents the fulfillment of a patient’s dying wish. In this context, when appropriate, patients should be referred to the regional organ procurement organization prior to WLST for further evaluation related to donation while the ICU team continues to care for the patient in his or her best interest. Palliative extubation generally involves placement of an active order to allow natural death/do not resuscitate/do not intubate; discontinuation of neuromuscular blocking agents; administration of appropriate medications for relief of dyspnea, agitation, and other symptoms; extubation with or without prior incremental reduction of ventilator support; and ongoing family/caregiver support.⁵¹

Actively dying patients may experience noisy respirations caused by uncleared upper airway secretions pooling in the posterior pharynx; these are likely to be more distressing for family and caregivers than for an unconscious or minimally conscious patient and generally can be managed with glycopyrrolate and positioning. Similarly, family members concerned about their loved one's dry mucous membranes will be reassured to learn that dry mouth is not representative of thirst in the dying patient but may nevertheless derive comfort from providing oral care with moist sponges. Dying patients and their families often grapple with existential concerns surrounding meaning ("Why am I suffering?" "What has my life meant?"), value ("What value do I still have for my family/workplace/community?"), and relationships ("Whom have I loved?" "Whom must I forgive?"). The ICU team can facilitate the "work" of the dying through efforts to maintain comfort and cognition, being available for listening and emotional support, encouraging family presence, allowing for grieving, and providing as peaceful as possible a setting for the dying patient and his or her family. Invasive and noninvasive monitoring, pulse oximetry, suctioning, laboratory draws, and all non-beneficial treatments should be discontinued. The so-called doctrine of double effect legally and ethically empowers physicians to provide medications and therapies intended to relieve suffering (eg, opioids for pain and dyspnea and anxiolytics for agitation), even if these hasten death as a collateral consequence of their use.⁵² Transition to home or inpatient hospice should be facilitated if possible and concordant with a patient's wishes, although moving patients in the last hours of life is generally discouraged. Medical/Provider Orders for Life-Sustaining Treatment (MOLST/POLST) forms, representing actionable orders reflective of the SDM and advance care planning that has taken place in the ICU, should be completed prior to such transfers to ensure that patient preferences are honored across all health care settings.

Helping critically ill patients and their caregivers prepare for and cope with a future outside the ICU is an important challenge at the frontier of critical care. The practice of reflective writing in ICU diaries is one intervention shown to have reduced symptoms of PTSD among European survivors of critical illness, and efforts to understand what benefits it offers to family are ongoing.¹⁷ Depression screening for caregivers at ICU admission, during the ICU course, or in follow-up after discharge is the subject of ongoing investigation into ways of improving caregiver outcomes and should be considered.^{19,53} Families of ICU decedents, particularly when children are involved, are ideally referred to bereavement support groups. Caregivers report increased satisfaction associated with receiving spiritual support services, condolence cards from the treating team, and clinician attendance at their loved one's funeral.⁵⁴ Periodic interdisciplinary memorial services, or ICU death rounds, may be effective in building resilience and combatting burnout among critical care providers.^{38,55,56} Ultimately, these palliative efforts, as adjuncts to high-quality prognostication, communication, and decision making, help yield positive critical care outcomes for all those whose lives are touched by the ICU.

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