

34th Donald F Egan Scientific Memorial Lecture

Caring for Patients With Critical Illness and Their Families: the Value of the Integrated Clinical Team

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Summary

Because of the severity of illness, the intensive care unit (ICU) is a setting where death is common. Approximately 20% of all deaths in the United States occur in ICUs. Although optimal palliative care of out-patients may prevent many ICU admissions, the ICU will always remain an important setting for end-of-life care because of the severity of illness of patients in the ICU. This review provides an overview of the principles and practice of integrating palliative and critical care, with a focus on 4 specific areas: the role of palliative care in the ICU; symptom assessment and management; communication with patients and family members; and interdisciplinary communication and collaboration. This review also describes the development and evaluation of a new intervention for hospitals and individual ICUs: Integrating Palliative and Critical Care (IPACC). The goal of the IPACC intervention and this paper is to teach ICU clinicians basic palliative care skills and the language of palliative care, and to encourage all ICU clinicians to prioritize palliative care as one of the important things that we do in the ICU. Key words: end-of-life care, palliative care, critical care, intensive care. [Respir Care 2008;53(4):480–487. © 2008 Daedalus Enterprises]

Introduction

It is a great honor to be asked to present the Donald F Egan Lecture and this corresponding paper. I did not know

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Donald Egan personally, but his contributions are legendary. In addition, it is also an honor for me because the American Association for Respiratory Care is an important and vibrant professional society and because Dr David J Pierson, the retiring editor of the society's journal, *RESPIRATORY CARE*, is one of my role models.

There is a growing interest in improving the quality of palliative care in the intensive care unit (ICU). This is an issue that resonates with many critical care clinicians because they see the effects of poor quality of palliative care in the ICU setting on a daily basis. Improving palliative care in the ICU is within reach, and I believe it should be the responsibility of all members of the interdisciplinary ICU team. This paper will provide a rationale and specific tools for ICU clinicians interested in addressing this important subject. I will cover (1) understanding the role of

palliative care in the ICU, (2) the importance and value of communication with families, (3) the role of interdisciplinary communication and the importance of the interdisciplinary team in providing the best care possible for patients and their families, and (4) an intervention that my research group developed and is testing, Integrating Palliative and Critical Care (IPACC), which is a hospital-level intervention to improve the quality of palliative care in the ICU setting.

The Role of Palliative Care in the ICU

Palliative care is important in the ICU for a number of reasons. First, many patients die in the ICU. Approximately 1 in 5 deaths in the United States occurs in an ICU, which is well over 500,000 deaths per year.¹ That's a staggering number. Therefore, clinicians who practice in ICUs take care of a large number of dying patients. Furthermore, a large proportion of our ICU patients die during their time in the ICU; between 5% and 30% of our patients, depending on the type of ICU, die either in the ICU or shortly after discharge from the ICU. However, I want to make the case that palliative care also applies to many patients who survive a stay in the ICU. The majority of ICU patients are at risk of dying; that is why they are in the ICU. Palliative care issues may be of importance to these patients and their families, even if they ultimately survive the ICU stay.

In fact, many ICU patients, even if they do survive, live on with substantial reductions in their quality of life, particularly after severe illnesses such as sepsis and acute respiratory distress syndrome.² Furthermore, many of them are at risk for returning to the ICU, either because of their critical illness and the sequelae thereof, or because of the underlying chronic illnesses that put them there in the first place. Thus, the ICU can also be an opportunity to begin to address palliative care issues, to discuss the circumstances under which the patient might return to the ICU, and to make sure that the patient and family have an opportunity to talk about these things. This is an opportunity that, unfortunately, we frequently miss.

Therefore, if we really want to improve ICU care for patients and families, an important aspect of ICU care is to consider palliative care as not just the care we provide after we make a decision to withhold or withdraw life-sustaining treatments, but as a much broader component of care, including explicit discussion about the goals of care and patient-centered and family-centered decision making; communication with the patient (if he or she is able) and their families; pain and symptom assessment and control; communication and collaboration among the interdisciplinary team; and, when ongoing life support is either not indicated or not desired, withdrawal of life support in a way that minimizes symptoms for the patient and maxi-

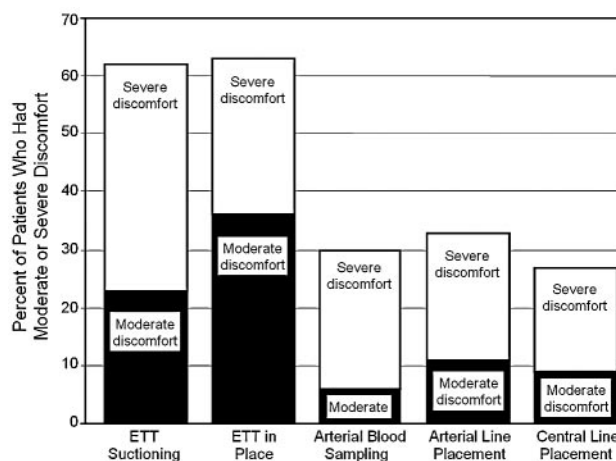


Fig. 1. Data from a study of 50 patients with cancer who were in a medical intensive care unit and able to respond to survey questions about their discomfort during 4 procedures (and one ongoing condition (endotracheal tube [ETT] in place). (Data from Reference 5.)

mizes support for the family members. This broader perspective on the role of palliative care in the ICU offers the opportunity to improve care for all critically ill patients and their families.

Symptoms Assessment and Management

Many ICU clinicians believe that we control symptoms very well and, if anything, too well; that is, they believe that we actually need to reduce the level of sedation in the ICU. Though we do often need to reduce the level of analgesia and sedation in the ICU, there is also a substantial burden of unaddressed symptoms in some ICU patients.^{3,4} For example, one study examined symptoms among 50 patients with cancer in a medical ICU, who are able to communicate well enough to report symptoms,⁵ and that study found a substantial burden of symptoms in those patients. The symptoms were diverse, including discomfort, thirst, sleep problems, anxiety, pain, hunger, depression, and shortness of breath. A substantial number of the patients reported either moderate or severe symptoms in those categories while they were in the ICU, which suggests much room for improvement. The study also examined discomfort associated with ICU procedures.

Figure 1 shows the proportion of patients who had moderate or severe discomfort during 4 common ICU procedures (suctioning the endotracheal tube [ETT], arterial blood sampling, placement of an arterial line, and placement of a central line) and one ongoing condition (having an ETT in place).⁵ I find it fascinating that, if you add the moderate and severe discomfort, the procedure that was most uncomfortable for those patients was ETT suctioning. Prior to more invasive procedures we provide sedation

and analgesia, but we rarely consider analgesia for endotracheal suctioning, and often clinicians don't even appropriately warn the patient or provide verbal comfort.

There are also data that suggest that there is a lot of variability in the way we approach issues around making decisions about withholding or withdrawing life support. One study examined 6,303 deaths in 131 ICUs in 38 states,⁶ and found that the proportion of deaths in each ICU that were preceded by withholding or withdrawing life support varied dramatically from ICU to ICU. The range for the proportion of deaths preceded by withdrawing life support was 0% to 80%. There may be a lot of reasons for variation, and there may theoretically be some good reasons for some variation, such as differences in patient preferences. However, studies suggest that patient preferences do not explain regional variations in end-of-life care,⁷ so this dramatic variation suggests inconsistencies in quality of care and implies that we have substantial room for improvement.

Communication With Family Members of Critically Ill Patients

If you ask family members, they think communication is one of the most important areas of ICU care, and I think communication is one of the areas where we have the most room for improvement. In the ICU, most patients are not able to participate when decisions are made about withholding or withdrawing life support.⁸ Therefore, communication is primarily with family members. Family members rate our communication skills as equally or more important than our clinical skills.⁹ This took me, as a clinician, by surprise, but if you think about it, communication is how family members understand what is happening to their loved one and the care that their loved one is getting, and therefore it is critically important to them. The other surprising factor about communication with family members is that family members of patients who die in the ICU are more satisfied with ICU clinician communication than are family members of patients who survive the ICU.¹⁰ I believe this is because we tend to ignore family members' needs and concerns if we think the patient is going to survive. This provides additional rationale for targeting all ICU patients in our efforts to improve communication with family members and improve palliative care.

A number of studies show that families are under immense burdens when they have a critically ill loved one in the ICU. Family members have high levels of anxiety and depression while the patient is in the ICU.¹¹ This burden of symptoms affects their ability to understand us and communicate with us, and must be taken into account. There is increasing consensus that the way we should approach decision making about goals of care in the ICU should be based on the model that's been described as "shared de-

cision making."¹² This model proposes striking a balance between it being the clinician's decision on one hand and the family's decision on the other. There are some key factors that should affect that balance. Most importantly, there is considerable variability in how involved families want to be in decision making, and that must be the primary factor affecting where this balance lies. Although, on average, family members prefer a shared decision making approach, some families prefer to make these decisions while others prefer to leave the decision to the clinicians.¹³

Another factor to consider is the prognosis and our level of certainty in the prognosis. The worse the prognosis, the more important it is that we be willing to take responsibility for the burden of decision making.¹⁴ Similarly, the higher our certainty about that prognosis, the more we should be willing to take responsibility. However, when the prognosis is less certain, the patient's values must take a central role in decision making. The other thing I think is very important about shared decision making is that it doesn't mean that everybody at the table is playing the exact same role. The patient, if he or she is able—and the family if the patient is not able—is the expert in the patient's values and preferences, and he/she/they should be treated as the expert in that. However, we are the experts, as clinicians, in the treatments that are indicated, and we should take the responsibility to make a recommendation to the patient or family members. Therefore, shared decision making should be the default starting place, but this default should be modified based on the family's preferences about their role in decision making, and by the prognosis and our certainty about the prognosis.

A key component of shared decision making is communication and how well we communicate with family members. My research group audiotaped ICU family conferences to study the communication that occurs in this setting. We audiotaped 51 family conferences that included 214 family members and 221 clinicians.¹⁵ On average, the conferences were 32 minutes long and, on average, the families spoke less than a third of the time, and clinicians spoke more than two thirds of the time. We were interested in whether either the duration of the family conference or the proportion of family-speech time to clinician-speech time would be associated with family satisfaction with communication during the conference.¹⁶ We found a significant correlation with the proportion of family-speech time; the higher the proportion of family-speech time (ie, the more we let the family talk), the more satisfied they were with clinician communication. There was no relationship with the duration of the family conference.

We also surveyed families about how well the family conference met their needs, and again we discovered the same finding: the more we let families speak, the higher their satisfaction with communication. There was no relationship with duration of the conference. These are obser-

- V... Value family statements
- A... Acknowledge family emotions
- L... Listen to the family
- U... Understand patient as a person
- E... Elicit family questions

Fig. 2. VALUE mnemonic checklist for improving intensive care unit clinician communication with family members.

vational data, so it is not possible to be sure that the higher proportion of family speech caused the higher satisfaction. Nonetheless, this finding suggests that one of the ways we can improve communication with the family is to let them talk more and to spend more of our time listening to the family.

We also examined whether specific clinician statements during the family conference were associated with family satisfaction.¹⁷ There were 3 types of statements associated with higher family satisfaction: assuring the family the patient would not be abandoned by the clinical team prior to death; assuring the family that the patient would be kept comfortable and not suffer prior to death; and, then, providing explicit support for the family about whatever decisions were made—whether the decision was to withdraw or to continue life support.

Finally, we examined these conferences for evidence of missed opportunities, and we found that the missed opportunities included missing the opportunity to listen and respond to family questions, to acknowledge emotion, and to address basic tenets of palliative care, including expressing the principle of non-abandonment, exploring patient preferences and values, and describing the principle of surrogate decision making.¹⁸

We summarized these data and developed a mnemonic that we call VALUE (Fig. 2), which is a checklist to remind clinicians about some of the important aspects of communicating with families in the ICU. None of the VALUE checklist communication items is exclusively the domain of physicians; the interdisciplinary team can contribute substantially in making sure that families have the opportunity to have this kind of communication with ICU clinicians.

A randomized trial of the VALUE strategy was recently published in the *New England Journal of Medicine*.¹⁹ The authors randomized 126 patients in the ICU who met the criteria that the attending physician believed that the patient would die within a few days. Patients were randomized to either the intervention or usual care. The intervention was a proactive family conference on the day of randomization or the next day. The clinicians

were asked to use the VALUE strategy at the family conference. In addition, the families were provided a bereavement pamphlet after that family conference. The outcome was family member psychological symptoms at 3 months after the patient's death. The authors measured anxiety, depression, and post-traumatic stress disorder, using previously validated questionnaires. What they found was a dramatic reduction in the symptoms of anxiety, depression, and post-traumatic stress disorder among the family members. Figure 3 shows the proportion of family members who had what these surveys suggest would be clinically important levels of anxiety, depression, and post-traumatic stress disorder in the intervention and control groups. The study showed that a relatively simple intervention (focusing on communicating with families) can have dramatic effects on family outcomes after the death of a patient in the ICU.

Interdisciplinary Communication and Collaboration in the ICU

I believe that interdisciplinary communication within the ICU team is probably one of the most important aspects of critical care and, perhaps, one of the most important areas for us to work on to improve palliative care for patients and their families. Each of the clinical disciplines in the ICU—physicians, nurses, respiratory therapists (RTs), pharmacists, social workers, spiritual care—often practice within their “silos,” and the communication between these silos is often relatively limited. This is improving in many ICUs. For example, in my ICU we now have interdisciplinary rounds where, for a few minutes every day with each patient, we work as an interdisciplinary team. But outside of that setting I believe that truly interdisciplinary care and decision making is relatively limited.

There is observational research that suggests that ICUs that have higher levels of interdisciplinary collaboration have lower ICU mortality, shorter ICU stay, lower ICU readmission rate, less physician and nurse conflict, and lower job stress, particularly for nurses.²⁰ Therefore there are several reasons to try to improve interdisciplinary communication, and improving communication with families is another important reason. In fact, one study found that families who reported that clinicians gave them mixed messages in the ICU were significantly more likely to have symptoms of anxiety and depression.¹¹

A study from France examined how often physicians and nurses collaborate in decision making about end-of-life care.²¹ Physicians reported that, on average, they included nurses about 50% of the time. Nurses, however, thought this proportion was about 25%. We don't even have good enough communication to have a similar perception of the problem. Another study compared physi-

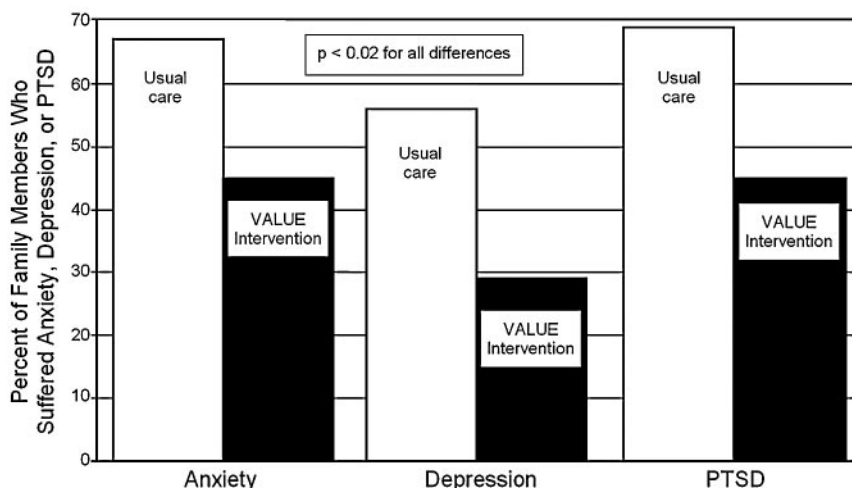


Fig. 3. Survey responses from family members of 126 intensive care unit patients in France who were randomized to receive either usual care or a communication-based intervention based on the VALUE strategy (see Fig. 2). The family members were surveyed 3 months after the patients died. PTSD = post-traumatic stress disorder. (Data from Reference 19.)

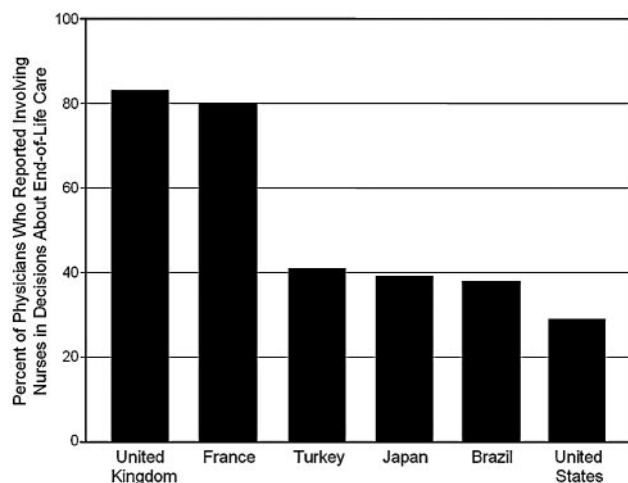


Fig. 4. Selected data from a survey of 1,961 critical care physicians in 21 countries, to assess international differences in attitudes about end-of-life care. (Data from Reference 22.)

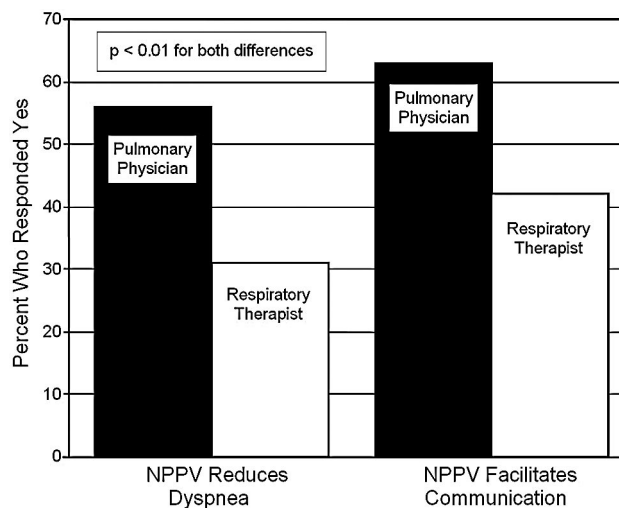


Fig. 5. Selected data from a survey of physicians and respiratory therapists, to assess their attitudes and reported practices regarding noninvasive positive-pressure ventilation (NPPV) with patients who chose to forego endotracheal intubation. (Data from Reference 23.)

cians' perceptions of interdisciplinary communication with nurses about end-of-life care in countries in North America, Europe, Asia, and South America, and found that physicians in the United States were less likely to report interdisciplinary communication about end-of-life decision making than any other country in the study.²² Figure 4 shows the proportion of physicians from the countries that reported involving nurses in decision making about end-of-life care in the ICU.

Data on interdisciplinary communication between physicians and RTs are limited, but a recent study examined physicians' and RTs' views on noninvasive ventilation in the palliative care setting.²³ Physician and RT perspectives on the rationale for noninvasive ventilation in palliative

care differed dramatically. The respondents were asked whether noninvasive ventilation reduces dyspnea in the patient who is at the end of life. Over half of the pulmonary physicians said yes, whereas only about 30% of the RTs said yes. They were also asked whether noninvasive ventilation facilitates communication between the patient and the family in this setting, and again there was a significant discrepancy: over 60% of the physicians said yes, but only about 40% of the RTs said yes (Fig. 5). I think this demonstrates a difference in clinical experience between RTs and physicians, and points to an opportunity to improve interdisciplinary communication among the team

as a first step to improving communication with patients and families.

Integrating Palliative and Critical Care

What can we do to improve all of this? My research group has been funded by the National Institute of Nursing Research (of the National Institutes of Health) to develop and evaluate an intervention that we call Integrating Palliative and Critical Care (IPACC). IPACC is a multi-faceted, nurse-focused interdisciplinary quality-improvement intervention that also includes physicians, RTs, social workers, and others working in the ICU.²⁴ We are evaluating the effects of the intervention at the level of the individual patient and family by surveying family members after a death in the ICU, and the nurses who took care of the patient on the shift that the patient died.

The IPACC intervention has 5 components. The first component is ICU clinician education in palliative care, which we deliver via lectures and a video that we provide to nurses, RTs, and others, and that are available online.²⁵ The second component is to identify within each ICU individuals we call “local champions”: nurses, physicians, RTs, and others who go to a full-day training on how to be a role model and to promote attitudinal change about these topics in their ICUs. The third component is academic detailing of the ICU directors to identify local barriers to improving palliative care and to try to identify solutions to those barriers. The fourth component is to provide a series of order protocols and pathways for hospitals to adapt and implement. One example is an order-form protocol for withdrawing life support, which we evaluated in our ICU and that is described in more detail below.²⁶ The fifth component is that we obtain and provide each ICU with ICU-specific quality-improvement data in the form of family satisfaction surveys from their own ICU, in a format that was described previously.²⁷

The withdrawal-of-life-support order form provides specific details about how to improve the process of withdrawing life support, and especially withdrawing mechanical ventilation. This form was developed at Harborview Medical Center in Seattle, Washington, by a multidisciplinary team, presented back to the staff multiple times for feedback and revisions. Once we had a final form, we also conducted in-service education in each ICU about using the form.²⁶ The form has 4 components. The first component is preparations: making sure that a Do Not Resuscitate order is written, documenting discussion with the family, and discontinuing all prior orders, including such things as daily radiographs and deep venous thrombosis prophylaxis. The second component is a ventilator-withdrawal protocol that ensures that we withdraw the ventilation in a way that minimizes patient discomfort. The third component concerns analgesia and sedation; it provides for in-

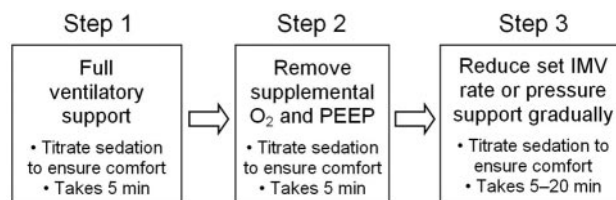


Fig. 6. Protocol to withdraw mechanical ventilation, in the setting of withdrawal of life support, in a way that minimizes the risk of patient discomfort during this procedure. PEEP = positive end-expiratory pressure. IMV = intermittent mandatory ventilation. (Adapted from References 26 and 28.)

fusion of benzodiazepines and opiates if needed for patient comfort. The protocol allows for a broad dose range, so nurses are not put in a position of trying unsuccessfully to call physicians to attempt to get an order to increase the dose of an opiate or benzodiazepine when the patient is demonstrating discomfort. The order form has no maximum dose of opiates or benzodiazepines, under the rationale that no dose is too high if lower doses have failed to control the patient’s symptoms. However, there is also a section that requires documentation of the evidence of discomfort that caused the dose to be increased. The fourth component of the form provides the principles of withdrawing life support, so that clinicians can review those, if needed.²⁸ An updated version of this form is also available online.²⁵

The protocol we developed for terminal withdrawal of the ventilator (Fig. 6) starts with a patient on full ventilatory support and allows time for the titration of sedation and analgesia to ensure patient comfort. Then we remove supplemental oxygen and positive end-expiratory pressure, assess the patient, and again titrate sedation and analgesia as needed for patient comfort, which usually takes about 5 min. Then the patient is placed on either intermittent mandatory ventilation or pressure support. We then drop the intermittent mandatory ventilation rate or pressure support by 50%, assess the patient, drop the rate or pressure support by 50% again, and repeat as necessary until the patient is no longer receiving substantial ventilatory support, then the ventilator is removed. The whole process usually takes no more than 10 min, but can occasionally take up to 20 min.

There is no definitive evidence to guide a decision about whether to remove the ETT after terminal withdrawal of mechanical ventilation. A recent study suggested that family ratings of care are higher if the patient is extubated, and I believe this should be our usual approach.²⁹ Nonetheless, I also believe this should be a case-by-case judgment that is based in part on family preferences, such as whether they would prefer to have the patient’s face unencumbered by an ETT, or whether they are so anxious about the possibility of gurgling and “agonal” respirations that they

would rather have the ETT in place. I also think it should depend on the level of ventilatory support that the patient is receiving, the amount of secretions, and the level of consciousness. A high level of ventilatory support, minimal secretions, and a higher level of consciousness all make it less likely that the family will witness terminal respirations that family members find distressing.

We examined analgesic dosing with this protocol for withdrawing life support, and we found that we used significantly more opiates and more benzodiazepines on average after implementing the protocol.²⁶ However, we also found that there was no increase in the average time from ventilator withdrawal to death, which suggests that although we used more opiates and benzodiazepines after implementation of the protocol, we did not do this in a way that hastened death.

We are conducting a randomized trial of the IPACC intervention but we do not yet have results. However, we examined the results of IPACC at one of our pilot sites, in a before-and-after study, and we found that nurse assessment of the quality of dying significantly improved after the intervention. We also found that family assessment of the quality of dying improved after the intervention, but that difference did not quite achieve statistical significance. In addition we found an average 1.7-days-per-patient shorter ICU stay among the patients who died. These findings suggest that we're improving communication and decision making and also reducing prolongation of dying. However, we will have to await the outcome of the randomized trial for definitive results.

Summary

The ultimate goal of IPACC and this paper is to teach basic palliative care skills and the language of palliative care to ICU clinicians, and to encourage them to prioritize palliative care as one of the important things that we do in the ICU. I also encourage critical care clinicians to obtain consultation from experts in palliative care or medical ethics in difficult situations, because studies suggest that those consultants can improve the quality of ICU care.³⁰⁻³³ I believe these simple steps can empower all ICU clinicians to intervene on behalf of patients and families to improve their experiences in the ICU. My ultimate goal is to shift the culture of ICU care toward being more embracing of palliative care, because I believe this will improve the experiences of all patients and family members in the ICU.

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