Palliative Care in the ICU: Critical Communication Skills

Q&A From the Live Webinar

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The AACN Critical Care Webinar Series is not only an efficient way to learn from true thought leaders within our community; it also serves as the seed of robust discussion among colleagues. To encourage continued discussion, our experts have responded to participant questions not addressed during the live webinar. Please enjoy reading the responses below.

Our experts’ responses to your questions:

Q:  How do we have discussions with our physicians about nurses’ level of empowerment in dealing with palliative care?

A:  Ideas on specific skills to use in the physician–nurse conversation can be found in the IMPACT-ICU project guide, available with the webinar resources. Having a clear understanding within oneself on what palliative care is, is a key first step. A couple of the other questions here touch on that topic, so please read on.

Q:  My question has to do with your opinion on Charles Grob, a psychiatrist and researcher at Harbor-UCLA Medical Center who was administering psilocybin to end-stage cancer patients, which reduced dramatically their fear of death while in the dying process. Assuming legislation and legal status change in the coming years to regulate administration of these alkaloid tryptamines, do you think that therapy would be a good option for patients who choose to use it?

A:  We do not know enough about the research described in the question to make an informed judgment. I think one caution that applies here is the same I’d apply when evaluating benzodiazepine use to address fear of death. That is, that the fear and anxiety a person experiences when facing their own death may not be pathological, but a normal response. Grief, spiritual distress, existential issues of unfinished business all might be playing a part. We’d want our medication strategy to facilitate our patient’s ability to work through these aspects of dying, rather than mask external symptoms. An analogy would be our concern with masking pain with sedation; we want to be able to assess and treat that pain. Likewise with the fear our patient may have in dying. We’d work with that patient and their family on whether a visit from clergy, social work, or similar colleague might be helpful. Parallel to that would be any pharmacologic support.

Q:  Most of the patients I care for are intubated, ventilated, and sedated or neurologically obtunded. How can these tools be used with the patient’s family, who are asked to make end-of-life decisions?
A: KATHLEEN TURNER, RN: In the case we used in the webinar, our patient Mr. P could speak. Let’s imagine that he is already on a ventilator and we’re at the bedside with his wife. (It will help to open the webinar presentation and review slides 24-27.) Instead of Mr. P telling us, “I’m afraid I’m not going to make it out of here,” we have Mrs. P saying “I’m afraid he’s not going to make it out of here.” We can use the same skills, and almost the same wording. “I hope he makes it out of here. I’m worried, though, too. Can you tell me more about what’s got you thinking he might not make it?” For patients who cannot speak for themselves, we ensure their voice is heard by asking open-ended questions like “What would your husband make of all this?” Even if Mr. P never spoke with his family about life support, his wife of many years can tell us a lot about what kind of person he has been and what is important to him in his daily life. With that kind of information, the clinical team may be able to make a recommendation as to what course of action seems most in line with what Mr. P would want us to do.

WENDY ANDERSON, MD: I agree with Kathleen. The skills and processes are all the same whether the decision-maker is the patient or a surrogate. In our in-person workshops, we have used a case for role play where the patient cannot speak and it is the family member who is the focus of communication. This case is included in the IMPACT-ICU project guide that is provided among the webinar resources. Also, we just completed filming a series of videos depicting nurses communicating in action, focusing on communication with surrogates. These will be available on the VitalTalk.org website in 2017—stay tuned!

Q: Is your palliative care consult order nurse-driven, or does it require a specific order from the physician/attending?

A: This varies by hospital. Where I practice, an order is required from a physician. This is in part why we developed the IMPACT-ICU project, with the goal of giving nurses the skills to do what we do in a palliative care consult, in case the consultation service cannot be accessed for a variety of reasons. Also, the coaching aspects of the IMPACT-ICU project have been very important; advanced practice nurses and educators round at the bedside with nurses to coach them in the process of identifying and addressing palliative care needs. Our nursing leadership and we felt that it was very important that nurses at the bedside have a way to access specialty palliative care nursing, even if a full consult were not available.

Q: How do we deal with the family who’s in denial about the patient’s worsening situation?

A: KATHLEEN TURNER, RN: Denial is a coping mechanism that provides a needed retreat to an overwhelmed individual. In my experience, denial often appears in the moment a family member realizes that things have taken a turn in a way he/she is powerless to fix. It’s the moment before the truck hits and you think, "This can't be happening." It presents a key opportunity for us as nurses. We must watch for and recognize that moment—it's when we need to change our approach. Our well-intentioned response of providing additional information may exacerbate the listener's fear and strengthen denial. An alternate strategy is to cultivate a feeling of safety for that person. We focus on building trust and an explicit regard for that family member’s pain. It's scary where they are; we can offer refuge. The key to making this approach work is that it has to be an end in itself, rather than a means for getting a family member to agree with the team. That gets us to the opening words of the question: "How do we deal...?" One resource we have gone back to time and again is an article by Goold, et al looking at conflict through the lens of differential diagnosis. The authors suggest a number of strategies applicable to nurses as we encounter denial. I also heartily recommend exploring the work of Cynda Rushton and Robert Truog on issues of potentially inappropriate care and moral distress. Reading and reflecting on others' perspectives helps identify assumptions and consider alternatives when we feel stumped by challenging situations we encounter at the bedside.
WENDY ANDERSON, MD: I agree. In my experience, most family members are petrified when someone they care about is in the ICU, so they often grasp the severity of the situation, and with good communication—empathy and open-ended questions—these fears can be brought out to be confirmed (or not). The most common reason for families not agreeing with clinicians about prognosis is misunderstanding of physicians’ prognostic estimates.2

A key part of the nurse’s role is making sure that prognostic information is clearly communicated by physicians and understood by family. Still, some families disagree about prognosis. This demands respect, support, and allowing time for emotional processing of a poor prognosis.3

Q: My facility has a palliative care MD, but not a team. A majority of families are not initially receptive to palliative care. As a nurse, how do I approach the family? My facility doesn’t have a program or training to help RNs deliver the discussion on palliative care.

A: I hope that some of the Tools and Resources on the webinar page will be helpful to you in discussing palliative care with families. In answering the question below on palliative vs hospice care, Wendy and I give some additional thoughts.

Q: What methods or strategies are best practices in teaching nursing students the basics of palliative care?

A: WENDY ANDERSON, MD: There is a terrific new palliative care curriculum for undergraduate nursing education, entitled “Palliative CARES – Competencies and Recommendations for Educating Undergraduate Nursing Students.” There are online materials that can be used flexibly in person or online only. The curriculum will be available to all 92 nursing programs in Idaho, Utah, Oregon, and Washington beginning in January 2017. Plans are underway for dissemination to nursing schools in the remaining 46 states.4

Q: In your experience, have you found it more beneficial to have a medical lead or a nursing lead for the palliative care team (with both fields participating, of course)?

A: WENDY ANDERSON, MD: I’m not sure that there is a clear answer to this for all institutions. As you mention, I think the most important thing is to have core clinical disciplines represented (nursing, medicine, spiritual care, social work), and to have a leadership structure where all have both clinical input and leadership input. I know of many programs where social workers run the discussions.

Q: I work weekend nights, and palliative care consults are Monday through Friday. I hate having to tell my patients and family members “I'll put in for a consult.” What can I do? I don’t want to overstep my bounds.

A: KATHLEEN TURNER, RN: My bedside work has been mostly weekend nights, as well, so I relate to what you’re saying. This is where primary palliative care skills are essential. I’d begin with a palliative care screening assessment to identify what specific needs my patient and family have. Then, I can reach out to appropriate members of the current team for help with symptom management, communication, and family support. Together, we can try different approaches, and capture the patient’s/family’s response in the medical record. When the palliative care service is available, they have the benefit of what was tried and learned in the off-hours. In the Tools and Resources for this webinar, the Primary Palliative Care Assessment, Pocket Card, and Patient-Nurse Rounding Record
may be useful. I would encourage all bedside critical care nurses, particularly if you precept or serve in the charge nurse role, to do continuing education in palliative care topics. Specialty certification in palliative care nursing is also available, and complements our critical care certifications.

Q: What can I say when trying to reframe hope realistically for the patient/family (e.g., realistic hope may be peaceful death, seeing a loved one before death...)?
A: KATHLEEN TURNER, RN: A story: On a busy night shift, I was caring for Mrs. F, who was as sick as she could be and still be alive. Her daughter Luisa had asked, with many family members present, whether I had seen someone as sick as her mom get better. I paused what I was doing and let the question hang while I took the temperature of the room, reading nonverbal cues from the family members in order to frame my response. I offered that, during my years in the ICU, I had not cared for someone this sick who lived, but that I had seen people who I did not believe could survive make it home. Luisa’s sister said, "So it would be a miracle like that." I replied that in my experience, when miracles come, they are different for each person. For one person, it might be to go home. For someone else, the miracle might be to see a loved one. For another, it might be for their pain to go away. We planned together to pray for whatever their mom’s miracle might be and for each to continue to make our best efforts for her.

Some quick steps to take on the issue of hope:
- Differentiating hope vs expectation. What is the expected outcome? Answer this from your own point of view, then from a family member’s point of view, then from the patient’s, then from the perspective of other team members. What are each of these people hoping for? The answers will not be the same. For instance, Mrs. F's family expected she would probably die soon. They hoped she would wake up and see they were all there with her. This waking up would be an unrealistic expectation, but was a comforting thing to hope for.
- Consider a hope/worry statement. In this example, we could say "I'm worried, too, about how your mom is doing. I'm hoping with you that we get a chance to see her open her eyes. In the meantime, we’ll keep holding her hands and talking to her so she knows we're here." Notice that this does not dismiss the gravity of the situation (worry statement), while building alignment with the family and empowering them (hope statement.)
- Consider an "I wish" statement. "I wish she was home fixing you another great Thanksgiving dinner." (Following on an earlier conversation about what Mrs. F would be doing if she weren't in the ICU.)

With common ground established around our hopes and wishes, the prerequisite trust is in place to address expectations. Families don’t have to discard their hopes when they change expectations; this may lessen the feeling of “giving up” on a loved one.

Q: I have had this question answered differently a few times, and often it is difficult for patients and patient families to understand. How do you best explain the difference between palliative care and hospice care?
A: WENDY ANDERSON, MD: Palliative care is specialized care for people with serious illness. It focuses on providing relief from the symptoms and stress of a serious illness. The goal is to improve quality of life for both the patient and the family. Palliative care is provided by a specially trained team of doctors, nurses, social workers, and other specialists who work together with a patient’s doctors to provide an extra layer of support (specialty palliative care), as well as by all clinicians who care for a patient (primary palliative care). It is appropriate at any age and at any stage in a serious illness, and can be provided along with curative treatment. So, palliative care is for all seriously ill patients at any point in their disease trajectory. Hospice care is comfort-focused care, so I think of it as a subset of palliative care. But not all patients will prefer...
comfort care, so it is not for all seriously ill patients.

KATHLEEN TURNER, RN: I'm glad you asked this question. A patient of mine saw the palliative care pin on my ID one night and said "I don't need that, I'm going to get better." I told him I hoped so, too, and asked him whether he felt there was room for improvement in his pain and breathlessness. "Yes." How was his family coping with this sudden event? Could they use a hand planning for life after this hospital stay? "Yes." How about communication with the teams of specialists? "I hear all these different things. I'm not sure how it all fits together."

Symptom management, family support, communication—that's primary palliative care. He agreed that palliative care in addition to critical care would make his recovery much better. An additional clarification about hospice care is that it is provided when patients are at the end stage of their illness. Their provider expects, based on specific clinical criteria, that the person will live ≤ 6 months. Curative or disease-modifying efforts are stopped and efforts are shifted to comfort.

Q: How can we, the nurses, offer a "realistic" view? I think that is where the doctors need to be present, like with a family meeting.

A: WENDY ANDERSON, MD: I agree that prognostic information should be provided by the clinician who is most expert/knowledgeable about the prognosis. This is often a physician. There are key roles for nurses, however, in helping to ensure that prognosis is communicated clearly: eliciting family questions about prognosis, educating family about information that was communicated, and helping families to emotionally accept a difficult prognosis.3

KATHLEEN TURNER, RN: On the ICU night shift, I see physicians and nurses working together to clarify our own understanding of prognosis. As the nurse at the bedside, I've heard/read input from all the teams and disciplines regarding my patient's condition. The cross-covering resident often does not have that depth of information. Sharing that in a nurse–physician conversation before the family meeting helps ensure families get a big-picture message.

References