End-of-Life Care

Overcoming Barriers to Palliative Care Consultation

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Palliative care consultations for patients with life-threatening illnesses provide benefits for the patients and their families as well as for the health care team. Patients have better quality of life and live longer but cost the health care system less. Still, many patients are not offered the opportunity to receive a palliative care consultation. Barriers to palliative care consultation for patients in critical care units include misunderstandings about palliative care and not having agreed upon criteria for referral. Critical care nurses can assist in overcoming these barriers. (Critical Care Nurse. 2015;35[5]:44-52)

In 1995, the SUPPORT study1 revealed that health care providers had difficulty determining when critically ill patients were approaching the end of life. Because of this difficulty, many patients died in pain after life-prolonging procedures that the patients would not have wanted. More recently, Curtis et al2 concluded that health care providers still have difficulty determining when patients may be dying and are often unaware of or have difficulty in communicating about patients’ preferences for end-of-life care. Thus, patients still experience the use of unwanted life-sustaining therapies and poor quality of life at the end of life. Moreover, Zhang et al3 confirmed that patients who received any life-prolonging procedure in the patients’ last week of life or of a stay in the intensive care unit (ICU) had significantly worse quality of life than did patients who did not receive such care.
Palliative care is an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial, and spiritual.

Many patients in the United States die each year after use of unwanted therapies. In a study published in 2004, Angus et al found that 22% of deaths of hospitalized patients (about 540,000 patients) followed admission to an ICU. Nelson et al noted that although some progress has been made, the problem is increasing because of the number of older adults with chronic health problems that can cause life-threatening illnesses. In light of this information, one might think that critically ill patients would receive palliative care consultations early in the patients’ admission. The reality, however, is that “widespread adoption of palliative care services appears to be slow.”

The World Health Organization definition of palliative care is shown in the Sidebar. Palliative care was developed in response to the need for individuals with life-threatening illnesses to receive state-of-the-art management of signs and symptoms, to have improved communications with the health care team, and to alleviate some of the strain on the individuals’ caregivers. The care has evolved into a service that provides psychological, spiritual, goal-setting, and decision-making support to patients with life-threatening illnesses and the patients’ families. Unlike hospice care, palliative care is appropriate early in the course of illness, and patients can have concomitant treatment for their illness, including therapies intended to prolong life. Table 1 provides important evidence-based benefits of palliative care for patients in critical care units.

**Misunderstandings as a Barrier to Palliative Care Consultation**

Despite the clear, established benefits of early initiation of palliative care for critically ill patients, palliative care is not being implemented until late in patients’ illnesses. One of the most common barriers to obtaining a palliative care consultation is misunderstandings about the care among health care providers and patients’ family members. The primary misconception is the idea that palliative care is appropriate solely for patients near death. Many health care providers, patients, and patients’ families do not recognize that palliative care should not be separate from standard care and that it can and should be incorporated into critical care. Health care providers often think that caring for a patient’s signs and symptoms in some way undermines the larger goal of trying to save the patient’s life. They may think that palliative care is not what critical care is about. Some physicians think that introducing palliative care means that they must “give up” trying to cure their patients, something that they are unwilling to do because their patients might die sooner. Additional misunderstandings of health care providers that constitute barriers include the idea of some...
The use of triggers, preferably a checklist specific for each critical care unit, provides an basis for determining the time to begin a conversation about palliative care.

tems, so most hospitals do offer some services. However, the services provided vary from region to region and hospital to hospital. Nurses interested in palliative care can circulate accurate information about palliative care in general, but more importantly can make certain that information about palliative care at their specific institution is readily accessible in the critical care unit.

Difficulty Initiating a Palliative Care Discussion as a Barrier to Palliative Care

Providing knowledge about the necessity and efficacy of palliative care in critical care is only overcoming the first barrier. The second and perhaps more marked barrier to initiation of palliative care is the difficulty that some health care providers experience when attempting to introduce the idea of palliative care to patients and patients’ families. Even though physicians may state that they have experience in dealing with patients with life-threatening illnesses, the physicians can experience moderate anxiety when providing such care. This anxiety may make them uncomfortable or unwilling to broach the idea of a palliative care consultation with a patient or a patient’s family. Aslakson et al. found that when surgeons attempted to open discussions about palliative care with patients, the discussions were often quick, inadequate, and ineffective.

A variety of strategies have been suggested to overcome the reluctance of health care providers to initiate discussions about palliative care. C. L. Mulkerin stated in a roundtable discussion that “critical care providers can be proud and protective of the work they are doing and hesitant to initiate a consultation.” Therefore, he recommended integrating palliative care consultation automatically into critical care. In order to accomplish this integration, Weissman and Meier advocate the use of evidence-based triggers for initiation of palliative care. The use of triggers, preferably refined as a checklist developed specifically for each critical care unit, provides an objective basis for determining the time to begin a conversation about palliative care. Waiting until a reluctant health care provider is ready to request consultation is no longer necessary. Using a list of standardized criteria or triggers for palliative care consultation can increase consultation rates from 41% to 82% and reduce 30 day rehospitalizations from 36% to 17%.

Table 2 provides a list of general criteria for palliative care consultation for anyone with a life-threatening illness and a list of evidence-based triggers for critical care patients. Weissman and Meier state that the most important of these criteria is whether the health care provider thinks the patient will die in the next year. When a health care provider answers that question positively, 85% of the time the patient does die within a year and most likely would have benefitted from palliative care. Both of the lists are fairly general, and neither is meant to be adopted as a checklist. Instead, the Improving Palliative Care in the ICU Advisory Board recommends that each critical care unit use the criteria to develop a list of triggers specific for the unit.

Cultural Issues as Barriers to Palliative Care Consultations

Another barrier to palliative care consultation is culture—both the culture of the unit and the culture of the patient and the patient’s family. The consultation needs to be customized to the particular ICU and sensitive to the culture of the critical care unit. According to Friedenberg et al., a technological imperative exists in some ICUs, leading to staff members’ unrealistic expectations about the results of care. The emphasis on using technology to rescue a patient each time a new complication
develops is more common in surgical ICUs, where the focus may be on treating everything and, rarely, if ever, acknowledging that a patient may die. In one study, a majority of surgeons thought they had contracted informally with patients preoperatively, explaining to the patients that the surgeons would decline to operate if the patients wanted to limit postoperative life-supporting treatments. Routine use of triggers for palliative care consultation might result in strained relationships between health care providers in the postoperative period, especially if the surgeons do not have an accurate understanding of palliative care.

A patient and the patient’s family may also have culturally based misconceptions about palliative care or they may not understand what is happening to the patient. Families may be confused and see the “small steps” the patient makes as real progress, and therefore develop false hope. They may be unwilling to acknowledge that the illness is life threatening and may not want to communicate with health care providers who mention that possibility. Or, a patient or the patient’s family may not be able to formulate questions because of a lack of knowledge (including medical terms and jargon), cultural misunderstandings, or the overwhelming number of professionals from various multidisciplinary teams who speak with them. These communication difficulties have been cited as reasons to avoid initiating palliative care consultations.

In truth, rather than being a barrier, culturally based misconceptions should actually be indications for consultation. O’Mahony et al studied requests for palliative care consultations in a culturally diverse, critically ill population of patients. The authors found that early involvement of the palliative care advanced practice nurse allowed for more discussion about the concerns of patients and the patients’ families and lessened misconceptions on the part of the families about the medical team’s intent to withdraw life-prolonging treatments. This early involvement allowed the health care team to focus on the needs of patients and patients’ families and provided patients and patients’ families time for closure. Patients’ families clearly benefitted from this intervention, experiencing less posttraumatic stress after the hospitalization.

### Role of Critical Care Nurses in Overcoming Barriers to Palliative Care Consultations

Critical care nurses need to be involved in overcoming the barriers to palliative care consultation for their patients so that patients’ suffering is decreased and patient outcomes are enhanced. However, nurses also need to be involved because the nurses themselves experience high levels of stress related to end-of-life decision making. As many as 45% of nurses have considered leaving a position because of moral distress. Being involved in decision making could provide nurses with a sense of control and reduce stress.

### Table 2: Criteria for initiating (possible triggers for) a palliative care consultation

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<tr>
<th>Criteria for any person with a life-threatening illnessa</th>
<th>Criteria for initiating palliative care services for critically ill patientsb</th>
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<tr>
<td>The health care provider would not be surprised if the patient died in the next 12 months</td>
<td>Physical signs and symptoms are difficult to control despite usual treatment approaches</td>
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<td>Admission was prompted by or involved physical or psychological signs or symptoms that were difficult to control</td>
<td>The patient or surrogates wish to explore supportive options other than intensive care, such as hospice</td>
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<td>The patient, staff, or patient’s family disagree about medical decisions, resuscitation preferences, or nonoral feeding and hydration</td>
<td>Staff have questions about the appropriateness of the life-sustaining therapies being employed</td>
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<td>The patient had an out-of-hospital cardiac arrest</td>
<td>Complex dynamics of the patient and his or her family affect decisions about use of life-sustaining treatments</td>
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<tr>
<td>The patient has been in the intensive care unit for more than 7 days</td>
<td>Staff, patients, or patients’ surrogates disagree about prognosis and/or use of life-sustaining treatments</td>
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<tr>
<td>The patient has had an extended stay in the intensive care unit, defined variously from as short as 7 days to as long as 2 months</td>
<td>The patient has any one of a number of conditions, including global ischemia after a neurological event, multisystem organ failure, active stage IV malignant tumor</td>
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* Based on data from Weissman and Meier.16
* Based on data from Campbell et al8 and Norton et al.11

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making rather than merely enacting the results can limit nurses’ moral distress.

Approaches to palliative care decision making that rely on the involvement of nurses have been successful in advancing palliative care for critically ill patients. Examples include attendance of a palliative care nurse practitioner at daily multidisciplinary rounds to address the appropriateness of patients for palliative care consultation, daily pre-rounding with nurses to identify patients at risk for poor outcomes who might benefit from a consultation, and requiring consultation when specific hospital-identified criteria for palliative care consultation are met.

A common thread identified in strategies that led to successful integration of palliative care into critical care was the presence of nurse or nurse practitioner champions. These nurses were generally well known and respected in the specific critical care environment and were compelling advocates for palliative care consultations. Nurses who were palliative care champions advocated for consultation based on specific criteria (triggers) and were engaged in regular meetings with staff during which they elicited feedback about the effects of the palliative care intervention. The exchange of information and concerns among health care providers and the involvement of primary care nurses were critical to the success of strategies that routinely integrated the consultation into critical care.

To overcome barriers to palliative care consultation, critical care nurses need to be champions for palliative care on the policy level of both the hospital and the unit and on the level of individual patients. On the policy level, nurses should ask to be included in the group that develops unit-specific criteria for critical care consultation. The advisory board of Improving Palliative Care in the ICU recommends using published criteria (eg, those listed in Table 2) in conjunction with hospital-specific data (eg, mean ICU length of stay for patients who survive) to develop each unit-specific criterion. Mirel and Hartjes have described the process that nurse leaders used to develop a set of triggers for 1 unit.

Once the criteria have been identified, a decision must be made about how they will be used. Will they be displayed on the computerized record? If so, who will complete the documentation and who will view it? Or, as described for successful strategies earlier, will discussion about the palliative care criteria be part of daily patient care rounds so that all members of the care team can be involved in the discussion? Finally, when the criteria are met, does that mean that the patient is automatically referred to the palliative care team? If so, does the critical care team or the palliative care team make the initial overture about palliative care to the patient and the patient’s family? Nurses should be involved in making these decisions.

Nurses also need to be involved in determining and documenting the outcomes of palliative care consultations. In a round table discussion, K. Puntillo argued that focusing on the outcome of adequate management of signs and symptoms and emphasizing the wide variety of signs and symptoms that critically ill patients experience in addition to pain can help advance palliative care consultations. Palliative care consultants have more experience and additional strategies to deal with the physical signs and symptoms of fatigue, thirst, nausea, anxiety, depression, and delirium as well as the pain that critically ill patients experience. Critical care nurses can recognize when signs and symptoms persist and advocate for palliative care consultation. Nurses see not only when their patients are experiencing persistent pain or delirium but also when the patients are experiencing any of the myriad of other physical signs or symptoms or emotional and spiritual pain common in the critically ill. Reminders that these issues have not been sufficiently addressed during multidisciplinary rounds can help the health care providers realize that a patient and the patient’s family need more support than the critical care team can provide. Once a palliative care consultation has improved quality of life for a patient and/or the patient’s family, the improvement should be conveyed through documentation in the medical record and by reporting to the critical care team. Doing so may make the critical care team aware of the array of strategies that a palliative care consultation can bring to relief of signs and symptoms, thus increasing the likelihood of future consultations.

Finally, nurses can work with the palliative care team to ensure that a consistent message is conveyed. Patients and their families recall feeling supported when they were told by palliative care specialists and nurses. We promise we will work with you to manage your signs and symptoms, and we will stay with you. We can set goals...
Mr Smith, a 75-year-old man, was admitted to the critical care unit because of respiratory failure associated with exacerbation of chronic obstructive pulmonary disease (COPD) and a history of systolic heart failure. His last documented ejection fraction was 15%. This admission is the patient’s third one related to COPD in the past 6 months. He is given intravenous diuretics, intravenous steroids, and nebulized bronchodilators and is started on bilevel positive airway pressure, but he remains tachypneic, with oxygen saturations hovering at 85%. He is a full-code, and his wife states that he “wants everything done.”

The nurse caring for Mr Smith recognizes that the COPD and congestive heart failure (CHF) are progressive and life-threatening diseases that at some point most likely will lead to his death. Intubation and mechanical ventilation may soon be necessary, and, indeed, he may recover from this event. But what will recovery look like? And what would Mr Smith like recovery to look like?

The nurse is concerned that Mr Smith and his wife may not understand all the implications of “doing everything” for a patient with advanced disease. The nurse suggests a palliative care consultation, but the pulmonologist says, “He’s not dying.”

The critical care nurse replies that palliative care consultations are not meant solely for patients near death. The consultations are also appropriate for patients with life-threatening illnesses, who may die during the next year. She mentions how a trigger system (which has indicated that Mr Smith is an appropriate patient for palliative care) helps identify patients who would benefit from these consultations, and she mentions her concerns that Mr Smith and his family may not understand the severity of his illness and may not understand what “doing everything” means. Last, she reminds the physician that this patient has had 3 hospital admissions in the preceding 6 months for COPD.

After being asked for a consultation, the palliative care provider and counselor meet with Mr Smith and his wife. Encouraging Mr and Mrs Smith to tell their story is the strategy the palliative care team uses to convey the team’s willingness to help as well as to learn about the couple’s values and beliefs and what is important to them. The team also assesses perceptions of Mr Smith and his wife about Mr Smith’s illness, the progression of COPD/CHF, and their emotional and cognitive ability to receive sensitive information. Mr Smith states that he has not been able to leave his home for several months because of shortness of breath and weakness, and he knows he is “getting sicker.” He says he is “tired of fighting” and just wants to “go home.” When Mrs Smith is asked what is most important to her, she replies “for my husband to live.” She breaks down and says she is “so afraid of losing him.”

Acknowledging Mrs Smith’s fear at this time is important because display of empathy by a health care provider can help patients work through their emotions so that they can begin to process information. With an appropriate pause and assessment of the ability of Mr and Mrs Smith to continue the discussion, the palliative provider might say, “I’m hearing that you want him to keep fighting (looking at Mrs Smith) and that you are getting tired of the fight (looking at Mr Smith).”

When Mr and Mrs Smith are ready, the team could discuss the progression of advanced COPD/CHF with them as well as different options for treatment based on the couple’s goals. A goal to live as long as possible (ie, quantity of life) would coincide with a plan including intubation and ventilation. A goal to focus on quality would look more like care at home, with a primary emphasis on managing Mr Smith’s signs and symptoms of shortness of breath and helping him remain at home. However, in both scenarios, the palliative care team would provide continuity of care as Mr Smith made transitions in his health care and would assist with management of his dyspnea and fatigue.

Patients’ decisions after palliative care consultations are not predictable. But research indicates that the consultations help patients maximize quality of life, improve management of signs and symptoms, and in some instances may help patients live longer. Palliative care also reduces costs to hospitals and health care systems.
Conclusion

Barriers to palliative care consultation for critical care patients include misunderstandings about palliative care and a lack of agreed-upon criteria for referral to palliative care. Critical care nurses can help overcome these barriers by ensuring that other health care providers, patients, and patients’ families understand the services that palliative care provides and the benefits it brings to patients and families. These benefits include early initiation of comfort-focused treatment goals, decreased length of stay, reduction in cost of care without an increase in mortality, and continuity of care. Critical care nurses can also promote palliative care by working with other health care providers to develop unit-specific criteria for patient referral and by ensuring that appropriate patients receive referral. When nurses provide feedback to the critical care team about the benefits of palliative care and consistently advocate for it, palliative care is more likely to be integrated into critical care. When they can do all these things consistently, critical care nurses can become champions for palliative care. CCN

Financial Disclosures

None reported

Table 3 Barriers to palliative care consultation and strategies to overcome barriers

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<thead>
<tr>
<th>Barriers</th>
<th>Strategies</th>
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<tr>
<td>Misunderstandings has palliative care is appropriate only near death</td>
<td>Nurses can educate other health care providers about what palliative care provides critically ill patients. They can implement principles of palliative care into critical care standards and curricula, emphasizing early discussion of goals of care with patients and families.</td>
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<tr>
<td>Palliative care undermines the focus of saving the patient’s life</td>
<td>Nurses can emphasize to families and other health care providers that the symptom management skills that palliative care specialists bring to care of a patient improves patients’ outcomes.12</td>
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<tr>
<td>A palliative care specialist is not needed to provide good palliative care</td>
<td>Nurses can emphasize to other health care providers that palliative care providers have more time and more options for symptom management to offer patients with life-threatening illnesses, a situation that improves the quality of care.23</td>
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<tr>
<td>Difficulties in initiation of palliative care consultations</td>
<td>Nurses can advocate for development and use of specific criteria (triggers) that require a palliative care consultation be obtained for patients.</td>
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<tr>
<td>Cultural and communication issues</td>
<td>Nurses need to ascertain if other health care providers understand what palliative care has to offer patients and to ask surgeons to explain any preoperative agreements the surgeons made with their patients about life-sustaining treatments.</td>
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<tr>
<td>Patients and their families may not understand when life-prolonging interventions are no longer capable of curing the patient</td>
<td>Nurses can work with other health care providers to ensure that a consistent message is provided to the patient and the patient’s family.</td>
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References


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