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## Nurses' Role in Clarifying Goals in the Intensive Care Unit

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AMERICAN  
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NURSES

# Nurses' Role in Clarifying Goals in the Intensive Care Unit

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## PRIME POINTS

- Nurses play a pivotal role in facilitating communication with critically ill patients and their families.
- Nurses must be proficient in communication skills in addition to clinical skills.
- Nurses can use evidence-based knowledge related to disease trajectory and prognosis to advocate effectively for patients and families.
- The nurse has an essential role as a team member in establishing the goals of care in the ICU.

### Case Study, Part 1

It is 6:30 AM and report has ended. JS has the same assignment that she has had for the past 3 days, and not much has changed with MR in room 1. MR, a 78-year-old man, was admitted because of pneumonia and exacerbation of chronic obstructive pulmonary disease (COPD). He has a history of diastolic heart failure, diabetes mellitus, hypertension, chronic kidney disease (stage III), and gout. Multiple attempts to wean him from mechanical ventilation have been unsuccessful. As JS enters his room to start her assessment and replays the report in her head, she pauses and asks herself, Where are we going? What are we doing for him now? Why do we keep trying the same thing again and again?

**T**he uncertainty that JS feels most likely is due to the experience of caring for an ever-increasing population of chronically, critically ill elderly patients who have little chance of surviving hospitalization. Because

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of the increase in life-prolonging therapies, people are living much longer with chronic disease. Many of these elderly people die in an intensive care unit (ICU).<sup>1-3</sup> Up to 11% of Medicare beneficiaries spend more than 7 days in an ICU within the final 6 months of their life. In some instances, only 35% to 50% of all elderly patients in the ICU survive to discharge.<sup>1,4,5</sup> Among critically ill patients who require prolonged mechanical ventilation (>14 days), have cancer, or have multisystem failure, mortality often exceeds 50%.<sup>3,6-8</sup>

In caring for chronically ill elderly patients, nurses may struggle with understanding the relationship between the diagnosis, a poor or uncertain prognosis, and the treatment plan. Questions may arise about how much a patient's family understands or accepts an uncertain prognosis, the expected disease progression, or the patient's current clinical condition. Compared with attending physicians, nurses often may have a more realistic impression of a patient's ability to recover.<sup>9</sup> The reasons for this impression may be the events that nurses witness on a daily basis and participation in

ongoing aggressive therapies that do not benefit patients.<sup>10</sup> Christakis and Lamont<sup>11</sup> found that physicians overestimated survival in advanced illness by a factor of 5.3. For example, if a patient was given a life expectancy of 5 years, the patient survived only 1 year. No additional primary data illustrating this fact have been published, but many clinical experts<sup>8,10,12</sup> agree that the phenomenon still exists.

Nurses may feel responsible for inflicting suffering on patients who the nurses think will not survive the hospitalization. Nurses may also at times internalize and feel isolated in their responsibility of supporting patients' families.<sup>9,13</sup> These feelings may stem from some ICU cultures that do not support nurses in facilitating discussions about code status, end-of-life issues, or patients' preferences.<sup>14</sup> Nurses in this situation have been termed "the responsible powerless" when they are asked to care for patients and carry out prescribed orders but are not allowed or encouraged to discuss such important and serious topics with the patients, the patients' families, or colleagues.<sup>14,15</sup> The concept of "moral distress" in ICU nurses is directly correlated to feeling pressure to continue aggressive treatment when the nurses did not think the treatment was beneficial. Moral distress has even led to nurses' leaving their bedside positions.<sup>8,16,17</sup>

In results from the Study to Understand Prognoses and Preferences for Outcomes and Risks of

## Case Study, Part 2

JS knows MR has been in the ICU for 16 days and requires ventilatory support because of COPD. The course of intravenous antibiotics is complete, and MR has no further evidence of pneumonia or acute infection. Additionally, he is receiving 12 medications for treatment of his multiple chronic illnesses. His maximum score on the Glasgow Coma Scale has been 7, and he has delirium.

Because all of his reversible conditions, except the delirium, seem to have been resolved and MR is not showing any indication of returning to his previous baseline function, JS is becoming more concerned about his ability to recover or even survive this hospitalization. MR is evaluated daily by a respiratory therapist to determine if he can be weaned from mechanical ventilation, and so far each attempt has been unsuccessful because of overwhelming respiratory fatigue and distress when ventilatory support is decreased. After each attempt at weaning, MR requires sedation to maintain comfort and tolerance of mechanical ventilation.

As she studies his medical chart, JS learns that MR does not have an advance directive. She notes that MR's wife, who has been a consistent reliable caregiver, has repeatedly asked for "everything to be done." No documentation is available on actual conversations with MR or his wife about long-term prognosis or the progression of the chronic lung disease, and JS has not witnessed any actual conversations between the clinicians and MR's family. JS knows that if MR does not dramatically improve in the next several days, discussion about tracheostomy and long-term ventilator support will be introduced.

Later in the shift, MR's wife visits and after a brief time comes to JS and tearfully says, "He always pulls out of this, but he looks worse. Is he going to get better this time?"

Treatments published in 1995,<sup>18</sup> patients and patients' families did not think that physicians provided honest, realistic information about prognosis and end-of-life issues. Since then, many studies<sup>12,13,19,20</sup> have supported this communication deficiency, especially in the ICU with critically ill patients with an uncertain prognosis. In contrast, patients' family members reported an increase in their satisfaction with patient care when unified, consistent

information was provided to them about their loved one's status.<sup>9,13,19,21,22</sup>

Where do nurses fit in this equation on communication, and how can nurses feel support in facilitating difficult discussions about code status, treatment goals, prognosis, and the preferences of patients and patients' families? Some disagreement exists about a nurse's ability, responsibility, and role in initiating end-of-life discussions, primarily discussions about do-not-resuscitate status.<sup>12</sup> Although many experts<sup>9,13,14</sup> agree that patients and patients' families benefit from a collaborative approach to these issues, some investigators<sup>9,13,23,24</sup> have suggested that because of the close relationships that develop

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between nurses and patients' families in the ICU settings, a patient's nurse is the right person on the care team to encourage open dialogue. According to the American Nurses Association and the American Association of Critical-Care Nurses,<sup>5,14,23-25</sup> nurses have a duty to educate and promote dialogue about patients' preferences, goals, and end-of-life issues.

We use this case study of an elderly, chronically critically ill patient to illustrate the role of nurses in identifying the need for and facilitating effective communication when prognosis is uncertain and the goal of care is unclear.

### Communication With Patients' Families

The lack of communication between the health care team and MR and his family that JS has identified is not unique. In a landmark study published in 1979, Molter<sup>26</sup> described the needs of relatives of critically ill patients. Of the 10 most important needs, 6 were clearly related to communication. In subsequent studies,<sup>19,27</sup> the needs had not changed significantly. Multiple investigators<sup>18,19,28-32</sup> have found that despite this knowledge of the needs, communication between health care

providers and patients' families is generally deficient.

Researchers and experts have tried to determine why these needs continue to be unmet and why communication in end-stage disease is difficult.<sup>15</sup> One barrier reported by nurses and physicians is discomfort: the health care providers themselves are uncomfortable with death.<sup>28,33</sup> Levy<sup>33</sup> suggests that clinicians accept, as human beings, the reality of death. Death does not have to be viewed as good or bad, but it is inevitable. This acceptance promotes a clinician's ability to face the discomfort and uncertainty associated with caring for patients with irreversible diseases. With acceptance, clinicians may be better able to have honest discussion with patients and patients' families about terminal, incurable illness.

JS must assess and acknowledge her own beliefs and values related to chronic illness and end-stage disease. She must also realize that her colleagues may have different beliefs and values. Because patients' families may not recognize the need or may feel uncomfortable initiating a conversation about end-stage disease or end-of-life care, nurses must feel comfortable in starting these conversations. Creating an environment

conducive to open dialogue among patients and patients' families is a primary task that nurses should view as an obligation.<sup>23,34,35</sup>

Although a nurse's role does not include determining individual prognoses, nurses can collect information that will support determination of a patient's prognosis, and they can provide education on a patient's most likely course. In this case, when MR's wife asks if MR is going to get better this time, JS realizes that this question is appropriate and valid. To address the question, JS must collect information about the course of MR's disease, his performance status, and factors that will affect his prognosis. By empowering herself with this information, JS will be able to meet the communication needs of MR's family members and prepare them for what may lie ahead.

### Disease Progression, Performance Status, and End-Stage Disease

The question asked by MR's wife is impossible to answer with precision. Predicting survival in non-cancerous advanced illness is difficult because of the "roller coaster" phenomenon of exacerbations and remissions.<sup>36-38</sup> Zier et al,<sup>39</sup> however,

Because patients' families may not recognize the need or may feel uncomfortable initiating a conversation about end-stage disease or end-of-life care, critical care nurses must feel comfortable in starting these conversations.

Providers work with patients and patients' families to determine not what *can* be done but what *should* be done in each situation.

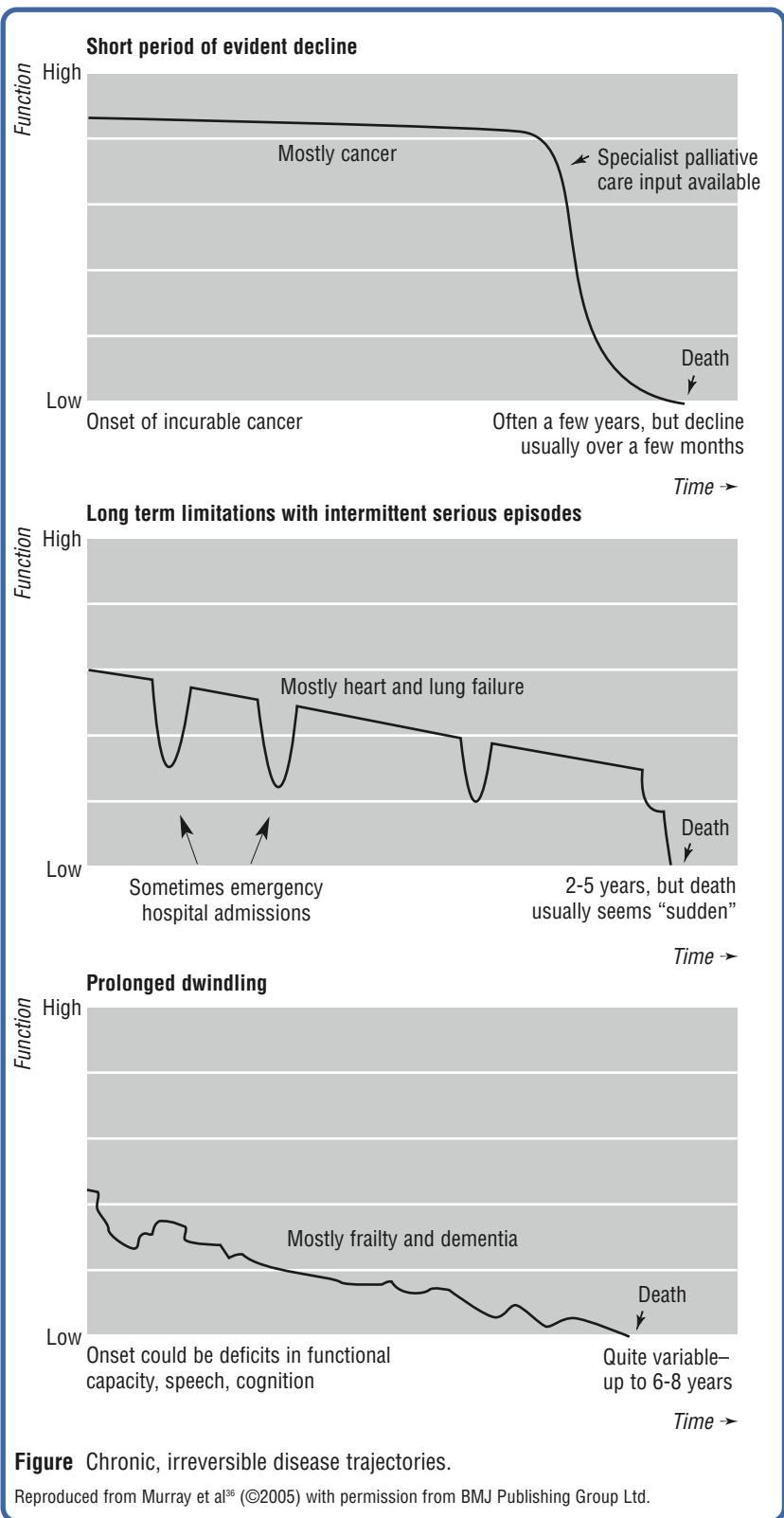
Improving the quality of care for patients with terminal, irreversible illnesses is an important component of ICU care.

found that surrogate decision makers accept the inaccuracy of prognostication in critical illnesses. Decision makers value rough estimates to inform their decision making.

In chronic, irreversible disease, overall progression is one of decline.<sup>36</sup> As shown in the Figure, decline has 3 primary trajectories, which are based on functional status and time alive. The first trajectory is a short, evident decline after a relatively stable prolonged plateau; this trajectory is typical in cancer. The second is a slow decline in baseline values or condition interrupted by short acute episodes of acute illness; this trajectory is consistent with chronic and advanced illness. The third is a prolonged slow decline with acute issues but no major episodes; this trajectory is typical of overall debility or dementia.

In an ICU, clinicians are accustomed to using physiology-based tools, such as the Acute Physiology and Chronic Health Evaluation scoring system, to aid in determining life expectancy and disease severity.<sup>40-44</sup> However, prognostic accuracy can be complicated by a patient's multiple comorbid conditions, pre-morbid functional status, and requirement for frequent or repeated ICU stays.<sup>45,46</sup> Performance status, defined as one's ability to care for oneself and participate in daily activities,<sup>47</sup> is one of the most accurate factors in prognosticating in advanced or critical illness.<sup>10,48,49</sup>

Recently, the Palliative Performance Scale<sup>50</sup> (Table 1) was developed and derived from the Eastern Cooperative Oncology Group Scale and the Karnofsky Scale, which is commonly used in oncology patients. The Palliative Performance Scale



applies to all cancer and noncancer diagnoses and has more of an observer-based focus than the scales

from which it was derived. The scale is determined by a patient's history, caregiver reports, and current

**Table 1** Palliative Performance Scale<sup>a</sup>

%	Ambulation	Activity and evidence of disease	Self-care	Intake	Consciousness level
100	Full	Normal activity No evidence of disease	Full	Normal	Full
90	Full	Normal activity Some evidence of disease	Full	Normal	Full
80	Full	Normal activity with effort Some evidence of disease	Full	Normal or reduced	Full
70	Reduced	Unable to do normal job/work Some evidence of disease	Full	Normal or reduced	Full
60	Reduced	Unable to do hobby/housework Significant disease	Occasional assistance necessary	Normal or reduced	Full or confusion
50	Mainly sit/lie	Unable to do any work Extensive disease	Considerable assistance necessary	Normal or reduced	Full or confusion
40	Mainly in bed	Unable to do any work Extensive disease	Mainly assistance	Normal or reduced	Full or drowsy or confusion
30	Totally bed bound	Unable to do any work Extensive disease	Total care	Reduced	Full or drowsy or confusion
20	Totally bed bound	Unable to do any work Extensive disease	Total care	Minimal sips	Full or drowsy or confusion
10	Totally bed bound	Unable to do any work Extensive disease	Total care	Mouth care only	Drowsy or coma
0	Death	NA	NA	NA	NA

<sup>a</sup> Based on data in Wilner and Arnold.<sup>50</sup>

functional level related to a patient's ability for self-care as advanced disease progresses. This scale has been studied primarily in patients receiving palliative care, but it is being used more and more in patients with advanced disease during critical illness and in the ICU. Lower scores strongly correlate with a decreased survival and escalated reporting of unpleasant symptoms such as dyspnea and pain.<sup>47,51</sup>

A patient's prognosis must be evaluated in the context of the patient's constellation of medical problems. As for other noncancerous advanced illness, performance status, comorbid conditions, and severity of illness all contribute to 1-year and in-hospital mortality. In the setting of poor performance status, multiple comorbid conditions,

and severe illness, 1-year survival does not exceed 50%,<sup>18</sup> and in-hospital mortality is close to 25%.<sup>49</sup> Specific to chronic obstructive pulmonary disease, age, increasing degree of dyspnea at rest and with activity, oxygen dependence, hypercapnia, low serum levels of albumin, weight loss, cor pulmonale, hypoxemia, need for prolonged ventilatory support, functional status, and frequent hospitalizations may be predictive of a poor prognosis with a possible life expectancy of 6 months or less. These characteristics define end-stage lung disease.<sup>10,52,53</sup>

Examples of the criteria that define other end-stage diseases are presented in Table 2. Although these criteria are published by the National Hospice and Palliative

Care Organization, nurses in any setting can use them to determine if a patient's disease is end stage. Combining these criteria with knowledge of the patient's disease trajectory and performance status can provide much information for the determination of prognosis.

### Treatment Goals

In the case study, JS sees no evidence that discussions about MR's prognosis have occurred. As described, MR may not survive this hospitalization, or if he does, he may be dependent on long-term mechanical ventilation for survival. An essential step is to ascertain if MR has communicated any preferences about treatment options such as artificial life support and resuscitation attempts.<sup>24,25</sup>

**Table 2** Factors associated with poor prognosis<sup>a</sup>

**Chronic kidney disease**

Creatinine clearance less than 10 mL/min (<15 mL/min in diabetic patients) *and* serum creatinine level greater than 8 mg/dL (>6 mg/dL in diabetic patients)

Signs of uremia such as confusion, obtundation, nausea and vomiting, generalized pruritus, restlessness

Oliguria

Intractable hyperkalemia

Uremic pericarditis

Hepatorenal syndrome

Intractable fluid overload

In hospitalized patients with acute renal failure, factors including mechanical ventilation, malignant neoplasms, lung disease, advanced cardiac or liver disease, sepsis, AIDS, albumin level less than 3.5 g/dL, cachexia, thrombocytopenia, age greater than 75 years, disseminated intravascular coagulation, and gastrointestinal bleeding are predictive of a poor prognosis

**Heart failure**

New York Heart Association class IV (symptoms of congestive heart failure at rest)

Ejection fraction 20% or less

Persistent symptoms of congestive heart failure despite maximum medical management with diuretic and vasodilator therapy

Possibly a history of ventricular arrhythmias, cardiac arrest and resuscitation, unexplained syncope, cardiogenic brain embolism, infection with human immunodeficiency virus

**Chronic obstructive pulmonary disease**

Dyspnea at rest with worsening performance status (usually bed to chair)

Poor response to bronchodilators for dyspnea

Forced expiratory volume in the first second of expiration less than 30% of predicted

Increased visits to the emergency department because of infections or exacerbations

Cor pulmonale or right-sided heart failure (associated with lung disease) documented by echocardiography, electrocardiography, chest radiography, and physical assessment

Hypoxemia at rest when receiving supplemental oxygen

Hypercapnia

Unintentional weight loss of 10% of body weight or greater in 6 months

Resting tachycardia greater than 100 beats per minute

**Other contributing factors (may be common in all disease processes)**

Poor pre-morbid functional status

Frequent hospitalizations or visits to emergency department

Unintentional weight loss

Serum level of albumin less than 2.5 g/dL

Combination of advanced medical problems

<sup>a</sup> Based on data from the National Hospice and Palliative Care Organization.<sup>53</sup>

Nurses must recognize that the overall goal of care (or treatment goal) is specifically related to a patient's values and quality-of-life preferences and should not be confused with daily goals, care plans, and treatment tasks. Keeping in mind the "big picture" related to a patient's individual goals, values, and quality-of-life preferences will aid in determining the aggressiveness and limitations of prescribed treatments. Whether a patient's overall goal is medically achievable

should dictate what specific medical treatments will be offered. Providers work with patients and patients' families to determine not what can be done but what should be done in each situation.

For example, a patient or the patient's family may think that artificial nutrition (tube feedings and intravenous nutrition) will help the patient achieve functional recovery after a stroke. More important determinants of functional recovery are the characteristics of the stroke

and the patient's comorbid conditions. Discussion of what the most likely recovery will be and what is an acceptable quality of life for the patient should influence whether artificial nutrition is an appropriate intervention. The plan should be based on reasonable medical treatments, focused on achieving a goal.<sup>54</sup> In the United States, multiple organizations and groups<sup>5,55,56</sup> are working to establish guidelines and quality measures for individualized treatment focused on patients and

patients' families to improve outcomes and satisfaction within the ICU.

JS's own questions about MR (Where are we going? What are we doing for him now?) are also appropriate and valid. She recognizes that although MR may not be at the end of his life this admission, he has end-stage, irreversible disease. It is appropriate to gain an understanding of MR's quality-of-life preferences to be used as a basis for his ongoing plan of care. His wife has opened the door to an opportunity to initiate this discussion. Armed with knowledge about the trajectory of chronic diseases and factors associated with prognosis, JS can use effective communication skills to gather information related to MR's prognosis, provide education as needed, and better understand the goal of care, as based on his quality-of-life preferences.<sup>57-59</sup>

JS can start the conversation by avoiding the use of false reassurance. "Don't worry, he's going to be OK" may seem like a compassionate response, but it is nontherapeutic and possibly inaccurate. A more appropriate intervention is to offer comfort and to assess his wife's readiness to talk at this time. Table 3 provides questions or statements that nurses can use to gather information from patients' families about the patients' disease trajectory, performance status, factors associated with prognosis, and quality-of-life preferences.<sup>22,60-63</sup>

### Summary

Empowered by knowledge related to disease trajectory, performance status, and factors associated with prognosis, JS was able to advocate effectively for her patient

## Case Study, Part 3

JS acknowledges the emotions of MR's wife and asks if she would like to talk more about MR's situation. JS shares her own concerns about MR's current course. Through effective communication, JS determines the following: MR has been oxygen dependent for 4 years; he has had 3 hospitalizations because of COPD exacerbations in the past year; his functional status is declining, and he has had to use a wheel chair since his last discharge home 2 months ago; he has lost 9 kg (20 lb) during the previous 6 months; and his symptoms of dyspnea, cough, and pain have increased each time he has been admitted to the hospital.

JS determines that MR's trajectory has been one of overall decline with more frequent episodes of acute illness; she knows this trajectory is characteristic of chronic, irreversible advanced disease. MR's score on the Palliative Performance Scale before admission was 40. She estimates his score is now 20. She is also able to identify several factors associated with a life expectancy less than 6 months, including MR's age, increasing dyspnea, oxygen dependence, weight loss, declining functional status, and frequent hospitalizations.

MR's wife states that she and MR have had many discussions about his disease process. JS shares information about the trajectory of irreversible, chronic disease, and MR's wife reflects on the downhill course she has been witnessing during the previous few years. She reports that MR has said that he is less and less satisfied with his recovery after recent hospitalizations. JS reviews MR's performance status and informs his wife that the decline is an indicator of end-stage disease. JS explains that declining performance status, along with the identified factors, indicate that MR is approaching the end of his life. She explains that an exact prognosis is impossible to predict but that MR's course will continue to be one of overall decline; he is unlikely to recover to an improved functional status.

MR's wife tearfully acknowledges that she knew this situation was coming. JS provides emotional support by quietly listening and being present. MR's wife begins to reminisce about his "healthier days" and activities he enjoyed. JS allows her to reminisce and carefully listens for information related to MR's quality-of-life preferences. His wife shares that he enjoyed outdoor activities and that he valued his independence. She states they had many conversations about his lung disease and that MR had completed a living will 2 years ago. She has been reluctant to bring it in because to her it was an indicator that the end was near. JS gently emphasizes that it is most important to honor MR's preferences about his quality of life. MR's wife is in complete agreement and asks, "What do I do now?"

JS carefully summarizes what she has learned about MR's values and quality-of-life preferences to ensure that her understanding is accurate. She asks MR's wife to bring in the living will so his preferences can be discussed with his health care team. JS helps MR's wife identify additional resources for support and offers to ask the chaplain to visit. She gives assurance that MR is receiving excellent care and that she will keep his wife informed of any changes. Finally, JS arranges a time for MR's wife to meet with the team to discuss MR's quality-of-life preferences and the goal of care.

**Table 3** Questions and statements to gather information from families of patients such as MR

Information needed	Communication options
<b>Disease trajectory</b>	<p>How long has MR had chronic obstructive pulmonary disease (COPD)?</p> <p>How long has MR received oxygen at home?</p> <p>How have things been going for the few months before this admission?</p> <p>How many hospitalizations or visits to the emergency department has MR had in the past year?</p> <p>Many patients with chronic diseases have more frequent hospitalizations with shorter intervals between them. They often do not recover to their previous level of function. Does this sound like what has been happening with MR?</p> <p>COPD is not curable; it does get worse over time. A slow decline is expected.</p>
<b>Performance status</b>	<p>How much has MR been able to do for himself at home?</p> <p>How much time does MR spend in the chair at home? How much does he sleep?</p> <p>Does MR need help with his bathing, dressing, and eating?</p> <p>I see that MR has had some weight loss. How much does he eat when at home?</p> <p>For most patients with chronic, irreversible diseases, the course is one of overall decline. It sounds like MR has been experiencing decline in his functional status, or ability to care for himself.</p>
<b>Disease stage</b>	<p>Tell me what you know about MR's medical situation at this time.</p> <p>How does he seem to be doing to you?</p> <p>What has his doctor been saying about the COPD?</p> <p>Tell me about MR's shortness of breath. How much activity makes him short of breath?</p> <p>How often has MR been using his inhalers at home? Do the inhalers seem to be working as well as in the past?</p> <p>MR's treatment has been focused on disease modification and treating complications/exacerbations; there is no cure for COPD. At some point, the treatments to manage COPD become less and less effective. This change is an indication that the disease is reaching its final stage.</p>
<b>Quality-of-life preferences</b>	<p>I have read the chart and reviewed MR's course, but I don't know how the current situation has been for MR. Can you tell me how he has been doing with all this?</p> <p>What would MR think of the current situation?</p> <p>What would MR say if he could sit here with us now?</p> <p>What does MR enjoy and how does he spend his time?</p> <p>Did you and MR ever talk about his need for mechanical ventilation?</p> <p>Did MR ever complete an advance directive—a living will?</p> <p>We know MR as a patient and would like to know him more as a person. What can you tell me about how MR lives his life?</p> <p>It's important for us to understand MR's preferences regarding quality of life. We want to honor his wishes.</p>

and his wife. Improving the quality of care for patients with terminal,

**dotmore**

To learn more about communication in the ICU, read "Intensive Care Units, Communication Between Nurses and Physicians, and Patients' Outcomes" in the *American Journal of Critical Care*, 2009;18:21-30. Available at [www.ajconline.org](http://www.ajconline.org).

irreversible illness is an important component of ICU care. Because of the increasing numbers of patients with chronic, irreversible disease, the ICU has become a common location for discussions about goals of care.<sup>56,64,65</sup> Because of their constant presence, knowledge, and skills, acute and critical care nurses

have a pivotal role in promoting this communication. Benefits to be gained with effective communication include optimal patient outcomes and enhanced staff satisfaction.

To strengthen the emphasis and need for communication, researchers should examine why deficient communication is still such a problem

in acute care. Determining the true etiology of this deficiency would be an important first step in solving or at least improving the situation. As ICU patients are older and live longer with increasingly more chronic illnesses, the need for optimal communication becomes even more critical. Clarifying the true basis of the deficiency can lead to improvements in the health care system, the satisfaction of patients and their families, and job satisfaction for all health care professionals. **CCN**

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**Financial Disclosures**  
None reported.

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