

# Withdrawal of Life Support

## Intensive Caring at the End of Life

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### THE PATIENT'S STORY

Mrs J is a 77-year-old woman who presented to the emergency department following several days of worsening shortness of breath. On evaluation, she was in hypercapnic respiratory failure thought to be due to an exacerbation of chronic obstructive pulmonary disease. Chronic radiographic changes made it difficult to exclude a concomitant pneumonia, so she was treated with ceftriaxone and doxycycline in addition to corticosteroids and nebulized bronchodilators. After Mrs J became agitated during a trial of non-invasive ventilation (biphasic positive airway pressure [BiPAP]), she was sedated, intubated, and transferred to the intensive care unit (ICU). Several days later, the medical team learned that the patient carried the diagnosis of pulmonary fibrosis and that previous pulmonary function tests documented a significant restrictive ventilatory deficit. Her lack of improvement and this historical information made it likely that the patient would be slow to wean from mechanical ventilation. The inpatient attending physician (hospitalist), in discussion with the patient's primary care physician and the ICU team, initiated discussions with the patient's 2 sons and daughter regarding appropriate goals of care and potential limitations to therapy. One of the sons, Mr G, held the durable power of attorney for health care.

The family reported that the patient's overall quality of life had been declining. Mrs J's eyesight was failing, and she became dyspneic with minimal activity. She had told her children that she did not wish prolonged life support. The family decided to withdraw ventilatory support but first wanted to see if Mrs J could wake up to speak with them. Once sedation was lightened, the patient was aware of her family's presence. She was able to interact with them but not to speak or to participate in decisions regarding her care. She was subsequently extubated. Small doses of morphine were administered to treat dyspnea. She appeared comfortable before gradually becoming somnolent and then unarousable. She was transferred from the ICU to the hospital's inpatient palliative care unit, where she died peacefully the following day.

The family was appreciative of the clinicians' efforts and grateful that their mother was able to awaken before her death even while they remained conflicted over their decision-

The technology and expertise of critical care practice support patients through life-threatening illnesses. Most recover; some die quickly; others, however, linger—neither improving nor acutely dying, alive but with a dwindling capacity to recover from their injury or illness. Management of these patients is often dominated by the question: Is it appropriate to continue life-sustaining therapy? Patients rarely participate in these pivotal discussions because they are either too sick or too heavily sedated. As a result, the decision often falls to the family or the surrogate decision maker, in consultation with the medical team. Decisions of such import are emotionally stressful and are often a source of disagreement. Failure to resolve such disagreements may create conflict that compromises patient care, engenders guilt among family members, and creates dissatisfaction for health care professionals. However, the potential for strained communications is mitigated if clinicians provide timely clinical and prognostic information and support the patient and family with aggressive symptom control, a comfortable setting, and continuous psychosocial support. Effective communication includes sharing the burden of decision making with family members. This shift from individual responsibility to patient-focused consensus often permits the family to understand, perhaps reluctantly and with great sadness, that intensive caring may involve letting go of life-sustaining interventions.

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making role. A Perspectives editor interviewed Mrs J's son, Mr G, and the hospitalist, Dr M, 1 month after Mrs J's death, and the intensivist, Dr K, 3 months later.

## PERSPECTIVES

MR G: *They've had to intubate her several times over the last couple of years. . . . There were no discussions about taking care of her other than the way we were doing it now. Last time one of her doctors, a pulmonologist, told me there was no cure for pulmonary fibrosis and that it would just get progressively worse and worse and, at some point, she was going to die from it.*

DR K: *I didn't think that she was going to survive beyond the next 8 to 12 months. Her pulmonary function tests were poor but I thought she might be marginal enough to be discharged either to her home or to some kind of rehab facility. That part I couldn't predict. That was difficult for the family because I think it would have helped everybody's mental preparations, if nothing else, to know exactly how end-stage this current episode was.*

The central issue in decisions to limit or to withdraw intensive therapies from critically ill patients is not the timing of a transition to "comfort" measures. Appropriate analgesia and sedation rarely conflict with disease-specific treatment, so comfort can and should be ensured while a cure is sought.<sup>1</sup> The central issue is whether continued aggressive therapy offers realistic hope of recovery or, if not, whether it is appropriate to allow the patient to die. To frame the issue in this way highlights the gravity of the decision as well as the difficult issues facing parties attempting to reach consensus about how to proceed.

### Legal and Historical Background

North American physicians,<sup>2-5</sup> nurses,<sup>6-8</sup> bioethicists,<sup>9,10</sup> lawyers,<sup>11,12</sup> and the public<sup>13</sup> have reached a broad consensus that decisions to withdraw life support are appropriate in many clinical situations. The ethical and legal justification of withdrawal of life support rests on the importance of patient consent, which itself is rooted in the concept of autonomy. Every adult patient with decision-making capacity has the right to determine what treatments he or she will receive. This right does not end with the patient's incapacity but can be exercised on the patient's behalf by an appropriate surrogate.<sup>14</sup>

The belief that it is generally inappropriate to use critical care technology to prolong dying represents a recent and hard-fought consensus.<sup>11</sup> When mechanical ventilation first became widely available, decisions to withdraw ventilation were extremely controversial. In 1975, after their daughter lay in a persistent vegetative state for 9 months, Karen Ann Quinlan's parents asked that her ventilatory support be withdrawn. They had the support of their primary care physician but were opposed by most professional medical societies, including the American Medical Association. The parents sued and won a landmark ruling in the New Jersey State Supreme Court permitting their daughter's extuba-

tion.<sup>15</sup> The Quinlan decision sparked 15 years of intense debate about the appropriate use of life support. In 1990, the US Supreme Court acknowledged the patient's right to forgo life support while affirming the State of Missouri's prerogative to establish an evidentiary threshold for surrogate decision makers.<sup>14</sup> More recently, the Court has rejected the argument that limitations to life support constitute physician-assisted suicide or euthanasia.<sup>16,17</sup>

Setting limits to life-sustaining therapy has become common practice in North American ICUs. Survey data from 1994 through 1995 show that approximately 25% of deaths in ICUs in the United States and Canada followed a failed attempt at cardiopulmonary resuscitation, while 75% followed a deliberate, considered decision to withhold or withdraw some form of life-supporting therapy.<sup>18,19</sup> Some physicians have acknowledged stopping treatment in spite of patient and surrogate requests to continue life support.<sup>20</sup>

As decisions to limit life support become routine, the intense debate and controversy that once arose around this practice are being forgotten. Younger caregivers and those in training may have little understanding of the wrenching struggles clinicians have experienced over withdrawal of ventilatory support, or of the complex cultural and emotional associations raised by limiting nutrition and hydration.<sup>21</sup> Without this perspective, young clinicians may misunderstand families whose response to withdrawal decisions may have more in common with the response of the practitioners who first confronted these issues in the 1960s and 1970s than with the response of 21st-century practitioners following 3 decades of intense bioethical, legal, and social debate.

### Advance Care Planning

MR G: *When we signed the durable power of attorney, I was with her with the lawyer. She [Mrs J] said at that time, "I can't make this decision [withdrawal of life support] right here and now. I want you to make it for me. And I trust that you will make the right decision at the time." I probably didn't feel very comfortable with it at that time, nor did I feel very comfortable at this time.*

Advance care planning is perceived as an opportunity for patients to direct their care even when illness prevents them from speaking for themselves. Unfortunately, studies have shown that advance directives do not cause patients' wishes to be followed more closely,<sup>22</sup> there does not appear to be any impact of advance care planning on care received in the hospital<sup>23</sup> or the ICU,<sup>24</sup> and medical costs are not affected.<sup>25</sup> The reasons for the ineffectiveness of advance care planning are complex.<sup>26</sup> This patient's story highlights several difficulties common to ICU patients.

Diligent pursuit of advance care directives may yield little guidance. During a previous hospitalization, a pulmonary specialist spoke explicitly to Mrs J's son about his mother's progressive pulmonary fibrosis. The patient's primary care physician subsequently addressed the need for advance care planning with the patient, specifically identifying intuba-

tion and resuscitation as issues. Mrs J was unable to commit herself to specific decisions about her care. She preferred to appoint her son as her durable power of attorney. Her instructions to him were, in essence, "Do the right thing."

Many patients find it threatening to contemplate the circumstances under which a decision to limit life support might be invoked. This reluctance to make specific decisions is neither unusual nor unreasonable, but it should not end the discussion. A decision to forgo intubation or resuscitation may be beyond the patient's capacity, but that insight marks the beginning of another discussion about the patient's interests and goals.<sup>27</sup> The clinician might have responded to Mrs J: "We know that you have severe, progressive lung disease. You have required intubation in the past and will likely need it again in the future. In the event that you develop respiratory failure and require intubation, but do not recover as quickly as you have in the past, what guidance would you offer your son and your doctors? How long would you want us to continue to keep you on a breathing machine if it looked as though you would not be able to breathe without it?"

Clinicians who conduct these discussions must learn to address the emotions underlying the patient's preferences. Mrs J's instruction to her son might have prompted the involved clinician to pursue her reluctance to speak about dying. If it proved too difficult for her to explore her fears, then perhaps she would have been willing to talk about her hopes. What did she enjoy about her life? What would she want, and, by extension, what would she have found unacceptable? A second strategy would have been to address directly the patient's reliance on the son. He accepted this responsibility dutifully but uneasily. Was she aware of his discomfort? How could she be confident that he would know what to do? If it was difficult to offer her own wishes, would she be willing to offer him guidance?

Estimating the prognosis is appropriately a part of advance care planning, but it is always easier in retrospect to say that a patient was not going to survive. Mortality prediction models can provide precise and accurate estimates of patient mortality across populations,<sup>28</sup> but for individual patients the trajectory of dying remains unpredictable.<sup>29</sup> Mrs J had an underlying, progressive, and usually fatal disease (pulmonary fibrosis) carrying a median survival of 2 to 3 years from diagnosis. After developing acute respiratory failure of uncertain cause requiring intubation, she was alive but with severely impaired respiratory function. As noted by Dr K, an attempt to predict short-term survival in this particular patient, in this context, is (educated) guesswork.

Of course, it is the physician's responsibility to attempt such guesswork. Both clinicians and patient surrogates are helped by a clear understanding of probable outcomes, and most advance directives presuppose a degree of prognostic confidence.<sup>30</sup> Two related insights help the critical care practitioner in this situation. First, narrowing the confidence intervals around prognosis is rarely helpful in making indi-

vidual patient care decisions.<sup>31</sup> The majority of patients like Mrs J have a small chance of surviving their ICU course but not so small that the predicted mortality itself becomes dispositive. Second, prognosis defined as survival to ICU discharge is only a small factor in a complex decision.<sup>32</sup> A majority of patients with advanced lung disease are concerned about functional recovery and quality of life, and most want limits placed on the use of mechanical ventilation.<sup>33</sup> Clinicians help families by acknowledging prognostic uncertainty directly and by building on that uncertainty to expand the discussion beyond an exclusive focus on survival.

Patients need reassurance that limiting life-sustaining treatment does not mean limiting care.<sup>34</sup> Patients with progressive diseases and poor chances of recovery may equate acceptance of death with surrender or even abandonment. A major goal in conversations with patients is to reassure them that they will be treated as aggressively as is consistent with their wishes, but that their physicians' goal is to understand those wishes should curative efforts fail. Collaboration and communication among members of the health care team can provide support and reassurance to family members.<sup>35,36</sup>

## ONGOING ICU CARE

### Guiding the Family

*DR M: I usually start by talking to the family about the patient's medical course to make sure we're all on the same page about how sick the patient is. When patients are this sick, we know that it is very unlikely that they will return to any sort of quality of life. The alternative was really just to keep doing what we were doing and then eventually try to wean her off the ventilator. Even if she did get off the ventilator, they needed to think about whether or not they wanted her to be reintubated.*

*DR K: Her pulmonary disease was such that during the next few months, or within the next year, the chances were that she would have another one of these episodes. . . . I had to adjust the discussion from "Let's get your mom better, extubated, and out of the hospital" to "Sure, we might be able to do it this time but maybe this is something that needs to be addressed before she leaves the hospital. . . ."*

*MR G: I got a phone call from my mother before they intubated her. She said, "I can't breathe and they want to put on this [BiPAP] mask and I don't want it." I said, "Mom they're trying to help you. You've got to do what they want. They may have to intubate you, put the tube down." And she said, "Oh, I don't want that. I don't want it." When I arrived she was totally sedated. She was not conscious at all. . . . I was hesitant about taking the tube out and saying, "That's it." I wanted to see if she could make it without the tube. This was discussed when we finally met. They [the physicians] felt that they would be happy to take the tube out but . . . they wanted me to tell them not to put the tube back in if she failed.*

The son's perception of the decision-making process was that the final responsibility was his alone. As a matter of law and ethics, Mrs J's physicians shared decision-making re-

sponsibility. The failure to ensure that Mr G appreciated their role placed an undue burden on him.

The patient's illness does not abrogate her right not to be treated without her consent. This right may be exercised on the patient's behalf by a surrogate decision maker. If the patient's wishes are known, this surrogate should apply the patient's wishes explicitly (substituted judgment); when the patient's wishes are unknown, the surrogate should attempt to make a decision in the best interests of the patient. In this case, it seems clear that Mrs J had communicated to her son substantial reluctance about intubation and intensive care. If the hospitalist and the intensivist were unaware of this crucial information, then their effectiveness may have been undermined. Critical care physicians need to be active participants in this exploration of the patient's wishes.<sup>37</sup> They might have approached Mr G as follows: "We need to understand what your mother would want in this situation. We can bring medical information and an understanding of prognosis, and you can bring knowledge of who she is as a person and how she has viewed her life. Together, we can try to make the best decision for her."

These 2 standards for surrogate decision making—substituted judgment and the best interests of the patient—represent essential shifts in both perspective and moral responsibility.<sup>38</sup> Mr G felt burdened by the perceived responsibility to decide whether this was the day that his mother would die. His real task was less onerous: he was in the best position to help the physicians to understand his mother's wishes. Because Mrs J's physicians focused the discussion on actions rather than on Mrs J's prior wishes or best interests, Mr G perceived, rightly or wrongly, that he was left with responsibility for his mother's death. Shifting the perspective to the patient's wishes is crucial to effective decision making at the end of life.<sup>39</sup> Family members whose own grief prevents them from deciding to limit treatment may affirm the appropriateness of limits out of respect for their loved one's wishes. By speaking for their loved one and not for themselves, family members may truly substitute the patient's decision for their own and that positive affirmation may make their loss more bearable. This shift in perspective is the difference between the language of "giving up" on someone, which inevitably carries extremely negative connotations, and that of "letting go," which allows a more self-effacing, even altruistic, interpretation.

Family members and physicians cannot predict perfectly a patient's wishes.<sup>40,41</sup> This finding has been cited as evidence against surrogate decision making,<sup>42</sup> but some patients have not established preferences for end-of-life care,<sup>43</sup> and many patients, like Mrs J, prefer their surrogates to use their judgment rather than be bound by the specifics of living wills.<sup>44,45</sup> Patients cannot anticipate all the possible circumstances of dying, but they can direct the people who have cared for them in their lives to continue to care for them as they die.

Families arrive at decisions to withdraw life support through a social process that has cognitive, affective, and interpersonal

**Box 1. Letting Go: Processes Whereby Family Members Work Through Their Grief to Arrive at the Point of Being Able to Let Go of a Loved One**

**Cognitive Aspects**

Seek information and understanding about the critical illness, including reassurance that medical care is good and the providers of that care are trustworthy.

**Affective Aspects**

Bring closure to a life. Tell the patient's story in a way that creates meaning for the patient's life. Frame the prospect of death to avoid the cultural taboo of "giving up."

**Interpersonal Aspects**

Protect and maintain family relationships threatened by the decision to withdraw life support.

Adapted from Swigart et al.<sup>47</sup>

sonal aspects (BOX 1).<sup>43,46-48</sup> Certain milestones indicate that families are moving through this process: a willingness to admit that recovery is not likely or not possible, acknowledgment that the patient would not have wanted to continue in his or her current medical condition, and struggling with the conviction that they are doing the right thing, ie, that the decision will not threaten important relationships among surviving family members.<sup>47</sup>

The framework in Box 1 can guide clinicians in their family interactions. Family members need clear, consistent information in language they can understand. They need that information as soon as it is available. Delaying giving information to families undermines the anticipatory grieving that is an important part of the affective process of making decisions about withdrawal of life support.<sup>49</sup> Prognostic uncertainty in the ICU also can prevent family members from working through with each other the impact of the illness and decision to withdraw. To allow families to process their emotional responses, they need to be aware of the possibility of death even as they are supported in their hope of recovery. Helpful and problematic clinician communication strategies are shown in BOX 2.

**Resolving Conflicts**

DR M: [*The decision to withdraw life support*] was actually very, very easy. They didn't ever want their mom to suffer. They realized that her quality of life was significantly impaired. We stopped by after the withdrawal process to make sure the family was OK with it and they were thrilled. . . . In the brief period of time that she was lucid, she was kind of joking with them. The family was wonderful, and was most grateful for the opportunity to share some laughs with their mother before she expired.

MR G: *She was aware that we were there, we kind of made her laugh . . . you could see her chest move and she smiled, but*

**Box 2. Supportive and Burdensome Clinician Strategies****Supportive Strategies**

- Frequent, timely (ie, as soon as poor prognosis is recognized), and consistent communication across providers and consultants
- Availability of physician staff to answer questions when they arise
- Encouragement of family discussion while maintaining focus on what the patient would have wanted
- Good symptom control
- The practices of empathy and presence

**Divisive/Burdensome Strategies**

- Delaying discussion of withdrawal of life support despite poor prognosis
- Withdrawing from contact with the family as death approaches
- Placing the burden of decision on one person
- Arranging for withdrawal of life support, then delaying the actual withdrawal

Adapted from references.<sup>50-53</sup>

**Box 3. A Dozen Needs of the Family in the Setting of Critical Illness**

- To have questions answered honestly
- To know specific facts about what is wrong with the patient
- To know the prognosis for recovery
- To be called at home about changes in the patient's status
- To receive information from the physician (at least) once daily
- To receive information in understandable language
- To believe that hospital personnel care about the patient
- To be assured of the patient's comfort
- To be comforted
- To express emotions
- To find meaning in the death of their loved one
- To have the opportunity to eat, drink, and sleep

Adapted with permission.<sup>65</sup>

*then she would go back into this sort of dazy, glazy kind of look on her face. . . . She made some sounds when I tried to get her to say something but it was incoherent even at the best of times after the tube was removed. I look back on it and I still don't feel comfortable about having had to make this decision [to remove the endotracheal tube]. The doctors at the hospital knew,*

*I guess they've gone through this before, they said they didn't want me to feel guilty.*

Most families are open to setting limits on intensive care, and most withdrawal discussions are not contentious.<sup>32,54</sup> Disagreements about how to weigh the continuing burdens of treatment against a small chance of improvement are to be expected and are usually handled through an intuitive process of negotiation.<sup>55,56</sup> Guided by an appreciation of the patient's wishes, the parties often agree on a time-limited trial of therapy, followed by review and withdrawal of life support, if the patient does not improve. Physicians and families are about equally likely to desire continued aggressive therapy.<sup>54</sup>

In this case, the hospitalist perceived Mrs J's family to be comfortable and satisfied with limitations on life support following a trial of aggressive therapy. The family's experience was quite different. Mr G seems conflicted about his role in his mother's death, leading to lingering guilt over the decision. Despite Dr M's careful attention, he does not appear to have been aware of the depth of Mr G's grief. Even well-intentioned and capable physicians may become so accustomed to the withdrawal of life support that they focus on decision making but fail to attend to the human drama involved. Families have cited the opportunity to voice concerns as important to their experience,<sup>57</sup> but little is known about the long-term effects on families of decisions to limit life support.<sup>58</sup>

Medical futility frames the dispute over continuing intensive therapy as an issue of prognosis,<sup>59</sup> so that if the likelihood of functional recovery after a proposed course of therapy is less than 1%, then physicians may assert the prerogative to withdraw therapy without the consent of the patient or surrogate decision maker. However, other researchers have criticized this approach for the absence of any consensus definition of futility, the absence of applicable clinical research data to define this 1% threshold, the variable application of an arbitrary standard, and the setting of goals of care by assertion rather than discussion.<sup>60,61</sup>

Some regions have assessed community values to mitigate unilateral, futility-based decision making. In Denver, Houston, and other areas, conflicts over continuing aggressive life support are resolved through an algorithm that relies on community-based consensus standards,<sup>62,63</sup> an approach adopted by the Council on Ethical and Judicial Affairs of the American Medical Association.<sup>64</sup>

Futility tends to emphasize power over persuasion, whereas family members of ICU patients desire clear information about the illness and the patient's prognosis (BOX 3). Unfortunately, skill in communication is not a universal strength of critical care practice.<sup>66</sup> In one study, 23% of 461 family members believed that neither the patient nor the family was part of the discussion about end-of-life decisions.<sup>67</sup> In a 1990 survey of physician members of the American Thoracic Society, 34% of 879 respondents reported continuing therapy that the patient or surrogate had requested be stopped, and

82% made unilateral decisions to withdraw therapy, often without the knowledge or consent of the family and sometimes in spite of their explicit objections.<sup>20</sup>

An arbitrary futility threshold does not acknowledge the role of families in decision making,<sup>68</sup> the complexity of the decision-making process for families<sup>47,50</sup> and physicians,<sup>69</sup> or the insights into effective dispute resolution gained in other fields.<sup>55</sup> If family members feel excluded or marginalized, disagreements may be more likely to progress to conflict or harden into impasse (BOX 4). In one randomized controlled trial of ethics consultations in conflicts over ICU treatment, an intervention focused on dispute resolution led to significantly fewer ICU days and ventilator days, and less use of artificial nutrition and hydration, in patients who subsequently died.<sup>70</sup> Physicians and nurses who recognize the affective and social dimensions of family decision making will be more effective clinicians.<sup>66,71</sup>

## TAPERING LIFE-SUSTAINING INTERVENTIONS WHILE PROVIDING COMFORT

### Symptom Control

DR M: *[The family]* didn't ever want their mom to suffer. . . . So one thing we negotiated was we didn't want to see her have any distress but they wanted to talk to her.

MR G: *I was expecting her to talk after the tube was out, but she never regained enough facility to talk to me. I did get her to blink her eyes at one point, because I thought that she was in pain. I said, "Mom, would you blink your eyes and tell me if you need more pain shots?" And she blinked.*

Mrs J's family decided to withdraw her ventilatory support. She was extubated and small doses of morphine were administered to treat dyspnea. She appeared comfortable before gradually becoming somnolent and then unarousable. Opioids used to treat dyspnea in patients with advanced respiratory illness can depress respiration and hasten death, but when carefully titrated to control refractory symptoms, this use is established practice<sup>2</sup> and appropriate to end-of-life care.<sup>16,17,72</sup> Acceptance of the risk of hastened death is legally<sup>14</sup> and morally<sup>73</sup> justified by the rule of double effect.

The critical care team managed a difficult balance between allowing Mrs J to awaken but not to suffer. Unfortunately, Mrs J's experience may not be the norm. In the SUPPORT Study,<sup>74</sup> almost half of the 5176 patient or family members who were able to respond reported patient pain, with 15% reporting extremely severe or moderately severe pain occurring at least half of the time.<sup>75</sup> Some patients may be able to use simple tools to indicate pain, even when intubated.<sup>76</sup> If direct patient communication or self-report is impossible, ICU physicians and nurses may sometimes rely on the proxies of behavioral and physiological signs of pain.<sup>77,78</sup>

Families report that seriously ill, hospitalized patients also experience agitation, anxiety, depression, confusion, dyspnea, and fatigue,<sup>79-81</sup> but few data exist concerning the symptoms experienced by dying ICU patients. More than half of

### Box 4. Families' Reasons to Refuse to Consider a Recommendation to Withdraw Life Support

#### Mistrust of Medical Professionals

Conceptual, based on cultural and economic factors  
Experiential (eg, failure of clinicians to show empathy; prior experience of perceived prognostic inaccuracy)

#### Poor Communication by Medical Personnel

Failure to convey a clear understanding of the medical facts  
Reluctance of clinicians to acknowledge dying until initiating withdrawal of life support  
Mixed messages from multiple clinicians

#### Guilt on the Part of Survivors

Fractured relationships, made worse by time or distance  
Family's perception of personal responsibility for the patient's death, especially when a decision to withdraw life support is framed as "giving up" on a loved one

#### Cultural, Religious, or Scientific Views Outside the Mainstream

Withdrawal of life support interpreted as active euthanasia  
Ability to find meaning in patient outcomes considered poor by medical personnel (eg, survival in a persistent vegetative state)

50 ICU patients who could respond to a modified Edmonton Symptom Assessment Scale reported moderate to severe discomfort, thirst, difficulty sleeping, anxiety, pain, and unsatisfied hunger.<sup>82</sup> Pain, anxiety/agitation, and dyspnea can all be effectively managed pharmacologically,<sup>73,83-85</sup> and can be augmented by positioning, eye care, and mouth care.<sup>86</sup>

### Managing the Withdrawal of Therapy

Any therapy that supports life may be withheld or withdrawn.<sup>87-93</sup> The most frequently withdrawn therapies are (in order) blood products, hemodialysis, vasopressors, mechanical ventilation, total parenteral nutrition, antibiotics, intravenous fluids, and enteral feedings. Physicians frequently withdraw therapies in a sequence,<sup>90</sup> and vary in their practice of withdrawal,<sup>87</sup> depending on familiarity, expense, and invasiveness.<sup>94</sup> The mechanics of withdrawal of life support are frequently coordinated with families' explicit social, ethical, and religious objectives.<sup>50</sup>

Many algorithms for withdrawing different technologies have been suggested<sup>39,95-97</sup> and are based on expert opinion. Few studies have assessed patient comfort, family satisfaction, or the experience of caregivers during treatment withdrawal.<sup>98</sup>

The best means of withdrawing mechanical ventilation is debated, weighing the merits of reducing ventilatory support while leaving the endotracheal tube in place (terminal weaning) vs removal of the endotracheal tube (extu-

**Table.** Things Clinicians Can Say and Do With Family Members of Dying Patients

Activities Related to Patient and Physical Environment	Activities Promoting Optimal Communication
Personalize and domesticate the patient's environment through use of family pictures, afghans, religious ornaments, personal pillows, music from home	Carefully listen to the family member; use clear and understandable language; share information in a timely manner; explain all procedures in understandable, lay terms
Arrange for time to talk and visit with patient	Help the family to understand the implications of prognostic information
Encourage a family dialogue with and about the patient (eg, tell family stories)	Anticipate that some family members may respond with anger, emotional outbursts, or temporary inconsolable grief
Provide for family privacy with the patient so that personal words can be expressed	Assist family members to understand, participate in, and accept the transition from aggressive, care-saving goals to end-of-life, palliative care goals
Provide for tissues and chairs at the patient's bedside	
Remain in visual contact, but outside of hearing range, in case the family needs support	Coach the family in communicating with various members of the health care team, including physicians, clinical nurse specialists, social workers, pharmacists, clergy
Help the family to prepare for the patient's death; this may involve having family members participate in various aspects of care (eg, bathing, hair combing)	Ascertain whether family members want to be present during withdrawal of treatment (eg, during terminal weaning or extubation), and advocate for the family's wishes
Involve willing family members in assisting with postmortem care	

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bation).<sup>95,99,100</sup> Patients receiving high levels of ventilatory support, and those with difficulty clearing secretions or protecting their airway, frequently struggle and gasp when extubated and may benefit from having the endotracheal tube in place. Conversely, extubated patients who can support their own ventilation, even briefly, benefit from closer contact with loved ones, and may be able to communicate more easily.

### Setting: Creating a Caring Environment in the ICU

DR M: *One of the sons is an opera singer and he actually sang to her in the ICU and was thrilled that he'd gotten the opportunity to do that.*

MR G: *I sang "The Lord's Prayer" to her. . . . She was raised a Roman Catholic and I felt it was important.*

Family participation in patient care may provide a sense of comfort, intimacy, and involvement when families might otherwise feel helpless. Caregiving activities can include assisting with face washing or hair combing, or even assisting with postmortem care. Family members can communicate with their loved one through speech, through touch, through visual aids (eg, pictures or photographs), and, as in this example, through song. The TABLE outlines practices that may assist in creating a caring environment in an ICU.

It is important to acknowledge family concerns and preferences for inclusion in activities at the end of life. Respect

for emotional limits is itself a caring practice. As Mr G acknowledged, "For some reason I did not want to be in the room. I was dreading, literally dreading, the moment when she passed away if I was in the room." Many family members, however, prefer to be present at the time of death. Creation of a supportive milieu around death in the ICU includes allowing for sacred end-of-life rituals. Usually, these are best conducted by the patient's own spiritual leader. ICU clinicians may want to be involved and, in the process, may be positively affected by participating.<sup>102</sup>

End-of-life rituals are not limited to patients and their families. Health professionals have not been prepared adequately to deal with the emotions associated with death and dying.<sup>103</sup> They may need encouragement and assistance in processing their emotional responses to continue to feel positive about their work with dying patients and their families. Support from unit leaders, hospital chaplains, or members of the ethics committee can and should be made available to ICU clinicians who struggle with ethical and other practice issues during their care of dying patients.<sup>36</sup> Physician and nurse colleagues can develop a philosophy at the unit level about what constitutes good end-of-life care and can receive comfort from debriefing discussions after the loss of a patient.

### CONCLUSION

The primary goal of critical care is to save the lives of patients who would die without its aggressive interventions. Four decades of experience have refined the responsibilities of physician and nurse intensivists toward those patients who live but cannot recover. For such patients, continued curative therapy is rarely appropriate. Intensive care may become aggressive symptom control allied with attention to family needs during the dying process. The focus of such decisions rests with patient wishes and family beliefs as to the patient's wishes, in active discussion with their treating clinicians. The willingness to undertake these discussions, and the skill to manage them effectively, have become core competencies for intensivists in the 21st century.

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**Other Resources:** For a list of relevant Web sites and video resources, see the JAMA Web site at <http://jama.ama-assn.org/issues/v288n21/abs/jel20003.html>.

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## Other Resources

### Web Sites

Americans for Better Care of the Dying  
<http://www.abcd-caring.org/index.html>

Mt Sinai Hospital, New York, NY  
Center to Advance Palliative Care (CAPC)  
<http://www.capcmssm.org/>

The Cochrane Pain, Palliative Care and Supportive Care  
(PaPaS) Collaborative Review Group  
<http://www.jr2.ox.ac.uk/cochrane/>

Beth Israel Hospital, New York, NY  
Department of Pain Medicine and Palliative Care  
<http://www.stoppain.org/caregivers/index.html>

American Association of Colleges of Nursing—End-of-Life  
Nursing Education Consortium (ELNEC) Project  
*Advancing End-of-Life Nursing Care*  
<http://www.aacn.nche.edu/el nec>

End-of-Life Physician Education Resource Center  
<http://www.eperc.mcw.edu>

The EPEC Project: Education for Physicians on End-of-  
Life Care  
<http://www.epec.net>

American Thoracic Society (ATS)  
Official statements, including *Withdrawing and Withhold-  
ing Life-Sustaining Therapy* (1991)  
<http://thoracic.org/statements/>

Growth House, Inc  
*Guide to Death, Dying, Grief, Bereavement, and Other End-  
of-Life Resources*  
<http://www.growthhouse.org>

### Video Resources

Society of Critical Care Medicine  
<http://www.sccm.org/>

*Compassionate Care in the ICU: Creating a Humane Envi-  
ronment*. Compassionate Care Video Series: professional and  
family versions. 2001. Sponsored by Ortho Biotech.