

# When Do We Stop, and How Do We Do It? Medical Futility and Withdrawal of Care

Moderator: Daniel B Hinshaw, MD, FACS; Panelists: Timothy Pawlik, MD, MPH, Anne C Mosenthal, MD, FACS, Joseph M Civetta, MD, FACS, James Hallenbeck, MD

**Dr Hinshaw:** Welcome to the general session entitled “When Do We Stop, and How Do We Do It? Medical Futility and Withdrawal of Care.” This symposium is one of an ongoing series of symposia focused on palliative care organized by the Work Group for Surgical Palliative Care, jointly sponsored by the College and the Robert Wood Johnson Foundation.

We are fortunate to be able to make this a highly interactive session, in which the Audience Interactive Response System will be used throughout the presentations to increase your involvement. Presentations include a brief introduction to the problem, followed by examination of the ethical issues involved in determining medical futility, how a determination of futility and the need for withdrawal of life-sustaining treatment is made, how withdrawal of life-sustaining treatment is accomplished effectively and compassionately, and, finally, the educational issues that add complexity to this topic will be examined.

By way of introduction, I present an illustrative case, drawn from my practice. A 56-year-old man presents 5 months after having had a palliative choledochenterostomy for a mass in the head of the pancreas and, unfortunately, a lymph node in the hepatoduodenal ligament that was positive for adenocarcinoma.

Since the operation, he’s had more than a 30-pound weight loss, and has increasing weakness and fatigue, especially in the last 2 months. For the last 3 weeks

before this presentation in clinic, he’s had significant, worsening postprandial vomiting. He now presents with a very large distended stomach with a mass obstructing the proximal duodenum. An endoscopist was unable to stent this, and the patient asked me to fix it. What should I do next?

1. Tell the patient it’s hopeless, there’s nothing more that can be done.
2. Place a percutaneous endoscopic gastrostomy for gastric decompression.
3. Determine the patient’s understanding of the problem; what does he mean by “fix it”?
4. Encourage the endoscopist to reattempt the stenting of the obstructed segment of duodenum.
5. Institute nasogastric decompression in anticipation of performing a palliative gastrojejunostomy.

It looks like there were two responses that seemed to be predominantly of interest to you: No. 3 and No. 5, and my own bias is toward No. 3. The issue here is to sort out what the real problem is. Is it about a series of inadequate treatment options, and I’ve listed several, or is it really about what the objectives are in my introduction; ie, issues of communication, advance care planning, and defining the goals of care? You might consider doing those other things, but there are some issues, in terms of communication, that need to be first addressed when someone comes to you in dire straits and asks you for help. This is particularly important to address before someone enters acute care or the intensive care unit, which will be a large part of the focus of the other presentations this morning.

So how do you go about communicating bad news? Well, the setting is extremely important. You need to find a quiet, private place, and you need to minimize interruptions. That means you’re not going to run out, responding to a page. Make sure that the timing is right

Received January 13, 2003; Accepted January 13, 2003.

Presented at the American College of Surgeons 88th Annual Clinical Congress, San Francisco, CA, October 2002.

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for the patient, and that there is enough time, both for the patient and for yourself, or the other people who will be giving the bad news, and then, you've got to give the news, if at all possible, in person.

In my training in palliative medicine, one of my mentors said that the most important tool that a palliative physician has is a chair. You need to sit down. He went even a step further. He said: "If the news is really bad, and the person is in bed, you kneel at the bedside below their eye level." So it's important to sit close to the patient and avoid bad body language. Don't lean back and cross your legs; but sit forward, give them your full attention, and if it's appropriate—and this is something depending on how well you know the patient—you may or may not use a comforting touch.

The next point is extremely important, but, again, you have to be sensitive to patient privacy and what the desires are. If it's at all possible, and if they want it, you should try to have either the spouse, or a significant other, or a support network, like the family, present. Then, before you give some information to the patient, you need to find out what they already know. It gets back to that question of, "Well, Doctor, fix it." What do you mean by that? What's your understanding of the situation? Then, be quiet and listen to the patient.

One of the things you can do to reduce, or at least break, somewhat, the level of tension, because they're expecting something bad, is to give them a little bit of a warning, prepare them with sort of a warning shot. "I'm afraid I have bad news," or "Things are not going as well as we thought." Then, you have to tell the truth. That doesn't mean you have to force the truth on patients, though. You need to find out how much information they want at that time, and how much they're able to bear. If you use certain loaded words up front, they won't hear anything more you say. Sometimes communicating bad news involves more than one session. Then, silence is extremely important, and it's very difficult, I think, as a clinician, or in any walk of life when you're having a deep conversation that's potentially stressful with someone, to allow silence to occur. The tendency is to try to fill that void with chatter. But if you've told something to somebody that affects their very existence, it's very important for them to be allowed to process it, respectfully, in silence, and if they then need to start crying, or respond angrily, or whatever, you need to be there, giving them your full attention, awaiting their response.

Another very important thing, where we have diverse cultures, is that in many cultures, information, including bad news, is processed through the family, or in a different way than we're used to in our Western orientation toward autonomy. That's particularly true in the Mediterranean cultures, so one needs to be sensitive to that and bring the appropriate people to bear in the communication.

Finally, you must convey hope. Now, how can you convey hope, as in the case of my 56-year-old with end-stage pancreatic cancer? It's not realistic to talk about cure, but there's always hope. There's always hope that you can reduce the amount of vomiting he has, make his pain better, and let him know that you're not going to abandon him. You're going to do everything you possibly can to give him the best quality of life that he has remaining.

Now, let's discuss advance care planning. This is the second case scenario I want to present as an introduction. This is an 81-year-old woman with advanced, widely metastatic breast cancer, refractory to therapy, who presents in the emergency department with progressive shortness of breath and debility. A 2-year-old advance directive exists stating her desire to "live as long as I have a meaningful quality of life, and heroic measures are acceptable as long as there is a chance of recovery."

1. The first option is to invoke her advanced directive and admit her to a general care ward for comfort measures only.
2. Ask the patient, "If your heart should stop or you're unable to breathe on your own, would you want us to do everything possible to get your heart started again and keep you breathing?"
3. Invoke the advance directive and admit her to the intensive care unit for workup and potential ventilatory support.
4. Discuss with the patient, and her family, their understanding of the situation, its meaning in relation to her disease process, and clarify her goals of care. (95% for No. 4.)

**Dr Hinshaw:** Everyone, I think, agrees with me that the other options are not really good. The reason I present it this way is that often advance directives are as

vague as the one I just described. One could easily, particularly in the heat of battle, see the advance directive, and, depending on their perception of her trajectory along her disease course, could assume there's more we can do, or there's really nothing more we can do, depending on what element she talks about, in terms of her quality of her life and what could be potentially done. I think that meaningful quality of life is a very vague statement, and this is one reason why advance care planning has some potential problems.

Advance directives, typically, are also referred to as a living will, and they may or may not include a durable power of attorney for health care designation, or the designation of the surrogate decision maker. What's interesting is that, in a relatively recent Gallup survey, less than 30% of the adult population in our country had actually executed or prepared an advance directive, so it's not something that's been widely adopted.

One might ask: What's the value of this? The typical thing that we think of with an advance directive is that it's going to help guide us in terms of determining when the do-not-resuscitate order should be written in the case of potential or apparent medical futility. Well, one can ask the question: Do advance directives make a difference? There was an interesting study from the University of North Carolina in which patients were interviewed prospectively about their preferences regarding aggressive measures to sustain life, and then followed for 6 months. There was actually no significant association between the patient's willingness to receive aggressive therapy and whether the patients actually received aggressive therapy when they were critically ill. In other words, whether or not your advanced directive was honored was a total toss-up in this study. So it was almost irrelevant, at least in this cohort, whether they had a formal advance directive or not.

I would argue that there is some value to an advance directive, and it's mainly for the patients and their loved ones, because if they go through the process of thinking about the problem, and communicating with their loved ones what their preferences might be, that collective memory will come back to bear at some point, when they can't express their wishes, regardless of what the written document says. Also, it will help them and help their loved ones be prepared for potential terminal illness. At least, be better prepared.

I think one of the big issues here is that the "D" word has to come out of the closet. People actually have to talk

about death. It's almost an anathema for physicians to talk about death, but our patients die. Everyone in the room here will die. That's the one thing that's guaranteed, but we don't like to talk about it. It's an obscenity. So, instead of asking somebody or giving them a menu of options: If your heart stops, would you want us to start it again? Well, of course, if I asked each of you that, you would say, "Of course I want my heart to continue to beat." But, then, if you put it in the appropriate context, when you die from this illness, which is a fatal illness, a terminal illness, an attempt to resuscitate your body will happen by default. It's a hospital policy. In most hospitals, if someone has a witnessed arrest, you have to resuscitate them, unless they have designated their wishes otherwise. So would you want this to occur? Perhaps, in that discussion, pointing out that it will not change anything, but potentially, be very disturbing for those caring for you and your loved ones who might witness it.

The final point I want to make relates to determining the goals of care. This always involves asking the informed patient, and surgeons are very, very aware of the importance of informed consent. This is a part of informed consent. Always remember the context. What is it that's realistic under the circumstances, what is it that's possible, and what is it that the patient wants?

If patient wishes can be put into a realistic context, you can have a real dialogue about determining the goals of care. So, for example, with the first patient I described, once he can articulate what he means by fixing it, then you can have a dialogue about your understanding of how this disease is progressing, and so on. When he comes to an acceptance of what it all means, then you can talk about some things that we can do to make a real difference for him, help him be more comfortable, help him have a better quality of life with the remaining life that he has. So a goal of care might be to reduce his vomiting to once a day, reduce his nausea, and get better pain control, for example.

So we're really confronted with both a dilemma and a challenge. I want to quote from an internist who wrote a letter to the editor in the *Annals of Internal Medicine*. This is a very nice summation of this problem that will be coming forth in the following presentations. There is a dilemma and a challenge.

In principle, people want a peaceful, dignified, comfortable death, but in reality, they don't want it quite

yet. They prefer life-prolonging care in the hope that their peaceful, dignified, comfortable death can occur later. We will have an impact only when we assiduously treat the uncomfortable symptoms of all seriously ill patients, whether they are receiving life-prolonging care, with its treatment-induced discomforts, or only palliative care.<sup>1</sup>

**Dr Hinshaw:** I'd like to introduce our first speaker. Dr Timothy Pawlik is a surgical oncology Fellow at the MD Anderson Medical Center in Houston, TX. During his surgery residency, he was fortunate to obtain not only basic research experience, but also a Master's degree in theological studies in ethics, at the Harvard Divinity School. So he brings the experience of a newly minted surgical trainee with ethics training to this discussion.

**Dr Pawlik:** Thank you. The ethics of palliative care and the topic of medical futility are complex issues that cannot be comprehensively covered in any single symposium. Rather, what I hope to accomplish this morning is to discuss the ethics of death and dying in the intensive care unit, and, in addition, I wish to examine the concept of medical futility, in particular, the conditions of determining medical futility and the consequences of such a declaration.

The nature of the patient-physician relationship is a fiduciary one. Physicians are expected to serve the best interests of their patients over their own self-interests and the interest of society at large. This relationship can usually be relatively easily maintained in the clinic and on the wards. The intensive care unit is an arena where technology and the acuity of the clinical situation complicates and intensifies the patient-physician relationship.

A number of factors make decision making around death and dying in the ICU even more ethically complex.<sup>2,3</sup> Often critical care technologies that support life also cause significant pain. Patients are frequently unresponsive, their earlier wishes are unknown, and traditionally, the ICU is seen as a special place of heroic measures, where life is sustained, not where care is withheld or withdrawn. Finally, the pace of medical intervention and care is often accelerated and does not lend itself to the deliberate, methodical decision-making process.

In spite of the clinically and ethically complex terrain, decisions about the foregoing of life-sustaining therapies and the implementation of palliative care are becoming more and more prevalent in today's ICUs. Surveys have

shown that between 40% to 70% of ICU deaths follow the foregoing of CPR or other forms of life-sustaining therapy.<sup>4,5</sup> So it appears that withholding and withdrawing of life support have become almost commonplace in American ICUs. Further analysis shows that there is significant variability in different ICUs in terms of their willingness to withdraw or withhold life-sustaining support. In fact, studies have shown that individual physicians' age, gender, specialty, marital status, and experiences of severe disease within their own family are all associated with their decisions to pursue either palliative or aggressive treatment when faced with terminal care issues.<sup>6-9</sup> This variability demonstrates that true practice standards do not exist in the area of foregoing life-sustaining therapy.

Given the lack of professional practice standards, the challenge of the ICU setting, and the nuances involved in deliberations about death and dying, surgeons are often ill equipped to confront the decisions to forego life-sustaining therapies. Traditionally a philosophical pursuit, medical ethics has been compelled to change, becoming more of a practical discipline. There is a myriad of ethical theories and perspectives, ranging from utilitarianism to virtue ethics to casuistry to principlism. It is this last mode of moral reasoning, the principled approach, that has been championed by Beauchamp and Childress,<sup>10</sup> and which has gained the most attention in medical ethics. It is for this reason that I explore, more fully, how the principles of biomedical ethics apply to decisions to forego life-sustaining treatments in the ICU.

The major ethical principles in palliative care relate to autonomy, respecting the values of the patient; beneficence, acting to benefit patients by sustaining life and treating illnesses; nonmaleficence, a correlative principle to beneficence, meaning to refrain from harm; and, finally, justice, the balance between the personal needs of the patient and societal resources.

Before embarking on our discussion, I would like to begin with a case. In this case, a 72-year-old woman with pancreatic cancer, metastatic to the liver, who has had an endobiliary stent in place, presents with decreased mental status, decreased urine output, and other signs of acute biliary sepsis. The family fears a protracted ICU stay, with an inevitably poor outcome, and, given her overall dismal prognosis, states that the situation is futile, and requests palliative care.

The housestaff sees a different story. They want to

treat the septic patient with IV antibiotics and ERCP and change the biliary stent, claiming that this is an acute episode that can be treated, and that she can still live another few months. You're attending on the service. What should you do?

1. Agree with the family that the situation is hopeless and there's nothing to do.
2. Treat her with antibiotics and pressors, but no more invasive procedures such as ERCP or a percutaneous transhepatic cholangiography tube.
3. Try to convince the family that it's not futile and treat the patient aggressively.
4. Initially treat the patient aggressively, but if she doesn't respond within an initial period of 24 to 48 hours, change to a more palliative approach.  
(60% for No. 4.)

**Dr Pawlik:** The results are similar to what I suspected. My wife, who is a nurse, agrees with you. This case highlights issues of autonomy, bringing up questions about a patient's self-determination and participation in end-of-life decisions, and issues of proxy decision making. Autonomy has acquired the meaning of privacy, individual choice, freedom of will, and the right to self-determination. Whereas paternalism dominated clinical medicine before the 1960s, since that time, autonomy has been elevated to its current preeminent position. Ethics and law have given primacy to patient autonomy, defined as the right to be a fully informed participant in all aspects of medical decision making, and a right to refuse unwanted, and even recommended life-saving medical care.

The principle of autonomy recognizes that each patient has a fundamental right to control his or her own body and to be protected from unwanted intrusions. So, when a decision to shift from life-sustaining therapies to comfort care is begun, the patient should always be directly involved in this decision-making process. Open discussions with the patients should help them decipher their exact wishes around end-of-life choices. If the patient is able to actively participate in the decision-making process, their contemporary wishes should always take precedence over wishes expressed in a previously written advanced directive.

Unfortunately only 60% to 70% of seriously ill patients are able to speak for themselves when decisions to limit treatments are considered.<sup>11,12</sup> As Dr Hinshaw al-

luded, only 10% to 20% of patients have even completed advanced directives, and these usually apply only to patients who are clearly terminally ill or permanently unconscious, categories often inapplicable to many ICU patients.<sup>13</sup>

Given this, physicians need to be aware of the concepts of substituted judgment and the best interest standard of decision making. Substituted judgment occurs when a surrogate attempts to determine what the incompetent patient would have decided, had that patient been able to choose. This can be used only if the patient was, at one time, capable of developing preferences and values, and left reliable evidence of those attitudes concerning their current medical condition.<sup>14</sup>

The best interest standard attempts to promote the good of the individual as viewed by the shared values of society. Such factors as the avoidance of death, relief of pain and suffering, preservation or restoration of functioning, and quality and extent of life are all usually taken into account.<sup>15</sup> The Quinlan and Cruzan cases firmly established the legal and ethical centrality of both autonomy and extension of autonomy through surrogate decision makers. Despite this, physicians do not always follow patient or surrogate requests. In one study, 34% of physicians were found to continue life-sustaining treatment despite patient or surrogate wishes that it be discontinued. In addition, 42% withheld or withdrew life-sustaining treatment unilaterally because they judged additional intervention futile.<sup>15,16</sup>

These are clearly alarming statistics. In deliberating about "when do we stop," the principle of autonomy dictates that the wishes of the patient directly, and through their surrogates indirectly, take a prima facie, although not absolute, precedence over the physician's opinion. Although physicians should not be forced to limit the care of critically ill patients when such care is available, physicians must also realize that the withholding or withdrawing of life support is entirely compatible with the ethical principles of beneficence and nonmaleficence.

The principle of nonmaleficence asserts an obligation not to inflict harm intentionally. It has been associated in medical ethics with the maxim *primum non nocere*, "above all do no harm." Morality requires not only that we refrain from harming people, but also that we contribute to their welfare. Such beneficial actions fall within the heading of beneficence. The principles of nonmaleficence and beneficence hold many implica-

tions for palliative care ethics. In particular, these principles are used to elucidate distinctions between withholding and withdrawing life-sustaining treatments and the distinction between killing and letting die.

Debate about the principles of nonmaleficence in foregoing life-sustaining treatments is centered on the omission-commission distinction, especially the distinction between withholding and withdrawing treatments. Many physicians feel ethically justified in withholding treatments they never started, but not in withdrawing treatments already initiated. Physicians find it easier to limit resuscitative efforts, such as chest compressions, defibrillation, or antiarrhythmic therapy, rather than to withdraw life-sustaining treatments such as mechanical ventilation, nutrition, or hydration.<sup>17</sup>

Physicians also prefer to withdraw forms of therapy supporting organs that failed for natural reasons, rather than iatrogenic factors, and to withdraw recently instituted rather than long-standing interventions.<sup>18</sup> Caregiver discomfort about withdrawing life-sustaining treatments appears to reflect the view that such actions render them more responsible, and thus more culpable, for the patient's death. The ethical haziness surrounding the distinction between withholding and withdrawing treatment can lead to an overtreatment in some cases, and delay the implementation of more appropriate comfort care.

Most ethicists have concluded that the distinction between withholding and withdrawing is morally irrelevant. Treatment can always permissibly be withdrawn if it can be permissibly withheld. This permits the possibility of taking the potentially life-saving step without being forbidden to reverse the decision if it proves, with further information, to have been the wrong choice.<sup>2</sup> This moral acceptability is also crucial in making treatment decisions in the face of the prognostic uncertainty that surgeons face every day. The distinction between withholding and withdrawing treatment does not provide an ethical justification for prolonging a patient's clinical course that will end in inevitable death.

When a decision to focus on comfort care is made, the concept of double effect is often espoused. The doctrine of double effect was formulated in response to the recognition that an act may have both a good and bad effect. It also serves to clarify the ethical distinction between killing and letting die. For example, administering morphine to a terminally ill cancer patient may be necessary to ease his or her pain, but it may also depress

respirations and hasten death. Is this killing or comforting the patient? The principle of double effect provides an ethical rationale to how such an action is justifiable and morally licit.

The action in question is permissible based on the fact that the bad effect, death, was merely foreseen, but not intended.<sup>19</sup> In addition, for the act in question to be ethically permissible, it must be the case that, first, the act itself is not intrinsically wrong; the good effect is produced directly by the action and not by the bad effect; and that the good effect is sufficiently desirable to compensate for allowing the bad effect. The concept of double effect is controversial, and critics argue that the principle is confusing and difficult to apply. It is not always easy to know whether a result is intended or merely foreseen, and some individuals argue that those who use this approach intend to hasten death at the same time that they intend to relieve pain. Regardless, in the principle of double effect, we can see the spirit of both beneficence and nonmaleficence. In deciding how and when we stop life-sustaining care, the surgeon must always tend to minimize needless suffering, relieve pain, and avoid interventions that are proportionally more harmful than beneficial, given the patient's overall prognosis.

Finally, let us briefly examine the principle of justice. Distributive justice demands the fair, equitable, and appropriate distribution of resources in society. In an era of cost containment, where a large proportion of health care expense is expended in the last days of a patient's life, physicians may feel pressure to factor in issues of distributive justice in deciding when to stop.

I believe that this can endanger the fiduciary nature of the patient-physician relationship, whereby the physician is entrusted to act solely on behalf of her patient. In general, rationing and distribution of societal resources should not factor prominently in a physician's decision to withdraw life-sustaining therapies and implement palliative care. One area of possible exception is the area of medical futility. Futile treatment or treatment that does not confer benefit to patients has never been regarded as something to which patients are entitled.<sup>20,21</sup> To assign such a right would be to confer a benefit to patients at odds with ethical traditions in medicine, ie, to offer something with no benefit, but with potential harm. In addition, it would waste society's resources at a time when resources are increasingly scarce. So, a declaration of medical futility would seem to be an ethically

acceptable rationale for physicians to withhold certain treatment options, procedures, or resuscitative efforts.

Many have argued that once a treatment has been deemed futile, medical professionals have no ethical obligation to provide it.<sup>21,22</sup> The claim that a treatment option is futile has serious ethical consequences for both the patient and the physician. Given this context, the foremost ethical concern now must be how we define "futile."

Before examining the definition of futility, let's look at another case. In this case, a 57-year-old gentleman who is status postcoronary artery bypass grafting, complicated by a sternal dehiscence, a rectus flap that has been necrotic, and a prolonged thoracic intensive care stay of 4 months, has a progressively downward course, with intermittent bouts of sepsis, decreased blood pressure, and occasional episodes of arrhythmias, which can be treated. His wife, who is the durable power of attorney, is emotionally, physically, and financially drained, requests that her husband be allowed to die, and requests no further use of the IV pressors or defibrillation. The cardiothoracic surgeon strongly disagrees. He's invested 4 months into this patient, and he acknowledges that although the patient is only making slow progress, he's still salvageable and wants to forge ahead. You're on the ethics committee. What should you do?

1. Acknowledge that the wife is the durable power of attorney, and respect and follow her wishes.
2. Obtain a psychiatry consult to see if the patient is competent to give his opinion.
3. Agree with the surgeon that the worst is behind him and to forge ahead.
4. Attempt to explore the wife's decision to seek a change in her husband's care at this time.  
(88% for No. 4.)

**Dr Pawlik:** Again, the result is as I expected. I use this case to focus discussion on medical futility. The whole issue of who decides, what constitutes a futile situation, and what a physician's responsibility is, once a treatment course has been deemed futile.

A futile action is one that cannot achieve the goals of the action, no matter how often it's repeated. The likelihood of failure may be predictable because it is inherent in the nature of the action proposed. Futility as a concept should be distinguished etymologically from impossible or hopelessness.<sup>22</sup> Futility does not refer to an act that is

physically or logically impossible to do, ie, walking on the moon or resuscitating the completely exsanguinated trauma patient. Nor is futile synonymous with hopelessness. Futility refers to the objective quality of an action; hopelessness describes a subjective attitude. In other words, someone can say, "I know this is futile, but I still have hope." The term *futile*, rather, is both descriptive but also operational. It denotes an action that will fail and that ought not be attempted.<sup>22</sup>

A number of ethicists have expressed concern that medical futility cannot be clearly defined, that it involves hidden value judgments, and that it may undermine the principle of patient autonomy. If futile treatment is defined as treatment that can no longer be expected to achieve beneficial ends, the question becomes what is a reasonable level of expectation, and who defines what constitutes beneficial ends. In this sense, futility has two aspects, one quantitative and the other qualitative.<sup>22</sup>

Quantitative futility focuses on the probability that a particular outcome can be achieved and involves the judgment that once this probability falls below a threshold, it is not worth pursuing, ie, is futile. The decision not to provide "useless" therapy requires two sets of judgments. The first involves setting the futility threshold. Some physicians may only invoke futility if the success rate is 0%; others will invoke futility for treatments with success rates as high as 10% or 20%.<sup>23</sup> A defined rate of success below which care would be deemed futile has never been agreed on and is fraught with problems of ambiguity and arbitrariness.

Even if a defined threshold could be agreed on, trying to predict patient outcomes reliably from various prognostic scoring systems is notoriously unsuccessful. Some have shown that systems, such as the APACHE system, have a positive predictive value of 80%, yet others have shown that critically ill patients, judged to have 0% likelihood of survival, actually have a 12.5% survival rate.<sup>24-27</sup> These scoring systems of prognostication also do not account for other goals that various treatments might be capable of achieving, such as keeping a patient alive long enough to see loved ones.

This brings us to the second aspect of futility, the qualitative dimension. Describing a therapy as futile incorporates a value judgment that carrying out the therapy is not worth it. In other words, usefulness or futility can only be judged relative to an end. This aspect concerns a judgment that an outcome will fall below the minimally acceptable level. The basic question becomes

who decides whether the quality of life associated with medical treatment is futile? Such discussion is particularly important because physicians consistently judge patients' quality of life to be significantly lower than patients judge their own quality of life.

One response to this question asserts that only patients should have the authority to decide what constitutes such a poor quality of life, below which care would be deemed futile. An alternative view is the position that, at some point along a continuum, the quality of life associated with the intervention is so poor that a decision to withhold or withdraw treatment no longer rests with the patient, but instead becomes the physician's prerogative. In support of this last argument, some argue that refusing to offer life-sustaining care to someone deemed terminal is not too dissimilar to the common practice of surgeons declining to operate on someone in the face of overwhelming risk of operative morbidity.

I believe that the problem with the second argument is its paternalistic nature. In deciding when treatment is qualitatively futile, physicians must begin by calling attention to the privileged position of the patient. Only patients directly experience the subjective satisfaction or dissatisfaction associated with their quality of life. Onlooker assessments of patient quality of life are limited. Different patients will have a different ability to tolerate pain, and rank the self-importance of communication, mobility, even levels of consciousness. Applying a public standard of qualitative futility may result in denying treatment that would enable the patient to lead the life he or she finds personally meaningful.

The concept of medical futility is not only ethically problematic but pragmatically ineffectual. Not unlike the word *murder*, the word *futile* is a tautology. Everyone can agree that murder, and in this case, futile care, is morally wrong. The real issue is how to define the term. In the end, the term *futile* eludes definition. The very word *futile* has a categoric ring that masks the more subtle ethical and clinical complexities facing the physician at the bedside. We need to treat futility as the courts treat pornography, acknowledging that while it cannot be defined, we certainly know it when we see it.<sup>28</sup> This approach acknowledges the value-laden, context-dependent judgments involved in decisions to withdraw life-sustaining treatments.

One word that has been proposed to possibly replace or augment *futile* is the concept *reasonable*, meaning rational, not excessive, and generally agreed on.<sup>21</sup> Reason-

ableness allows for more latitude than futility in that interventions considered unreasonable need not always be ineffective, and benefits considered unreasonable need not be incapable of being achieved.

In the end, the ethics involved in the decision to forgo life-sustaining therapies in favor of palliative care demands more than a respect of the four principles of autonomy, beneficence, nonmaleficence, and justice. It demands that the physician acknowledge the unique context that surrounds the care of each patient. The goal of the physician should not be to avoid value-laden judgments, but rather, through communication and compassion, to come to understand those values held deeply within the lives lived of each dying patient.

**Dr Hinshaw:** It's my pleasure to introduce our next speaker, Dr Anne Mosenthal, an associate professor of surgery at the University of Medicine and Dentistry in New Jersey, at Newark, and also the chief of surgical critical care at her institution. She'll be speaking about withdrawal of life support, when to do it.

**Dr Mosenthal:** Good morning. I'm going to carry on from Dr Pawlik's presentation. I'm going to take some of those ethical principles and bring them into more practical application on how to make decisions on withholding and withdrawing life support, and provide a framework to make these decisions in a clinical setting.

I'm going to start with a case of a 59-year-old man, a trauma patient who was the unrestrained driver in a motor vehicle crash, who arrived in the emergency room and on his initial evaluation, was found to have a pneumothorax, pulmonary contusion, multiple rib fractures, a concussion, and a radius fracture. His family arrived and informed the team that he had a past medical history of COPD, but he had never seen a physician for this, and the extent of the disease was unknown. He was intubated, on admission, for hypoxia. What should you do?

1. Continue all aggressive critical care?
2. Make the patient "do not resuscitate" immediately, but continue to support him?
3. Withhold any major new interventions but continue his present care?
4. Withdraw the ventilator in anticipation that this man's COPD is going to make him ventilator dependent for the rest of his life?  
(92% for No. 1.)



**Dr Mosenthal:** I think, as most of us would agree, at this point in this man's care we would all continue aggressive care, but I think that, even though that seems fairly obvious, we need to think about how we made that decision, and is it unreasonable even to consider withdrawal of life support at this point in his care?

We made that decision, I think, based on three things, some of which Dr Hinshaw has alluded to, and I'm going to elaborate on. One is, what is the likely outcome for this patient, and can we predict what the outcome is? I think, at this point in his care, it's very difficult to do so.

The second issue is, what are the benefits or burdens of the therapy that he's either receiving or we're contemplating providing for him? Third, what are the goals of the patient, and what is the acceptable quality of life that he would desire, given all these circumstances?

So what is the likely outcome for this gentleman, and what do we know, and how can we know? This is the next question for you all: What is likely to happen to this man?

1. Is he going to die during his hospitalization after a long ICU stay?
2. Is he going to survive but be ventilator-dependent and live in a nursing home for the rest of his life on a ventilator?
3. He survives, has a long ICU stay, but eventually goes to rehabilitation and returns home, but has diminished function and quality of life?
4. He survives, does well, returns to his previous function after a 3-month hospital stay?
5. We just don't know.  
(61% vote for No. 5.)

**Dr Mosenthal:** I think most of us would agree, 61%, that we really don't know. Although No. 3 is possible, he survives and eventually goes home and has diminished function is also quite likely. So it's very difficult to tell, and how can we make rational decisions about withholding or withdrawing life support if we really don't know what the prognosis is?

Can we be better at predicting the outcomes of some of these patients in the ICU? One way of doing this is to look at some of the objective measures available in the literature: Injury Severity Score, probability of survival, APACHE score. All these are useful for large groups of patients, with similar diagnoses, in predicting percentages of mortality or survival, but for an individual

patient, they're not particularly helpful. This man has an injury severity score of 17. His probability of survival is about 50/50. Not very helpful in this individual case.

In addition, there is considerable literature that physicians, despite the availability of all these objective scores, rarely use objective scoring in predicting prognosis, and we all generally use our clinical judgment and experience. So how, then, do we proceed? The second issue is what are the therapies that we're contemplating withdrawing or withholding? What are the benefits of these therapies, and what are the burdens? This is the second step in this whole decision process. Take, for example, mechanical ventilation, which is what we're considering for this man. The advantages or benefits are that it will prolong his life. It will support his physiology until he heals. The disadvantages are considerable. It's painful, causes great anxiety, and there are complications, such as ventilator-associated pneumonia. It may just prolong his dying process, which is really poor end-of-life care.

The third consideration is what the patient's goals and preferences are. Most patients want to live, no matter what; but for some patients, that's not the goal, and that's not the most valuable thing to them. Some patients only want to live if their quality of life is acceptable. Some people would not want to live if they were in a persistent vegetative state, if they were going to live in a nursing home, or be dependent in any way.

We need to understand, for each patient, what is acceptable to that patient. Do they have an advance directive that would be helpful? As we heard in the previous two discussions, advanced directives are not always helpful in a specific situation. We need to remember that death is not always the worst possible outcome for some people. In this particular case, the patient's preferences, at least immediately, were unknown.

Getting back to our case, by hospital day number 10, this man had nosocomial pneumonia, his respiratory failure had worsened, and he was developing multiple organ failure. The family has had several discussions with the staff, and they informed us that the patient's wife died approximately 2 years ago, after a laryngectomy, and that he cared for her in her last days of life, he would never want to be on a ventilator for the longterm, he would never want to be dependent and live in a nursing home, and he lives alone. Given this

new set of information on his course, what should we do?

1. Continue aggressive critical care, as we're doing, in the hopes that his multiple-organ failure will resolve and he will ultimately be able to come off the ventilator?
2. Do a tracheostomy, a percutaneous endoscopic gastrostomy (PEG) for nutrition, and continue care to see what happens?
3. Make him DNR, but continue with the ventilator and all other care?
4. Withhold any major new interventions, but continue what we're doing?
5. Withdraw the ventilator?

At this point in the patient's course, I think there are a lot more responses that seem reasonable, and we can see that, in the audience, it's about a third, a third, and a third for responses 3, 4, and 5, which would be make him DNR, but continue everything; withhold any major new interventions, but keep him on the ventilator; but a third of us would actually consider withdrawing the ventilator at this point. This demonstrates the variability, for a variety of reasons, in this type of situation.

Let's just take a little bit different scenario, and see if we would change our mind if this patient were 85 years old. Would we choose a different answer? These are the same answers, numbered 1 through 5. Let's have a show of hands for No. 5. As I would have expected, age does play a role in our bias, whether we like it or not.

Same scenario, but what if the patient were a 20-year-old man? How many people would pick No. 5? Fewer. How many would pick No. 3, DNR, but continue all critical care? How many would pick No. 1, continue aggressive critical care? I really raise that because I think it's helpful for us to see how much our biases, in terms of patient age, which, when we think about it, maybe should not have that much influence, affect our decisions in withdrawing and withholding of life support.

Another patient had a tracheotomy and a PEG inserted, we did make him DNR, and he did improve over the next 4 weeks, and then we hoped that he would come off the ventilator, but he did not, and he became a chronic ventilator-dependent person. At this point he was awake. His other organ failure had resolved, and he

was quite clear that he wanted to be removed from the ventilator. What would you all do at this point?

1. To avoid the problem, send him to a nursing home and let them figure it out.
2. Wait a little bit longer, and see if maybe we can get him off the ventilator.
3. Withdraw the ventilator.  
(60% for No. 3.)

**Dr Mosenthal:** Again, two-thirds of us would withdraw the ventilator, but I see that about a third would wait a little bit longer, which is interesting. We actually did wait a little bit longer, but he continued to be unable to wean from the ventilator. So we consulted the ethics committee and the psychiatry department, to evaluate if the patient was truly competent and not depressed, and after much discussion, it was believed that, really, it was consistent with the patient's wishes, both historically and presently, that he not remain on the ventilator, and it was withdrawn. He was medicated for his dyspnea, and he actually died, with his family at the bedside, 24 hours later.

Was this good end-of-life care? Well, we can apply the retrospectroscope and think many different things. If I had known that he wasn't going to wean, I would have withdrawn it much sooner. This man had a 6-week length of stay in the ICU, and ultimately died. This was futile care. He should never have been on the ventilator to begin with. Then, the other side is, well, maybe if I had waited longer, he might have survived and come off the ventilator. There really is no one right answer when you apply this kind of analysis.

So what are the challenges in this decision-making process, and how can we get around them? Well, the challenge really, as I mentioned, is that the prognosis is very often uncertain, and in the surgical ICU, we really don't know who is going to live and who is going to die on an individual basis. There's very little good information on quality-of-life outcomes, particularly in the ICU, but also about other surgical diseases, that help inform our prognosis and help us to advise the family.

Is withholding better than withdrawing? I think Dr Pawlik had a nice discussion of the fact that those are ethically equivalent, even though many of us feel more comfortable withholding something, rather than withdrawing it once it's started. The other difficulty is know-

ing what futility is. I think, again, Dr Pawlik alluded to some of the difficulties concerning that. And how can I know the patient's preferences? The vast majority of intensive care unit patients are unable to participate in the decision making, and you rely on the family.

The current practice, at this point, in intensive care units across the country despite these difficulties, shows that withholding or withdrawing life support in the ICU is really the standard of care. There was a study<sup>29</sup> done in 1998 on 5,900 dying ICU patients, and the vast majority, 77%, had some sort of life support withheld or withdrawn; only 23% had CPR at the end of life. So we really need to be able to do this and manage death in the ICU. Physician practice is highly variable. There are many, many studies looking at this. Most DNR orders are written just before death, within 24 hours. This depends, somewhat, on the specialty of the physician, surgery versus medical versus pediatrics. There are studies showing that if you're in a teaching hospital, your practice is different than it is in private practice, and a lot of this may depend on patient demographics.

This was mentioned earlier. Physicians prefer to withhold therapy, rather than withdraw it; and physicians prefer to withdraw therapy, if they do do it, in a particular order. Everyone is much more comfortable withdrawing dialysis or medications, and the last thing to be withdrawn is the ventilator. This is really based on our comfort level, rather than the ethical basis for this.

The SUPPORT study<sup>30</sup> really looked at a lot of these issues in great detail. It was funded by the Robert Wood Johnson Foundation, and the hypothesis was that the reason physicians have so much variability and withdraw life support late is that they don't know the objective prognostic information, and they don't know the patient's preferences, and if someone would communicate this to them, that would help. Then they actually provided this intervention, informing physicians of objective life expectancy and prognosis, and the preferences, but they found that, really, this had no impact on physician decisions.

Many of us have a lot of assumptions about the quality of life that the patient hopes for and what is acceptable. But there are many patients with chronic illness or disability who still would want to have aggressive life support therapy to prolong their life, despite our assumption that their quality of life is poor. So we cannot assume, for any given patient, what they would want.

We've already discussed futility. There is a lot of controversy, but essentially, a therapy is futile, rather than a whole course of care. But if you consider each individual therapy, it could be futile if it is unlikely to result in a successful outcome.

So let's talk about the decision-making process. First, we must establish the goals of care for the particular patient. In order to do that, you need to understand what the likely or possible outcomes and prognoses are for a given patient. I think, in our case, there are many different possible outcomes, and the family needs to be informed of the range of outcomes and the likelihood of one versus another, if that's possible. You need to elicit, from the family or the patient, their preferences, given the expected outcomes for therapy and what their expectation of quality of life is, and from this, develop goals of care.

Now, goals of care may be "I want to live, no matter what." Goals of care may be, "If I'm dying, I just want to be comfortable. I want to be able to talk to my family," so being on the ventilator would not meet the goals of care. For some people, the goal of care may be "I just want to survive the next 2 weeks to see my daughter get married." So these are highly individual and may have nothing to do with prolonging life.

The role of the physician in all of this is really to communicate possible outcomes to the family, or the patient, if they're participating, and to elicit patient preferences as the family understands them, and with this communication, establish the goals. Then, each therapy that you're considering withholding or withdrawing needs to be analyzed with respect to the goals, how much it will help, and whether it is likely to be successful. Each therapy should be discussed individually. One is not necessarily related to another.

So, does the therapy meet the goals? For the patient in our case, the goal was not to be in a nursing home and to live an independent life, and being on the ventilator for a long period of time was not going to meet that goal, as it turned out. So, in a sense, his ventilator support did become futile, even though he was not truly dying. Is the therapy painful? Does the burden of the therapy outweigh the benefit? Again, each therapy should be evaluated separately. Just because a patient is DNR and is refusing CPR does not mean they cannot have surgery to palliate a different medical problem. They can still be on the ventilator. Conversely, if you decide to withdraw the

ventilator, and the patient survives, they may still, for example, want to have CPR, or they still may want nutrition. So each one needs to be evaluated separately in this decision process.

Withdrawal and withholding of life support are ethically equivalent, as we just heard, and it's perfectly appropriate to have a time-limited trial of therapy to see if it meets the goals of care. If it does not, it can be withdrawn. If there is conflict between the physician and the family, or the patient, ongoing discussion is really necessary to revise the goals of care, because things can change, so that the patient really receives the appropriate care.

The physician is really critical here and needs to make recommendations, based on what she knows of the likely outcomes and progression of the disease, to the family about specific therapies. You don't want us to just ask, "What do you want us to do? Do you want me to give a blood transfusion? Do you want me to give this? Do you want me to give that?" That's not really appropriate communication. You're really there to advise the family and inform them so that they can make a decision with you and the patient.

So, in summary, the decision-making process around withholding and withdrawing is grounded in the ethical principles that we just heard about, and the decision process is really based on the likely outcomes, the patient's preference, establishing goals of care, and then examining whether the therapy meets the goals of care or should be withdrawn or withheld. This is really all accomplished through communication with the family. The fact that there is a lot of uncertainty regarding prognosis, outcomes, what patients would actually want, should not prevent this decision process from occurring.

**Dr Hinshaw:** Our next speaker is Dr Joseph Civetta, Professor of Surgery, and former chair of surgery at the University of Connecticut in Farmington, CT. He's had a long-standing interest in surgical critical care. His topic is withdrawal of life support and how to do it.

**Dr Civetta:** "He died peacefully in his sleep at home. It was such a blessing. I hope it happens to me that way." Such statements or variations on the same theme are often heard, but, in reality, that sequence is rare at this point in time. More often, patients undergo long courses, which include many difficult decision points requiring choices that are hard for caregivers, families,

and patients alike. The following case history exemplifies many of the difficulties encountered, along with my comments, and I hope it can serve as an introduction to an approach that may help direct our efforts more effectively in similar confusing cases.

An 81-year-old widow lived alone in her private home, although she was afflicted with a number of medical illnesses. She had had insulin-dependent diabetes for a number of years, significant aortic stenosis, supraventricular arrhythmias and congestive heart failure, prior transient ischemic attacks, and a cerebral vascular accident, yet she was able to function well and take care of herself. She developed vaginal spotting and went to see her primary care physician. It was ascertained that she had endometrial carcinoma and she was scheduled for a hysterectomy. On the morning that surgery was scheduled, she was informed that the most recent chest x-ray revealed lung metastases, removing the possibility of a curative procedure. An oncologist was consulted who advised three courses of chemotherapy. At the conclusion of these three courses, there was remarkable resolution of the metastatic lesions and he suggested three further courses of chemotherapy. During the first 3-month period of chemotherapy, each course sapped both her physical strength and mental acuity, although she was still able to live alone. At the time of her hospitalization for her fifth course of chemotherapy, her hematocrit was 23% and two units of packed cells were ordered. Because of the history of previous congestive heart failure, an order was written for furosemide at the conclusion of the blood transfusions. The medication was given at 11:00 PM. At six o'clock in the morning, a nurse, entering the room, noted that the patient was lying at the side of the bed unresponsive and in a pool of urine. It was not clear whether she fell on the way to the bathroom and became incontinent or became incontinent and then slipped and fell hitting her head against the side of the bed. She was in coma but the family was not notified. She had been scheduled for discharge that day and her daughter arrived with the intention of taking her home only to find that her mother was in coma. A CT scan revealed subdural and frontal hematomas and a neurosurgeon predicted a 2% chance of recovery and asked the family to decide whether an operation should be performed. At this point, I am going to list alternatives for care that are taken from a large Canadian study by Cook:<sup>3</sup>

1. Continue curative possibilities
2. Continue as is, not further
3. All but CPR
4. Withhold new therapy
5. Withdraw therapy

For the purposes of our discussion, I would like you to respond, not as a doctor making decisions for a patient, but rather be the daughter, who was asked in this real case. The results of the voting were that 65% chose No. 5: Withdraw therapy. Actually, by the time she consulted with her brothers, 2 days had passed; during that time, her mother emerged from the coma before the operation was performed, but she remained disoriented and delirious. The recommendation for burr holes was accepted by the family but, because of the earlier chemotherapy, her platelet count was considered too low to proceed. The burr holes were finally done 2 weeks later, but there was no improvement in her mental status. After another month in the hospital, the consulting physicians decided that there was no indication for operation and she was transferred to a nursing home for rehabilitation. At this time she was talkative but demented, had limb weakness, and was unable to live alone.

In the nursing home she remained dependent and incompetent. Chemotherapy was suspended. Her vitality and personality were gone. Her daughter noted "she is in a peaceful place, and waiting." Two weeks later she suddenly developed an episode of severe dyspnea. She was transferred by ambulance to the hospital. Chest x-ray revealed a pleural effusion totally filling the right hemithorax. A chest tube was inserted to drain the pleural effusion. Her dyspnea was relieved, but cytology revealed malignant cells. She was returned to the nursing home. Again, as a member of the family, what would you choose (we will use the same set of choices):

1. Continue curative possibilities
2. Continue as is, not further
3. All but CPR
4. Withhold new therapy
5. Withdraw therapy

In this situation, 55% chose to withdraw therapy, slightly less than at the first decision point. My reason to "borrow" the choices from the published study was to see if this group was similar in that there are numerous

individuals who chose each of the alternatives: of the 60 possibilities in Cook's study,<sup>31</sup> only one was selected by more than 50%, similar to the "splaying out" of answers here.

Although I was not involved in this case as one of the treating physicians, I had a very close personal relationship with the patient for 30 years and with her four children. One was a psychiatrist, another had a Master's degree in education, and the other two were lawyers. This well-educated and cohesive family was never asked questions such as: What would your mother want us to do at this time? Was continuing aggressive care futile treatment? Which of her current treatments could be considered helping her? What could be considered hindering proper resolution of her case?

These questions are important in deciding what care should be continued and when care can be considered "futile," placed in quotes because there are many points of view concerning futility. It is often difficult to decide when care should be continued because there is a chance of saving the patient's life AND restoring a quality of life acceptable to the patient or stopping because further intervention just will prolong the patient's dying but usually has no gain for patient, family, or caregiver. Futility only becomes an issue if families demand that care that seems useless and unreasonable be continued, leaving caregivers frustrated and causing pain and suffering for the patient and family and wasting scarce human and costly hospital resources. Part of the problem comes from definitions. It seems that life is still considered a categorical variable—either present or absent. I<sup>32</sup> have developed a quantitative approach to life based on a 0 to 100 scale. If someone has a chronic disease that interferes with normal daily living, we might think that he or she had about 80% of his or her normal "quantity of life." After a severe stroke, which leaves the patient with a dense paralysis and aphasia, perhaps the resulting quantity would be only 50%. But because some quantity remained, no matter how small, life would still be present. Quality of life can be considered on a 100 to 0 scale to define the lowest level that the patient would accept to justify continuing treatment. It is well established that a patient may decline life-sustaining treatment even if imminent death does not occur. If we believe that medical care can achieve the quality of life deemed acceptable by the patient, then care could be considered worthwhile (of course, we do not know that ultimately this desired overlap will be achieved, but the

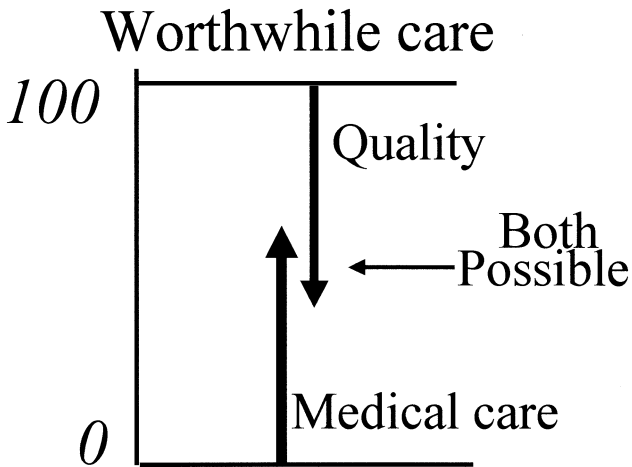


Figure 1. Worthwhile care.

belief serves as a rationale to continue (Fig. 1). We could then define futility as a gap between the highest level of functioning achievable by medical care for the patient and the lowest quality of life acceptable to the patient (Fig. 2). In this situation, medical care would be considered futile and could be discontinued. This gap may be considered a quantitative expression of futility. The answers to the questions unasked by her providers could help define whether care was worthwhile or futile.

I lived about 1,500 miles away and was only able to visit occasionally during these 6 months. But after one such visit, on the flight home, I began to think of all the medications she was receiving and tried to formulate some sort of benefits/burden balance. Perhaps there was

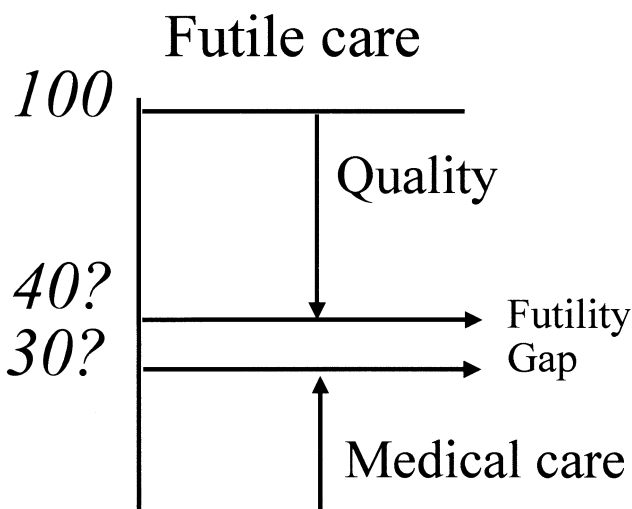


Figure 2. Futile care.

a way to analyze her current care and decide whether or not continuing was indeed futile. I started considering the final precursors to death. It seemed to me that there were certain ways that it would be desirable to die and others clearly quite undesirable. I thought that increasing obtundation, a sudden arrhythmia, or hypovolemia might be desirable. In her case, metabolic abnormalities such as hyperglycemia, hyperosmolar coma, or renal failure would all lead to a relatively symptom-free death. On the other hand, uncontrollable pain, nausea and vomiting, dyspnea, pruritis, delirium, and depression did not seem to me to be particularly desirable as the last events in anyone's life.

Keeping this distinction between benefits and burdens in mind, I reviewed her current therapy and realized that many of the medications that she had been receiving for reasonable indications earlier were now impediments to "desirable" ways of dying. Her insulin now prevented hyperglycemic hyperosmolar coma. Her antiarrhythmics and antiplatelet drugs may have prevented a fatal arrhythmia or stroke. Correcting electrolyte abnormalities might just prolong this process. If the patient developed a fever and infection, antibiotics might be effective in treating the infection and ineffective because they prevented a fatal outcome. Dialysis and diuretics may be indicated or could be contraindicated, depending on the patient's wishes and mental status. I will show you a list of medications: Which one do you think would be the most burdensome to you if you were now at the end of life—by preventing an illness that might let you die relatively peacefully? The choices are:

1. Anticoagulant
2. Antiemetic
3. Antipruritic
4. Antibiotic
5. Antiarrhythmic
6. Antiplatelet drug

The results of the voting show that you favored not taking anticoagulant and antiarrhythmics, with just a spattering of other answers chosen.

On the other hand, there were other medications that should and could be considered in setting up treatment plans that almost always would be beneficial. We say "comfort measures only" but it's really a lot more complicated than that. For instance, medications can be prescribed for somatic, visceral, and neuropathic pain.<sup>33</sup>

There are specific agents and dosing regimens that are unfamiliar to most physicians not well versed in palliative care. Analgesics, anxiolytics, antiemetics,<sup>34</sup> and drugs that can relieve symptoms, such as dyspnea<sup>35</sup> and pruritis,<sup>36</sup> are nearly always beneficial. Sedatives have an appropriate role near the end of life but, again, have to be considered in terms of the effect on consciousness, diminishing the ability of the patient to interact with family during these final moments.

Then I thought of my practice, particularly in the ICU, where many of our standard treatments could now be considered burdens at the end of life. But, how about the audience? Please vote for the treatment that you would consider the most burdensome. Here are the choices:

1. Endotracheal suctioning
2. Oxygen
3. Foley catheter
4. Turning side to side
5. Nutrition/fluids
6. Arterial line
7. Nasogastric tube

The results of the vote show 43% chose a nasogastric tube and 39% an endotracheal suctioning. Your choices are consistent with queries of ICU patients. Of all their experiences, patients usually remember endotracheal suctioning and respiratory physiotherapy as two of the most burdensome. Even turning patients from side to side, essential to prevent decubiti, can induce considerable pain in patients with bony metastases, abdominal distention, dyspnea, and other conditions common in dying patients. It seems deeply ingrained in us that we need to provide nutrition and fluids, yet, it is quite clear that patients do not suffer from thirst, that they often become quite uncomfortable in trying to eat and drink to satisfy both caregivers and family members, and usually develop euphoria rather than thirst when fluids are stopped. Oxygen may be comforting to a patient with dyspnea or confining if a patient feels claustrophobic. Medications given by any route other than intravenously will be burdensome. Even an extra peripheral IV is a burden because, when it eventually infiltrates, most often it will just be restarted, which is often painful as someone searches for quite some time to find a patent vein without considering whether it is really needed.

Much of our routine testing is also burdensome at the

end of life. We need neither laboratory tests nor x-rays to document the downhill course. But particularly in the ICU, the process of taking a chest x-ray can be quite painful in lifting the patient, positioning the x-ray plate, taking the film, and then lifting the patient again to remove it. Any method of blood drawing, whether a finger stick, venous puncture, or even withdrawing from an arterial line or central venous catheter, can be burdensome. The latter two are not burdensome during blood drawing, but if they fail to function, knee jerk reactions result in restarting them, often a painful procedure. Measuring intake and output is no longer necessary but devices such as a Foley catheter may either be beneficial in preventing the patient from becoming incontinent or burdensome if they are uncomfortable. Similarly, a nasogastric tube may be quite uncomfortable, but not as uncomfortable as persistent vomiting if it is removed. After scribbling down all these thoughts on the flight home, I called the patient's daughter the next day and discussed them with her. She and her brothers approached the physicians and requested that all of the medications be discontinued as well as the testing and treatments. Their conclusion that their mother would not have wanted these burdensome elements of care was unanimous and communicated to the physicians. But, the daughter, who lived closest, had to repeat their understanding of their mother's wishes at each nursing shift to each set of caregivers. The patient died in an obtunded state within 3 days. These events happened 9 years ago, before I was acquainted with the growing body of knowledge of palliative care. Particularly today, the End of Life Physician Resource Center (EPERC) ([www.eperc.mcw.edu](http://www.eperc.mcw.edu)) and Education Physicians on End of Life Care ([www.epec.net](http://www.epec.net)) make this information only a mouse click away for all of us. EPERC has a series of Fast Facts—one page of information about specific topics. An individual can also register and receive them by e-mail. I have found them very helpful in filling in the gaps in my own knowledge base.

In addition, in 1995, four of us at the University of Miami/Jackson Memorial Medical Center realized that we really didn't know exactly how to withdraw treatment, especially in the ICU. Dr Pat Caralis, chairman of the Bioethics Committee, asked Dr Philip Villaneuva, director of the Neurosurgical ICU, Dr Daniel Kett, director of the Medical ICU, and me to try and formulate a plan that we could use throughout the hospital. The

following sections contain a synthesis of the information from these three sources.

### **Discussion with the family and proxy**

It is important to make sure that the family understands that withdrawing care is not abandoning the patient. Time must be provided for leave taking. Caregivers should be aware of anticipatory grief and especially in differentiating this normal process from a treatable depression.<sup>37</sup> We should encourage people to use whatever rituals, music, or religious ceremonies that they feel can be of help.<sup>38</sup> It is also important to emphasize that analgesics and anxiolytics will be continued and to discuss the principle of double effect with the family. Respiratory depression has often been mentioned as a “bad” effect of morphine, but tachyphylaxis to the respiratory depression occurs quite quickly without affecting the analgesia.<sup>39</sup>

Families often look for direction; it is most important to relieve their anxiety and to reinforce that there is no “right way” to say goodbye. We should be sensitive to cultural differences that are and will continue to become more common given the changing pattern of immigration in the United States.<sup>40</sup> Three common patterns that I believe should be reinforced are family members who feel that they must be at the patient’s bedside at the time of death, families who want to wait perhaps in the waiting room but not at the bedside, and, finally, particularly in cases where a long drawn out course of multiple organ system failure has sapped the families’ emotional strength, those who want to go home because they have “had enough.” It is also important to emphasize that once treatment has been discontinued, there may be a variable time to death. Although patients who are receiving many different active treatments may die within minutes, other patients may linger for hours to days. It is not uncommon for families (and, for that matter, caregivers) to question whether they “did the right thing” in withdrawing treatment if death does not come quickly. If indeed the decision was carefully made, support for the family during this period is extremely important.

At the same time it is important to document the clinical findings, the discussions with the family, and the care plan in the chart.<sup>41</sup> If the family members wish to stay, support should be provided for children. Again, as families often look to us for direction, they can be encouraged although not pushed into touching the dying patient and talking to them. It is also very important to

describe what will be done in detail; because these things are familiar to us, we should not assume that families understand. First, the patients will receive premedication before withdrawing treatment in an attempt to ward off any distress. Exactly which treatments and which devices will be removed should be explained and, in particular, a discussion should be held concerning the withdrawal of ventilators.

Ventilator withdrawal can be subdivided into immediate extubation and what has been called “terminal weaning.”<sup>42</sup> There are advantages and disadvantages to both approaches. With respect to immediate extubation, if patients are conscious and have no secretions they may be able to talk with family members. On the other hand, after extubation, patients may develop distress or the “death rattle” from secretions in large airways. In “terminal weaning,” ventilator settings are reduced gradually or immediately but the endotracheal tube is left in place. Secretions are usually not a problem nor is there a “death rattle.” On the other hand, the presence of the ventilator and endotracheal tube create a scene that is not as natural as immediate extubation. Families should understand that symptoms will be managed but they should also be told that patients are not suffering if they are moving about or even gasping. An explanation of agonal breathing patterns can prepare the family so that they do not become anxious that the patient is suffering respiratory distress. At the time that the treatment will be withdrawn, the patient’s identity should be confirmed by another caregiver. If paralytic agents have been given to facilitate mechanical ventilation, they should not only be discontinued but reversal of their effect should be confirmed. Discontinuing ventilatory support in a patient who is paralyzed, in my opinion, is not covered by the principle of double effect. Death is the intended outcome because the patient is unable to breathe because of the administered neuromuscular blocking agent. With respect to premedication, it is important to know what doses the patient had been receiving, as many patients will be tolerant and need high doses to achieve an effect. Analgesics and anxiolytics should both be administered. Bolus IV doses followed by intravenous continuous infusions can be effective in eliminating distress. After administration of these agents, a few minutes should be allowed to elapse so that they may take effect. Additional doses should be at the bedside and a propofol infusion should also be available.

Next, after the patient is sedated or if the patient is



already in coma, restraints can be removed. Also, all tubes and devices should now be removed. The question of whether to remove or leave the endotracheal tube should have been answered in earlier discussions with family. Disable all of the alarms on all of the equipment, although the ECG tracing may be left on the monitor. All other displays should be discontinued. All active treatment should be discontinued. We have applied the term "life support" to many of our common ICU treatments. Because the opposite is now our intent, clearly there should be no distinction among what active intervention should be withdrawn. We should treat agitation or other signs that may signify real distress if suffered by the patient. On the other hand, we must remember that a certain amount of emotional distress is present in everyone at the bedside including the caregivers.

How should we approach this apparent distress? First, it is unlikely if the patient has been premedicated. Agonal breathing is normal and common; it is not easily relieved by narcotics and is not likely related to pain or suffering.<sup>43</sup> Before I knew these facts, I once tried to treat agonal breathing patterns but they persisted after the administration of 300 mg of intravenous morphine in 30 minutes. The fact that we were uncomfortable and persisted in giving repeated doses probably was transmitted to the family and increased their own discomfort.

The solution is the explanation of what to expect, leaving time for discussion and answering questions. A physician should stay at the bedside during withdrawal to provide this support to the family. On the other hand, what if the patient is truly suffering distress? Propofol is an excellent agent with rapid onset and these signs of distress are relieved quickly. An initial dose of 25 to 50  $\mu\text{g}/\text{kg}/\text{min}$  is reasonable; when propofol is used as an anesthetic, doses of 120 to 140  $\mu\text{g}/\text{kg}/\text{min}$  are used, to provide a reference point. I now have learned that large repeated doses of opioids may not work or may not be needed; they may stretch the principle of double effect and can raise legal questions or ethical uneasiness in increasing the rate of administration in patients who do not show signs of real distress.

### Final stage

When the patient actually dies, expect an acute grief reaction, even in a family who has been prepared and appeared comfortable with the decision.<sup>36</sup> Have tissues ready to absorb patients' secretions and also tears among family members and even caregivers. There is still a role

for oral suction and hygiene. Support should be available for whoever is at the bedside, including family and caregivers. Involvement from the clergy should be considered depending on the family's wishes. Allow the family to stay after death and be ready to answer questions.

Bereavement teams are now available in many hospitals. At Hartford Hospital, ICU caregivers have been prepared to provide emotional support first. There are also packets that contain a signed sympathy card; a booklet entitled "What to do next" that describes contacting funeral directors, etc; and a resource list. They offer mementos to the families including a lock of hair or a hand print in modeling clay. After an initial period of unease, the staff members have found that families are intrigued and quite accepting. The staff then felt more comfortable and now it is a common practice to have hand prints made for each of the grandchildren. Later, followup cards are sent, as are invitations for memorial services including support groups for particular patient types including healing hearts, trauma support, and donor services.

All too often once the event is over, we move on to the next case. A condolence letter should be considered; there are two goals: one to offer tribute to the deceased and the second to offer comfort to the survivors.<sup>44</sup> Such letter should acknowledge the loss and express sympathy. If possible, note special qualities of the deceased and recall a special memory. Offer help, not with a generic "If I can do something, please call" but be specific. Finally, end with a phrase of sympathy.

As we know, nothing is ever new. In 1985, Professor Dunstan<sup>45</sup> said, "The success of intensive care is not to be measured only by the statistics of survival, as though each death were a medical failure. It is to be measured by the quality of lives preserved or restored; and by the quality of the dying of those in whose interest it is to die; and by the quality of the human relationships involved in each death."

Dying is a normal part of life; dying in a hospital or an ICU makes it harder to truly believe and internalize this simple fact. I truly believe that we must devote more time in learning the attitudes, knowledge, and skills necessary to take care of the dying patient, even at the expense of learning so much about curative efforts in esoteric diseases.

**Dr Hinshaw:** Our last presentation before the panel discussion will be the challenge of educating housestaff about medical futility and withdrawal of life support, by

Dr James Hallenbeck, from Stanford University and the Palo Alto VA health care system. Dr Hallenbeck is the director of palliative care at that facility. He's a member of the department of medicine at the university, and is a leader in developing palliative care training programs within the Department of Veterans Affairs.

**Dr Hallenbeck:** I'm grateful for the opportunity to speak with you today. I'm grateful for the invitation, and I'm particularly grateful to my colleagues for dealing with all the difficult stuff, the ethics, the difficult problems of prognostication, and how to withdraw support. I feel I have a relative luxury to talk to you about education.

In working in education, one of the things I've noticed is that most of us, in our professions—I'm an internist—we develop scripts when we're teaching housestaff or others. Although the title was "Teaching Housestaff," I would argue that housestaff are also teachers. Housestaff teach medical students. We're all, in some capacity, teachers. But we develop scripts. I developed a script when I was a resident. For example, "We have an upper GI bleeder. What do you do?" I'd say, "Well, first you've got to type and cross, and then you've got to do this and that." You've gotten a lot of information over the last hour and a half. When you go back to your facilities, what might you do differently? How might you incorporate this, in some way, into your teaching, in whatever capacity you're working in health care?

How many faculty do we have here working with housestaff in some capacity? How many housestaff or fellows? A few. Any medical students? A few, too. Great. So all of you will be teachers in some capacity, and I want to encourage you to think about it. I would actually encourage you to write down on the back of something, "I want to try to do something different." In my opinion, this session would be an educational failure if you leave here, and you do absolutely nothing differently. I do hope it was entertaining, I hope you're having a great time, but I think the real proof is in the pudding. Will you be doing something different?

So here is my case. This is a real case from about 2 months ago, when we were called by a palliative care consult team to see a man on the cardiothoracic surgery service. He was an 83-year-old with a 4-months post-valve replacement for critical aortic stenosis, who was on chronic ventilatory support. He had suffered multisystem failure and was now thought unweanable. His wife was extremely angry at the cardiothoracic surgeon for

doing the surgery and then lying about his prognosis; she asked that the tube be removed and that he be allowed to die with dignity.

That was the case that we had, and you could analyze this case very much along the lines that earlier speakers have. What are the ethical issues? What is this fellow's prognosis? How might it have changed over his trajectory? Then, if you were to withdraw support, how might you do it?

But I want you to look at this with a little different eye. If you were now the attending, or perhaps you're the chief resident on the surgery service, and you're now looking at the next person down on the totem pole, what would be your script? What would you teach that person? What are the issues that you might address? So, in teaching about possible ventilatory failure, what topics might be the most important to address?

1. Relevant ethical principles
2. Proper drug use for palliation, postextubation
3. Communication skills
4. None of the above
5. All of the above  
(72% for No. 5)

**Dr Hallenbeck:** My own preference would, indeed, be all of the above. I think all of these are legitimate, although, certainly, you might want to change your script a little bit. It would be fine to develop a script that focused primarily on ethics. It would also be fine to talk about how we might do this, and it would also be fine to talk about what the communication issues are here.

I'm going to talk a little bit about education in this area, relative to knowledge, attitudes, and skills, and a concept that's been important to me as an educator, which is looking at overt and covert tension in education. What are the educational challenges, particularly around this difficult area of treatment withdrawal in general; with some presumption, fear, and trembling on my part, as an outsider, as an internist, what the particular challenges might be for surgeons; and then, what are the challenges specific to the decisions that we've been talking about today, such as ventilator withdrawal.

Think about, in that case, or in this topic area, what the most important area of knowledge is for learners to possess? Certainly, an understanding of relevant ethical principles, as was highlighted initially, a knowledge of relevant therapies, the role of opioids, and the roles of

sedatives, for example. And, as I think we heard, particularly in the last presentation, a knowledge of relevant support systems.

One of the things I've learned, particularly around very difficult decisions like this, is you cannot do it alone, or, if you do, you do it at great risk. So how do you involve the social worker, the chaplain, the support system that might be most appropriate for a person of some other culture, a cultural guide to help you on your way.

Attitude objectives in education are some of the most difficult and misunderstood objectives. A rather simple way to think about it is you want to wonder about your audience. It might be the housestaff before you. What attitude do you think they have, and how would you like that to shift? That, again, is a little presumptuous, and perhaps a little bit arrogant, but certainly, in designing an educational intervention, that's a critical step for me.

One that I would suggest would be that withdrawal of support is purely a medical decision. If your learner has that discussion, as you heard, a big emphasis in today's talk was, no, in fact, although there certainly are medical facts and decisions to be made, the goals of care by the patient and family are also critical to this difficult decision.

Another attitude that I find—and I'll give you a little more data on this in a minute—is that previous experience and training for a physician was adequate in addressing this issue. I've made it through residency. I made it through chief residency. I'm now an attending physician, so I must know how to deal with this, whether or not, in fact, you ever had any training on that in your residency training. That's an attitude problem.

Another mistaken attitude is that treatment withdrawal is solely an ethical problem. As was well highlighted in the earlier presentations, ethics are indeed important, but a lot more is involved in this than simple ethics. How to do it, how to deal with the family, and how to support the family are all very relevant to such a difficult decision.

And then, "It's not my job." We have a palliative care consult team, and we want to help people, but I hope that palliative care, as consult teams become more common, does not take away from the primary physician having the responsibility to work with patients in dealing with the problem. So when I get a consult from someone who says, "Well, you know, I haven't really talked to them about hospice, end-of-life care, or whatever. It's not really my job. I've got to get back to the

operating room," I have an attitude objective in my education in working with that, whether it's a surgeon or an internist.

Surgeons, I think, are really role models in medicine for teaching skills. Certainly, I learned in my surgical rotations as an internist, why I should not be in an operating room, because I was such a klutz, and I was really respectful of the way that surgeons learn to impart skills, and I would suggest that surgeons really could build on that in some other domains, particularly communication.

What are the skills necessary for dealing with such a difficult decision as, perhaps, a ventilatory withdrawal? One that I'll talk about a little bit more, in a moment, is the ability to address the cognitive and affective components of communication. You might even work with housestaff, rather than just talk, as we heard, in generalities. "Well, you might want to do some morphine, but perhaps a little bit of this, or you're going to do that," say, if you were teaching this in a noon conference, "Why don't you write an order set? How would you write your initial orders for doing this?" Then they actually can practice the skills, and you can comment on it. "Gee, how did you pick that opioid dose? Where did that come from? How might you titrate that up?" That's the same concrete kind of skill learning. Trying it, watching, and getting feedback from the mentor are critical for that kind of skill training.

Access skills. Demonstrate the ability to access support for a grieving family. Would you know who to contact? For example, my sister has multiple sclerosis, and let's say she was dying. Would you have the skills to know how to access someone from a multiple sclerosis society who might come and help? Or if you have a child who is dying from some rare congenital abnormality, there's probably a support group for that society that might come, or spiritual support for that patient. Accessing the necessary support is a skill.

How would they find it? Do they have the skills to go to the Internet, put in the word, find the support group, and find the local chapter; and if the family wanted that, to say, "Would it help to have someone from the local MS society, or whatever, come out to be with you, to help you with this?" or "Would it help to have someone come from your church to be with you?"

Education, to work well, requires tension like a battery. So, when I'm working with a learner, one of the first questions that I ask is: Where is the tension in the

learner? Now, I have to say, again, as an outsider, when I see the surgeons rounding in our ICU, what I see is a lot of tension. There is a lot of uptightness there, and I think it's ripe for learning, but it often is not directed specifically to these kinds of issues. So you have to identify where the tension is, if you are going to successfully engage it for education.

One way to think about that is in terms of overt and covert tension. Overt tension is that which people identify as the problem. When we get a palliative care consult, it's often along the line of, "Well, Dr Hallenbeck, you've just got to go see this guy. You know, they just don't get it. I think they're in denial. If we don't get this straightened out, we're going to trach this guy, we're going to have to put a PEG tube in him, and his sodium's falling, and if we don't, he'll lose capacity, and that could be really tough. So you've got to work your palliative care magic in order for us to take care of the problem." That's the overt tension. In doing palliative care consults, we're very careful to address that tension. You want something. You want to clarify some issues.

The covert tension is usually the unspoken, and often, semiconscious or unconscious tension that's there. It may be, "I feel way out of my league. In my training and residency, I had no preparation for this." The ethicists may say—and I would agree from an ethical point of view—that treatment withdrawal and not instituting treatment are morally equivalent, but is it the ethicist who is going to turn off this tube, and the person will be dead in 2 minutes? It sure feels different to me. That's an affective component on the part of the learner or the housestaff. "It feels different, and I don't know how to deal with that." That's the covert tension that's there, and that's where the juice is for learning. The question is: How can we engage that?

Related to this covert tension is the concept of subtext, and, often, the subtext around these difficult decisions is emotionally charged. It's truly often dynamite, but it's often not addressed. It's often not addressed in patients and families and in ourselves. So, in the particular case that I introduced my talk with, when I talked to the wife, she said, "You doctors are just using him as a guinea pig. Now you just want to get rid of him." What is the emotional subtext there? Anger, upsetness, hurt. How do you think the surgeon felt in hearing that? What was his emotional subtext in hearing that? Defensive. "You don't understand." Frustrated. "Do you know what critical aortic stenosis is really like, lady?"

So it's a skill to figure out when to address this emotional subtext or not. Studies of physicians in general have noticed that physicians tend to address the cognitive aspects of communication to the exclusion of the affective. What we see in our palliative care unit is, often, when people are dying, a family member—since we're in California, they're usually from the East Coast—flies in, and says, "Goddamn it, I want an IV, and I want it now."

We face a choice how to respond. One choice is to say, "Well, you know, randomized controlled studies have not definitively demonstrated that IV therapy at the very end of life is helpful." That's addressing the cognitive part. But addressing the affective might be, "You seem really angry or upset. How long has it been since you've seen your dad? Wow, I bet he's changed a lot, hasn't he?" And that may be the whole issue. This person may have been trained, in a sense, to talk through therapies, which is something I commonly find, to get to us, where they learn how to talk doctor talk, when what the person is saying, the subtext, is, "I am feeling overwhelmed by this, and I need to do something to advocate for my dad, and this is the only thing I know how to say." You do need to address cognitive aspects, but watch for whether you should be addressing the affective subtext.

We are going to rank your knowledge on some of these areas. On ethical principles related to treatment withdrawal, rate your own knowledge:

1. Minimal. Inadequate.
2. Barely adequate and struggling.
3. Adequate.
4. Superior.
5. You are a master.

So people think, "Well, I'm pretty good at this." The majority of the people, 52%, believed they were adequate, but, notably, almost a third thought they were struggling. One question I would have for you is: How would you adjust your curriculum, based on which group of learners you had, predominantly?

If you had people who were superior or masters, maybe there is still something they can learn. For the two masters out here, maybe there is a different trick on how to teach this. That's what you may be able to learn. But it may also be, as we have found, that particularly attending physicians tend to overrate their absolute mastery, and maybe it's an attitude adjustment, and you may not know quite as much as you think you know.

The next one, getting to the nitty-gritty, please rank your knowledge of drug uses for dyspnea and agitation from 1, minimum, to adequate, to 5, the master, the Jedi master. I'm going to show you some data that will relate to this, for internists, in a minute.

Again, most of the people are in the middle of the pack; 46% say 3. Now I've scared everybody. Nobody wants to be a master. Sorry about that. There is, obviously, no right answer to these. What I am suggesting is, depending on where people think they are—and I don't really know, there really may be a Jedi master out there—you may want to adjust the way you teach them a little bit.

Next, rank your skill in using communication skills such as the one that I just mentioned. Do you know how to address cognitive and affective components, address goals of care, as reported earlier, from 1, minimum and inadequate, to Jedi master?

Compared with the other two questions, this is a little more confident. We have one or two people who did admit to mastery; but almost 50% felt they were superior. This is not uncommon in communication skills. Indeed, when teaching about communication skills, we have to start by recognizing that you did not get this far in medicine without having excellent communication skills. So you never want to give the impression, when teaching about this, that you, the group out there, are somehow poor communicators, because I really believe you are quite masterful in that. Rather, I think what's important to highlight is this is really difficult stuff. This is, as someone I worked with said, "high-level" communication. It requires special skills around such a difficult issue, and that's what we really need to stress.

Now for comparison, rank your skills in teaching communication skills from 1, minimum and inadequate, to 5, Jedi master. We have a sense of where this audience feels they are in ability to perform, but how about teaching? Do you have your scripts down for how to teach communication skills about these issues?

This is quite common. We're back to the middle of the pack. About 50% answered 3, that it was adequate; but there is a little bit of a gap there, and appropriately so, I think, between the ability to actually do excellent communication and the ability to teach it. That suggests there is some tension, and it suggests that maybe some people in the audience want to work a little bit more on what my script would be. How would I teach this at the bedside? When you're going around in ICU rounds, how

would you model, for example, addressing cognitive and affective skills?

My impression is that often it is just not done in didactic forums such as this, but through a process of modeling. Perhaps laying out, when I go in to talk with them, something to give them the idea of what's a cognitive and what's an affective domain. "I want you to watch how I do that, and see the choices I make as to when I address cognitive versus affective components of communication." That might be an example of a skill in this area. So this leads up to some general challenges in palliative care education that I'm going to zero in on. They relate to something that some people call the arrogance and ignorance phenomenon and the "hidden curriculum."

These are some data from a study<sup>46</sup> that I've been involved with that David Weissman, referenced earlier, is really the principal investigator on. We have had a project, sponsored by the Robert Wood Johnson Foundation, where we have been working with internal medicine residency programs across the country to incorporate more palliative care education. We've worked with just about half the residency programs in the country. As a part of that, we offered, from PGY-1s through faculty and fellows, a 35-item test, across the country, with an N, as you can see, of about 5,000 or so. This is a very large study that looked at common domains in end-of-life care: pain, nonpain, communication, and the terminal care knowledge base.

In all domains, the faculty knew more than the interns did. That's really good news, and, in fact, if you apply a p value to that, it is significant. Internists, at least, learn something over 3 or 4 years of residency. But are you overwhelmed by the extraordinary knowledge base of the faculty relative to the interns? The PGY-1s got 52% of the pain questions correct, but the faculty only got 60.5%; and these questions were carefully done to be basic, basic questions we believed all interns should get approximately 90% to 100% correct.

We also asked questions about how worried you are about this stuff. What we learned is that, in a linear fashion, the interns, and then the second-year residents, and third years are really worried. They know they don't know much about pain, and they know they're struggling with communication. In a study I was involved in, we found they're aware they know very little about active dying, and they're worried, and they have overt tension.

What do you think we learned from the faculty?

"We're fine." The faculty said, "Yeah, I not only know this stuff, I can do it. I can teach it." "What, me worry?" as Alfred E Newman used to say.

So that was important for us in designing curriculum. What we know is that interns, who are struggling on a day-to-day basis with this stuff, are like little baby birds with their mouths open. You just need to drop the food in. They're really ready for this learning. Frankly, the larger challenge is working with the faculty who are the teachers of those residents who have less overt tension for learning in this area. We think the phenomenon is that simply by being anointed as faculty, they have been cultured into the belief that they must know this stuff, and it's sort of a self-fulfilling prophecy. When, in fact, I will tell you that my education, as an internist, in anything related to palliative care was abysmal. It was absolutely horrific. It wasn't until I was dropped into a nursing home and took over a hospice that I recognized how incredibly poorly I had been trained. So this raises the issue of the curriculum or the hidden curriculum. End-of-life care issues, in general, are often relegated to the hidden curriculum, not really worthy of formal instruction or modeling by attendings, but are passed on by modeling by residents and students. So for the attending surgeons out there, you understand very well what modeling is. You know that you need to be in the operating room and say, "See, when I cut it this way, it works right, and there's not a lot of blood all over the place. Do it like that." That's my internist's version of what I think you do.

My question is: Are you doing the same things in this area? Are you modeling talking to dying patients? Are you modeling sharing bad news? Are you modeling how to establish goals of care, which I would argue is equally critical? And the reference that I want to share with you is a study of surgeons, done not too long ago by Rappaport and Witzke.<sup>46</sup> They found that 84% of junior and 50% of senior surgery residents reported never having heard an attending discuss how to deal with a terminally ill patient. Never.

In this study, residents were asked how often they were with the attending when he or she talked with the dying patient. Among junior residents, 64% said less than once a month; for senior residents, 43% said less than once a month. What this means is that many critical palliative skills, how to treat dyspnea, how to treat pain, how to share bad news, definitely how to pronounce a patient, are relegated to the hidden curricu-

lum. These skills are passed down in the very, very shallow soil of the residency program. How I learned how to pronounce a patient was, I asked my senior resident, during a noon conference, while he was chomping pizza, when I got my first call as an intern, "How do I do this?" "Well, what you do is you kind of go in there, and you do this stuff, and then you pronounce them dead."

Think about that for a minute. I don't know what impact that has on the patient or the family. If there is a sacred moment other than birth, it must be that moment, and to have that relegated to something that is passed down in that way is a shame. So do they ever have an opportunity to see you, as attendings, to see how you pronounce a patient, how you deal with these difficult things? Look for those opportunities.

Now, having gone totally out on a limb, I'll saw it off, and comment a little bit on special challenges that I've perceived in working with surgeons. It has been observed by some that surgeons tend to work in a somewhat hierarchical organization, which may inhibit free discussion of controversial issues such as we're talking about today. As I recall, from my surgical days as a house-staff, where the medical student would say, "Should we—do you see the tube?" "Do you see the tube?" "Do you see the tube?" It went all the way up to the chief resident, "Stop the tube." "Stop the tube." "Stop the tube." Does that sound at all familiar? Are they still doing that now? That sort of inhibits free-flowing conversation.

Surgeons are, to their credit, task-oriented people. We need people who literally know how to fish or cut bait. Withdrawal of support issues may be linked, at least emotionally, to earlier actions of surgeons. I think this is, in my experience, one of the biggest differences between surgeons and internists. When we deal with, for example, ventilatory withdrawal in someone with COPD, with internists in the ICU, they don't have the sense of "I caused this COPD," but in the patient that I started this discussion with, the subtext for the surgeon was, "I operated on this guy when he was, the day before, out mowing the lawn. She's blaming me for that and saying I did this to him." That has a totally different flavor to it than he got COPD because he smoked five packs a day. We have to recognize and respect that.

Surgeons, from my internist's perspective, seem to sometimes have trouble dealing with those emotions. Maybe I'm wrong on that. So, in this case, the wife said, "He was mowing the lawn, and now you've made him a

vegetable.” When I talked to that very wonderful surgeon, he said to me, in great frustration, “She just doesn’t get it. It was a risk, but I thought it was a greater risk not to operate. You know what critical aortic stenosis is like.” And I did. As a physician, I knew, and frankly, it made sense to me. I could not see anything that the surgeon had done, but I can guarantee you this affective milieu affected this total decision making, but it remained largely part of the subtext.

So, finally, some challenges specific to difficult decisions. Particularly in looking at something like ventilator withdrawal, I’ll point out that the action is usually extremely discrete and clear. The tube is either in or out. Dialysis is either on or off. But, as I think was highlighted through the earlier discussions today, these discrete actions must occur in an environment of uncertainty and ambiguity. What is there uncertainty and ambiguity about? Frankly, while we have these concepts, and I certainly support them, in principle, of autonomy, frankly, many people really don’t know what they want. It’s not just a question of getting it. Patients often strike me as deer in the headlights. They never thought about it. They seem unprepared for the terrible decisions in which they must participate.

Certainly, there’s uncertainty as to outcomes. We don’t always know when people are actually going to die, but I would suggest there is a bigger deal. We don’t know what it means to be dead. If we talk about evidence-based medicine, we like to think about what the outcome is of this arm of the protocol versus that. Well, we don’t know. We may have beliefs about what it means to be dead, whether we’re going to be in heaven or hell or nowhere, but we don’t know that, and that’s almost never raised. This may all be very silly. If it really is all wonderful for any of us, why are we agonizing about this? We just don’t know.

People often have ambiguous feelings, particularly around a difficult issue like ventilatory support, in the face of prognostic uncertainty. When a decision is finally made to withdraw support, sometimes the people who are fighting the hardest to keep the person alive then have a sort of subconscious vested interest in seeing that the decision was right, and that decision is validated by the fact that the person dies on time. So, in fact, if the tube were withdrawn, and they died promptly, the clinicians and the family, might feel validated. If they don’t, maybe it was a wrong decision, and that causes some churning.

Families can be ambiguous in that, while they’re, almost without exception, advocating as best they can for the good of the patient, they also are exhausted. They also are suffering. They can have ambiguity in that they want their suffering to end as well, and that may make them feel incredibly difficult. How do they balance their advocacy for their loved one with the fact that they want this over because they, too, are suffering miserably? From that can come a lot of guilt, which may or may not be addressed.

Finally, I don’t think we really know, in an absolute sense what the right thing is to do. That’s probably a simplistic way of boiling down ethics. We are just beginning to develop the principles. I don’t know if you know, but it was alluded to, the concept of substituted judgment. This was not inscribed as the 11th commandment. The first reference that I’m aware of, in American ethics and law, to substituted judgment occurred in 1985 in a case in Massachusetts. We’re all very new at this. We didn’t have to invent this stuff, simply because this didn’t exist before about 40 years ago. In that sense, I think we all have to cut each other a lot of slack. We’re struggling with these very, very difficult problems, and we’re still working out the rules.

In summary, what I would argue is, for very difficult decisions like ventilatory withdrawal, what is required is exquisite competence, not just basic understanding. For those of us who work with patients who are at risk for something like ventilatory withdrawal, we need to work toward that competence. If we don’t have it, one of our skills must be to figure out how to access it. I would argue that, although ethics committees are wonderful, and ethics consultants are wonderful, I also think there are others who might also be of assistance. I predict that in the future, most hospitals will have palliative care consult teams that will be able to assist people with these extremely difficult decisions.

So here’s a summary checklist. As you leave this conference I’m hoping that you’ll have an idea that you want to try this differently; you want to do one thing differently. It could be in the area of knowledge. Maybe you were really interested in the concept of double effect. How might you incorporate that into your teaching?

It might be about proper drug use. How often does morphine lead to hastening of death? What are the data? It’s often invoked in the principle of double effect. I can tell you there is virtually no evidence that morphine substantially hastens death when appropriately used for

pain. Having just reviewed a paper that looked at this in a very large population, simply, the incidence of respiratory depression in pain use was in the area of 1%. Vastly overestimated.

How to access support systems. Do you know how to do that? What are your skills in drug use? Would you be comfortable in seeing how your residents and trainees wrote the orders, and would you know how to give feedback on those orders? Do you have the communication skills that are necessary for such high-level communication? Have you taught, and are you able to model how to give palliative support to patients, family, and staff in such difficult decisions?

Final words for me are that, in historical terms, these issues are very recent innovations. As a society, we have not caught up with such innovations, and for all specialties, education in palliative care in general has been sorely lacking. So we need to work harder to figure out how best to incorporate the needed training into our existing curricula. It's for that reason that I'm so pleased that the American College of Surgeons is having this symposium.

**Audience Member:** I'm a surgical educator. One thing I've noticed as a surgical educator is that whenever we're going to have a family conference to discuss these issues, the residents seem to disappear rapidly, and I was wondering how to overcome this aversion. Do you have any suggestions for that?

**Dr Hallenbeck:** I guess that would be for me, a sort of an education question. Frankly, we often raise this subject up as to say, we're here to help you, not take over. If you don't have a consult team, it's the same phenomenon, to really point out to them this is part of their education as well. Now, for surgeons, certainly, one of the things I've noted is that they have more discrete conflicts than internists; like you're either in the operating room or you're not. So it can be challenging, and it may not be doable in all places.

Often residents or students are relegated by you to come to this conference; you're going to spend an hour, but they have no role at all. Spend even 5 minutes beforehand giving them a task. "My goal in this conference is X, Y, and Z. One of things I want you to watch for is how I address cognitive and affective aspects of communication, or how I address goals of care, and when we're done, I want to get your feedback on how I did that." If they have a reason to be there, you might have a little better chance, I think, to get them hooked in.

**Dr Hinshaw:** So the issue is how to bring students and residents into a family conference, usually an area where they tend to run in the other direction. I think Dr Civetta has some remarks on that, too, before we go to the next question.

**Dr Civetta:** I think that a lot of it has to do with modeling. David Weissman just ran the first course for surgical residencies to start learning how to teach palliative care. One of the exercises was how do you know when your patient is dying? We worked in little groups, and in our little group, one of the answers was—this is an ICU patient—when the attending surgeon stops coming for daily visits. So I think that part of the answer is that the residents take their cue from the attendings.

Certainly, at both Hartford and in Miami, when we scheduled family conferences with the ICU team, the surgical team, and the family, the surgeons were off doing some other case, or something. So I think that modeling has a lot to do with it, so our commitment to making sure that it's brought in at the earliest stages and as a normal part of what you're supposed to do is the only answer, which means that it's going to take at least 5 more years to get interns to chief resident level.

**Audience Member:** I just want to comment on your use of the term of "palliative care consult." We had an ethics consult team composed of a physician, a nonphysician, and an ethicist, which worked very well, but we found that many times, we were dealing with matters that had nothing to do with terminal care or palliative care. We were dealing with other things, primarily helping to avoid lawsuits, in many cases because physician/family interactions had escalated to where people were very unhappy, and a lot of other things that are very interesting.

We also dealt with the end-of-life issues, and I can never forget one afternoon when I spent 2 hours counseling one family who wanted to turn somebody off who shouldn't have been, and then 2 hours counseling another family who wanted to keep somebody going who really shouldn't have been. I don't know how you get into these, but I think there's more to it than just palliative care.

**Audience Member:** I recently saw a 56-year-old woman with adenocarcinoma of the abdomen of unknown etiology, and she also had brain metastasis. She's a very spunky, sweet lady, and the medical oncologists wanted to start chemotherapy. I wanted to run in the room and say, "Please run and get out of here as fast as



you can, and go do something that you really want to do. I don't know that this really works."

But then there is another part of me that does not want to take away her hope. So we talked some about hope. My dilemma is, and something that doesn't happen very much where I am, there's almost this dishonesty with the patient. I've had another one, with oat cell cancer who wants a port, and it's like this, "Go ask your medical oncologist, is this going to really help you live longer?"

My dilemma is how honest we need to be, realizing there are a lot of variables, but with some of these issues, I mean, they're going to die. That's just the way it is, but nobody says, "You know, this is going to take your life." I really need your help on how you handle this, sort of the honesty versus the dishonesty versus the denial.

**Dr Hallenbeck:** Certainly, one comment I want to make is on the issue of hope. Hope is a complicated thing. It is or it is not a very simple thing. There have been studies done. One of the perceptions is that if you say, "This therapy won't work," that hope must disappear, or when referring to hospice, someone's going to lose all hope. Although people may lose hope, studies have found on hospice referral, that hope went up, not down.

Well, how could that possibly be? It's sort of like the flip side to medical futility. It's a question of what they were hoping for. So, yes, it may be true that it would be unrealistic to hope for a cure, and then, it may go on for hope for life prolongation; but they can hope for a better day, hope for pain relief, that sort of thing.

I guess what it leads up to is something that I had a little misgiving about for this conference: the focus is treatment withdrawal. A saying that is dear to me is that no one is going to love you for what you don't do. If you only talk to people about what you're not going to do, there is no reason for patients or families to like what you're going to say. You have to balance what you're not going to do by what you're doing. It's just like a tap on the knee. If you're saying, "I don't think it would be helpful to continue ventilation," or "I don't think it would be helpful to do dialysis," you must be able to follow that up with what you think would be helpful. If you don't have that, then I suggest you think about that before you go having the discussion, because if, indeed, it is seen not as abandoning your physician role, but it's, "Well, we don't do antibiotics, we don't do IVs, we don't do blood transfusions, we don't do this, and have a nice

day." If that's what they're hearing, they're not going to be crazy about that as an option, and they will, indeed, lose hope.

**Dr Pawlik:** I want to follow up on that, because I agree, and you mentioned an honesty issue. I wholeheartedly agree that I think hope, in some way, is based on expectations, and expectations can be realistically formed only if people have an honest assessment of the situation.

So I think it's important to be very frank with people, not to hold things back from them or try to protect them. I have a very great belief—and maybe it's because I'm young and naive—that people can make the right choice. Traditionally, physicians have sold patients short. I think that, given the right information, and the right amount of energy expended by surgeons and physicians to sit down with patients and to process through that information, the high majority of the time, everyone ends up on the same page. The problem is that when the commitment to that communication isn't there, then people kind of get off the same page.

**Dr Hallenbeck:** I just want to offer one more comment. Good physicians have a right to disagree, just as we have a right to disagree with patients and families. But I think that our obligation is to clarify if there is miscommunication going on, and a common one with oncologists is around the word *palliative*. Often I see arguments, "It's just a palliative chemo," and, in fact, there's not unanimity of opinion as to what that word means. In a review I did of non-small-cell lung cancer, where I looked at what the outcomes were, matched a Medline search against the word *palliative*, all outcomes had to do with life prolongation and 5-year survivor curves. There were no outcomes measures related to quality of life. So oncologists tend to use the word *palliative* as noncurative life-prolonging therapy. That's fine. There's no copyright on the word. People in palliative care tend to look at it more as an issue of assessing quality of life.

If there is a dispute in this case—and I occasionally disagree with oncologists—I think my obligation is to try to clarify what the goals of care are for the patient. If a patient says to me, "My only goal is to be comfortable, and I have absolutely no interest in living longer," and if an oncologist is offering palliative chemotherapy where the only outcome measures that have ever been demonstrated are life prolongation, I may or may not believe that that's an appropriate therapy, but I feel my obliga-

tion is to point out an apparent mismatch between the therapy and the goals of care that I've heard from the patient.

**Dr Hinshaw:** That really is important. I emphasize with my patients in palliative care that if I know for certain—as with your first patient, where it's not likely that the treatment is going to actually cure the disease, and may be true of the second patient you mentioned—that I would talk about living with the disease. That they'll be living with that disease, and then getting them used to that concept, and then recognizing that the disease itself will shorten their life. Then sorting out, as Dr Hallenbeck has mentioned, what it is that they're trying to accomplish. I mean, they may have a very important graduation or wedding event for a grandchild, or something that's coming up in a few months, and there may be a chance that life-prolonging therapy is worth it to them, depending on what their priority of values and goals is. But it means listening to them, and getting better acquainted with what they're trying to accomplish, within a framework of understanding, mutual understanding about what their horizon looks like realistically.

**Dr Civetta:** This is such an important issue. For so long, in a paternalistic way, we have defined what outcomes are for patients. The whole outcomes movement that the government says we should have been doing for the last 15 years, we're still not doing. When you mentioned the proximate goal of the patient, it reminded me of Elizabeth Kubler-Ross's original book on death and dying where the third stage, as she called it, was the bargaining stage, and this woman had a daughter who was going to get married within a couple of weeks, and she hoped that she would live until the day that her daughter got married, and, sure enough, the way things worked out, she did. So Elizabeth Kubler-Ross was waiting in the room for her that evening, when she returned, and the woman walked in, and Elizabeth Kubler-Ross said, "Well?" And the woman said, "But I have three sons, too."

**Audience Member:** I am a pediatric surgeon and often deal with short-gut syndrome, and we can offer a glimmer of hope for these kids with liver/small bowel transplants. It's faint hope, and I know, Dr Civetta, you've thought about these problems for a long time. How much of a factor should age be, and is it ethical to consider age?

**Dr Civetta:** Well, some time ago, when I was first

talking about these issues, someone came up to me afterward and gave me a quote from the Talmud, and it's that from the moment of birth, you're old enough to die. So I personally don't think that the fact that many young people are involved in health care, and so, they identify more with the young person, that it's inappropriate for that person to die, but someone at the end of life who has lived their long and full life, that it's okay for them to die. We had too many people in the ICU who had been married for 50 years and moved to Miami, "the retirement community," and they were all alone. And for those people, the loss of their spouse was really horrible for them to contemplate because they were all alone, and they did not remember not being together.

So I think this whole issue about changing the expectation based on the fact that someone is old or young is totally wrong. Each person should be dealt with in the context of where they are in their own particular portion of the life spectrum. The statistics are getting better, and if you remember, just a few years ago, there was a moratorium on doing liver transplants because the outcomes were so bad. So I don't see any reason why we shouldn't proceed with a reasonable amount of hope as long as you're honest about it.

**Dr Hallenbeck:** I sort of agree, and take issue, perhaps, with it a little bit. Certainly, the issue serves as a warning on all sides. Working largely with geriatric patients, I think there is a warning to not just assume that somebody who is, perhaps, over the age of 60 is completely over the hill, and we should do nothing. The converse for pediatrics is simply because they are a child, we must do absolutely everything, no matter what, even if it is certainly approaching medical futility and the net suffering is greater than the net benefit. Both of those strike me as things for all of us to ponder.

Where I might differ is on an ethical principle, which is, for most elders, at least there was an opportunity for that person, assuming that they had normal mental capacity, to develop a set of values to guide decision making. That is often not so for children. So the whole premise, in Western ethics, of substituted judgment is problematic, in my opinion, for a child because we can't substitute a judgment for that child who may not have had time to develop, depending on their age, a well-formed set of values that might guide the opinion.

Plus, the incredible emotional burden of the parent and parent's responsibility unavoidably affects the decision making. Surrogate decision making had, as its idea,

that you would take the head off the person who was unable to make a decision, and put it on the other person who could speak with their head. That's a simplistic image, but I will tell you, as a parent of a severely disabled child, who has been in that position, it is not that simple. I don't know how to take my daughter's head off and speak with her voice over very, very difficult issues like that.

So that's not offering an answer, but, while I would agree that, at an ultimate level, we have to be careful not to be ageist in either direction. I think there is food for thought, for example, about a minor who may not have had time to develop values, might alter the way we think about this to some degree.

**Dr Pawlik:** First, I think that age is an important factor, because I think that we know that for patients it's important. People approach the death and dying of a family member who is 90 quite differently than they approach the death and dying of their 1-year-old child. I think that it is an ethical factor.

Do I think it should be the sole ethical factor on which something hinges? No, but it's part of the context, and it needs to be acknowledged. The second part is that with children, I would argue a little bit with you that it's actually not substituted judgment because, strictly speaking, substituted judgment is when I sat down, and I had a conversation with you, and we talked about things, and now you're incapacitated, and now I substitute my judgment for yours.

Really, with children, what you're looking at is the best interest standard, to separate those two out and tease that apart. What society has said is that it really is the best interest of the child, and who knows better than anyone else what the best interest for the child would be than their parents. So that's kind of how our society has designed a lot of interest around decisions for children. Perhaps in other Eastern societies it's not the parents, it's more of communal, not as nuclear, and extended family is involved. But I think it is different, and I don't think it hinges on substitute judgment. It hinges more on the best interest standard.

**Dr Hallenbeck:** You're absolutely right to clarify that distinction. I overstated my case, because many people haven't gotten to see that distinction. There is a debate about how to do that. Parents may know their children best, but they may be so severely emotionally invested, are they actually able to take that perspective. It suggests that they may need a distance to judge what would be

best for the person, when, in fact, they're so emotionally involved that it may interfere with the ability of exercising best judgment.

**Dr Pawlik:** And that has come up multiple times in court, especially around Christian Scientists, who perhaps don't involve traditional medicine, and then their children have poor outcomes; are they culpable or not?

**Dr Civetta:** Actually, I would like to take a little exception to the concept of the best interest standard. In our critical care textbook, I asked Lawrence McCullough to write the chapter on informed consent and refusal, and in the first two editions, he called it best interest standard. In the third edition, he called it the patient's interest standard, and he said that ethicists have been talking about the fact that it's a little arrogant for us to say that we knew what the patient's best interests were. So this was allegedly a more objective standard in which you balance benefits and burdens, and you try to come out with a decision that is in the patient's interest, but not the best interest, because we're not necessarily able to make that distinction.

**Dr Pawlik:** I guess I was just assuming it's always the best interest of the patient, and I try to highlight specifically that this is when the principle of justice gets involved, because maybe you look at the best interest overall. The best interest of society would be to stop that ventilator care, save that money, but maybe the best interest of the patient isn't to do that because they want to stay alive so they can go to that wedding. So I would agree with you that it needs to be the best interest of the patient, and not the best interests, necessarily, of society.

I'm interested in your model of the futility gap, but I see the futility gap providing a scheme in which to think of the problem, but not really of substance to answer the question. In other words, I think it's helpful to look at the futility gap in order to frame the question, but I know you alluded, in your talk, that it could help solve some of the philosophic issues, and I don't know exactly how that can help.

**Dr Civetta:** No, I don't think I meant it to be a philosophic concept. What I meant to say is that having read a lot of literature on futility, and, as you know, there are all sorts of people who say, for instance, if somebody is in septic shock and you put them on more noradrenalin and their blood pressure goes up, even if they die a week later, it was not a futile intervention because that's its purpose, which is to raise blood pressure, so it did it.

What I was trying to do was to say, rather than getting

into the statistical model of presenting it to families and, say, in the last thousand cases, that we've been doing CPR, nobody who is in sepsis on a ventilator in the ICU for a month has ever been successfully resuscitated to hospital discharge. Those arguments haven't worked very well. So I tried this as an additional approach to be able to talk to families. Not as a way of solving ethical issues, but as a way of presenting information in a way that we could see where, if the lowest level that the patient wanted and the highest level that we wanted left a gap between the two, then maybe that would help them in the understanding and internalization so they could start the process of giving up.

**Audience Member:** I'm a clinical ethicist and a director of pastoral care, married to a surgeon, and I spend the majority of my clinical practice time working with families and patients making the decisions. It's wonderful that this is being addressed in this venue because it's taken a lot of time for physicians to start thinking more this way, and the idea of communication is the most important thing. I live in a community where the people are not really very well educated, and so they don't understand a lot of the medical stuff, and they look to the physician not to make their decision, but a lot of times I see families who think that they'll be seen as a bad family if they bring up the idea of stopping treatment, and the patient thinks that their family will see them as giving up, as not fighting anymore, if they do that. I find, for a lot of those families, they're so appreciative if the physician will sit down and say, "If this were my dad, this is what I would do." I do want to compliment you. This is really wonderful. It's an excellent presentation.

**Dr Hinshaw:** Thank you. I think I'll just reinforce one comment, too, that I think came out in the presentations, but I wanted to segue from what you're saying. That is, I think we do a great disservice to patients when we ask them to make decisions about specific treatments. We need to talk about the big picture, and help them either transition to being a dying patient who is no longer wanting curative therapy for, hopefully, good reasons, or a patient who is expecting cure for a reasonable thought process, and is still going to be supported either way. Those major distinctions are the ones that will help guide care, I think, and also guide decision making around the withdrawal or withholding of care.

**Dr Mosenthal:** Even though we need to communicate with the family about the patient's preferences, and to develop the goals of care, it's so important not to

burden the family with the entire decision, and as you allude to in your community, the families look to the physician for guidance, and I think it's critical that we provide that so that the family does not carry with them forever the fact that they killed grandma because they took her off the ventilator.

**Audience Member:** I was very fortunate to have learned a lot from Dr Civetta. I have a question for you, Dr Civetta, and really, for the whole panel.

We all occasionally see outcomes that were unexpected. We may see a time when you expected a bad outcome that turned out better. As time has gone by, as you've gained years of experience with this, has your ability to determine the point of medical futility, or the time when that has been reached, are you more or less certain when that arrives than, maybe, years ago?

**Dr Civetta:** I'm much more certain that I'm not in charge, and I think most of us have accumulated a fair amount of experience and had the epiphany of when everyone on the team has decided that there is no possible way, particularly in the ICU, you know, based on all sorts of ventilatory support, and you finally say, "Let's stop," and the patient survives to hospital discharge. That has happened enough times for me to, first, get over my panic reaction, "My goodness, how could we have all been so wrong?"

Now, I find that reassuring, because I'm not in charge, and I do the best I can, try to give the best advice I can, try to find out as much as we can, in terms of communication, and then what happens happens. I also did the same thing with Swan-Ganz catheters, trying to predict what the cardiac output and resistance would be, and to see whether, after doing it since 1970, I was any better at guessing, and that's not true. I'm not.

This is the same kind of thing; there are certain areas where you can study and learn, and maybe you can improve, and there are other areas where you have to be comfortable that you're not going to be right. It's really the process of getting together with the family and the patient and the team to come to a decision you're all comfortable with.

**Dr Hallenbeck:** I wanted to comment on one aspect, I think, of your question; and I'm going to shift it slightly from medical futility to a broader question of prognosis for people with serious life-limiting illnesses. There is a fellow by the name of Nicholas Cristakis who wrote a wonderful book called "Death Foretold,"<sup>47</sup> who looked at how good we are as prognosticators for people

who are toward the end of life. This is not so applicable to the ICU, but more to advanced COPD, congestive heart failure, metastatic cancer. The most striking finding for me in his study was that, on average, physicians overestimated prognosis by a factor of fivefold. That's the average.

So to put it simply, if a physician tells you, on average, you've got 5 months left to live, on average, you're going to live 1 month. That's very significant, particularly for hospice referrals, because it's all around that period of time. Related to his work, when there is uncertainty, there are certain things we can learn to help with prognosis. One of the things he stressed was that physicians tend to look for the holy grail, whether it's an APACHE 2 or some new method of prognosticating, when in fact, it is in that uncertainty that we can sometimes find common ground with patients and families.

In other words, we can start with the statement, "I wish I knew." "I wish we could tell 100% for sure." In acknowledging, as you pointed out, our own frailty, our own humility, and not being able to be perfect prognosticators, that actually offers the possibility of common ground with patients and families, and I think that's, as Cristakis comments in his book, too rarely done.

**Dr Hinshaw:** It's really important to emphasize, as Dr Hallenbeck mentioned in his talk, that just as the beginning of life is a sacred or a sacral moment, so is death, and death is fundamentally a mystery. Patients in the intensive care unit are in close, intimate contact with it, whether they walk out of the ICU or not. The sum of all these presentations is, because you cannot predict with any reasonable certainty about the outcomes, in an intensive care situation, in particular, all patient suffering should be addressed. If we don't do that, if we make the assumption that we'll institute comfort care for you, or comfort measures to relieve your pain and other symptomatic distress, if we think you're actually dying, then the implication is that we will tolerate suffering of people who may survive.

As Dr Hallenbeck has mentioned, we always assume everyone is going to get well. That was even one of the response slides early in the series of presentations. No one was really willing to say, even though I think it was Dr Mosenthal's patient, that the "injury severity score" predicted a 50/50 chance of survival; everybody was going on the positive side of that. We're all optimists. Otherwise, we would probably not want to be providing care

for the sick. But the problem is we cannot predict, and so why should we limit relief of suffering only to the dying?

**Dr Civetta:** There is a quote from an article written by Joseph Califano,<sup>48</sup> called "Physician-Assisted Living," from 1998, in *America*, and it was about the time that Kevorkian was doing his thing, and there's one slide that's just really beautiful. "It is time we recognize in the dependency of the terminally ill the dignity and beauty of dependency that we have long celebrated in the early days of newborns." It's a great article. I recommend it to you.

**Dr Hinshaw:** Are there any other comments or questions? Thank you all very much for coming.

## APPENDIX

### Surgical Palliative Care Workgroup

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