

Virtual Mentor

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Humanist Approaches to Care at the End of Life

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From the Editor

Compassionate care at the end of life

In the world of modern medicine dying can be, and too often is, a dehumanizing process. Paradoxically, death is also the most human of moments, rife with sadness, joy, revelation, forgiveness and closure. One of few universal experiences, death is a certainty. Yet the individual experience of it varies greatly. For some, death is embraced as one stop in the natural progression that is life. For others, it lacks meaning. In each case, and in the great spectrum of experience that lies between, suffering emerges as a common theme and hurdle. Hence, an exploration of suffering is central to the discussion of care at the end of life.

Despite countless advances in treating disease, we often seem to falter when addressing “illness,” the lived experience of disease within the context of an individual’s life and personhood. This is especially true with regard to suffering, which defies empirical measurement despite biomedical advances. As Eric Cassell so eloquently wrote, “Suffering is experienced by persons, not merely by bodies, and has its source in challenges that threaten the intactness of the person as a complex social and psychological entity” [1]. Sadly, physicians are not taught to recognize suffering, nor do we typically know much about how to address it. After all, such an assessment is hardly part of the standard history and physical. Thus, as we preoccupy ourselves with “pain scores,” we often fail to consider the *meaning* of this pain in our patients’ lives. We also forget that the absence of pain hardly rules out suffering, and we shy away from exploring the meaning of illness in our patients’ lives.

Understanding the nature of suffering is particularly central to the experience of dying. While medications can treat physical pain, suffering may persist and can lead to far worse anguish. Tolstoy’s story of Ivan Ilyich famously illustrates this notion. It is told through the eyes of a man whose last days are haunted by the frightening thought that he has not lived as he believes he should have and that much of his life has been a lie [2]. His doctors know nothing of this thought, nor does his wife, and no one bothers to explore his fears as death approaches.

This issue of *Virtual Mentor* directly addresses a number of common but rarely discussed difficulties faced in the care of dying patients. At this level, it is practical. But I hope it serves more than this practical purpose. Underlying each of these articles is the essential tenet of humanism: the assertion of human dignity. The humanist physician believes that ignoring suffering is an offense against human

dignity. This issue of *VM* challenges us to be more holistic, for we cannot respect human dignity if we fall into the Cartesian trap of mind-body dualism and fail to treat the body and spirit of the whole human *person*. Doing so forces us to recognize and “treat” suffering. Only then can we be true physicians, and true healers.

Ivan Ilyich eventually finds comfort through the compassionate care provided by his servant. In practical terms, the servant does very little other than spend time with Ilyich. Tolstoy’s character can teach us a great deal about therapeutic presence, the power of good communication and the importance of just *being with* a patient, particularly at the end of life. This is true compassion, whose root meaning is literally “to suffer with.” The humanist physician is called to be like this servant and to suffer with his dying patient. While even modern medicine may exhaust its supply of treatments at times, there always remains this one proven therapy. It is the therapy of human companionship, the power of listening, the healing embrace.

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Clinical case

Code status

Commentary by Lorraine M. Stone, MD, MSPH, and James A. Tulsy, MD

George Johnson was admitted to the hospital with nausea and abdominal pain. His blood levels of amylase and lipase were markedly elevated, and he had a history of alcohol abuse. Dr. Jones, the intern on call, was confident that the 45-year-old Mr. Johnson was suffering from a routine case of acute pancreatitis. As morning rounds began it became clear to the inpatient team that Dr. Jones was utterly exhausted. The senior resident, Dr. Smith, felt a bit uneasy about the situation, having seen “routine pancreatitis” degenerate into systemic inflammatory response syndrome and a trip to the intensive care unit. Although she was sympathetic to Dr. Jones’s fatigue, she considered this important enough to merit a brief discussion and a learning point for the students.

After a short talk about the potentially serious complications of pancreatitis, Dr. Smith asked the intern about Mr. Johnson’s code status, pointing out that it was not mentioned in the chart. Dr. Jones replied that he believed it was unnecessary to discuss resuscitation since Mr. Johnson was stable and would surely be discharged within a couple of days given the nature of his illness. Dr. Smith emphasized the importance of discussing code status with all patients, even those who appear stable, since it is not possible to predict who will do well and who will not. She encouraged Dr. Jones to return to Mr. Johnson’s room after rounds to discuss this issue more formally.

Entering Mr. Johnson’s room, exhausted and feeling the time pressures of his other duties, Dr. Jones raised the subject abruptly. “There’s something important we need to discuss, Mr. Johnson. If something bad were to happen to you, would you want us do CPR?”

Shocked at the mention of this topic seemingly out of the blue, Mr. Johnson worriedly exclaimed, “What? Am I dying? Am I going to die? What’s wrong with me doc? Tell me what’s going on!”

Startled by his response, the intern replied, “No, no, I’m sorry, I didn’t mean that. It’s just that...well...we really have to get this information in everybody’s chart, just in case.”

Visibly upset at both Dr. Jones and the subject matter, Mr. Johnson yelled, “What are you, crazy? I’m not going to die, and this is hardly the time to ask me to think about it. Now get out.”

Dr. Jones left the room quickly, angry at Dr. Smith and her advice. Was it really so important to discuss code status with this man or with other hospitalized patients who had simple, curable conditions? What could he do in future encounters to better broach this difficult subject?

Commentary

Dr. Jones is learning by experience how difficult it is to start conversations about CPR preferences out of context. The intention of asking all hospitalized patients about their CPR preferences is a good one, but in most cases it requires more than a quick, casual question. In the case before us, George Johnson is, at 45, a young member of today’s hospitalized population. He has a history of alcohol abuse, but there is no other report of chronic medical illness or repeated hospitalizations. This may be the first time Mr. Johnson has been approached with a conversation regarding his mortality. The situation is exacerbated by Dr. Jones’s exhaustion and his inability to introduce the subject properly. Mr. Johnson responds with obvious shock and confusion, thus turning a potentially meaningful discussion into an angry outburst.

One can easily understand why Dr. Jones was hesitant to ask Mr. Johnson whether he would want CPR; few 45-year-old men without multiple comorbidities will refuse CPR or other life-sustaining treatments. The question is really not about what to do in the event of an acute decompensation. Rather, the physician’s goal is to gain greater understanding of the patient’s underlying values and goals for care and how these might influence difficult treatment decisions should his condition deteriorate significantly over time. This conversation can be had in a less abrupt manner by providing a more explicit context [\[1\]](#).

Approaching the patient to discuss care preferences

Initiating a conversation about CPR preferences warrants thoughtfulness and preparation on the part of the physician. Next time, Dr. Jones should pause before entering his patient’s room, reflect on his own physical and emotional state and assess whether these will impact negatively on the conversation. While fatigue and haste cannot always be avoided, recognizing their presence can help prevent their deleterious effect. Dr. Jones can also make sure he appears professional and shows the patient respect, with his shirt tucked in and white coat on. Once in the room, Dr. Jones should sit at the patient’s level and, tired as he may be, focus entirely on the patient [\[2-3\]](#).

Connecting with the patient

Most likely this is the first time Dr. Jones has interacted one-on-one with Mr. Johnson, so they do not really know each other. Taking a moment to understand who his patient is by asking questions about his life outside of the hospital shows interest

and helps develop trust. Understanding more about the patient's personal background can also provide insight into care preferences. Dr. Jones should pay attention to his patient's affect and make an effort to empathize with his fear, sadness or distress.

Introducing the subject of CPR

It is often most effective to enter into discussions of this nature by using the technique of “ask-tell-ask.” Dr. Jones can first *ask* the patient to describe his understanding of his medical situation. If the patient does not fully comprehend the situation, Dr. Jones can *tell* him his understanding of the illness and attempt to correct any misperceptions. This may be followed by another *ask* to clarify if the patient now understands correctly. If Mr. Johnson does have a correct understanding of his illness, then Dr. Jones can repeat the information back to him, assuring him that he has grasped the situation. In this case, Dr. Jones has the luxury of providing appropriate reassurance to Mr. Johnson by reinforcing that Mr. Johnson's recovery is going well and that he expects him to continue on that course.

After discussing Mr. Johnson's current medical situation, Dr. Jones may wish to ask him whether he has ever thought about what would happen if he didn't get better or if some future illness were to take a turn for the worse. Again, the patient can be reassured that this is something that the doctor discusses with all of his patients. Patients who have had loved ones in similar situations, or who have themselves been in an ICU, may have very clear ideas on the subject. If this question does not elicit the information needed, Dr. Jones must get more specific. He might say, for example, “Have you ever thought of what kind of care you would want if you got so sick that you had to be in the intensive care unit on a ventilator or life support to stay alive?” The patient's answer to this question is less important than his answer to the follow-up question: “Can you tell me why you feel that way?” These answers provide insight to the values and reasoning underlying the stated preference and offer a foundation for insight into what Mr. Johnson may want in other situations. Finally, the most useful information Dr. Jones can obtain in this setting is Mr. Johnson's choice of a health care surrogate. Dr. Jones should encourage Mr. Johnson to discuss his preferences with his chosen surrogate; without discussion, the surrogate's assessment of Mr. Johnson's preferences is unlikely to be accurate [4-6].

General strategies

Conversations about CPR preferences vary greatly depending on the age, health and health literacy of the patient. With all patients it is important to avoid vague or overly technical terminology and to use vocabulary they understand. The question “Would you want us to do everything?” is not helpful for eliciting preferences; it confuses patients and implies that less than optimal care may be offered if the patient answers “no” to the question. CPR should not always be the standard of care, so it is crucial that patients understand the difference between withholding CPR and withholding treatment of their underlying illness and its associated symptoms.

Dr. Jones should also learn to give his professional opinion regarding the appropriateness of CPR just as he would for other procedures. Physicians are trained

to give opinions and recommendations so that patients can make informed decisions. After Dr. Jones takes the time to understand his patient's general care preferences, he can make a recommendation about the value of CPR in achieving the patient's goals. The recommendation ought to be based on the expected efficacy of CPR in achieving the patient's stated values—not the physician's.

A more complicated conversation

Medical residents learn the importance of knowing a patient's code status early in their training. The term is found on history and physical forms and daily rounding sheets. Unfortunately this simple term ignores the complicated nature of the conversation. A 45-year-old's opinion on whether he wants CPR is going to depend on his chance for recovery and baseline functional status as well as on his underlying values. Mr. Johnson's case illustrates the challenge of discussing CPR preferences with members of a young, relatively healthy population. In situations such as this, the patient's values and goals need to be discussed in the context of present and possible future illnesses to shed light on what his or her preferences may be as the medical situation changes. With practice, Dr. Jones will make conversations about care preferences, rather than code status, a routine part of every new patient admission.

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Clinical case

Communication failure in the ICU

Commentary by Diane E. Meier, MD

Jane Patterson was brought to the emergency department after an automobile accident in which she sustained serious but not life-threatening injuries. After being stabilized, she was wheeled to the orthopedic floor for surgery to repair her broken femur. Jane, who was 33 and unmarried, called her parents from the hospital. When they arrived several hours later they were relieved to find that she was doing well. Surgery was performed the next afternoon, and the repair was successful. But events soon took a turn for the worse.

While her parents were out eating lunch, Ms. Patterson was found to be unresponsive by her nurse. A quick assessment revealed that she was in cardiac arrest. A code was called, and CPR was initiated. After multiple defibrillator shocks and injections over a 30 minute period, a regular heart rhythm was finally restored, but Ms. Patterson remained unconscious and no one was sure how long her brain had been oxygen-deprived. After the team was confident that Ms. Patterson was stabilized, she was intubated and transferred to the intensive care unit (ICU).

Upon returning from lunch, the Pattersons were shocked to find Jane unconscious and on a ventilator. The medical team suspected that a fat embolus had caused her acute decompensation. The ICU team recognized the gravity of the situation, but given Ms. Patterson's age they decided to pursue aggressive measures to restore her to good health. Over the next week she appeared to improve; her blood pressure stabilized and she began making spontaneous movements. Each day the ICU team reported Ms. Patterson's progress to the family, discussing the daily lab values and their daughter's overall physical functioning. The Pattersons clung to these updates and believed that their daughter was getting better. The ICU team knew that, despite the change in some physical functions, Ms. Patterson remained neurologically impaired, with little hope for a meaningful recovery. Her parents also knew that she had not regained consciousness and waited expectantly for her to come out of her coma.

The medical team was unable to wean Ms. Patterson from the ventilator, and the time had come to decide on a tracheotomy for permanent ventilator support. The next day, the ICU attending physician scheduled a conference with the Pattersons to discuss Jane's prognosis and raise the possibility of forgoing this traumatic procedure and letting an infection that Jane had recently developed take its course.

The Pattersons were visibly upset at the mention of their daughter's brain injury and seemed unprepared to discuss the likelihood that she would never regain consciousness. The attending physician was puzzled by the family's reaction because she believed that this outcome had been clear all along. Angry and emotionally distraught, Mr. Patterson said, "Each day you tell us she's getting better. Her blood pressure is stable, and the blood tests look good, and pneumonia is treatable. Why would we want to stop now? We don't want our daughter to die."

This reaction greatly frustrated the ICU team, who believed the family "just didn't get it." Jane would never recover, and they were no longer comfortable with providing painful and expensive treatment to someone they considered to be in a vegetative state. The team tried to explain this and attempted to reason with the family, but the message never seemed to get through. Each day the team became more exasperated, until eventually its members actively avoided Jane's parents and hurried by her room. When it came time to discuss moving Jane to a long-term care facility, the ICU team felt unable to communicate with the Pattersons. At this point, the palliative care team was called to intervene.

Commentary

What happened here?

A previously healthy young person sustains injuries in a motor vehicle accident, none of which is life-threatening. After a surgical fracture repair, a presumed fat embolism leads to cardiac arrest and anoxic brain injury. What should have been an uneventful recovery and return to a normal life suddenly becomes an inconceivable tragedy. Both the physicians and the patient's parents struggle at first to deny the irrevocability of this event, focusing instead on signs of stabilization in blood pressure or laboratory findings—choosing to "observe her and see how she does." The parents, picking up on the can-do atmosphere of the ICU with its attention to the physiologic details of critical illness, gladly narrow their focus in concert with the care team. The physicians soon realize, however, the low likelihood of meaningful neurological recovery, but the awkwardness of shifting from the hopeful stance of the first few days, combined with the sense of professional failure about this terrible outcome, inhibit their communication of the gravity of the prognosis to the distraught parents.

As more days pass, the physicians assume that the hopelessness of the situation is obvious to the parents. The parents, meanwhile, are still hoping. They have taken their cues from improving lab tests and limb movement, a stance established by the watchful waiting approach of the first few days, and do not draw the same conclusion as the medical team. Their daughter is in the ICU on all kinds of life support—surely modern medicine can fix this. The physician's belated attempt to bring the unfortunate reality to the parents' awareness is met with disbelief and cognitive dissonance. "You told us to wait and see how much function she would recover. Are you giving up on her after only a week? If you thought she wasn't going to get better, why do have her in the ICU on all these machines?" Forgetting that the

patient's parents don't share their knowledge of the usual outcome of such an injury, the physicians are surprised by this refusal to accept what is obvious to them. The parents no longer trust the physicians to put the best interest of their daughter first and instead go into an oppositional and advocacy mode—"We have to protect our daughter from these doctors—they've already given up on her."

Why does this happen?

A number of factors contribute to this scenario—frustrating but common during critical illness. These include the knowledge gap between family members and physicians; unconscious reactions and feelings of family and doctors toward each other, also known as transference and countertransference [1]; physician discomfort with and avoidance of patients with bad prognoses and outcomes; and lack of physician education in the skills necessary to care for patients when medicine can't save them.

1. *Knowledge gap.* After a lengthy period of cardiac arrest with no oxygen to the brain, a young woman fails to wake up from her coma. Interestingly, both parties (doctors and family) hold fast to hope for recovery early in this patient's course. She is young and previously healthy. But after a week with no improvement, the doctors shift their expectations based on the data—the odds of neurological recovery sufficient to allow return to an independent existence are close to zero. Meanwhile, deluged with stories of miracle recoveries after comas from friends and family members, the parents are gathering their strength for a long but hopeful vigil. They have no way of knowing "the numbers," nor have they witnessed such a situation before. If their online searches suggest that the risks of permanent coma are high, they figure this outcome does not apply to them, given Jane's recent progress. The kidney specialist says their daughter's kidneys are back to normal; the infectious disease doctor says there is no sign of infection; the ICU doctors are suggesting a tracheotomy as a step toward weaning her off the ventilator. The family experiences these comments as evidence of desperately sought hope.

Though obvious to the health professionals, the neurological facts have not been consistently conveyed by the different specialists and are neither self-evident nor tolerable to contemplate from the family's standpoint. These unstated and opposed perspectives are a major source of misunderstanding, mistrust and compounded suffering for all concerned. No matter how well-educated or seemingly "with-it" a family member may be, shock, denial and the need to hold on to hope inevitably cloud judgment and prevent a truly rational understanding of the big picture.

2. *Transference and countertransference.* It is hard for physicians to internalize and understand the hope and power invested in them by desperately ill patients and their families [1]. Even among sophisticated, well-educated people, confrontation with mortality and suffering normally leads to an

almost childlike faith in the physician-healer as the holder of the secret knowledge that will bring about the hoped-for miracle. This unconscious assignment of powers and abilities to the physician is called transference in the psychiatric literature. Although psychiatrists are trained to recognize and respond appropriately to the unconscious thoughts and desires of their patients, physicians of all specialties need these skills in order to both understand and respond professionally to the behaviors and the suffering of patients and their families.

Physicians experience an equivalent unconscious reaction to the patient or family, called countertransference. Countertransference is normal and inevitable, but recognizing and understanding it requires a conscious attempt on the part of physicians who wish to provide appropriate professional care to patients and families. In this case, the physicians' anger at the parents for their (understandable and normal) stubborn hope for recovery is a good example of countertransference. Physicians unconsciously want to be forgiven for the patient's bad outcome; they personalize and cannot bear the parent's disappointment and rage, normal and understandable as those actions are. And not least, the confrontation with the senseless and random loss of life in a person of their own age is frequently painful. As a result of these physicians' failure to monitor and control behaviors stemming from their own unconscious feelings, the suffering of this family is enormously compounded by what they experience as a devastating breach of faith with their previously trusted physicians.

3. *Physician discomfort with bad outcomes.* Modern medical care is characterized by a typically American can-do attitude that asserts "with enough research, all disease and death can be defeated." This culture of cure infuses medical education both in the classroom and on the floors of the hospital and clinics [2]. Learners are humiliated for missing a diagnosis and are expected to prevent and cure disease in all their patients. The inconvenient truth is that every patient will sicken and die, and it is beyond our power, even though we are physicians, to prevent it. Yet acceptance of mortality—how to learn to live with it and provide supportive presence and guidance to the patients and families going through it—is seldom named as an important physician competency and remains a rare skill among the attending physicians responsible for mentoring our students and residents [2]. Medical education must begin to convey the fact that all humans die and that, as a consequence, an essential competency of all physicians who care directly for patients is expert care of the dying and their families.
4. *Lack of education in how to approach the care of the seriously ill and their families.* The skills required to engage in conversation about bad and sad medical outcomes are teachable and effective at improving patient-family understanding and satisfaction with care [3, 4]. These skills include the ability to open a dialogue, to listen, to reflect on what has been said and relay

it back to the participants, to convey information in comprehensible bits, and to establish an ongoing relationship and treatment plan that demonstrates nonabandonment and commitment to the patient and family. Examples of the kinds of words that create trust and connection [5] include: “I am so sorry about what has happened to your daughter and I wish things were different.” “Have you or others in your family ever been through a situation similar to this one?” “What have the other doctors told you about what to expect at this point?” “What is your understanding of your daughter’s condition and what the future holds? What are you hoping we can accomplish for your daughter?”

After explaining the likely outcomes, pausing for clarification and questions and allowing the expression of feeling, it is time to lay out the options. The basis for establishing the alternatives to cure begins with an understanding of who the patient was before she was sick, her values and goals in life, and any opinions she might have expressed about her own life or that of highly publicized cases like that of Terri Schiavo.

In our case, the family now faces three choices. The first is to discontinue artificial life support and allow their daughter to die of the brain injury she has sustained. The second is to continue full life support including tracheotomy and feeding tube placement for a pre-specified period. This so-called time-limited trial of therapy allows for the small possibility of recovery and gives the family needed time to come to terms with what has happened. Option three is to accept for their daughter a life in an institution permanently dependent on medical technology without return to consciousness. Any one of these choices may be the best one for this patient and her family. It is the physician’s job to present the options and their pros and cons and to help the family relate these choices to what is known about the patient and her values and wishes or, if these are not known, her parents’ assessment of what is in her best interest. It is the parents who will live with themselves and the memory of their decision for the rest of their lives. Enhancing their ability to heal from this loss and to feel proud of the care they chose should be a high priority for physicians in a situation like this one. Our personal opinion of what the best decision might be for ourselves or our own family is not relevant to this family’s decision and must consciously be kept separate from the advice and counsel we give the family.

Managing expectations

The antipathy that developed between the family and the doctors in this case was painful for all concerned and might have been prevented by avoiding false hope, assuring consistent communication from specified communicators, early focus on the patient as a person and her probable preferences, involving other team members for support, offering time-limited trials of treatment with clear endpoints and presenting realistic alternatives for a decision.

Avoid false hope. When the patient’s prognosis is poor, it is important to avoid instilling false hope. This can be conveyed by saying, for example, “She has suffered

a devastating injury to her brain and we do not expect her to recover fully. We'll watch her carefully over the next few days and speak with you daily here in the ICU about what the options are for her if she remains in a coma." Hedging, focusing on irrelevant positives such as the blood pressure or renal function and providing encouragement about the possibility of outcomes that cannot realistically be expected only confuse and distract the family from the work of acceptance that they must begin.

Control communications. Minimize communication to the family from different subspecialists and arrange for a selected physician and nurse to consistently provide updates and support to the family. These individuals should spend more time listening to the family and their concerns than talking. Talking aloud helps people understand and modify their own thinking and brings the situation closer to reality.

Focus on what the patient would want. Begin early to ask about the kind of person the patient used to be—her values and beliefs and whether she said anything about what she might want if she were ever in a situation like this. This shifts some of the decision burden from the shoulders of the parents and toward an effort to honor their daughter's spirit and beliefs.

Mobilize support. Engage other forms of support for the family—a social worker, chaplain and other family members or friends. This signals a shift in focus of care to the grieving family and helps convey the gravity of the situation to them.

Establish time-limited trials of therapy. Set time frames by saying, for instance, "If she does not show clear signs of neurological recovery by Friday, the odds are poor for a return to an independent life outside an institution. We will wait until Friday to discuss her future options, but in the meantime let's think about what your daughter would want if she could tell us." Time-limited trials give families space to come to terms with what has happened rather than rushing them into irrevocable decisions.

Clarify the choices. Offer realistic alternatives without judging the patient or family's values. When deciding among alternatives—stopping life support, continued time-limited trial for a pre-specified period or institutionalization with long-term ventilator and nutritional support—there is no right answer, only the solution that is most consistent with who the patient was before the accident and what her parents can live with. Our presence and our expression of sorrow about what has befallen this family can be a powerful form of healing and comfort. Francis Peabody said it best—"The secret of the care of the patient is caring for the patient"—or, in this case, the patient's family.

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Clinical case

When doctors disagree

Commentary by David J. Casarett, MD, MA

Mr. Williams was admitted to the hospital with febrile neutropenia, a common complication for patients receiving aggressive chemotherapy. He had been diagnosed with lung cancer six months before, and more recently the doctors discovered that the cancer had spread to his brain and bones. This time, the care team planned to discharge him as soon as possible because of his poor prognosis and the possibility of his acquiring another infection. After broad spectrum antibiotic therapy, Mr. Williams' fever subsided. Even though he would continue to need a few weeks of antibiotics, it was thought that he would be more comfortable receiving this treatment in his own home. His discharge plan included daily visits from a home health nurse for further therapy and care.

Two days after being discharged Mr. Williams returned to the emergency room, again with a high fever. Having now spent more time with Mr. Williams and his family, the team began to suspect that he lacked a full understanding of his prognosis, and they decided to consult the oncologists. The oncology fellow visited Mr. Williams, but was clearly uncomfortable with the situation and failed to have a substantive discussion with him about his cancer therapy and quality of life. He later informed the inpatient team that Mr. Williams most likely had less than six months to live. The fellow emphasized that, after their discussion, Mr. Williams still wished to continue his treatment and have full code status.

The inpatient team became frustrated. Despite Mr. Williams' prognosis of less than six months to live, the oncologists seemed unwilling to be frank in their discussions with his family, "not wanting to remove hope" and pushing for an aggressive alternative treatment strategy. This is what the family would want, they reasoned. But the inpatient team knew that the family failed to understand Mr. Williams' prognosis and thus could not make a truly informed decision. Looking back through his records, they discovered that Mr. Williams had spent more than half of the past six months in the hospital and that each hospitalization stemmed from a known complication of chemotherapy. It seemed as if the therapy was killing him faster than his cancer and had significantly lowered the quality of whatever remaining time he had.

The inpatient team confronted the oncology fellow, who became upset and defensive. "We're not ready to give up on Mr. Williams, and neither is his family,"

he interjected. The inpatient team countered, explaining that the Williams family did not understand that this therapy was making Mr. Williams so sick and that it really had no medical benefit. It was time for hospice, the team reasoned, so that Mr. Williams could live out his remaining months more comfortably, in his own home. This suggestion only made the oncologist angrier. An impasse had been reached, and the fellow stormed off, threatening to discontinue his participation in Mr. Williams' care.

Commentary

The chief problem in this case is not the conflict between physicians per se, but rather that Mr. Williams and his family are caught in the middle of that conflict. It's unrealistic to expect that health care professionals will always agree about which plan of care is best. It is essential, though, that they discuss their differences openly. A physician's primary obligation is to the patient, and it is never appropriate for a physician to abandon a patient, as this oncologist appears about to do, over a clinical disagreement with other members of the health care team.

While there is reason for legitimate uncertainty in this case, surely there are some points that the inpatient team and the oncologists can agree on. For instance, it is important that Mr. Williams and his family have the best possible estimate of his prognosis. Even an estimate that lacks precision (e.g., "a few months" or "less than 6 months,") can help Mr. Williams and his family to plan for the future. Trying to come together on a prognosis—even an inexact one—would be a good place for the disagreeing physicians to start resolving their conflict.

They should also agree that Mr. Williams and his family need information about his treatment options and alternatives in order to make an informed decision. Continued chemotherapy may or may not be the best choice for him, but Mr. Williams should be the one to make that decision. Assuming that aggressive treatment is what the family would want is a poor substitute for an open and honest discussion.

One of the treatment alternatives that Mr. Williams and his family should have the opportunity to consider is hospice. Hospice programs provide a unique set of benefits for dying patients and their families. For instance, patients enrolled in hospice receive medications related to the hospice-admitting diagnosis, durable medical equipment, home health aide visits and the services of an interdisciplinary team of health care workers experienced in end-of-life care. Families also receive emotional and spiritual support while the patient is enrolled in hospice and bereavement counseling after the patient's death. A growing body of evidence indicates that hospice delivers quality care that meets with high levels of patient and caregiver satisfaction [1-4].

Only a minority of dying patients in this country take advantage of hospice care, however. Furthermore, those who do enroll in hospice generally do so very late in the course of illness. The median length of stay is only three weeks; one-third of

patients are referred in the last week of life and 10 percent are referred in the last 24 hours [5].

As these numbers indicate, Mr. Williams' situation is all too common. Even when hospice is a logical, clinically appropriate choice, physicians are reluctant to discuss it with their patients. In large part, this reluctance stems from the eligibility criteria that the Medicare hospice benefit requires. To enroll in hospice, patients must have a prognosis of less than six months and must forfeit many aggressive therapies. Physicians tend to be reluctant to discuss hospice, fearing that it will be perceived as taking away hope.

But these discussions do not need to be difficult, nor do they require patients and families to give up hope. Several techniques can be useful in structuring hospice discussions to make them as easy and as productive as possible. First, as with any important health care conversation, Mr. Williams' inpatient team should identify a time and place where an uninterrupted conversation can take place. Because hospice decisions are often shared with family members [6, 7], it is also important to make sure that family and friends who will help a patient make a decision regarding hospice enrollment can be present.

Second, the team should determine what Mr. Williams and his family know about his prognosis. Patients often have overly optimistic views of their prognoses given the severity of their illness [8-10]. Furthermore, physicians may contribute to this discrepancy by inflating the prognostic estimates that they provide to patients [11]. Therefore, it is useful to ask patients to describe, in general terms, their perceptions of their current medical situations.

Third, the team should help Mr. Williams define his goals for care. In some situations, it is enough for the physician to summarize the goals in the form of a question, e.g., "From what you've told me and the things we've talked about in the past, it seems like what's most important to you is.... Is that right?" In other circumstances, a patient's goals may not be clear or may be unrealistic. In such cases a formal discussion of the topic is essential. At a minimum, it is important to inquire about patients' hopes and their fears, which offer insights into their values and desires (e.g., remaining at home, avoiding discomfort) [12].

Fourth, the team should define Mr. Williams' needs for care and services. In addition to planning for management of symptoms like pain, fatigue and constipation that are common in patients with cancer [13-16], it is important to identify those that are less common e.g., dyspnea, depression, anxiety, but that still respond particularly well to the multidimensional treatment that hospice can provide, even in a home setting.

At this point in the discussion, the team can introduce hospice as a way to achieve Mr. Williams' goals and meet his needs for care. Ideally, this part of the discussion should connect Mr. Williams' understanding of his illness, goals for care and needs for specific types of care in a way that makes some sense to him. This can help his

team to present a coherent plan, with clear links between what he wants, what he needs and what hospice can offer him and his family.

There are at least three advantages to this approach to discussing hospice, which emphasizes the positive aspects of hospice and hospice services. First, it helps physicians to avoid temporarily patients' and families' misconceptions about hospice and hospice eligibility. Many believe that hospice is only for patients who are imminently dying or only for patients with cancer. Others believe that hospice only provides inpatient care [5, 17-18]. By focusing first on the patient's goals and needs for care and introducing hospice late in the discussion, physicians can ensure that patients and families hear the benefits of hospice before negative preconceptions color their responses.

Second, by beginning with a discussion of the patient's goals and needs for care, physicians can more clearly explain why hospice is a good option. They can demonstrate their understanding of the patient's wishes and how the hospice recommendation is based on this common understanding. They can also emphasize the services that hospice provides and describe it in a positive light. This element of transparency is a key feature of consent discussions and of good communication more generally [20].

Third, this strategy can avoid concerns that a hospice discussion will take away a patient's hope. If done well, a hospice discussion offers an opportunity to define a patient's hopes and to present hospice as a way to help him or her achieve those goals. Viewed in these terms, a hospice discussion offers an opportunity to recalibrate the patient's expectations and to set goals that are achievable. For instance, it may no longer be reasonable for Mr. Williams to hope for a cure. But he might still hope to see a daughter graduate from college, go on a fishing trip or simply return home for whatever time he has left.

Finally, it is essential to recognize and respond to the patient's and family's feelings. The team can do this by acknowledging their responses, by legitimating their emotions and by reassuring Mr. Williams and his family that a hospice referral does not mean he only has a few days to live. The physician and his or her colleagues should conclude the conversation by reinforcing their commitment to care for the patient and family regardless of the decision they make.

Conclusion

Physicians' own fears and uncertainties should not prevent them from discussing hospice when it appears to be an appropriate option. Of course, as with many end-of-life discussions, discussion of hospice can be emotional, particularly when patients and families have strong preconceived ideas about hospice care. However, the communication techniques summarized here can make hospice discussions easier for physicians, as well as for patients and families.

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Clinical case

Myths and misconceptions about palliative sedation

Commentary by Timothy E. Quill, MD

Mrs. Mancini was in the hospital for her third admission in three months. She required dialysis almost daily, but her worsening heart function was complicating the situation. On a few occasions her blood pressure dropped so low that she had to be given intravenous vasopressors in the intensive care unit. At 62 years old, Mrs. Mancini was well known to most of the critical care unit staff, who were familiar with her extended hospital stays and many comorbidities. New to the team was Dr. Hayden, a first-year resident, who had been monitoring Mrs. Mancini's case since her admission three months ago.

During that hospitalization the care team helped Mrs. Mancini document her advance directives and assisted her in choosing which medical procedures she would want in the event of a medical emergency. "I guess I don't want any life support, except for dialysis—if it would even make a difference. But no, no CPR—I don't want to just be some vegetable." The team was in agreement with this plan, and Mrs. Mancini was encouraged to share her wishes with her daughters and her brother. Several weeks later Mrs. Mancini called Dr. Hayden in a panic. "Ya know, I've been thinking, if I ever get really sick, I think that it would be best if I had CPR and a respirator. Who knows, these things might keep me alive long enough for them to find a cure for what ails me."

Now Mrs. Mancini was back. Her cardiomyopathy and severe peripheral arterial disease necessitated use of pressors that had to be administered in an inpatient setting. This medication was only a short-term intervention and did not resolve the long-term concerns related to her severe hypotension which compromised her ability to safely receive dialysis. The medical staff agreed that Mrs. Mancini's health was failing and that it was time to discuss the next steps with her. Her internist, Dr. Tyler, and Dr. Hayden called a team meeting. Dr. Hayden took the lead: "Mrs. Mancini, it's time to make some tough decisions. You can no longer receive dialysis effectively because of your failing heart. If you stop your heart medication, your blood pressure will not be regulated. We need to discuss where to go from here. Unfortunately, we don't have many options to offer. What we *can* do is assure you that we will make you comfortable, be honest with you, and make sure whatever questions you have are answered."

After a moment of silence, Mrs. Mancini began rapidly asking questions. “What’s going to happen to me? Am I going to be in pain? What am I going to do about my family? How long do I have before I *have* to make this decision?” She was teary-eyed, but after spending several hours with the social worker, nurses and the doctors, Mrs. Mancini concluded that she was ready to have DNR orders; instead of waiting to die from lack of dialysis, she would stop taking her heart pressors; and she would be given a sedative by her doctor when the time came, so that her death would be as painless as possible.

The next day Mrs. Mancini called her family to tell them the news. Her family was understandably distraught, but after meeting with members of Mrs. Mancini’s health care team and having their questions answered, they realized that this was their mother’s choice and that they were fortunate to be with her at the end.

The morning that Mrs. Mancini chose to have the pressors stopped she confessed to her doctor, “I’m not scared. All of the people I love are here, my spirits are high and I am sure that there is nothing more that can be done.”

Over the course of the morning the room began to overflow with friends and family and the sound of music, prayer, and tears filled the halls as nurses and other members of the hospital staff came to offer their condolences. Just before noon Dr. Tyler gave Mrs. Mancini a sedative and everyone felt as “ready” as they could be. The assembly, which included nurses, physicians, social workers and the clergy, congregated around her, held hands, prayed, cried and watched as Mrs. Mancini quietly, and peacefully, died.

Commentary

This case presents a relatively common dilemma of a patient with end-stage renal disease on dialysis who subsequently developed advanced heart failure, so that she required intravenous vasopressors to maintain high enough blood pressure to tolerate dialysis. The initial question was whether to attempt cardiopulmonary resuscitation (CPR) in the future should she experience cardiac arrest. Mrs. Mancini initially declined, presumably based on the anticipated lack of efficacy of CPR given her multiple chronic diseases, but then she rescinded the decision in a moment of desperation. Her change of mind reflects the profound ambivalence frequently associated with making decisions of such critical import as the decision to have do-not-resuscitate orders (DNR), even when the treatment is harsh and without significant prospect of working. Rather than simply changing the order, the health care team should have scheduled a family meeting to try to understand Mrs. Mancini’s change of heart and perhaps deal more directly with some of her underlying fears and concerns.

A second question arose after Mrs. Mancini began to depend on intravenous vasopressors to sustain her blood pressure enough to support dialysis. At that point the team faced some tough decisions. They acknowledged that Mrs. Mancini’s medical options were limited and that the main thing they could offer was comfort,

honesty and an attempt to answer all of her questions. After several hours of discussion, Mrs. Mancini indicated that she wanted to stop not only dialysis but also vasopressors so she would “not have to wait to die from lack of dialysis.” Provided Mrs. Mancini was clear about the implications of her decisions, her desire to die sooner rather than later would not be a reason to deny her requests; she had a clear right to have treatments stopped based on her right to bodily integrity. The team’s obligation would be to ensure she understood all reasonable alternatives and that she was fully informed about the likely consequences. They then would be expected to palliate all symptoms that arose as the process unfolded. Since her decision consciously invites death, the medical team would want to be sure that Mrs. Mancini’s thoughts were clear and not distorted by depression, anxiety or delirium [1]. Close family should be centrally included in the decision-making process, rather than informed the next day as in this hypothetical case.

But the case crosses into more ambiguous ethical territory when we learn that Mrs. Mancini will be given a sedative so that death will be as painless as possible. I have difficulty with the terminology at this point. What is the purpose of the sedation? Is it intended to be *palliative* sedation or *terminal* sedation (also called *heavy* sedation or *sedation to unconsciousness*), which introduces the possibility of voluntary active euthanasia [2]. This is a time when ambiguity should be minimized and honesty and clarity about the purpose of the sedative maximized [3]. Clinicians administering *palliative* sedation, as usually construed under these circumstances, would be prepared to provide as much sedation as needed to relieve the suffering associated with discontinuing the vasopressors. The sedation would be proportionate to the level of Mrs. Mancini’s distress, which might be nonexistent, mild, moderate or severe. The dose would be increased progressively to provide relief from whatever degree of distress Mrs. Mancini experienced, but there would be no intent on the part of the clinicians to actively hasten her death [4].

Terminal sedation refers to sedation given for the purpose of rendering the patient unconscious as the only means for escaping otherwise intractable suffering at the very end of life. Hence terminal sedation is distinct from the more standard and relatively common practice of palliative sedation. Linguistically distinguishing this practice as terminal sedation is intended to put practitioners on alert and to make them think carefully and exercise caution. Terminal sedation is on the far edge of the spectrum of palliative sedation and should be reserved for the most severe physical symptoms and only when all other palliative measures including lesser levels of palliative sedation have been tried and failed. It should be used only as a last resort, because, while other palliative measures try to preserve consciousness as much as possible, terminal sedation causes the patient to lose the ability to interact with his or her family and environment. Furthermore, with terminal sedation, patients also lose the ability to eat and drink, and all other life-sustaining therapies including artificial hydration and nutrition are generally stopped. It has been argued that palliative sedation does not hasten death [5], but that argument is less credible when the practice crosses into terminal sedation. Terminal sedation is distinct from euthanasia in that the dose of the sedating medication is not increased once adequate sedation is

achieved, and no agent that actively induces death is added. But it borders on euthanasia [6], and should be reserved for the rare cases where less aggressive measures have been ineffective.

So what happened in this case? The patient accepted that it was her time to die, family and friends were assembled to say goodbye, and eventually she was given the sedative and died peacefully with everyone in attendance. It appears on the surface to have been a meaningful and comfortable process, yet the details of what was actually done are critically important. If Mrs. Mancini was given some mild sedation as the vasopressors were discontinued, and the dose of sedation was adjusted in proportion to the distress she was experiencing, then this would be an appropriate use of palliative sedation, and there would be nothing controversial about it [5]. If she was pharmacologically rendered unconscious at the outset to prevent awareness of any potential suffering that might have occurred as a result of stopping her vasopressors and her dialysis, then this would be a case of terminal sedation that would be controversial because of the absence of severe symptoms. Under this scenario, the sedation would have been given prophylactically to treat suffering that *might* occur rather than as a response to suffering that *was* occurring. This approach invites the question whether one has to wait for the onset of severe symptoms before providing the sedation. Careful presence and readiness to treat with a proportionate amount of sedation is probably a better approach.

We are not given a time course or sufficient medical detail about how Mrs. Mancini actually died. We learn that she died quietly, peacefully and, by implication, quickly, which raises the specter of euthanasia. Was the dosage of the sedative such that it intentionally sped up her death? Was the amount of sedation correct for achieving the desired level of sedation? My hunch is that some family and staff would also be left wondering what exactly happened and what the medical role was in the patient's death. This is why it is so important for medical personnel to be as clear as possible about what they are intending in such cases, what they are actually doing, and why.

If the clinicians believed that terminal sedation was indicated in this case because Mrs. Mancini's symptoms were going to be severe and because she was terrified about them, then they should have discussed this possibility explicitly with her, her family and the staff and sought second opinions from colleagues in ethics or palliative care because that treatment is irreversible and ethically controversial. It is also imperative that Mrs. Mancini's care team document their actions carefully and extensively in the medical record. If the clinicians were planning to provide sedation as needed to address symptoms aggressively as they arose, then this treatment would be much more standard, but still discussion and documentation would be critical. Because it is so easy to misinterpret what really happened and because there is potential to blur the boundaries between palliative sedation, terminal sedation and euthanasia [6] (as illustrated in this case report), it is paramount to assure complete informed consent from the patient and family, to document exactly what one is doing and to get help from experienced clinicians in ethically and clinically complex cases such as this.

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Medical education

Taking your communication skills to the next level

by Anthony L. Back, MD, and Robert M. Arnold, MD

Communicating with patients who have life-threatening illnesses is a core medical skill. Often after watching an experienced attending physician guide a patient through the transition from disease-modifying treatment to end-of-life care, students assume that this expertise comes naturally. Nothing could be further from the truth. In fact, end-of-life communication skills require deliberate intent, practice and reflective work—little of which can be detected by watching a master. An expert skier can make a black diamond run look easy; expert communicators can make difficult conversations look simple.

The myth about communication is that you can just jump metaphorically onto the skis and zoom down the slope. But, in the same way that simply throwing yourself down the hill will not make you a better skier, just talking to patients will not make you a better communicator. You will find that the moguls are bigger and icier than they look and that technique and practice are needed. The good news, though, is that you can learn to communicate more effectively with the right kind of practice. Physicians (and nurses) who speak of communication skills as a mystical, inchoate God-given talent are empirically wrong. In this article, we discuss some things medical students can do to maximize their learning.

Find a good role model that you can watch in action. In our opinion, most students have not seen enough examples of good communication. You need to learn how to approach an end-of-life conversation—we call this having a cognitive map that will tell you where you should go next. You can read these cognitive maps in the medical literature [1-5], but it's like reading about how to ski; you need to watch someone put it all together—the map, the verbal skills, the nonverbal behaviors.

After the observed conversation, ask questions. When you are in a reasonably private space ask your role model two questions: (1) what were her goals for the conversation, and (2) what was one skill that she used to achieve that goal? Don't expect any one person to give you a long tutorial—learn one thing from each conversation. You want to build a repertoire of communication tools that you can use with patients.

When you are ready to begin having difficult conversations, plan ahead. Before you enter the room to talk to the patient take a couple of minutes to plan what you are

going to say, think about how the patient might respond and decide what your next step should be. Start small. As a student you should not be talking about end-of-life decisions by yourself. A better way to start would be telling a patient that he can't go home that day (a bad news conversation). Or if you are working with a resident or attending physician, ask for a small role in a difficult conversation. For example, at the beginning, you might talk about some lab or CT scan results without discussing the meaning of these results for prognosis and treatment. The resident can pick up from there.

Ask for feedback. Ask the resident or attending who observed you talking to a patient for an assessment. Here you might want to be a bit cautious: not everyone can give useful and constructive feedback. Don't open yourself up to a known character assassin. You can help the person who is critiquing you by asking for something specific. For example, "My goal was to be very clear about the CT results. What did you see that I did to help accomplish that goal? What could I have done better?"

Do your own written debriefing. After a difficult conversation, write for five minutes about your reactions to the conversation. Don't censor what you write, just get it all on paper—what it was like for you, what you think it was like for the patient, how you would rate your communication, and other thoughts about the experience that come to mind. This is for you only, and not to be placed in the chart or to be seen by anyone else. There is a lot of information flying around during these conversations, and it can be hard to sort out. A day later, look over your notes and see if there is something to take away as a lesson.

Learn to respond to emotions—the patient's and your own. Notice when a patient brings up his own emotions as a topic, e.g., "I'm worried about this test result" and learn to respond empathically [1, 6]. Emotions are the key to what's going on in a difficult conversation. Once you recognize the patient's emotions, you next want to notice and use your own emotional reactions as a diagnostic and therapeutic tool [7]. Remember that you are not trying to fix yourself (very often the tacit message in medical professionalism is that you are supposed to simply suppress everything that does not make you look rational, detached and objective); you are trying to cultivate a different capacity—one that integrates the emotional and human side of people with the biomedical facts.

Ask yourself what the patient is trying to tell you. This is not the same as simply trying to detect how much a patient understands. Communication is not about delivering an information pill and seeing how much the patient can swallow; it is about sending messages to the patient and receiving messages in return. If you are too busy sending messages to read the replies, chances are that the other person will stop bothering to send. By failing to pay attention you will be missing many opportunities to understand what is going on.

Cultivate a beginner's mind. This is something that we still use every day. By having a sincere desire to learn about a patient's hopes, goals and worries, you can gain trust

more rapidly than if you are content with what you think you know. Because the truth is, you don't know more than a tiny fraction of what patients are thinking about, and pretending you do can come across as condescending.

Be patient with yourself. We all criticize ourselves because we lack patience, have an inadequate spiritual life, distract ourselves with petty aspirations or fail to understand dying, because we believe we're supposed to be experts. Think of mistakes as indicators about where you should focus your learning. The capacity to be present with someone who is facing an enormous, life-changing existential situation is a life's work [7]. You're not finished yet.

Pay attention when someone thanks you. This work, despite its difficulty, is incredibly rewarding. Don't miss out on the rewards. If you have worked your tail off, and someone notices and says thank you, don't brush it off. Don't say "it was nothing" or "that's my job"—that diminishes the compliment. Take a deep breath, enjoy the moment, and say "you're welcome."

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Virtual Mentor

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Journal discussion

CPR—Is it always an appropriate option?

by Tom LeBlanc, MD, MA

Blackhall LJ. Must we always use CPR? *N Engl J Med.* 1987;317:1281-1285.

In her landmark 1987 paper, “Must We Always Use CPR?” Leslie Blackhall tackled a rather contentious issue in medical ethics: the appropriate use of cardiopulmonary resuscitation (CPR) [1]. Intimately intertwined with this topic are questions about code status and do-not-resuscitate orders (DNRs). While these topics were hardly novel 20 years ago, Blackhall’s approach and insights were unique. Writing as a medical resident, she effectively challenged the status quo by forcing physicians to ask, “Must we always use CPR?” She argued that physicians need not offer CPR as a treatment in cases where it offered no known medical benefit or where it was more likely to cause harm. Equally striking was her recommendation to rely on an evidence-based strategy to inform physician use of CPR, rather than simply deferring to patient self-determination.

Since its development in the 1960s, CPR has become a standard medical practice. In the absence of a documented DNR order, it is used on any patient who suffers cardiac arrest, regardless of the cause. Blackhall attacked this practice from many angles, describing a troubling but all-too-common case from her residency and supplying a plethora of condemning data [2]. At the time of its development, CPR was intended only for those who had suffered an acute insult, such as a myocardial infarction (MI). It is known that the most common cause of death following an MI is actually ventricular arrhythmia. If CPR is initiated quickly and effectively, and defibrillation is performed soon after, patient outcomes are quite good. But Dr. Blackhall pointed out that by 1987, CPR had become standard practice for patients with cancer, renal failure or other forms of advanced illness, despite the fact that it was not intended for such purposes. Unfortunately, outcomes are rather poor in these cases, throwing into question the wisdom and value of using CPR on patients with an advanced illness.

Blackhall reviewed a great deal of data that clearly suggested that survival after CPR was strongly correlated with the underlying illness and cause of the arrest [3]. Many studies carried out over the two decades prior to her article concluded that patients with chronic debilitating illnesses were highly unlikely to benefit from the use of CPR, and indeed might suffer great harm [3]. For example, Peathfield et al. analyzed the outcomes after CPR in more than 1,000 patients over a 10-year period. Only 8.7

percent survived until hospital discharge; in the subclass of patients with cancer, all died. On the other hand, 15 percent of patients who suffered an acute MI requiring CPR survived, a rate that is likely to be even higher today [4].

There is more at work here than just raw data. Blackhall asked the difficult yet critical question of why physicians continued to consider CPR for patients among whom it was known to offer no benefit. Her response was that physicians, due in part to their own discomfort with death and dying, tended to avoid end-of-life discussions, with the result that CPR and DNR conversations often didn't take place in the nonacute setting. Family members are then faced with the pressure of considering—on the spot—what their loved one “would have wanted.” After all, it is much easier and less uncomfortable to present CPR as an option than to inform a patient that she will die soon regardless of the intervention. Blackhall also implied that physicians were, on average, rather poor at having these discussions [5], and a 1995 study by James Tulsky supports her claim [6]. In a tape-recorded analysis of patient encounters, Tulsky found that medical residents discussed the likelihood of survival after CPR in only 13 percent of cases, and that none provided the patient with a statistical probability. Less than one-third of the residents mentioned the consequences of intensive care, and only about 10 percent initiated discussions about patient values and goals of care. Coupled with the public's rather skewed and inaccurate perception of CPR's efficacy, one can easily see how these emergency situations frequently lead to confusion.

Challenging the status quo

With its emphasis on patient autonomy, modern medical ethics dictates that patients and their families should play an active and leading role in making decisions about CPR and DNRs. Unfortunately, this assumption often leads to conflict between physicians and families at the end of life. As Blackhall astutely argued, patient autonomy cannot be our only guide, especially when patients are so poorly informed about the risks and lack of efficacy of CPR in chronic illness [4]. In such cases, said Blackhall, the physician's offer of CPR had become a sort of “high-technology placebo” and that served as a rather poor substitute for the difficult discussion that should have taken place [7]. Instead, evidence-based knowledge about the efficacy of CPR should have informed physicians' recommendations, and CPR should not always be offered as a “treatment.”

While it may sound paternalistic, Blackhall claimed that most patients lacked the medical knowledge needed to fully understand the role of CPR, especially when media depictions of the procedure tended to be skewed toward favorable results [7]. Blackhall challenged the presumption that patients always have a right to CPR any more than they have a right to receive a medically nonsensical treatment. After all, if the data are accurate, one can hardly call CPR a treatment in certain circumstances. Indeed, in some cases it would seem that a physician's primary duty to do no harm would preclude the provision of CPR. Furthermore, just as a physician would not ask a patient which antibiotic she wanted—patients generally lack the fundamental knowledge about pharmacology and microbiology needed to know which medicine

to choose—so should a physician refrain from offering CPR as an option when a patient is not fully informed about its risks, likely outcomes or benefits.

Still, the clinical question remains: How does one decide that CPR is unlikely to be useful? Statistics are of limited value from the perspective of an individual patient whose outcome is somewhat binary. Blackhall's article is now close to 20 years old, and the CPR data she draws upon are even older. Have survival rates changed significantly since then? We have all seen that, as medicine advances, what was once a death sentence is often no longer as dire. CPR protocols have changed dramatically as well. More recent studies still conclude that CPR is generally ineffective for patients with chronic disease or advanced age, with rates of survival-to-discharge continuing to be abysmally low [8, 9].

The next step

If the above analysis and discussion are fair and well-reasoned, where does this leave us? For one, the current system of CPR use may need modification. One might posit that hospitals overtreat terminally ill patients out of fear of litigation. This surely puts pressure on physicians to routinely perform CPR, despite its known medical futility in many cases. Yet if CPR is not medically recommended, and indeed thought to be detrimental for a certain patient or subset of the population, sound clinical judgment dictates that it should not be offered as a treatment option in all cases. This change will require a significant alteration in physicians' mindset and documentation practices. Regardless of safeguards, there will always be a gray zone of uncertainty in which it remains unclear whether CPR is a potential benefit or harm. In these cases, it would seem reasonable to defer to the patient and family, provided full and informed consent has taken place.

Given our litigious society, it seems unlikely that offering CPR to certain patients will be barred. To push for this would be unrealistic and perhaps counterproductive. Still, Dr. Blackhall's article provides much food for thought and highlights the vast need for improvement.

Conclusions

As a first step, medical students and residents must be made aware of the data regarding CPR's efficacy. The fact that they are not is quite troubling since most interns and residents discuss CPR with countless patients throughout their careers. If physicians do not have the most up-to-date and relevant data, our patients may suffer unnecessarily.

Second, efforts must be made to teach students, residents and practicing physicians how to have better discussions with their patients. Although most doctors think they possess more than adequate communication skills, Dr. Tulskey's study suggests otherwise.

Finally, physicians need to increase their comfort level with death and dying. Personal discomfort is no excuse for the provision of poor care at the end of life.

Sadly, when doctors fail to inform their patients properly about CPR, neglect to discuss outcomes and shy away from difficult conversations, patients and families suffer the consequences. We must absorb and integrate Dr. Blackhall's insights into our daily practice of medicine, lest we continue to neglect our patients when they are most vulnerable and most in need of our help and compassion.

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Related article

[Why physicians avoid straight talk about CPR](#), September 2006

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Virtual Mentor

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Clinical pearl

Causes, clinical manifestations and treatment of fat embolism

by Sarah Maitre

Fat embolism is most commonly associated with trauma. Long bone and pelvic fractures are the most frequent causes, followed by orthopedic surgery—particularly total hip arthroplasty—and multiple traumatic injuries. Soft tissue damage and burns can cause fat embolisms, although far less frequently than fracture. The most popular theory about the etiology of fat embolism is that fat globules (emboli) are released by the disruption of fat cells in fractured bone and enter through ruptures in marrow vascular beds. An alternative theory proposes that the emboli result from the aggregation of free fatty acids caused by changes in fatty acid metabolism triggered by trauma or disease. Regardless of the source, increased fatty acid levels have a toxic effect on the capillary-alveolar membrane in the lung and on capillary beds in the cerebral circulation.

Traumatic fat embolism occurs in 90 percent of individuals with severe skeletal injuries, but the clinical presentation is usually mild and goes unrecognized. Approximately 10 percent of these patients develop clinical findings, collectively known as fat embolism syndrome (FES). In its most severe form, FES is associated with a 1-2 percent mortality rate [1]. FES can also occur under several nontraumatic conditions. It can be seen following cardiopulmonary resuscitation, parenteral feeding with lipid infusion, liposuction and pancreatitis. FES has also been proposed as a major cause of the acute chest syndrome in patients with sickle cell disease [2].

Fat embolism syndrome is characterized by pulmonary insufficiency, neurologic symptoms, anemia and thrombocytopenia. The diagnosis is based on clinical presentation of symptoms which usually appear one to three days after injury. Onset is sudden. Presenting symptoms are myriad and include tachypnea, dyspnea and tachycardia. The most significant feature of FES is the potentially severe respiratory effects, which may result in adult respiratory distress syndrome (ARDS). Neurologic symptoms may also be present; initial irritability, confusion and restlessness may progress to delirium or coma. Petechiae appear on the trunk and face and in the axillary folds, conjunctiva and fundi in up to 50 percent of patients and can aid in diagnosis [1-3]. Of these symptoms, respiratory insufficiency, central neurologic impairment and petechial rash are considered major diagnostic criteria, and tachycardia, fever, retinal fat emboli, lipiduria, anemia and thrombocytopenia are considered minor diagnostic criteria [4].

The most effective approach to treatment of FES is prevention. An accepted prevention strategy is early stabilization of fractures, particularly of the tibia and femur, which allows patients to mobilize more quickly. This has been found to decrease the incidence of FES, ARDS and pneumonia and reduce the length of hospital stay [5-7]. Aggressive fluid resuscitation and maintenance of an adequate circulatory volume have also been shown to be protective. More controversial is the use of prophylactic corticosteroids. Nearly all trials of both low and high dose methylprednisolone have demonstrated a reduction in the incidence of FES as well as less severe hypoxemia [8-10]. Since most cases of FES are mild and the great majority of patients recover, concerns regarding the risk of infection and wound healing impairment have limited the routine use of corticosteroids. Once symptoms develop, treatment is supportive. Corticosteroids may be beneficial if cerebral edema is present. Respiratory insufficiency is treated with oxygen therapy and continuous positive end-expiratory pressure ventilation.

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Health law

The evolution of surrogates' right to terminate life-sustaining treatment

by Matthew Stonecipher

Depending on one's beliefs and philosophical leanings, removing life-sustaining treatment can be viewed as causing a patient's death or allowing a patient to die. The dramatic and very public debate surrounding the medical decisions made for Terri Schiavo illuminate widespread societal disagreement about the moral consequences of withdrawing support. This divergence stems from the differing attitudes about life and death that inform people's views regarding the kinds of end-of-life decisions that deserve legal protection. American courts have long protected patients' right to consent to care, which necessarily implies a reciprocal right to refuse care [1]. The "right to die," however, is a relatively recent concept made contentious by advances in life-sustaining medical technology.

The movement to challenge the decisions made for Terri Schiavo threatened to destabilize end-of-life law that had developed over the last quarter of the 20th century, principally through the cases of Karen Ann Quinlan and Nancy Cruzan. The New Jersey Supreme Court's opinion, *In re Quinlan*, articulated the interests at stake in a decision to remove life-sustaining care from an incapacitated person, and the United State Supreme Court's opinion in *Cruzan v. Director, Missouri Department of Health* balanced the right to die against the interests of the state. Although the extensive public discussion about Schiavo had little effect on right-to-die jurisprudence, it dramatically illustrated the range of difficulties that can complicate decision making concerning the termination of treatment. These three cases helped to create and to solidify the legal justifications for permitting a surrogate to make treatment decisions that result in the death of an incapacitated person.

The Quinlan Case

On April 15, 1975, 21-year-old Karen Quinlan ceased breathing for at least two 15-minute periods [2]. Three days later, Dr. Morse, the neurologist in charge of her care, diagnosed her as comatose and in a persistent vegetative state. A respirator and nasogastric feeding tube sustained Karen's body.

The Quinlan family was not immediately unanimous in its decision to remove Karen from the respirator after learning that her condition was unlikely to improve. Her mother and siblings believed it was appropriate to cease care, but her father remained hopeful that she would recover—both parents' decisions were shaped by their religious beliefs. Eventually, her father agreed to end treatment, having been

reassured by his priest that doing so was not a sin. Quinlan's friends and family supplied evidence of her wishes, noting that she had spoken on several occasions about not wanting to be kept alive by extraordinary means. Karen's family released the hospital, attending physicians and staff from liability, but Dr. Morse refused to take her off the respirator, believing that doing so was not justified within the tradition of medical ethics. Thus, in this first right-to-die case, the conflict lay between the family's unified desire and the physician's ethical beliefs.

Quinlan's father petitioned the court to appoint him as her guardian, with express power to authorize the discontinuance of all extraordinary medical procedures that sustained her life, because these presented "no hope of her eventual recovery" [3]. He also sought to prevent the physicians, hospital staff and the county prosecutor from interfering with the decision. The New Jersey attorney general intervened to protect the state's interest in preserving life.

The New Jersey Supreme Court, appreciating the gravity of the case, wrote:

The matter is of transcendent importance, involving questions related to the definition and existence of death; the prolongation of life through artificial means developed by medical technology undreamed of in past generations of the practice of the healing arts; the impact of such durationally indeterminate and artificial life prolongation on the rights of the incompetent, her family and society in general; the bearing of the constitutional right and the scope of judicial responsibility, as to the appropriate response of an equity court of justice to the extraordinary prayer for relief of the plaintiff. Involved as well is the right of the plaintiff, Joseph Quinlan, to guardianship of the person of his daughter [4].

In finding for the Quinlan family, the court identified a right to decline life-saving medical treatment under the general right of privacy developed in *Griswold v. Connecticut* and *Roe v. Wade* [5]. The court held that life support could be removed if the physicians and a hospital ethics committee agreed that Quinlan had no reasonable possibility of returning to a "cognitive, sapient state" [6]. Her right to privacy, according to the court, outweighed the state's interest in preserving her life, and her father, as her surrogate, could exercise that right for her. Quinlan lived for nine years after doctors removed her from the respirator [7].

The Cruzan case goes to the U.S. Supreme Court

Many states followed the *Quinlan* decision, and passed legislation that provided legal immunity to physicians who carried out their patients' written instructions (i.e., advance directives) for end-of-life care should they become incompetent [8]. The court's decision also gave great impetus to the formation of hospital ethics committees [9]. In 1990, the case of Nancy Cruzan provided the Supreme Court of the United States the opportunity to address the issues in *Quinlan* at the national level.

Nancy Cruzan fell into a persistent vegetative state after sustaining injuries in a car accident on January 11, 1983 [10]. Her parents, after learning of the permanence of her condition, asked the hospital to remove the artificial feeding and hydration tube. The hospital refused to do so without court approval. Cruzan's parents won authorization to remove treatment from the Missouri trial court, which found that a person in Cruzan's condition had a state and federal constitutional right to refuse "death prolonging procedures" [11]. The court ascertained her wish to exercise this right based on the testimony of a former roommate, who recounted that Cruzan had said during a somewhat-serious conversation that she would not want to continue hydration and feeding unless she could live "halfway normally." The State of Missouri and Cruzan's court-appointed guardian appealed the decision.

The Supreme Court of Missouri reversed the lower court decision, holding that the common law right to refuse treatment was outweighed in this case by the state's interest in preserving life. The Court declined to follow *Quinlan*, and did not recognize a right to privacy that encompassed a right to refuse all medical treatment. Additionally, Missouri law required "clear and convincing evidence" of an incompetent person's wishes before allowing a surrogate to decide to withdraw treatment; the Court held that the evidence was unreliable and insufficient to establish that Cruzan would have refused the treatment. The Court demanded that "[a] decision to refuse treatment, when that decision will bring about death, should be as informed as a decision to accept treatment" [12]. Under this standard, casual remarks were not considered adequate evidence even if they accurately reflected Cruzan's desires.

The U.S. Supreme Court, which had turned down an appeal to *Quinlan*, agreed to hear the Cruzan case. The federal government chose to enter the fray alongside Missouri. Solicitor General Kenneth Starr represented the United States, arguing to the Court that the nation had an interest in preserving life and that, under a traditional reading of the Constitution, a right to refuse treatment could be derived from a general right to privacy [13].

In a 5-4 decision, the Supreme Court affirmed the judgment of the Missouri Supreme Court, holding that Missouri's evidentiary standards were not unconstitutional. In doing so, the Court construed the right to refuse treatment as a due process liberty interest, not as a privacy right which was the *Quinlan* Court's approach. By declaring that the right to refuse treatment was an "interest" rather than a "right," the Court said that the state's interest in preserving life outweighed Cruzan's liberty interest. The majority opinion described Missouri's clear and convincing standard as "a safeguard" of the best interests of the patient, rather than a frustration of Cruzan's and her family's will.

Justice Brennan disagreed strongly in his dissenting opinion. The decision, according to Brennan, ignored the consensus reached by Cruzan's family, her independent and neutral court-appointed guardian and a lower court judge about what Cruzan would have wanted and what would have been in her best interests. Brennan also disagreed

with the majority decision that letting the state exercise its interest in preserving life would protect patients' interests better than letting families decide what was in the patient's best interest.

The Supreme Court decision was not the final judgment on Cruzan's treatment—it only ruled that the Missouri's standards were not unconstitutional. The outcry following the decision prompted several more of Cruzan's friends to come forward to testify to her wishes, and, in December of 1990, a Missouri probate judge found that this added testimony created clear and convincing evidence of Cruzan's desire to refuse futile life-sustaining care. Cruzan died 12 days after her feeding tube was removed, but the three-year fight had taken an irreversible toll on her family [14].

Cruzan had a significant impact on end-of-life decision making across the country. Many states passed legislation related to health care decisions for the incapacitated [15]. With the establishment of these laws, the continuing development of hospital ethics councils and an increase in the number of advance directives in response to media coverage of the Cruzan case, it seemed that the court's role in reviewing life-sustaining treatment decisions had been minimized.

Enter Schiavo

Whereas *Quinlan* and *Cruzan* contributed to evolving legal standards for the termination of treatment for the incapacitated, the litigation surrounding Terri Schiavo engaged settled law. Rather than arising out of a disagreement between the family and an ethically concerned physician, or the family and a cautious hospital and state, the Schiavo dispute stemmed from a feud between family members.

On February 25, 1990, Terri Schiavo suffered cardiac arrest due to a potassium imbalance [16]. As a result of oxygen deprivation, she endured significant brain damage and fell into a persistent vegetative state. After eight years of "pursuing the best medical care for his wife," Michael Schiavo petitioned a Florida court to authorize the removal of her feeding tube [17]. Her parents disagreed with his decision, claiming that Terri would have wanted to remain in that condition, and they sought to obtain guardianship of their daughter.

What ensued was a legal struggle, that, at best, was perpetuated by Terri's parents' refusal to accept her medical condition. Some would argue that it was also driven by election-year politics and sensationalism [18]. Media commentators, Florida Governor Jeb Bush, U.S. Congressmen and even a television psychic questioned the overwhelming medical consensus that Terri was in a persistent vegetative state [19, 20]. Despite these external pressures, Terri's husband, her doctors and the medical community prevailed, using the procedures put in place in response to *Quinlan* and *Cruzan*. Schiavo died on March 31, 2005, after being in a persistent vegetative state for 15 years.

While family-physician communication is instrumental in preventing conflicts in end-of-life care, *Schiavo* demonstrates that some disputes arise outside of the

medical setting. With recognition of a right to refuse treatment—and clinical and legal mechanisms protecting incapacitated persons—the roles of physicians and courts in these situations are settled for now.

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Policy forum

Should cost be a consideration in palliative care?

by Maria J. Silveira, MD, MA, MPH

“We’ve got people knocking on our door all the time,” he said. “If you want us to pay attention, you’re gonna have to show us that what you have to offer can either save or make us some money.”

It was surprising to hear this coming from the mouth of a hospital administrator, especially after a tear-jerking presentation and heartfelt pleas for the funds to start a palliative care service at our institution. We had put so much time and energy into collecting the anecdotes of patients, families and staff to demonstrate the burden of needless suffering at the end of life and how good people could make a difference...and it all came down to *money*? Why should we care about money? This is palliative care we’re talking about.

Granted, the case can easily be made for why money is an important consideration in the provision of most medical care. After all, American medicine *is* a business. But should the same metric apply when talking about palliative care? Is there something special about palliative care that makes it a core service; that is, an essential service to which all individuals should have equal access, regardless of its cost to our health care system? I posit that, yes, palliative care is indeed special and that cost should be a secondary consideration.

While the miracles of science may allow us to diagnose and treat diseases, let us be mindful that, at their inception, the health sciences were meant to help people feel better, regardless of the pathology that lay beneath. This notion is embodied in the principles of nonmaleficence and beneficence upon which medicine was founded. Palliative care is the branch of medicine that attends to the physical and emotional suffering of patients with advancing conditions and the families of those patients. Palliative care is critical to accomplishing what medicine and nursing fundamentally seek to do: help people feel better. Palliative care, in short, is the most basic way hospitals meet one of their foremost responsibilities to patients and their moral obligations to society. For this reason, palliative care should be a core service that all hospitals provide. In short, wherever patients are dying, there should be palliative care.

The notion of core services is not new to medicine. All hospitals have services that are essential to their mission—internal or family medicine and general surgery, for

example, that allow an acute care institution to call itself a “hospital.” Regardless of what the bottom line shows, patient needs for primary care and general surgery must be met in some degree. A hospital that did not meet these needs would, simply stated, not be a hospital. These standards are reflected in the Joint Commission on Accreditation of Healthcare Organization’s standards of accreditation, which most hospitals voluntarily adhere to [1].

I believe that palliative care belongs among these core services that all hospitals should offer. Now, should it be offered regardless of the cost? After all, the bottom line is what allows hospitals to remain open. Without financial solvency, these institutions could not exist. To deny this fact of American medicine is tantamount to being the “bioethicist in a bubble.”

I acknowledge that money is an important consideration in determining whether a hospital can afford to offer palliative care, but I would argue that it should not be the primary consideration, as it often is for nonessential services. Palliative care should be held to somewhat less stringent standards of cost and profitability. This does not mean that hospitals should go bankrupt providing palliative care but that they should be willing to offset costs in palliative care by shifting profits in other areas—an option that arises when hospitals offer a diverse set of services.

Still, there are many other reasons why stringent accounting to determine the worth of a palliative program is not appropriate. Mostly these reasons boil down to the inability to capture intangible costs and value.

1. Palliative care recognizes that illness does not occur in a social vacuum. Unlike other branches of medicine that focus only on the patient, palliative care programs incorporate the patient, his family, his community and the people taking care of him into the plan of care. Palliative care specialists are able to address the substantial amount of suffering at the end of life that emanates from strained human relations, patchy family support and financial hardship due to illness and debility. This expanded sphere makes it difficult, if not impossible, to quantify the value and impact of palliative care. How do you identify all the people touched by one encounter? The stakeholders vary from day to day and case to case. So, where patient-level accounting might be an accurate reflection of value in other branches of medicine, it is not an accurate reflection of the value of palliative care.
2. Measuring the value of palliative care—or what you get for your money—is an impossible task. Standard outcomes, like “life years,” are irrelevant when most patients receiving palliative care are expected to die. Other outcomes may be difficult to measure. How do you ask the deceased if their death was good, for example?
3. Lastly, some services of palliative care are provided largely for cultural purposes. Much of what happens around the death of a patient, for example, the hand holding, caressing, suctioning, wiping and medicating, is done not only for the sake of the dying patient but also for the benefit of his family

who must live with the memory of his death. Practices such as these should not be subject to accounting.

In conclusion, palliative care is a practice that should be thought of as a core service and made available to all patients. Cost should be a lesser consideration than in other areas of health care because palliative care is a core service whose purpose is special, making its true costs and outcomes impossible to measure.

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Policy forum

Why physicians avoid straight talk about CPR

An interview with Leslie J. Blackhall, MD, MTS, associate professor of medicine and associate professor of medical education in the Biomedical Ethics and Program for Humanities in Medicine at the University of Virginia.

A resident observing the misuse of cardiopulmonary resuscitation (CPR) as practiced in the 1980s, Leslie J. Blackhall, MD, MTS, spoke out, writing “Must We Always Use CPR?” which was published in the *New England Journal of Medicine* in 1987. Still concerned about medical ethics, Dr. Blackhall teaches communication skills to a new generation of physicians and helps them to improve the quality of care at the end of life for patients and family alike. She sees less misuse of CPR today, but problems persist. “There has been little improvement in dealing with the idea of medical futility,” she says. “Doctors are more likely to tell patients that they would probably not survive CPR than that CPR would be medically futile.” She also points out troublesome inequities in care options for the rich and poor. Recently *Virtual Mentor* interviewed Dr Blackhall and asked her to update readers on her concerns about the ethical consequences of how end-of-life care is delivered.

Q. How have things changed since you wrote your article?

A. At the time I wrote the article, use of CPR on people for whom it had very little hope of success was common practice. Today, doctors and other health professionals are far more willing, I think, to admit to themselves when this is the case. In my experience, very few oncologists, for example, want to do CPR on someone with advanced metastatic cancer, even if they still believe in continuing chemotherapy. And for the most part they’re willing to convey that decision to their patients, so their patients are not ending up in the intensive care unit at the end of their lives or receiving CPR when they’re dying of aggressive metastatic cancer. By contrast, when I wrote the article it was extremely common to have people with end-stage cancer or people with advanced Alzheimer’s disease receiving CPR, so I think things have improved.

On the other hand, there has been little improvement in dealing with the idea of medical futility. Doctors are more likely to tell patients that they are probably not going to survive CPR than that CPR would be medically futile. And there is still a subgroup of people who, even though told by doctors that they would be unlikely to survive CPR, continue to insist on it. We’re sort of at a standstill on what to do in those cases.

Q. What are those cases?

A. It's not any particular type of case. But take, for example, someone whose diagnosis is widely metastatic cancer and whose need for resuscitation probably arises from that diagnosis rather than from any other cause. The issue here is not disagreement about the case itself—everyone agrees that the likelihood of this person surviving CPR and being discharged from the hospital is extremely low. But disagreement arises over whether we can ever say that there is zero chance someone will survive CPR. We can't say that. Recently there was that patient who woke up after having been in a coma in a minimally conscious state for 19 years. I remind people that this is only one case. But because of one case here and there—and everyone wants to be that one guy—we can't say there is zero chance. So that makes this a difficult issue.

And there's a second reason that many of us are reluctant to “ration” CPR, if you will. And that reason has to do with the fact that people with personal financial resources can afford and demand treatment that is clinically futile, which makes physicians uncomfortable in denying that care to poorer patients—even when we believe it is futile. I heard a presentation at a bioethics conference by some people who are dealing with a medical futility law in Texas. Let's say you have a patient in an intensive care unit with multiple organ systems failure who, all the physicians agree, is dying. The family refuses to allow withdrawal of therapy even though all the physicians believe that it is of no benefit. In such cases we usually call the ethics committee. Most ethics committees see it as their job to clarify the ethical issues, establish who the appropriate decision maker is and facilitate communication among all participants. If, despite this intervention, the patient and family continue to insist on care that the physicians feel is futile (however they define that term) there has been no recourse.

So in Texas they developed a legal procedure for such cases. After calling an ethics committee in clinical circumstances like I just described, you may call a prognosis committee that comprises physicians who are not currently involved with the case but have specializations in the area or areas of the patient's disease. This committee decides whether or not this is a case of futile treatment, and, if they agree it is, the family has so many days to accept or reject the decision. If they accept the prognosis committee's decision, care is withdrawn. If they don't accept the decision, they have the right to transfer the patient to another institution. But here's the problem: this situation often occurs among patients who don't have good health insurance; they have Medicaid or they have very little money. So other hospitals don't want to accept that patient in transfer.

We had a case at our institution very recently concerning a patient with metastatic lung cancer and a tracheoesophageal fistula. Nobody at our institution thought the patient was a candidate for surgery, but this patient was *not* poor; he had lots of money, and his daughter managed to get him airlifted to another institution. If that patient had had no insurance or minimal insurance, there's no way the airlift would have happened or that another hospital would have accepted him. So the person who

gets care withdrawn tends to be poorer. And this brings up uncomfortable questions of power relationships, rationing of health care and health care inequity.

Even though the care might have been futile, it makes a lot of people uneasy to let the doctor have the final say about that term “futility.” First, because we can never say any intervention has an absolute zero chance of working, and, second, because if the patient has resources, he or she may have the option to go to another hospital and get services that a less wealthy person cannot get.

Q. So there is a double standard.

A. When patients with resources can get services—even futile ones—that poor patients cannot, it raises that question. Everybody seems to agree about the right to refuse therapy. That’s the American way. But, we’re having a lot harder time dealing with the other side: the fact that one group of people who tend to have power dictate what futility means (in effect, they refuse to *provide* treatment) to the people who have less power.

When physicians use the argument with patients or the families that CPR is unlikely to be of help to them, most people can accept that. That’s why we do less futile CPR now. There will be a group that for one reason or another is willing to hold out for that .001 percent chance that they might have some meaningful life. So the question of how much money is too much to spend on the care, or how much time is too much or how many medical resources are too many—those questions remain unaddressed. It’s not primarily a question of when to use CPR.

Q. What would you propose if you were writing about this topic today?

A. As a palliative care physician, I think the problem is mainly one of communication. Often when I talk to people, I can help them make a reasonable choice about their resuscitation status because I’m straightforward about the likelihood that they will survive—not just survive CPR, but survive their illness. I think that part of this is about physicians’ reluctance to be forthright. I once had a resident tell me that I was the first physician he had ever heard use the word “dying.” The truth is that most patients and families *have* thought about death. But a lot of younger physicians and those in residency programs are hesitant to be straightforward about it.

A great study was done at Brigham and Women’s Hospital in Boston by CM Lilly asking whether physicians could decrease the amount of futile care that goes on in the ICUs [1, 2]. There’s a high rate of mortality in the ICUs; people there are gravely ill. There comes a point when the physicians realize that we probably need to pull back, but the patient and the family generally take a little longer to come to that point. So these researchers did an intervention in which every patient had to have a family meeting within 72 hours of being admitted to the ICU to clarify goals of care. The meeting included the patient, if possible, the family, physicians, nurses and other members of the multi-disciplinary ICU team to make sure that everyone was on the same page. For example, it might have been agreed that the goal of care was to help

this person with severe chronic obstructive pulmonary disease (COPD) recover from pneumonia and return to his or her prior health status. Participants from the initial meeting then had follow-up meetings every few days to ask, “Are we meeting these goals of care?” It’s far easier to have that discussion at first rather than just plowing ahead and then having that discussion a month down the line when everyone has just been going along without asking about the goals.

Similarly when I meet with a new patient in the Palliative Care Clinic of the cancer center at the University of Virginia, I ask them what they understand about the chemotherapy and their cancer. For patients who have metastatic cancer, I try to explain that there is almost no chance that the chemotherapy is going to cure them. The purpose of their therapy is either to prolong their life or shrink their tumor and improve their symptoms. Thinking about it this way allows us to ask, “How much is enough?” If the goal of chemotherapy is to improve your symptoms, and yet the chemotherapy itself is diminishing your quality of life, then maybe we don’t want to continue it. At the very least they can switch from thinking “I have cancer, I must get chemotherapy,” to “this is the purpose of the chemotherapy; what’s the likelihood it will provide that benefit?” Talking about goals of care and whether what we’re doing meets those goals is the type of communication people need to make decisions. If you have those conversations, most people make reasonable decisions. There will always be the family in which three of the five daughters say let mom go, but two say keep going because mom has always been a fighter. There will be a certain percentage of the time when family members will simply disagree, but studies show we can minimize that if we improve communication about the goals of care.

Q. Should physicians refrain from mentioning CPR or mention it and explain why it is not an option?

A. I come right out and say that we usually don’t do CPR on people with advanced cancer because it doesn’t work. This is how I put it. I say, look, if your cancer were to grow so much that it caused your heart and lungs to stop, doing CPR and putting you on a ventilator tends not to be beneficial because it doesn’t take the cancer away. If people are still getting chemotherapy, we can tell them we’ll do everything possible to keep them from getting to the point where the cancer causes their heart or lungs to stop; we can treat every infection. But if, despite all that, they get to that point, then in my experience CPR doesn’t help; the literature says it doesn’t work and we don’t recommend it. I always bring the topic up and talk with them about it. Everybody watches TV, and everybody knows what CPR is. And, as we all know, TV CPR is much more effective than real CPR, which gives people the wrong idea of what CPR is [3].

Q. Just to sum up, what would clinically appropriate CPR treatment look like?

A. For people who are experiencing chronic illnesses like cancer and Alzheimer’s for whom we can look ahead and see the CPR question coming, we must simply begin to discuss goals of care. Here is what you have. We don’t have a cure for this, but here’s what we can do to help it. I actually believe that many doctors think the outcomes are obvious, but for most patients they’re not obvious. Most doctors would

know that widely metastatic pancreatic cancer is a terminal diagnosis, but not all patients do. That doesn't mean that such patients shouldn't be receiving Gemzar or other chemotherapy; it just means they have a right to know what they're buying and what their doctor hopes it will do for them. So, frequent and early discussions of the goals of care and progress toward those goals is helpful. Then CPR becomes just another one of those discussions.

For people who've undergone acute devastating injury—for example, one moment they were sitting up talking and the next moment they've had a massive intracranial hemorrhage—those people need to have a decision-making process also. Two days ago “dad” was talking and planning to go on vacation and today he's completely unresponsive in the neurosurgical intensive care unit. Family members need to have their questions answered. Once again, start from the beginning, discuss goals of care and the likelihood of reaching them. Update the family when there are changes. This way, you're less likely to get into the situation where you or the nurses feel as though you are torturing the patient with futile care and the family feels angry on the other side.

In the small number of cases when I'm called to the intensive care unit because the family has talked with every specialist and still insists on doing everything, I ask them to tell me what they understand about what the doctors have said. If it seems they haven't gotten the doctor's message quite right, I try to restate what the doctors think, and I admit we are at an impasse. The doctors don't want to provide a certain treatment anymore. You—family members—disagree and are mad about it. Let's be mad at each other, but let's be open about it. We don't want to do it because we feel like we're hurting your dad, and you want to do it because you feel like he has a chance for life. We're having a disagreement about our values here. One of our values is we don't like to hurt people by continuing medical care that doesn't help them. Tell me why you want us to keep doing these things that we believe are doing more harm than good. That's the best we can do in these difficult circumstances; be straightforward with each other and continue the conversation.

Q. How can medical students learn these communication skills?

A. At University of Southern California and now at University of Virginia we have used standardized patients. In its most extensive form at University of Southern California, we had a little grant money to try this, so we had about five students at a time with five standardized patients (actors and actresses) all playing the same part and videotaped in different rooms with a very realistic-looking set-up. After the students interviewed the standardized patients, they watched their videotapes. And then we talked about what went wrong and what went right. This is time-consuming, but I think it works.

Q. How did the CPR scenarios play out?

A. One of the medical students was talking about intubation with a “patient” who had ALS. We looked at the tape and the medical student was sitting there holding his head in his hands. He was just talking around the subject and could not be

straightforward about it, and therefore nothing got decided. When it was over the medical student said that a friend of his had had cancer, and the doctors told him he was dying, which was a terrible thing for his friend to hear. The medical student promised himself he would never tell a patient that he was dying. But he realized as a result of watching the videotape that he couldn't keep that promise; that there were times he would have to tell people that they were dying. And in the next patient encounter you could see that, although it was difficult for him, he was able to get straight to the point and talk to the patient in a way that the patient could understand. That was an instance where you could see somebody acquiring an incredibly difficult skill set. The training has improved since I was a medical student, but we could do more. I think it's almost abusive to put young doctors into positions where they have to talk with the family of a dying patient when they are unprepared to do so.

Q. Dr. Weismann, who wrote for *Virtual Mentor*, came to the conclusion that nobody really wants to talk about death.

A. Nobody wants to face it. I give a “breaking bad news” presentation. When I give that talk, the first slide says “People want to know the truth.” The second slide says “They want the truth to be good news.” They want both of those things, which they can't always have. The same is true for doctors—you want to tell the truth—that's part of your ethos—but you want to tell good news. There tends to be collusion—there's a great paper about this actually [4]—between doctors and patients with a critical illness to just sort of “not deal with this now” because any encounter in which you *do* deal with it is going to be anxiety-provoking on both sides, and human beings are animals that try to avoid unpleasant emotion. I feel like it's my job to be the one who says, “I'm not avoiding unpleasant emotions.”

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Medicine and society

Dying well in America: What is required of physicians?

by Richard Payne, MD

A commonly heard joke in hospitals and clinics is that “death is optional.” Our popular culture reflects an obsession with perpetual youth and vigor and seems to devalue aging, particularly the frailty that often accompanies illness and aging. Our medical culture reflects these attitudes. The emphasis on problem-oriented medicine and the focus on subspecialty practice have reinforced fragmented and less-than-holistic models of care that sometimes isolate patients from their families and communities. This shortcoming of contemporary medical practice has particular consequences for individuals who are most vulnerable and in need of coordinated comprehensive care—those with advanced chronic and life-limiting illness, especially the elderly.

Although medical progress in the past century has nearly doubled life expectancy for Americans, and we now have the lowest annual death rate on record, it is still true that everyone must die. A review of Medicare records indicates that the average person experiences two years of disability prior to death [1], and recent studies have documented many deficiencies in our care of these seriously ill and dying patients beyond just fragmented systems of care. Poor symptom assessment and management skills, perceived low prioritization for documenting and respecting patient preferences for care, late referrals to hospice programs and general training deficiencies in palliative medicine have all been identified as contributors to less-than-optimal end-of-life care [2, 3]. Given the probability that most of us will experience chronic illness and progressive frailty before dying, what should physicians and our health care system do to maximize our likelihood of dying well?

Dying well

The term “dying well” is much preferred to the often-used phrase “a good death” since many believe there is nothing “good” about death itself. In psychological and emotional terms death is not “good” because it represents the disintegration of personal identity and separates us from family and loved ones. The physical realities of chronic illness leading to death—e.g., cachexia, bed sores and mucosal ulcerations—can even alienate patients from their own bodies. This threat of separation from personhood, family and community engenders fear that can lead to suffering. As physicians we can attend to this anxiety and suffering through models of caring that integrate the medical, psychosocial and spiritual needs of patients and families. This approach to healing is best exemplified by palliative medicine, defined

as an approach to care that attends to suffering associated with chronic advanced illness and emphasizes the physical, emotional and spiritual well-being of patients and their family [4]. Hospice care is the best-developed system for delivery of palliative care and is designed to maintain the highest quality of life for patients diagnosed with a terminal illness who choose comfort care over curative medicine. It is important to note that hospice programs invite primary care physicians to continue their relationships with their patients after referral to the program.

A public opinion survey of all North Carolina AARP members by the Carolinas Center for Hospice and End of Life Care asked respondents to list their most important end-of-life needs [5]. Although they listed medical needs such as freedom from pain, physical comfort, knowing what medications are available, honest answers from doctors and understanding treatment options as important, it is useful to review the nonmedical concerns of the respondents. Some of the most striking of these were: being at peace spiritually, not being a burden, having things settled with family and knowing how to say goodbye [5]. The message from this survey is that when we view care for the seriously ill and dying *only* in medical terms we risk neglecting equally critical psychosocial and spiritual needs.

Beyond medicine

What is our role as physicians with respect to the nonmedical needs of our seriously ill and dying patients? We can begin by adapting the philosophy of palliative medicine. Palliative and hospice medicine offer powerful options for doctoring, especially for patients who have incurable or terminal illness. A truly comprehensive palliative care approach avoids overly medicalizing care. Competency in palliative medicine provides physicians with the knowledge and skills necessary to continue caring for patients when we can no longer provide curative treatment and also provides a means for maintaining a legitimate presence so that we will not abandon our patients at the time of their greatest need.

Palliative medicine calls upon the physician's knowledge of the natural history of disease and requires her to lead an interdisciplinary team of health care workers who are truly practicing patient-centered care. Proficiency in palliative medicine also includes expertise in pain and symptom management. This is much needed; far too many patients still experience avoidable pain and distress [2]. We must effectively manage pain and other unpleasant symptoms such as nausea so that patients have the physical and mental strength to attend to their spiritual and existential concerns. Expertise in palliative medicine also requires excellent communication skills, including the ability to listen and connect to patients in a sincere and empathic manner. We must attend to suffering caused by the assault on the integrity of personhood if we wish to assist families as they struggle with the toll taken by advanced illness on the physical, emotional, spiritual and social aspects of their lives [6, 7]. Above all, competency in palliative medicine requires the ability to solicit and comprehend each patient's unique narrative [8].

As indicated in the Carolinas Center AARP study, spiritual concerns are high on the list of patient needs at life's end [5]. Although patients do not expect physicians to be their spiritual care providers, they do want their doctor's respect for their spiritual concerns which include fear of abandonment, guilt, anger with God and the fear of not being remembered [9]. Ira Byock, MD, director of palliative medicine at Dartmouth Medical Center has said to me, "Confrontation with death lays bare our spiritual concerns about life's end." We must learn to do routine assessments of the spiritual needs of our patients and include their pastors, hospital chaplains and faith leaders as part of the health care team.

As physicians we can provide the foundation and the space for our patients to "die well." We have a role in creating the conditions patients and families need in order to reach closure on important life issues—they need to say "goodbye," "I love you," "forgive me" and "I forgive you" [10]. Contemporary medical practice still has need for the physician to play this role as a true healer.

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Op-ed

Racial disparities in hospice: moving from analysis to intervention

by Ramona L. Rhodes, MD, MPH

Hospice is a program designed to provide comfort—rather than curative—care to terminally ill patients and support to their families. Hospice services are provided by a multidisciplinary team of physicians, nurses, social workers, clergy and volunteers who work together to help patients and their families meet the challenges of end-of-life care. Hospice services can be provided in a variety of venues including the home, inpatient hospice facilities and long-term-care facilities. Several studies have documented the benefits of hospice to patients and their families. For example, in a randomized, controlled trial of terminally ill cancer patients and their primary care givers, Kane et al. found that patients enrolled in a hospice program experienced significantly less depression and expressed more satisfaction with care [1]. Furthermore, caregivers of hospice patients showed somewhat more satisfaction and less anxiety than did those of controls [1]. Bereaved family members told Teno and colleagues in a national study that loved ones who died at home with hospice services had reported fewer unmet needs and greater satisfaction with their experience [2]. Finally, Miller et al. observed that hospice enrollment improves pain assessment and management for nursing home residents [3]. The literature consistently finds that participation in a hospice program improves the quality of care patients receive at the end of life.

Since the inception of the Medicare hospice benefit, hospice services have been available to many patients. Despite these additional sources of funding and the evidence of improved quality of care at the end of life, African Americans and members of other ethnic minority groups consistently underutilize hospice. For example, in a secondary analysis of the 1993 National Mortality Followback Survey, Greiner et al. found that being African American was negatively associated with hospice use regardless of the patient's access to health care [4]. In a retrospective analysis of more than one million Medicare enrollees, Virnig and colleagues found that the rate of hospice use was significantly lower for blacks than for nonblacks [5]. Furthermore, even though blacks made up 12 percent of the population of the United States in 2004 they accounted for only 8.1 percent of hospice admissions for that year [6].

Several possible causes for racial disparity in hospice utilization have been proposed. Research has suggested, for instance, that lack of knowledge about hospice programs is a barrier to their use in the African American community [7]. Mistrust of the

health care system, conflicts between individuals' spiritual and cultural beliefs and the goals of hospice care, and preferences for aggressive life-sustaining therapies have also been suggested as causes [8-12]. Some believe that providers' conscious or unconscious stereotyping of their patients may also lead to disparities in health care [13]. Additionally, the prohibitive cost of health care, barriers to access and a culturally insensitive health care system have been thought to contribute [8]. Few of these reasons for underutilization of hospice services by African Americans and members of other minority and ethnic groups have been studied in depth.

When compared with use by Caucasian patients, not only do African Americans underutilize hospice, they also perceive the quality of end-of-life care differently. According to Welch et al. blacks were less likely to rate the care their family members received at the end of life as "excellent" or "very good." They were more likely to have concerns about being told what to expect when their loved one died and more likely to be distressed about the amount of emotional support they received from the health care team during their loved one's last days [14]. There were, however, marked decreases in the disparities noted in perceptions about the quality of care once patients enrolled in hospice, particularly with regard to overall satisfaction with services and attending to the needs of family members [15]. Hence, there is evidence that having hospice care leads to improvements in African Americans' perceptions of end-of-life care.

Though initiatives have been implemented in some areas, more culturally sensitive education is needed to increase awareness of hospice and its benefits. Some studies suggest that cultural diversity among hospice staff may influence diversity among hospice patients [11]. Consequently, hospice programs should strive to increase diversity not only among their patient populations but also among their employees and volunteers. Given that conflicts between cultural preferences and hospice goals are thought to inhibit its utilization, cultural sensitivity should be emphasized to all health care workers, particularly those who care for patients at the end of life. Interventions directed at these areas are sorely needed, as is evaluation of their effectiveness.

Access to hospice has been increasingly thought of as a public health matter. The right to quality care at the end of life is one that should be extended to everyone regardless of race, ethnic background or socioeconomic status. Barriers to hospice utilization should be researched and identified so that appropriate interventions can be conducted to overcome these obstacles. The evidence that hospice is underutilized by those of underserved communities is substantial, but few steps are being taken to understand and reverse this trend. The time has come for research to move from the analysis of disparities in end-of-life care and hospice utilization to identification of barriers and interventions to reverse the trend.

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Op-ed

Suffering under the auspices of contemporary medicine

by Rashmi Kudesia, ScB

In the course of disease and medical treatment, patients commonly experience a kind of suffering that goes beyond physical distress. Emotional affliction can prove equally and sometimes more debilitating than bodily injury and deservedly clamors for attention from physicians. While earlier paternalistic conceptions of medicine viewed the body as a text to be read by a skilled physician, contemporary medicine has come to espouse the biopsychosocial model, which reminds doctors of the aspects of health that extend beyond the physical body. Yet in practice, psychosocial complaints are often relegated to a secondary status, and this can have dire consequences not only for patient outcomes but also for the patient-physician relationship.

Understanding suffering

Consider, for example, the case of a 35-year-old sculptor with metastatic breast cancer whose chemotherapy pains her not only physically but emotionally. She feels frightened and uninformed, misled about the severity of the resulting disfigurement and the virilizing side effects of a consequent oophorectomy. Her case culminates in a metastasis to the supraclavicular fossa that weakens her sculpting hand and prevents her from working. Despite these setbacks, this patient's disease eventually goes into remission. A holistic look at this woman, beyond the cancer diagnosis, reveals how her disease infects her livelihood and sense of self, despite therapeutic successes. Upon considering all her losses, one might anticipate the severe depression into which she soon sank. *This* is the nature of suffering.

In 1982, before the concept captured the public spotlight, Eric J. Cassel, MD, presented this case in an incisive yet expansive treatise on the subject of suffering and its place in medicine [1]. The framework for Cassel's "The Nature of Suffering and the Goals of Medicine" is the all-too-common situation of patients whose emotional and spiritual suffering goes unaddressed by their physicians. Cassel traces this deficiency to Descartes' mind-body dualism, in which the afflictions of the body—identified as an object of study—became associated with medicine and doctoring, while afflictions of the mind—identified as the abode of subjective personhood—did not. Over the centuries, the growing reliance on the scientific method and standards of care increasingly excluded mental disorders from the medical arena; thus many present-day physicians find themselves conditioned throughout their training to dismiss or at least minimize psychological concerns.

Patients, on the other hand, may often expect such concerns to be addressed and factored into their treatment plans. Unfortunately, these disparate expectations create a sizeable rift between patient and physician.

The integrity of persons

Cassel postulates that suffering arises from a threat to personhood that often accompanies physical illness or pain; it persists as long as the patient's perception of the threat exists and can thus outlast the illness itself. The threat is not necessarily commensurate with physical pain. For example, the considerable pain of childbirth does not usually engender extreme suffering; the joy of birth renders the experience more tolerable than a previous injury that may have demanded less physically. Cassel concludes that when people feel pain they cannot control, overwhelming pain, pain from an unknown source, pain that carries a dire meaning or pain of a chronic nature, suffering may take on a life of its own. In all these instances, the patient views his pain not within the scope of life or death, but as a threat to the continued integrity of his personhood. This fear stems from an undesirable and uncertain vision of the future. In other words, the patient dreads an alteration in his personhood that the pain will cause, a change that will negatively impact plans, goals and dreams. This anxiety causes the patient to suffer.

The Cartesian model of mind-body medicine that Cassel described in 1982 still exists, but there is now at least a recognized need to attend to the patient's suffering by putting these two aspects of the person on a rhetorically level playing field. Since Cassel's landmark article, the biopsychosocial model of medicine has gained credibility, informing physicians of their duty to consider how psychological and social forces shape disease processes and to address patients' mental and social well-being. As part of this movement the concept of emotional pain (suffering) has been explored carefully and developed under a multitude of new terms.

Yet the advances would be merely semantics without the effort that has gone into researching their shared fundamental premise: there is more to health and illness than mere biology. Indeed, examining the interplay between biology and the human psyche uncovers exciting truths. Medical conditions manifest in psychiatric symptoms, and vice versa; the two cannot be extricated. Even more astounding are cases in which symptoms exceed in magnitude the etiologic mechanisms that cause them. For example, biological treatment of adrenal insufficiency can alleviate its associated psychiatric woes, but in systemic lupus erythematosus, such an approach is unpredictable: mental health may improve or worsen [2]. Patients with lupus often experience psychiatric comorbidities, most commonly depression; undergoing medical treatment has been shown to ameliorate some patients' mental state and exacerbate the condition in others. While the factors guiding this outcome have been studied, they remain unclear [3]. What *is* clear is that to optimize patient care, one should be mindful of the full range of biopsychosocial components.

In these newer fields of study, much emotional and mental discomfort is labeled as "stress" [4]. Merriam-Webster defines stress as "a state resulting from... factors that

tend to alter an existent equilibrium” [5]. Stress can come acutely and chronically; repeated bouts have been shown to decrease the thresholds for developing illnesses [6]. So widely accepted is the concept of stress that it has become cliché, a part of the cultural consciousness in this country. Yet, if we exclude physiologic stresses imposed by exercise and so forth, and consider mental stress under the definition given above, then does it not come close to capturing Cassel’s notion of suffering? Both stress and suffering can occur on a small or large scale, and both result from an internal conflict between that which is present and that which was desirable or anticipated. Though the ubiquity of “stress” in contemporary society may trivialize its gravity, it is nonetheless a powerful word. It carries physical, emotional and psychological meaning, and as such is perhaps the best analogue to suffering that modern medicine owns. Accordingly, then, today’s new arsenal of linguistic descriptors frame stress as a result of a shift in the balance of one’s life, drawing the conclusion that mental distress can complicate and worsen biologic pathology and therefore deserves attention from the medical community.

Falling short of the mark

Yet even stress is not reliably treated, and patients endure their afflictions for years at a time. Problems that cannot be physiologically explained and pharmacologically treated are frequently ignored. Though hospitals with rich resources may in fact take the step of creating positions for stress-management consultants, the house staff is often neither made aware of these resources, nor otherwise encouraged to use them. Studies like one undertaken in California demonstrate the minimal attention psychosocial issues receive during medical school and residency training [7]. Student and resident respondents to the survey indicated that a lack of emphasis on mind-body medicine resulted in unfamiliarity with the evidence and practice methods of this type of healing. This seems to support the belief that biopsychosocial medicine is a token phrase, used cavalierly and taught without enough conviction to compel students and residents to regularly use the approach. Poor education leads to a lack of comfort in addressing anything beyond the patient’s physical problems; absence of positive role models to demonstrate expected behaviors leads learners to devalue the role of psychosocial contributors to illness, and emphasis on the bottom line forces house staff to solve the clinical problems as quickly as possible, rarely taking the time to explore the personal ones that cause suffering and beg to be discussed in depth.

It is disheartening enough that many young physicians cannot endorse the ideals of holistic medicine; it is more appalling that even psychiatrists often put more value on biologically explainable complaints than on mentally based ones. Miresco and Kirmayer conclude that the more psychological a process seems, the more the psychiatrist holds the patient responsible and blameworthy; belief that the illness has a neurobiological etiology has the opposite effect [8]. If those physicians who elected to be specially trained in disorders of the mind share this bias, then patients who suffer psychological and spiritual pain may find nowhere else to turn. Medicine has failed them.

Addressing the difficulties

What is the problem? What makes addressing stress and suffering so challenging? Perhaps an overestimation of the difficulty of this task. In some patients, a moderate amount of probing and an empathic response alone will help. But to satisfy our responsibility to consider the threats to a person's integrity we must come to appreciate how someone might feel besieged by her medical condition. Understanding the disease in the context of the patient's life can serve as a lens that brings the threat to personhood into clear focus. Consider again Cassel's 35-year-old sculptor; a physician who had queried the effect of her illness on her life and self-image would, at the very least, have deduced her risk for depression and validated it.

One way in which modern medicine manages stress is by classifying people as personality types: people with a type-A personality are theorized to handle illness in a very particular way—badly. Their highstrung, stubborn and take-charge nature puts them at a disadvantage when they are seriously ill: it is difficult for them to adapt to being cared for, deal with the unexpected, relax their hormonal excitation and so on [6]. Absent from this classification is mention of the power of spirituality, what Cassel calls the “transcendent dimension” in the list he proffered of the many constituents of personhood. Study after study has shown that coping approaches associated with religious beliefs can improve a seriously ill patient's quality of life [9, 10]. If a physician or caregiver elicits information about how disease is causing a patient's suffering, she may find a solution more easily than expected or, again at the least, offer the patient validation.

The goals of medicine

Pursuing the quest to alleviate suffering is more difficult and more personal than selecting a computer function that delivers a message to a phlebotomist to draw the patient's blood for a laboratory test. Cassel concludes that as medicine has historically excluded suffering from its sphere, it is unsurprising that suffering abounds and that it is often caused by medical treatment. Though he agrees that tackling this issue “presents problems of staggering complexity,” he reminds us that our knowledge of biology was once scant also. If we indeed believe that the relief of human suffering is a goal of medicine, then we have much work to do.

While the research in this field has exploded since 1982, room for improvement is vast; the first step is to persuade our doctors to believe in the mind's centrality in matters of health and illness. Though that might seem a monumental task, think about it for a moment. Is it not natural to expect that every now and then a doctor can take off his white coat, pull up a chair, sit down and engage in listening to and empathizing with the suffering of another human being? While humans may grow stronger with each blow that does not kill us, suffering without someone to share with, someone to validate us, slowly plagues our soul. How truly wonderful it would be, and how much more would we appreciate our physicians, if they tapped the ability within—their inner empathy and intuition—and used the available resources to treat not only our pain, but our suffering too.

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Medical humanities

An evening on the hospice unit

by Allison Grady

Nervous anticipation always swirls in the depths of my stomach when I hear the familiar “ding” of the elevator signaling that I have reached the top floor of the hospital. Some of the staff have said that hospice is put on the top level because you’re the closest to heaven, but, whatever the reason, riding past those other floors always gives me time to imagine what I will find once the double doors open.

As I walk out of the elevators I am most struck by the relative silence. There are no beeping machines, no broadcast pages, no nurses frantically running in and out of rooms. Instead there are six patient rooms, and all but one are exclusively for single occupancy. In addition to patient rooms the hospice unit has a family room complete with games, cable television and VCR, pamphlets about various diseases and about grief, and two telephones that allow the visitors to connect with those who are unable to pace the hospital halls worrying about a loved one. Adjoining the family room is a kitchen for family and friends. Several other rooms that are used less frequently fill the remainder of the floor. The French doors I walk through welcome me to the unit; to the left and right offices are discreetly tucked into corners.

Although there are no “visitor’s hours” on this unit—it never closes—the soft classical music I have to strain to hear gives the impression that no one has disturbed this area of the hospital in hours. I hustle by the large conference room, the supply room and the quiet room where private phone calls can be placed. Halfway down the hall, I cross an artificial threshold and enter into a more intimate portion of the unit. I see the first patient room and notice that, while the curtain is drawn shielding the identity of the patient, the heavy oak door is still open. It’s not until now that I smell the mass-produced meatloaf—Wednesday night’s dinner—and see the two nurses on-duty—Christine and Abby—charting notes at the cluttered work station to my left.

Christine, Abby and I exchange warm greetings as I slip behind the nurses station and into the small “report room” where I store my purse. As I put on my teal volunteer jacket I survey the walls for new cards from families of former patients thanking us for our care and concern during their loved one’s last days. I notice the card from Mr. Cutler’s family—a picture of a bird soaring into the sunset—and remember my interactions with him—the two baths I gave him, talking with his children and the drawings by his young grandchildren that papered his walls. But the

time for sustained remembrance is short—the patient census board hanging on the wall shows that we are full.

There are six patients on the unit. As I look at the volunteer report sheets that list the patient name, age, diagnosis, abbreviated psychosocial status, presence of family members or special friends, and any special instructions such as an indication that the patient should receive “nothing by mouth” (also known as NPO), Abby enters the report room and asks if I’m ready for the daily report. As I reach for a pen she launches into a more detailed explanation of the volunteer report sheet. “Mr. Nathan in 703 is very anxious—someone needs to check on him every ten minutes or so just to be sure that he’s not trying to get out of bed. He’s not able to communicate very well; the Alzheimer’s has really eroded his ability to speak, but he listens and is cooperative. Sometimes he likes people to read to him, so you can see if he’s in the mood for that.

Now, Mr. Geragos in 705 has a lot of family here. He’s not doing so well—probably hours to *maybe* a day but I wouldn’t be surprised if it happened tonight. Anyway, there are a lot of people here visiting including his wife, Judy, his two sons, and his three brothers. The two sons are about your age...” Abby continues to talk to me about Mr. Geragos, but for a split second I am jolted by her noting that Mr. Geragos’s children are my age. It is always jarring for me to hear that my peers are experiencing a loss that I have been fortunate enough to have evaded for so long. Snapping back to the present moment, I listen to the rest of Abby’s report.

It is the patients who teeter between this world and the next whose family members tend to be the most receptive to my help and compassion. As a volunteer I am not here to pity the family or to gawk at the patient, but rather to offer whatever objective support I can. Sometimes that means that I will make the visitors a dinner of soup or a baked good; other times I just talk to family and friends about their loved one. It is always fascinating to hear stories about the lives people have led and to be reminded that, no matter how globe-trotting or parochial one’s life has been, the fact remains that for most of us death will be a simple and humbling ending. For patients who have no family members present, volunteers strive to make dying as comfortable as possible by holding a hand, tidying up the room or providing basic personal care.

Armed with information and ready to take on the evening I first stop by each room and talk to family members and patients. I ask if I can bring them anything: water, coffee, a newspaper? Although most refuse, I like to use this time as a way of introducing myself and letting them know that if they need anything I’m happy to get it or locate the person who can. Moving to the kitchen, I throw away old food, make fresh coffee and wrap up and refrigerate any dinner trays that were not delivered to patients or eaten by their families. Finally I put a load of laundry into the washing machine. On this unit patients are encouraged to bring their old night gowns and pillow cases with them as reminders of home, and we have the ability to wash them separately from the hospital-issued linens. Once the housekeeping tasks are

complete, I'm ready to dive into my other favorite aspect of the volunteer experience: patient care.

Personal care

“Alli, can you get supplies ready for a bath for 701?” Abby asks. For some, referring to a patient by a room number seems impersonal, but confidentiality dictates that patient names should be protected in a public setting, so I glance at the report sheet to find out who Abby is referring to. Eagerly I gather the night gown and warm the moist wipes that we will use to wash Mrs. Kramer, find a fresh set of sheets and padding to be placed under her, and grab an adult-sized diaper to replace the one she is wearing.

As I enter the room with Abby, I introduce myself to Mrs. Kramer, who is chipper and alert. We explain that we're going to give her a bath and change her sheets and she seems agreeable to this pampering. Abby begins with her face and I with her feet; we use the warm wipes to wash her literally from head to toe. Mrs. Kramer's feet are dry and her toenails are hard but brittle. She is clearly self-conscious of this as she implores me not to look at them, but I assure her that I'm only here to clean, not to judge. As I move onto her legs, I can't help but notice that they are essentially bone covered by a thin layer of discolored skin—mostly from the months of radiation and cancer treatments along with age—but she enjoys my rubbing. She explains that these baths are the only human touch that she has had in months that did not involve invasive poking and prodding and for that she is grateful. After spreading some lotion on Mrs. Kramer's lower extremities, Abby and I meet in the middle of her body. We untie her nightgown and remove her arms from the oversize sleeves and wash her chest. I lift up each sagging breast—“a little modesty dear,” Mrs. Kramer chides—and I wash under and between them before covering her up again. Abby unpeels Mrs. Kramer's diaper, washes her front “privates” and checks to be sure that the catheter is in place.

Carefully we roll Mrs. Kramer onto one side and I wash her back. Like her legs, her back is bony and dry. I spread more lotion on her and I can feel her body relax. Abby and I fully remove the diaper, and the odor instantly forces me to breathe through my mouth. I'm used to this smell by now—feces, light sweat and sickness—sometimes worse than others; luckily this is not one of the worst. Embarrassed by her inability to care for herself, she apologizes and I do my best to assure her that this is not a problem at all and that we just want her to be as comfortable as possible. “But,” she says, her voice trailing away from me, “I feel badly. You'd think that with all of these tests and hospital stays I'd be used to it. But cleaning yourself is something that you almost take for granted after 76 years.” By the time she is done apologizing and explaining, I am done washing and have started to remove her old sheets and put on the new ones. Making a bed with someone lying in it is a unique skill, and based on my efficient tucking, pushing and arranging of the sheet, pad and diaper, I'd say that I'm becoming quite an expert.

Abby and I gently roll Mrs. Kramer over to the other side of the bed where Abby secures the new diaper, ties the nightgown and attaches the sheets onto that side of the bed. As Abby gently lifts Mrs. Kramer's head and shoulders, I slip in two freshly cased pillows and, once her head is positioned, we comb her coarse gray hair and ask her about the people who came to visit her today. Our final act with Mrs. Kramer is moving her up higher on the bed and this pull upwards is like a little ride for her. We stuff some pillows at the foot of the bed to prevent her feet from getting blisters, place a small homemade pillow under her slightly bent arm and another one behind her back to help ward off bed sores. Mrs. Kramer is grateful but exhausted after this half hour of activity and, as we pitch the dirty linens into the cart and wrap up the garbage, we notice that she is already sleeping lightly. We turn off the main lights and quietly exit the room.

The moment of death

When Abby and I emerge from Mrs. Kramer's room, we are struck by the relatively few people left mingling in the hall. It appears that most of Mr. Geragos's family have decided to go home for the night. All that remain are his wife and their two sons, and even they are preparing to leave. Mr. Geragos's wife, Judy, stands sullenly in the hallway, her eyes bloodshot and her nose raw. I can overhear Christine speaking with her, "Well, it could be anytime now. We just never know. But there is nothing wrong with going home and getting some sleep. You have to take care of you, too. We can call you as soon as anything changes..." I continue walking by and do not hear Judy's response, but infer that Christine's plan is acceptable because she puts on her jacket and heads for the dimly lit exit with her two silent children. "We'll call you as soon as he makes any changes or if things look imminent. But you have to know it can be any time now." Christine opens her arms to embrace Judy and they hug for a few seconds.

"I know this could be the last time I see him, but there is nothing more I can do. We've all said our goodbyes. Promise me you'll call as soon as anything changes. My cell phone is dead," Judy says looking at its blank screen, "but we'll be home in about 45 minutes." Christine and Judy continue to talk and I walk over to the nurses station where I catch up with my co-volunteer, Patti, for the first time all evening.

Once Judy leaves, Patti and I enter Mr. Geragos's room. His breathing is labored. His skin appears to be naturally olive, but now there is a tint of yellow to it. His large brown eyes are open but vacant and he takes big gasping breaths like he would take if he were drowning. Patti talks quietly to Mr. Geragos—it is said that hearing is usually the last of the senses to go—while I hold his hand and stroke his head. Twenty minutes pass and Mr. Geragos continues to grasp at life, but now the gasps are less frequent and more shallow. Patti tiptoes out of the room to let Christine know of Mr. Geragos's deteriorating condition, and Christine leaves a message on Judy's home answering machine as she promised.

Back in the room, I've begun talking to him while still holding his hand and stroking his head. When you don't know someone it almost feels like an intrusion to talk to

them as they straddle life and death. Sometimes words fail, and I find myself saying a silent prayer or just thinking intensely about the patient who is before me. Who was this person? What was he like? So many questions race through my mind. Working on this unit, you learn that silence, sometimes, is the best way of communicating.

When Patti re-enters, I let her take up the talking again, but she too, is realizing that this might be a moment when words are unnecessary. We exchange looks but do not say anything—we both know what is coming. The minutes tick by and the breathing becomes more spacious, the gasps, while still forceful, are now more shallow. Suddenly, the only sound is the classical music playing overhead. Patti counts in her head—I know this because I am doing it too—one, two, three, four, five—and then Mr. Geragos breathes again. I'm not sure why I count, but it helps me to get an idea of how far apart each breath is and I am able to compare it to the last. I tighten my grip on his hand, but it already feels lifeless. He does not squeeze back and it seems his eyes are further up in his head. Again, the sounds of the building strings and the booming percussion fill my ears and I restart my silent count—one, two, three, four, five, six—another breath. My mind cannot help but wonder if he is aware of his own struggles to breathe or if he is already in that next place. Nothing suggests that he is in any pain. I know that he was medicated earlier in the day, and he has not shown any signs of discomfort or pain since.

Patti begins talking again, quieter this time, and I rub his arms and shoulders giving his hand a rest. One, two, three, four, five, six, seven, eight, nine, ten—nothing. Patti and I wait, but we do not hear a sound. Time seems to have stood still. She reaches to touch him and—*breath*. We are both startled by it, but we are undaunted. We are committed to staying gathered at his bed until there is no reason to be there anymore. It's after eight and we both know that our scheduled volunteer time is up, but neither of us will leave this man here alone as long as he is alive. There is another silence—this time even the music is between movements—and I look skeptically at Patti. . . .ten, eleven, twelve, thirteen, fourteen, fifteen. Still nothing. We reach out to touch him just under his chin, but there is no reaction. Mr. Geragos seems more relaxed and we can only hope at peace. I move his hand closer to his side. Still nothing. We stand at his bedside and we both bow our heads. We wait a minute longer—could this be the time when he will breathe again—but we know from his posture and the eerie silence, no, not this time.

Patti goes to tell Christine that Mr. Geragos has died, and I walk out of the room, while taking one last look, and go to get my purse from the report room. I prepare to walk down that hall for the final time until next week and I feel satisfied with the work I have done. It is getting late and another day of non-hospice-related work awaits me in the morning. As I shuffle down the hall I can hear Christine saying, “No, no, Judy, two volunteers were with him. . . .Yes, the whole time. You can be sure that he wasn't alone.”

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Related articles

[Fred](#), January 2002

[In hushed tones](#), March 2002

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Theme issue editor

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Correspondence

Response to “Dermatology lab referrals: cash cow or ethical trap?”

The dilemma facing the fictitious Metro Dermatology Group in this vignette has been created by external forces, which have essentially reshaped the way that health care is provided in the United States. These external forces have caused physicians to work harder; that is, to see more patients in a given time frame with reduced compensation. The usual response of any prudent physician responsible for management of a practice is to seek ways to reduce expenses and ethically maximize income.

In states where labs and other service providers are not allowed to bill their clients—the dermatologist in this case—they must bill patients or the patients’ insurance carriers directly. In states where client billing *is* allowed, physicians can pay the medical service provider—in this case the pathology laboratory—directly and submit a claim for payment to the patient or, most commonly, to the patient’s insurance carrier. Client billing creates an incentive to seek out the lowest-cost provider. While this practice, where permitted, is not unethical, it could have an effect on a physician’s judgment. All physicians must always keep in mind the cardinal ethical principle which is sacred to medicine: *primum non nocere*, first (or above all) do no harm.

In the vignette, Dr. Vinaver is concerned about the group’s contracting with a “giant out-of-state lab.” The concern is reasonable because he doesn’t know anything about the pathologists who would be interpreting his patient’s biopsies. All clinicians, and especially dermatologists, should have a comfort level with the pathologist(s) who interpret the biopsy samples that they submit. Dermatologists are especially sensitive to this issue because of differences in terminology and philosophy among dermatologists and dermatopathologists. This comfort level or feeling of trust is established by knowing that the pathologist is well trained and qualified. Understanding terminology used, especially with pigmented skin lesions, and being able to communicate easily, effectively and in a timely manner are other requisites for a feeling of trust. The local lab and its pathologists are a known entity, and the large, remote, out-of-state lab is not—a reasonable concern for any physician who cares about the well-being of his or her patients.

I practiced in a community hospital for 15 years. For the last 22 years, my practice setting has been in a large commercial laboratory—Quest Diagnostics. Commercial laboratories offer the same high quality services as hospital or smaller pathology group labs, usually at lower cost. The lower cost is made possible by operational efficiencies, increased purchasing power and economies of scale, to mention the

more apparent reasons. The trust level mentioned above may be harder to establish in some cases because of geographical separation. In today's world, this lack of closeness can be overcome by a personal visit, if feasible, and telephone or e-mail communication. If a dermatologist is considering using the services of another laboratory, it is appropriate to interview the dermatopathologist(s) who will be responsible for interpreting his or her patient's biopsies.

The following are some specific questions that should be asked and answered:

- What agency inspects and accredits your laboratory for CMS?
- What criteria does your laboratory use to employ dermatopathologists?
- Where did you train? How long have you been practicing? Are you certified by the American or Osteopathic Board of Pathology or Dermatology? May I have a copy of your curriculum vitae?
- What terminology do you use for pigmented skin lesions? What do you mean when you say...?

The following exercise is often helpful in determining if you and the dermatopathologist are on the same page and can communicate effectively.

- Describe your laboratory's quality assurance process. Do you get second or consensus opinions from your colleagues in the laboratory? Can I get second opinions on cases when I request it?
- Will you notify me directly about malignant interpretations and problematic and delayed reports?
- May I see some copies of your reports with patient identification removed?
- How are your reports delivered?
- How can I contact you directly if I need to?

The questions noted above should be explored in as much detail as needed to establish a level of comfort or discomfort. In my practice setting, the questions can easily be answered to any reasonable physician's satisfaction.

Additionally, quality anatomic pathology laboratories should require a pre-employment slide test before considering a pathologist for employment. Biannual credential verification, similar to the systems used for granting hospital privileges, is also a sign of a quality-oriented laboratory.

Ongoing monitoring of a pathologist's performance is difficult because each interpretation represents individual value judgments based on experience, training and ongoing continuing medical education. An effective quality monitoring system, focused on error reduction and patient safety, should use random and targeted case

review to monitor an individual pathologist's performance. An ethical quality-oriented laboratory will not restrict pathologists from ordering additional slides, special stains or immunohistochemical stains when indicated. Pathologists should work at a speed or volume that is consistent with accurate interpretation.

The decision to use a large commercial laboratory should be made with the same care as selecting a physician to care for you or your family.

Herman Hurwitz, MD
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