

On the Other Hand...

Twenty-three years ago, I stood in a hospital room in Louisville, Ky., with my father and my two sisters and three brothers. We were gathered around my 54-year-old mother's bed. She lay there comatose, with tubes and wires snaking in and around her. Although her heart was beating regularly—as indicated by the jagged spikes marching across the EKG screen—she was able to breathe only with help from a mechanical ventilator. And there was no sign that she was aware of our presence. Still, we talked to her, joked nervously with each other, and waited for her to wake up and scold us for being noisy.

Gradually, we learned what had happened. My mother—who was notorious for avoiding doctors after years of unsuccessful treatments for debilitating rheumatoid arthritis—had collapsed at home with a paralyzing headache. Terrified, she'd asked my youngest brother, who was living with my parents at the time, to call an ambulance. At some point she lost consciousness. My father rushed home from a business trip in North Dakota, and the rest of my siblings and I flew in from all corners of the country.

A year earlier, my mother had had a bout of pneumonia that had seemed to linger. Her lungs had never fully cleared, and she had, reluctantly, started seeing doctors again. But they had been stumped, so my mother had resigned herself to the annoyance of chronic lung congestion. It was nothing compared to her years of suffering from the crippling pain of arthritis and from the side effects of treating it—such as the stomach ulcers caused by the thousands of aspirins she'd swallowed. She had had headaches in the past, too, but none as bad as the one that had landed her in the hospital.

From our huddle around my mother's bed, a neurologist ushered us into a small conference room. He explained that she had a tumor in her brain stem—the part of the brain that controls blood pressure, heartbeat, and breathing. It was the tumor that had wreaked havoc with her respiratory function, causing fluid to collect in her lungs.

Laura Carter is the associate editor of DARTMOUTH MEDICINE magazine. After completing the reporting and writing for this feature, she made sure that her own advance directives were on file at DHMC. All of the ethical scenarios here in italic type are based on actual cases that have come before the DHMC Ethics Committee, but the names and some identifying details have been changed in order to preserve patient confidentiality.

The excruciating headache was what tipped off the doctors that her lung problems had a neurological origin. The tumor was inoperable, the doctor explained gently. “We don't expect her to wake up,” I recall him saying.

Not wake up? Inoperable? Wasn't there *something* that could be done? The doctor shook his head sadly. “There's nothing we can do,” he repeated.

Stunned, we filed back into her room. I don't remember how long we stayed there, but at some point we said our goodbyes—to my mother, as well as to each other before we dispersed back across the country. My mother lived for 10 days on the ventilator. Then my father called each of us to say that she had been removed from life support and was gone. Her funeral was a few days later.

As I began working on this article, and hearing stories about other deaths fraught with complex choices, I thought back to my own family's experience. My father had made the difficult decision to take my mother off life support. I asked him recently what guidance the medical staff had offered during that trying time. Not much, he said. I can only imagine how lonely and scared he must have felt. Back then, decisions to limit medical treatment were often challenged in court. His lawyer had warned him to be careful. But my father was stoic, and my siblings and I trusted him to do what he thought was best—to make the decision that was right for our mother.

His thinking, as well as ours, was surely influenced by the famous case of Karen Ann Quinlan. She had died earlier that same year, 1985, after living for 10 years in a persistent vegetative state—a coma. In 1975, Quinlan, then 21, had collapsed after drinking alcohol and taking drugs at a party. She stopped breathing and went into a coma from which she never emerged. Her parents, once they understood that their daughter had suffered irreparable brain damage, wanted to remove her from the ventilator that was breathing for her. But they had to fight for that right in court. In 1976, a New Jersey Supreme Court ruling allowed them to have her removed from the ventilator, though she continued to be fed and hydrated artificially and lived for another nine years before dying of pneumonia.

My family had talked about the Quinlan case over the years, and

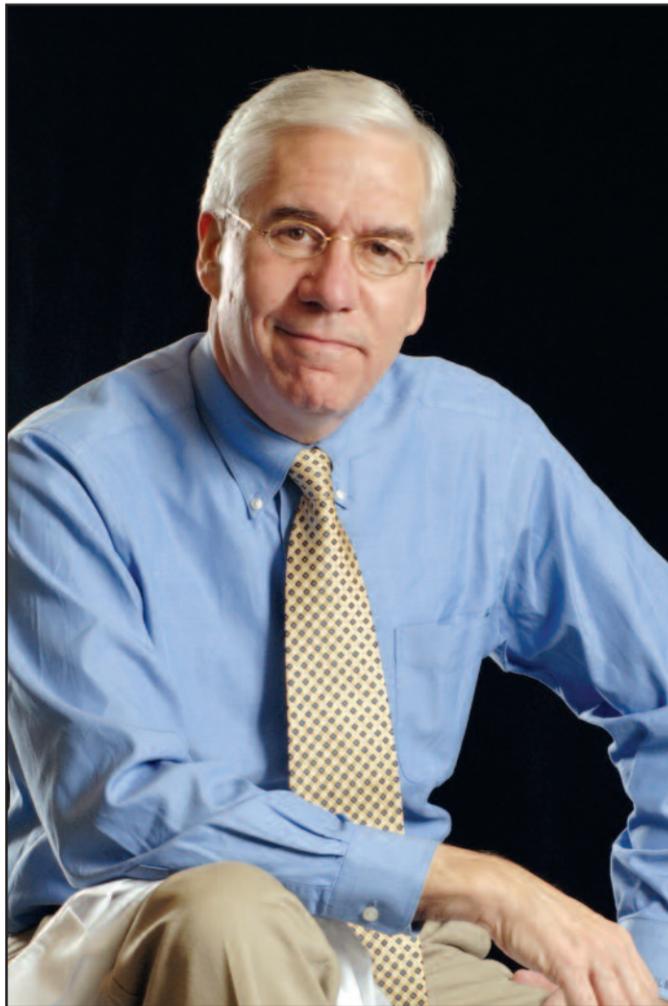
Resolving the ethical dilemmas presented by modern medicine is not for the faint of heart. As technology introduces ever more perplexing questions, medical ethics committees have stepped in to help caregivers, patients, and families chart the right course. Here's an inside look at DHMC's ethics committee, one of the nation's oldest.

Text by Laura Stephenson Carter • • • Photographs by Jon Gilbert Fox

For several **WEB EXTRAS** about medical ethics, including an interview with ethicist James Bernat, see dartmed.dartmouth.edu/winter08/html/hand_we.php.



Life-support devices like this ventilator (left rear) and nitric oxide machine (foreground) are blessings for some patients but present thorny ethical dilemmas for others.



James Bernat: The committee's "goal is to provide a forum for discussion"

I'm sure that at some point my mother had made it clear to my father that she would never want to live out her days "as a vegetable," the way Quinlan had.

Since then, laws have been passed that allow end-of-life treatment decisions to be made by patients (when they're able to play a role) and their physicians and families, without resorting to the courts. But what if the parties don't agree? Who decides what happens in that case? Today, at most hospitals, an "ethics consult" can be requested to objectively resolve such questions. Many concern end-of-life issues.

Dartmouth-Hitchcock Medical Center has one of the oldest hospital ethics committees in the United States. It was created in 1983 and since 1994 has been led by James Bernat, M.D., a neurologist and an internationally recognized medical ethicist. The 28-member committee includes physicians, nurses, social workers, administrators, a chaplain, a lawyer, and a medical student, as well as a public member—someone with no connection to Dartmouth or to medicine.

The DHMC committee not only consults on cases in which the appropriate course of treatment isn't clear, but also educates DHMC caregivers about bioethics, develops ethics policies, coordinates the New Hampshire-Vermont Ethics Network, collaborates with Dartmouth's Committee for the Protection of Human Subjects, and occasionally lobbies on ethics-related legislation. But it's the ethics consult subcommittee—or "ethics SWAT team," as some members of the group call it—that grapples directly with ethical dilemmas.

Herman, a man in his eighties, is admitted to the hospital with a twisted intestine that only surgery can correct. He has dementia as well as other chronic health problems and is not competent to make his own medical decisions. He vehemently objects, however, whenever anyone tries to put him on a gurney, insert a nasogastric tube, or perform any other kind of medical procedure—screaming, "No! No! No!" He isn't able to eat and vomits whenever anyone tries to feed him. His doctors and nurses don't want to force care on him. His daughter agrees with the health-care team, but his son thinks that his father should have the surgery.

So the ethics consult team—which is led by Bernat and Diane Palac, M.D., a palliative-care specialist—was called in. Some ethical dilemmas can be resolved with a telephone conversation between a member of the consult team and the physician. Or the consult team might meet with the patient's caregivers and coach them on how to communicate with the family in a way that helps them to understand what's best. But in other cases, like this one, a full-blown ethics consult is required. The team first gathers information to try to understand the facts of the situation: they check the medical charts and then talk separately with the patient's physicians and nurses, the patient if that's possible, and family members. Then the ethics consultants facilitate a meeting with everyone present so all parties get a chance to explain their perspectives on the case, hear the other sides of the story, and learn about the patient's own values and wishes.

At the meeting about Herman, the physicians and nurses went into detail about his health status and explained that the only way to force treatment on him would be to either tie him down—since an abdominal incision wouldn't heal well if the patient thrashed around—or sedate him. They didn't want to do either, pointing out that rehabilitation after surgery is a long and difficult process that requires cooperation from the patient in order for healing to occur. "You can't re-

James Bernat, who has chaired DHMC's Ethics Committee since 1994, is an internationally recognized ethicist. In 1997, he was one of ten scholars invited to Rome to advise the Vatican on how to define death.

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habilitate a patient who's sedated," says Palac, recalling the case.

The daughter felt that it was unlikely her father would do well after surgery and that he probably wouldn't even understand what was happening to him. But it was "clear that the [son] was the decision-maker," says Palac. It turned out he was worried that by refusing treatment, his father would be committing passive suicide, a mortal sin in his eyes. But a Catholic priest, brought in by the consult team, assured the son that refusing surgery and dying from an underlying bowel obstruction was not an act of suicide.

"One thing we really don't want is people participating in these decisions walking away feeling that they made a decision to kill a person," says Palac. "We take a great deal of pains to [emphasize] that this is nature taking its course and that we are trying to follow the wishes of the patient . . . the patient's own values with respect to life-sustaining treatment." Eventually everyone agreed in the case of Herman, Palac adds. "The treatment goal shifted from fixing the obstruction to allowing him to live comfortably in the time he had left."

Good communication is essential in order for an ethics consultation to be helpful. "We bring a framework and a source of information to the players so that we can reassure them, 'Yes, you're the appropriate decision-maker. Yes, it's ethically okay to go ahead and make this decision, whichever way you make it,'" says Kate Clay, a member of the Ethics Committee and the director of DHMC's Center for Shared Decision Making. "I wish more people knew that they had access to us."

People need reassurance that they are making the right decision, agrees Hilary Ryder, M.D., a hospitalist who became a member of the committee two years ago when she was still a resident. "A lot of times the families and the physicians are communicating on two completely different levels. One of the jobs of the ethics committee is to translate what the families are saying to the physicians, but also what the physicians are saying to the families."

Communication is key, agrees Timothy Lahey, M.D., a specialist in infectious diseases who is another member of the Ethics Committee. "A lot of time," he says, "the ethical issues just fade away once trust is restored and everybody's had their say."

One of the things that complicates end-of-life decision-making is the lack of advance directives. That's the official term for two documents—a living will, in which patients indicate their wishes about the type of medical care they wish to receive if they become terminally ill (or permanently unconscious, in New Hampshire and some other states), and a durable power of attorney for health care, which designates someone to make medical decisions on a patient's behalf if the patient is unable to do so. Only about 20% of U.S. adults have signed advance directives.

Longtime DHMC Ethics Committee member Marie Bakitas, D.N.Sc., a nurse practitioner in palliative care, is leading an initiative to get all DHMC and DMS employees, as well as their families and friends, to complete advance directives and to be sure they are on file in their hospital records. National statistics show that fewer than 30% of health-care workers have indicated their wishes in writing—a little, but not a lot, better than the rate among the general population. Bakitas reasons that if more medical staff have signed advance directives, they will be more likely to encourage their pa-



Diane Palac: "We are trying to follow the wishes of the patient"

In 1971, DMS became one of the first medical schools in the nation to offer a course on medical ethics. And in 1981, the School received a grant from the Ira W. DeCamp Foundation to support ethics instruction.

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Hilary Ryder: Communication often occurs on “completely different levels”

The Dartmouth-Hitchcock Medical Center Ethics Committee, which was established in 1983, was one of the first such groups in the nation. By 1987, 60% of U.S. hospitals had an institutional ethics committee.

Often, admits medical student Emily Rubin, caregivers neglect to explain what it means for elderly patients who are very ill to have their heart shocked back into rhythm. “When you really sit down and talk to families in detail, [they] often will rethink their initial decisions.”

tients to have them, too. (Any readers within DHMC’s service area who would like assistance in filling out an advance directive are welcome to call the Office of Care Management at 603-650-5789.)

“A lot of the cases that we deal with in the Ethics Committee that involve end of life could be eliminated—we wouldn’t have to have an ethics consult—if the patient had an advance directive,” explains Elizabeth Stanton, a lawyer in DHMC’s Risk Management Department and another longtime member of the institution’s Ethics Committee. “I think the plan, with Ethics Committee support, is to elevate advance directives to the status of flu shots, smoking cessation, and similar health-care initiatives.”

But some of the cases that come before the ethics team involve patients who *do* have an advance directive indicating that in the event of a terminal illness they don’t want to be kept alive by artificial means. Yet doctors may be torn between honoring the directive and continuing to deliver aggressive treatment. Or family members may not have accepted the situation’s finality. An ethics consult can help everyone reach agreement on what the patient would have wanted.

Advances in medical technology, and thus the ability to keep people alive longer than used to be considered natural, are a good part of the increasingly complicated nature of medical decision-making. And changes in technology are moving so fast that the law can’t keep up, says Stanton.

“Technical advances are coming in floods now instead of just waves,” explains Kate Clay. Along with new technology has come a flood of new technical terms that patients and their families often don’t understand. It’s difficult enough to make treatment decisions when the facts are clear, but today’s plethora of arcane terms adds to the confusion. Without thinking, medical professionals toss around terms like “CPR,” “DNR,” “DNI,” and “intubate” or “extubate.”

“The word ‘intubation’ has absolutely no meaning outside the medical community,” admits Sarah Stableford, R.N., a critical-care nurse who recently joined the Ethics Committee. “Intubation” refers to the insertion of a tube down the patient’s trachea; the other end of the tube is connected to a ventilator that breathes for the patient. “Extubation” means the removal of the tube when a patient is taken off a ventilator.

“I think most people don’t understand what intubation is, or what a mechanical ventilator is, or what CPR is for that matter,” agrees Emily Rubin, a lawyer who’s now in her fourth year at Dartmouth Medical School and is the student member of the Ethics Committee. “A lot of people have these conversations in a very rushed way,” Rubin adds. “There’s a lot of room to improve on the way we talk to patients about these things.”

CPR, which stands for cardiopulmonary resuscitation, is an emergency procedure administered after someone has collapsed and has no detectable pulse. It involves blowing into the mouth and pushing on the chest—and sometimes inserting a breathing tube into the windpipe, giving intravenous drugs, and applying an electrical shock to the chest—in the hope of restarting the heartbeat and breathing.

Often, admits Rubin, caregivers neglect to explain what it means for elderly patients who are very ill to have CPR and have their heart shocked back into rhythm. “When you really sit down and talk to families in detail about what it means to be DNR-DNI, or what might happen after somebody’s resuscitated, families often will rethink their

initial decisions.” She goes on to explain that “DNR” means “do not resuscitate”—in other words, if a patient’s heartbeat stops, CPR will not be administered. And “DNI” means “do not intubate”—that is, do not put the patient on a mechanical ventilator.

Families also have misconceptions about ventilators, says Priscilla Robichaud, R.N., a continuing care manager who serves on the Ethics Committee. They’ll sometimes want a loved one to come home on a ventilator. DHMC will send family members for training in the use of a ventilator, but Robichaud says people just don’t understand how difficult it is to care for someone in that condition in a home setting.

Mary, a woman in her late seventies, had suffered a major stroke. She is being kept alive by machines in the ICU and is also hooked up to a feeding tube. She is unconscious, and her caregivers have explained to her family that she will never recover. Her husband of 50 years isn’t sure whether to remove her from or keep her on life support, so an ethics consult is called.

“One role the committee can play is being an objective outsider” in helping patients, families, and physicians make decisions, says Margaret Plunkett, M.S.N., a clinical nurse specialist in psychiatry and a member of the Ethics Committee. The committee encourages physicians to have “clear and direct conversations about . . . specific goals of care that make sense . . . [and] what kinds of treatments really match that goal of care.”

Although Mary’s husband understood that no amount of aggressive treatment would bring her back, families often struggle with the thought of withholding artificially administered food and fluid at the end of life. “We equate feeding someone with loving them,” says Plunkett. “And yet at the end of life . . . providing them food and fluids through some kind of tube . . . may not provide them any more length of life and may actually provide some harms. And yet the idea that we’re not going to feed this person is a very difficult concept even for professionals to understand, let alone families.”

The ethics consultants were able to help Mary’s husband feel supported in the decision to let her die naturally. They also put him in touch with the palliative-care team, which provided him with spiritual and emotional support while ensuring that Mary was kept comfortable and didn’t suffer.

Jerry, a 14-year-old boy, is terminally ill with end-stage metastatic T-cell lymphoma. He’s been told that he has cancer but not that he is dying. His caregivers feel nothing more can be done for Jerry and they recommend that he receive only comfort care. His mother agrees but won’t challenge her husband, who insists that Jerry continue to receive curative care and that he not be told he is dying. Jerry’s caregivers call for an ethics consult.

During the group meeting, Jerry’s parents, who are Asian, explained that according to their cultural mores parents make all decisions for their children. They also pointed out that sons have special significance in their culture and that Jerry was their only son. They were confident that God would work a miracle. The nurses and doctors explained that they cared very much about the boy and were worried that further aggressive treatment would be more likely to harm him than help him and would cause him to suffer unnecessarily. It would be best, they said, to provide care that would ensure the boy’s comfort. They also felt strongly that Jerry should be told he was dying.



Kate Clay: “Technical advances are coming in floods . . . instead of waves”

DMS’s Bernat is past chair of the American Academy of Neurology ethics committee and the new chair of an ethics committee being set up by a division of the U.S. Health Resources and Service Administration.

“We equate feeding someone with loving them,” says nurse Peggy Plunkett. “And yet at the end of life . . . providing them food and fluids through some kind of tube . . . may not provide them any more length of life and may actually provide some harms.”



Bill Edwards: Ethics questions “almost by definition” have no clear answer

In 1990, Dartmouth received a National Institutes of Health grant for the first comprehensive study of the ethical implications of the Human Genome Project; the investigation was led by philosopher Bernard Gert.

Since it was likely Sharon would continue to use marijuana, should she still be encouraged to breast-feed? On the one hand, neonatologist Bill Edwards noted, breast milk is superior to formula. But on the other hand, could it offer more harm than benefit in this case?

With support from members of the ethics consult team, the father was eventually able to recognize that the treatment he was asking for would not promote his son’s comfort and that the staff truly had Jerry’s best interests at heart. When the boy was finally told the full extent of his illness, he wasn’t surprised. Instead, he had been worried about how his parents were doing and had been trying to protect them.

“Sometimes an ethics consult can break this logjam where people are stuck,” says Plunkett. The ethics consultants are careful, however, not to overwhelm patients and families with too many new faces and will sometimes spend most of their time meeting with the care team, coaching them on how to communicate effectively with patients and their families.

All ethics consults are also discussed by the entire committee, usually once the issue has been resolved. A few days after its resolution, Jerry’s case was presented at a meeting of the full Ethics Committee. Such discussions are viewed as educational, and committee members are encouraged to ask questions and express their own views, even though the question may be moot by then.

“Do parents have the right to tell doctors not to talk to their children about their medical care?” Bernat asked during this particular meeting. A lively exchange of views ensued.

“Is there some guidance on this?” asked another member.

There is, Bernat explained. In 1995, the American Academy of Pediatrics’ Committee on Ethics published a statement asserting the right of older children and teenagers to be involved in the medical consent process regarding their own care.

Sharon is 22 and has just had a baby; her premature newborn is in the intensive care nursery (ICN). Sharon herself is in a methadone treatment program and has admitted that she still sometimes smokes marijuana. The baby’s urine tested positive for marijuana metabolites at birth. The doctors and nurses who are caring for the baby have several worries, but the one they are most perplexed by—the question they bring to the Ethics Committee—is whether they should encourage Sharon to breast-feed her baby.

Neonatologist William Edwards, M.D., heads the infant-care arm of the Ethics Committee. Recently, he sought the full committee’s input about the breast-feeding dilemma his team had faced with Sharon. She wanted to breast-feed her baby, he explained, and DHMC’s practice is to strongly encourage new mothers to breast-feed. But since it was likely that Sharon would continue to use marijuana, should she still be encouraged to breast-feed? On the one hand, Edwards pointed out, breast milk is superior to formula. But on the other hand, could it offer more harm than benefit in this case?

Edwards added that he felt Sharon wanted to do what was best for her baby. “But when she’s stressed,” he said, “it’s hard for her not to smoke marijuana. Should we ever be complicit in recommending something that puts the baby at harm of illegal drugs?” He noted that the evidence is unclear regarding the effect on a baby of marijuana in breast milk, though some studies have suggested that it makes babies irritable. He also mentioned, in relation to the baby’s premature arrival, that other studies have shown an association between marijuana use and low birth weight.

“It might be good to encourage her to quit,” suggested a member of the committee. But another member worried that Sharon could be

alienated from the health-care system if her caregivers were too heavy-handed about her marijuana use.

“When this mom takes her baby home, what do you have control over?” asked someone else.

“Nothing,” Edwards answered.

“Have other risks been evaluated?” The committee was full of questions for Edwards.

She might be arrested, he responded, clearly concerned. “Or she might get stoned and crash her car.”

A neonatal nurse who had accompanied Edwards to the meeting spoke up, explaining that “there’s a lot of emotions among the nursing staff if they are compelled to go along with something they’re not comfortable with.”

“Tell the mother we don’t know the harms of marijuana, but that she . . . shouldn’t smoke it,” suggested a committee member.

“Do I send her on a path to breast-feed or not?” persisted Edwards, trying to pull the discussion back to the question of most concern to the neonatologists.

Several members noted that it was difficult to justify advocating against something without solid evidence of harm. “If you knew the mother was going to drink [alcohol] during breast-feeding, would you still set her on a road to breast-feeding?” asked a committee member.

“Yes,” Edwards admitted.

“It seems the illegality is what concerns you,” put in Bernat.

“So what did you tell her?” someone finally asked.

“We recommended she not smoke marijuana,” Edwards said, and “we recommended she breast-feed.”

A few weeks later, Edwards reflects on that committee meeting. It does not surprise him that there was no clear opinion from the committee. “Almost by definition,” he says, “an ethical dilemma is a situation where there is not a clear answer.”

“That’s the nature of the beast,” agrees Bernat. “Our goal is to provide a forum for discussion, [to] help people understand the issues. We don’t have decision-making authority.”

What did surprise Edwards, however, was that “there was very little concern . . . about the illicit drug use,” he says. “They were quite happy to go with breast-feeding and its known benefit, [despite the mother’s] continued participation in an illegal activity with undefined but probably low risk medically.”

The committee deals with many other kinds of cases, all of them heartrending for everyone involved. “There’s never an ethics consult that isn’t upsetting,” says one committee member. The decisions can be tough, painful, overwhelming, emotionally charged, and even nightmarish at times. Here are a few more examples:

Betty, now in her seventies, has suffered from bipolar illness since she was a young adult. Many years ago, she had signed what’s known as a Ulysses contract—named for the Roman hero who instructed his crew to bind him to the mast of his ship and not release him, even if he begged to be set free, while the ship sailed past the Sirens, whose beautiful singing lured sailors to their death on the rocks (his crew, meanwhile, plugged their ears with beeswax to keep from hearing the enchanting songs). Someone with a mental illness that occurs in predictable phases may sign such a contract during a healthy phase; it authorizes doctors to deliver the treatments they think best and gives them permission to disregard what the patient says when the



Peggy Plunkett: “Sometimes an ethics consult can break this logjam”

In 1991, the Veterans Affairs Medical Center in White River Junction, Vt., which is affiliated with Dartmouth-Hitchcock Medical Center, was chosen as the site of the VA’s National Clinical Ethics Center.

The cases that come before the committee are heartrending for everyone involved. “There’s never an ethics consult that isn’t upsetting,” says one committee member. The decisions can be tough, painful, overwhelming, emotionally charged, and even nightmarish at times.



Patrick McCoy: The committee's leaders "help the whole story unfold"

Reporters from prominent media outlets—from the *New York Times* to *People* magazine—interview DMS's Bernat on major ethics cases. He was quoted widely, for example, about the suit involving Terri Schaivo.

The ethics instruction that today's medical students receive—including at Dartmouth—"is done piecemeal" says Bernat. There is just too much that needs to be incorporated into the curriculum. "If I had my druthers," he adds, "we would have a required course."

mental illness is uncontrolled. So, for instance, since Betty's kidneys are failing, she is getting dialysis, even though she insists she doesn't want it. The problem before the ethicists is that Betty is now very sick—both physically and mentally. In addition to her kidney problem, she has been diagnosed with cancer. And she is not well mentally for long enough to revoke the Ulysses contract. (In addition, there is concern that the contract she signed didn't include a provision allowing her to change her mind even if she genuinely, rationally decided to do so.) At this point, neither Betty's caregivers nor her sister are sure what the right course of action is.

An ethics consult helped everyone understand that continuing aggressive treatment no longer made any sense. Betty was placed in hospice care and died peacefully.

David, a 35-year-old man, dies in a car accident. His wife wants to have his sperm harvested so she can use it to have a child. That would require nearly immediate harvesting, before the sperm lose viability, but it's unclear what David's wishes were.

The ethics consultants authorized the harvesting to preserve the option of using the sperm and then they deliberated. They ultimately decided that since David had never expressed his wishes in writing, his wife did not have a right to use his sperm. Since then, the committee has helped the ob-gyn department craft a policy that addresses such issues ahead of time.

Caroline, a 67-year-old woman, is dying of cancer. Her caregivers have recommended stopping aggressive treatment and providing only comfort care. Caroline had signed both a durable power of attorney for health care and a power of attorney for financial matters, naming her husband as her proxy in both. Her husband understands her status but would like to have her kept alive a few more days so he can finish some financial transactions.

The ethics team ended up advising Caroline's husband that it wasn't in her best interest to be kept alive for such a purpose. Her husband agreed, and aggressive treatment was discontinued.

Simon, an 85-year-old man, has had a major stroke and is unconscious. He has "DNR" tattooed on his chest. His caregivers aren't sure whether that serves as an adequate reflection of his wishes.

The ethics team, too, felt it was unclear, in case Simon had changed his mind since getting the tattoo. So, because Simon had a durable power of attorney for health care, they recommended that his caregivers confirm the decision with his health-care proxy. Simon's proxy agreed that the DNR order, as unorthodox as it was, should stand.

Peter, an infant who'd suffered severe abuse, is near death in the pediatric intensive care unit. One of his parents, the alleged abuser, wants a say in Peter's care. If the baby dies, the parent could be charged with murder. But if he's kept alive, the parent might be charged only with assault. Should someone whose judicial fate hangs on a patient's survival be involved in making decisions about that individual's care?

There is still the very occasional perplexing case that cannot be decided by the parties involved, even with the help of an ethics consult.

This was one of the few that ended up in the courts. In the end, however, the baby died before a judicial opinion was rendered.

None of the members of the DHMC Ethics Committee have formal degrees in ethics; it is a new enough field that degree-holding practitioners are only beginning to populate the nation's hospital ethics committees. But most of the DHMC committee members have taken advanced training in ethics or have been mentored in the discipline by others on the committee.

Committee members are concerned, however, that few in the medical profession have any training at all in ethics. Medical staff are rarely taught in any systematic way how to help patients and families deal with end-of-life issues—although they are required to learn CPR and other techniques used to extend life.

"I think that's great," says Marie Bakitas, agreeing it's appropriate for doctors and nurses to learn CPR and other such skills. "However, in this organization, a clinical person's likelihood of coming in contact with somebody who's needing resuscitation is probably 10 times less than their likelihood of coming in contact with a person who is not to be resuscitated." But, she adds, there's no mandated training regarding end-of-life care, the way there is regarding life-extending care.

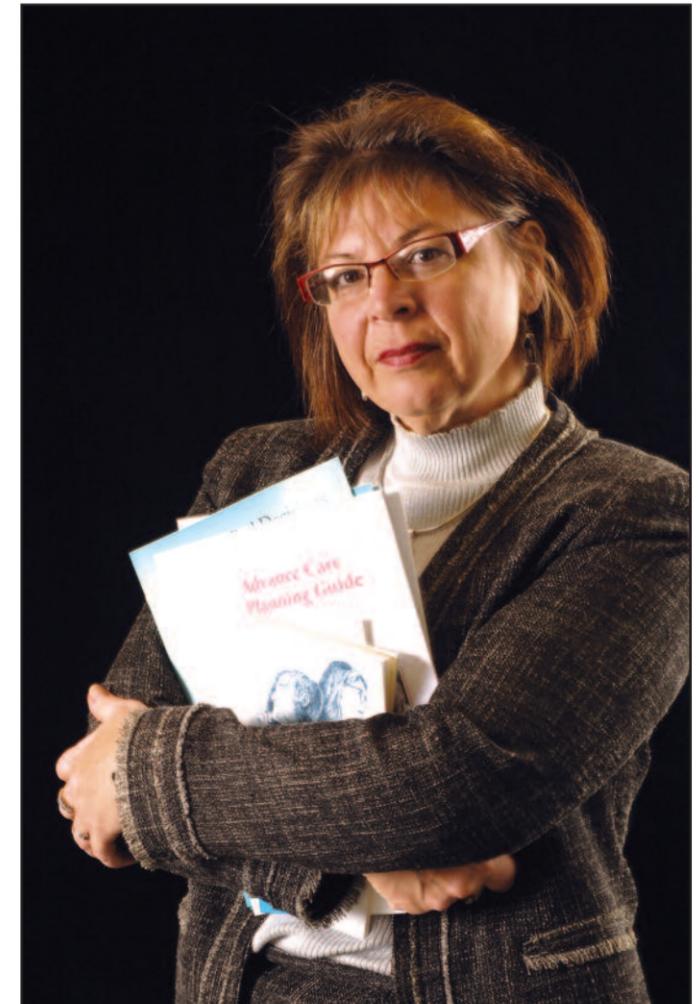
Even the ethics instruction that today's medical students receive—including at Dartmouth—"is done piecemeal," says Bernat. At DMS, he explains, "in the late 1970s and early '80s, there used to be a required [ethics] course in the first year, but that was stopped." There is just too much that needs to be incorporated into the curriculum nowadays. "My grandfather was a doctor, went to medical school during World War I," explains Bernat. "His medical school was four years. Our current medical school is four years. Despite the fact that there's a hundred times more information than there was 90 years ago, there are still four years that are devoted to it."

DMS students currently get a smattering of ethics in several different courses. Palac and Bernat present cases involving ethics and palliative care that first- and second-year students discuss in the required On Doctoring course. In the second-year neurology course, Bernat gives a lecture on brain death and the vegetative state. Many third-year students encounter an ethics consult during their clinical rotations. And fourth-years discuss medical ethics in the required Health, Society, and the Physician course.

"If I had my druthers," says Bernat, "we would have a required course in medical ethics where we'd start with a textbook and we'd go through it in a systematic way."

But Bernat and the other members of the Ethics Committee do feel—based on feedback from caregivers, risk management personnel, and senior Medical Center administrators—that the committee's work is valued. "We help to enhance communication, to understand what's wrong, and to help people find a mutually satisfactory solution," says Bernat. And in cases where families are angry, an ethics consultation "may take the edge off whatever the anger is. It's been shown in many studies to prevent malpractice suits and save money that way, but it also promotes quality care by enhancing communication." Other studies have shown that when ethics consults help parties reach a mutually agreeable decision, unnecessary care and suffering are prevented and prolonged hospitalizations are reduced.

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Marie Bakitas: There's no mandated training about end-of-life care

Ronald Green, an adjunct DMS professor and faculty director of the Dartmouth Ethics Institute, was on a 1994 blue-ribbon panel convened by the National Institutes of Health to study human embryo research.

Ethics consults have helped many people, but the team isn't called in as often as it might be—in part because some health-care providers are so focused on curing illness and fixing injury, at any cost, that they can't face offering less than the most aggressive treatment.

On the Other Hand . . .

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Lynn Peterson, M.D., a retired surgeon who is a member of DHMC's Ethics Committee, admits that he was once skeptical of the value of ethics committees. "It's very hard, I think, for a patient or a family to directly disagree with a doctor who's going to take care of them," says Peterson, who headed Harvard Medical School's Division of Medical Ethics from 1989 to 1997 and the Ethics Service at Harvard's Brigham and Women's Hospital from 1997 to 2004.

But a third party like an ethics consult team, Peterson came to realize, can let "the family express their concerns and their point of view without having to necessarily directly confront the caregivers."

Although ethics consults have helped many people, the team isn't called in as often as it might be. Part of the problem is that some caregivers and many families aren't aware of its existence.

Another problem is that some health-care providers are so focused on curing illness and fixing injury, at any cost, that they can't face offering less than the most aggressive treatment. "Doctors have been trained to save life," says Rosemary Evans, the public member of the Ethics Committee. "It's . . . very hard for them to let go."

Critical-care nurse Sarah Stableford agrees. "As a society," she says, "we're very comfortable bringing [people] into the world, and very uncomfortable letting them leave the world. Prolonging life is a great thing to do. Prolonging death is unconscionable, [yet] we do an awful lot of prolonging death."

A further problem is that some families resist the idea of a meeting with a group of medical professionals. "So many times, I think, people go to an ethics committee consultation thinking of the ethics committee as some kind of a tribunal," says the Reverend Patrick McCoy, a chaplain at DHMC and a member of the ethics consult team. "It is really a chance to problem-solve and to resolve conflict.

"I think the leaders of [the consult team] are really very good at acknowledging the emotional charge that's there," McCoy continues, at "trying to help the whole story unfold . . . the medical story of what the illness is, what the treatment process has been like,

what the options are, what the consequences of the options are . . . so that all of the different layers can be teased out and the family can be helped to articulate what the patient's wishes would be for decisions if the patient could participate."

Despite the committee's success at resolving thorny ethics problems, the number of formal consults has decreased over the years—partly because palliative care is beginning to fill the role that ethics consults used to. Palliative care often involves an ethics-oriented discussion, says Palac, to help patients decide whether to refuse or accept further medical intervention. And more and more patients are seeking assistance from the Center for Shared Decision Making, and so coming to decisions without requiring an ethics consult.

While the Ethics Committee continues its work, there's one problem it has not yet addressed—what Bernat calls the "collision between the financial and the ethical." Others share his concern that limited resources for health-care services could one day play a role in decision-making.

"In the best of all possible worlds," says Bernat, "if money weren't an issue, you could identify an ethical course of action" without thinking about cost. "But the costs are crashing down on us," he continues. "In the future, we are not going to have the luxury that we've had in the past, which is to not pay that much attention to how much things cost. . . . The way we operate is going to have to take [cost] into account."

"There's just no way we're going to be able to keep on doing what we're doing," agrees Paul Manganiello, M.D., an ob-gyn who's been on the Ethics Committee since its inception in the 1980s. Part of what's driven the escalation of medical services, he feels, is that "people just have too much faith in technology."

Bernat and his colleagues recognize some other issues that need to be addressed, too, such as the ethical implications of a dysfunctional health-care system and of millions of uninsured patients. But those may be problems too big for an individual hospital ethics committee to tackle.

So for now, the DHMC Ethics Committee will continue to help caregivers, patients, and families grapple with ethical dilemmas—one case at a time. ■

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