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The Ethics of the Unwelcome: Teaching about End-of-Life Issues

Delivering bad news will always be a part of medicine. The good news is that medical students at Michigan are learning how to do it better.

BY KIM CLARKE

Mel Barclay, M.D., is driven by memories.

The images are all there: The hospital room. Bewildered, grieving, family members. And a young medical intern clumsily explaining that their loved one has died.

"I remember the patients' names to this day," Barclay says.

More than 30 years after his internship at Detroit Receiving Hospital, Barclay, an associate professor of maternal and fetal medicine, remains convinced that he compounded families' pain and shock with his ham-handed efforts to deliver the news they did not want to hear. "Those poor people I had to tell it to," he says, lowering his voice as if to hide the decades-old sadness.

He has another memory of those days. After all the reviews, the clinical discussions and post-mortem meetings, no doctor or nurse asked about those patients' families.

"Nothing about, 'How did the family take it? Who told the family?'" he says. And he can't forget thinking to himself: There has got to be a better way to do this. Medical students at the University of Michigan today are benefiting from Mel Barclay's troubling memories. Teaching about end-of-life issues, including how to break bad news to families, is receiving increased attention, both as a medical issue and an ethical concern at Michigan. In

fact, a whole spectrum of ethical issues in clinical practice, including such matters as confidentiality, informed consent, dealing with medical mistakes, health care rationing, caring for the underserved, historical perspectives on medical technology and racial inequities, and how the trust-based relationship between patients and their physicians creates obligations for those physicians, are being dealt with by medical students as part of their education at Michigan thanks to the interest of a number of faculty in introducing such issues.

Third-year students in Barclay's classes may be challenged, for instance, with the discomfiting task of telling a woman, jubilant about her much anticipated and longed for pregnancy, that her 12-week-old fetus has died in the womb. Elsewhere in the Medical School, third-year students in their surgery rotation are forced to wrestle with how to tell an older woman she has life-threatening rectal cancer.

"We teach them to say 'cancer.' Don't say 'tumor.' Be real, concrete and specific, so a patient doesn't say, 'I don't have cancer, I have a tumor,'" says Lisa Colletti, M.D., coordinator of the clinical clerkship in general surgery. Colletti and her colleagues see nothing but good coming from these challenging new lessons that teach students to deal with issues ranging from placing a father into a nursing home to removing a sister from life support.

"So much training is focused on preserving life and not on the acceptance of the way of dying," says David Stern, M.D., Ph.D., assistant professor of internal medicine. He considers end-of-life care — moving from curing to caring — to be among the top three ethical issues facing students, the others being informed consent and everyday right-and-wrong decisions.

As the post-war baby boom begins to gray, and advances in technology prolong life, end-of-life issues are among those ethical issues in the medical curriculum that are gaining a great deal more notice. The American Medical Association has established a two-year education program known as EPEC — Education for Physicians on End-of-life Care. An offshoot of EPEC, which is run through the AMA's Institute for Ethics, will be a resource guide for those who teach end-of-life issues.

Evidence abounds that end-of-life matters remain difficult for both physicians and medical students. A 1997 survey of fourth-year medical students at Mayo Medical School and Georgetown



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—DAVID STERN

University School of Medicine found that only 41 percent of students felt their education about end-of-life issues had been adequate. Eighty percent said they wanted to learn more about addressing such issues.

A more extensive nationwide study carried out in the early 1990s at five teaching hospitals found shortcomings in communication and care in treating seriously ill patients in their final days of life. Funded by the Robert Wood Johnson Foundation and known as SUPPORT — Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments — the study found patients' final days were spent in pain, with their opposition to prolonged care often disregarded.

For U-M medical students, end-of-life issues are initially covered in their

second year in the Introduction to the Patient (ITTP) course, a two-year program that covers ethics, social and cultural themes, and exam-room encounters with individuals trained to portray patients. End-of-life issues include medications, support services, nursing needs, religious considerations and pain control. Communication with the family also is a critical skill. “As the patient nears the end of life, you often begin caring for the family as much or more than the patient,” Stern says. Susan Dorr Goold, M.D., who coordinates ethics education in the Medical School, says teaching end-of-life issues goes well beyond covering assisted suicide and the philosophies of Dr. Jack Kervorkian. “I try not to focus on just the headline ethics. On a practical level, you want to prepare doctors for what they're going to face every day. By every day, I mean how do you talk to a family about putting a loved one in a nursing home,” says Goold, assistant professor of internal medicine.



“I remember the patients' names to this day.”

—MEL BARCLAY

“You never know
if you’re ready.
You find out after
your first time.”



—FOURTH-YEAR STUDENT
JOHN DELEDDA

Standardized patient
Nancy Livermore:
“I always ask if I’m
going to die.”



“What really matters at the end of life,” adds Stern, “is understanding what patients want. Is it dying at home? Is it dying at the hospital? Is it kicking and screaming? To me, it comes back to the doctor-patient relationship.”

Goold and Stern, assistant director of ITTP, are the first to recognize the contrast between students discussing end-of-life issues and actually working with patients and their families. Readings and lectures go only so far in conveying end-of-life emotions and dilemmas. But faculty often are reluctant to have students dive into real-life situations, sharing tentatively in what can be terribly private and painful moments for families. “I don’t want a second- or third-year medical student to go in and say, ‘I’m sorry, you have colon cancer,’” Stern says. “And having to tell a person that a family member has died is a huge challenge. I don’t know that many physicians do it well. We don’t have as much opportunity as they do on ‘ER.’”

Between the textbook and the real-life situation, however, there is a third alternative, one that is gaining increasing popularity in medical classrooms nationwide: the standardized patient. Standardized patients, who are trained to act like real patients and who are paid for their services, provide medical students with the valuable opportunity to interact with real people in situations that feel very real even though they are

not. Nancy Livermore is one such person who provides this valuable service in Michigan’s Medical School.

To watch her in action is to marvel at her well-honed acting skills. As a medical student approaches her in the examination room, she appears frightened and on the verge of tears. Her eyes spill over when the student tells her that what she first believed was a bad case of hemorrhoids is rectal cancer. Her anus and rectum will have to be surgically removed, the student says, adding that a colostomy bag will become a permanent part of Livermore’s life.

“Am I going to die?” she asks.

She has heard her diagnosis of rectal cancer numerous times. Always, she says, she asks the nervous medical student sitting before her if she’s going to die. Livermore laughs a little when she recounts the answers she has received. “They all deal with it differently. The best response I’ve heard is, ‘Not if I can help it,’” Livermore says.

From her perspective as patient “G. Johnson,” a 66-year-old widow and grandmother, Livermore has an excellent vantage point of third-year students and how comfortable they are with difficult end-of-life discussions. While her diagnosis is not necessarily life threatening, it does involve cancer and disfiguring surgery.

Speaking clearly, showing your emotions, saying “I don’t know...”

Students in the surgery clerkship learn some techniques for talking with patients and their families when the story may not have a happy ending



There are several steps and techniques that surgeon Lisa Colletti, M.D., provides her students in teaching them how to break bad news to patients and their families. This is the first year the exercise has been made part of students’ surgery clerkships.

preparation

1. Know the medical and personal details of the patient.
2. Have all of the relevant information available.
3. Prepare yourself for what you will say.
4. Have a nurse present, if necessary.
5. If possible, the person delivering the bad news should have had at least some prior contact with the patient.
6. Assess/ask who the patient would like to have with them.
7. Have other relatives or friends available, if appropriate.

introduction

1. Introduce yourself properly.
2. Spend a few minutes establishing rapport.
3. Ask for information from the patient to assess their knowledge of the situation.

achieving understanding

1. Speak clearly and use non-medical terminology.
2. Write down any technical terms, if necessary.
3. Find out what the patient’s views are.
4. Assess the patient’s understanding of the situation/ diagnosis just given.

spacing and shared control

1. Allow pauses; silences can be appropriate and useful.
2. Try to lead the patient to the diagnosis.
3. Let the patient take some of the lead; involve him or her in the management decisions.
4. Allow the patient to ask questions.

responding to emotions

1. Touch the patient, if appropriate.
2. Reassure the patient that it’s OK to cry or express emotion.
3. Maintain eye contact. Be aware of non-verbal cues; try to use appropriate body language.
4. Show your emotion. Express sympathy, compassion.
5. Listen to the patient. Allow him or her to express emotions, fears, etc.

honesty

1. Offer both the worst and best scenarios.
2. If appropriate, leave the patient with some hope.
3. Take responsibility for mistakes.
4. Do not be afraid to say things like “sorry” or “I don’t know.” It is more useful to be honest when the situation is not clear or the possible outcomes are not known.

support

1. Highlight any positive things, e.g., pain relief.
2. Offer your continued support and advice.
3. Have a plan for the future (if possible).
4. Ask about available support systems to the patient.

closure

1. Summarize at the end of the discussion.
2. Finish with any positive issues, if possible.
3. Close the discussion by inviting questions.
4. Don’t leave the patient alone at the end of the discussion. Make sure the patient has arrangements to go home and/or support of family or friends available to them.
5. Set a time and date for the next meeting. Make sure to give the patient a phone number for reaching you.

Source: “Breaking Bad News” Simulated Patient Instructor Interview, Department of Surgery, U-M Medical School

Integrating ethics into residency programs:

Michigan helps lead the way



“You wouldn’t wing it treating people with antibiotics. Why would you wing it when discussing life support with a family?”

—SUSAN DORR GOOLD

“Once they get the word ‘cancer’ out, everything relaxes,” says Livermore, an Ann Arbor resident. “It’s difficult to tell someone they have cancer.” Livermore describes her work as “like method acting.” Her acting skills in simulating the behavior of a cancer patient offer medical students valuable opportunities for facing such real-life challenges as delivering unwelcome news.

Such opportunities, Colletti feels, are essential if students, who vary greatly in their ability to relate to others, are to understand and master the difficult communication tasks all doctors face. “This is not a test of medical knowledge,” she says. “This is a ‘communication skills-only’ experience. Some students are incredibly skilled. Others are incredibly awkward. The spectrum of performance on this is very broad.”

Colletti started the “Breaking Bad News” program in mid-1998. It grew out of a two-year grant Goold secured from the Charles E. Culpeper Foundation to develop a bioethics training program for faculty. “We did it because nobody was teaching this,” says Colletti, associate professor of gastrointestinal surgery.

The teaching covers such skills as making eye contact, responding to patient questions, dealing with tears and disbelief, and learning to listen. The listening skills are what Livermore pays special attention to in her role as patient. “They have a hard time doing that,” she says. “They want to tell. How they handle it is how they show the empathy and compassion for the patient.”

Ethics education soon will be a formal part of graduate medical education at the University of Michigan in what is believed to be a nationwide first in residency programs.

The teaching of ethics — a standard component in medical school — will be expanded into residents’ rounds, lectures and sessions with trained “patients.”

The Graduate Medical Education in Ethics Initiative is directed by Drs. Susan Dorr Goold and David Stern, assistant professors of internal medicine who have been leaders in developing ethics in the curriculum for the Medical School.

U-M medical students are exposed to ethics lessons in both the classroom and clinic. They learn about the wide range of moral dilemmas they will face as physicians, such as making mistakes, patient confidentiality, end-of-life issues and religious conflicts.

Ethics education for residents, however, is sporadic, with some departments taking a more formal approach than others.

Goold believes the U-M is the first medical school in the country to make ethics education part of the dozens of residencies it offers. She is pleased it will surface throughout the entire learning process — in classrooms, hospital hallways and examining rooms.

“The more you make it separate, the more marginalized it is, and the less important it is,” Goold says.

That same philosophy is being incorporated into a new Medical School Ph.D. program known as PIBS — Program in Biomedical Sciences. PIBS coordinates the first year of studies for graduate students in 10 doctoral programs. Faculty are just beginning to structure ethics teaching into the program, which is expected to draw about 50 students.

One of those involved with designing PIBS is Paul Hollenberg, chairman of the

Barclay is more blunt: “I tell them, ‘Just shut your mouth. It’s OK to not talk all the time,’” he says.

When he first proposed that students should address pregnancy loss in the obstetrics and gynecology clerkship, he encountered resistance from colleagues, Barclay recalls. Teaching students about death, loss or bad diagnoses made some faculty uncomfortable, he says, because they were uneasy handling such situations themselves.

“I was told, ‘No, you can’t do that’ about 58 different ways. What it means for a physician is failure,” Barclay says. “Physicians don’t like to fail. Nobody likes to fail.”

But the difficulty of delivering bad news, Goold insists, is no argument for taking a laissez-faire approach to incorporating it into the curriculum either. “You wouldn’t wing it treating people with antibiotics. Why would you wing it when discussing life support with a family?” she says.

Practice is the only good way for students to learn how to break bad news, adds Barclay, who has repeatedly had to tell women that their pregnancy ended in miscarriage. “Not necessarily the right way. Not necessarily the perfect way. Just ways.”

For fourth-year student John Deledda, his experience this year as a member of a medical team caring for a dying man who was estranged from his family gave him an insider’s view of what his teachers had been talking about.

The patient, fighting cancer that had led to brain damage and a blood infection, was extremely ill and being kept alive with life support. “It became apparent that the only reason this man was alive was because everything was being done to the extreme,” Deledda says. “The family was not a close family. None of them wanted to take responsibility for determining this man’s medical course or life.”

Deledda, who aspires to be an emergency room physician, was now feeling the pull he will undoubtedly face again and again: wanting to do nothing to harm the patient, which in this case he felt the machines were doing, yet wanting to follow a family’s wishes to keep the patient comfortable.

“It’s impossible to teach you in a book the right or wrong answer to those issues,” Deledda says. “Every day we thought he was going to die or the family would decide to withdraw care.” Deledda saw the situation take its toll on both the doctors and the family. Everyone grew tired. Finally, after four days, the family decided to turn off life support. “They said, ‘It’s time.’”

Through it all, Deledda listened and observed. He spoke if asked to speak. He had rotated through Barclay’s pregnancy loss exercise and understood the steps of explaining bad news, but this was all much more difficult than he expected.

Department of Pharmacology, where ethics education has been part of the curriculum for the past two years. The teaching is relaxed, typically taking place at the end of the day with students and faculty sharing a pizza while debating complex moral issues. The objective: Ethics is not to be studied and memorized only to be cast aside after exams.

“Ethics is something that should be part of your life,” Hollenberg says.

The graduate programs in PIBS are: Biological Chemistry; Biophysics; Cell, Developmental and Neural Biology; Cellular and Molecular Biology; Human Genetics; Microbiology and Immunology; Neuroscience; Pathology; Pharmacology; and Physiology.

For ethics education in residencies, Goold and her colleagues will spend this year surveying residency directors and physicians who have recently completed their residencies about what they believe should be included in ethics education in terms of skills, knowledge and attitudes.

Teaching and clinical activities will be offered starting in 2000. A “menu” of educational exercises will be available for residency directors to choose from when incorporating ethics into the already stretched days and nights of residents.

“We hope that coordinating efforts across departments will create a more consistent, higher quality and, perhaps, more efficient experience in ethics education in all the residency programs at U-M,” Goold says.

One component of the new program will be “ethics rounds,” with residents focusing on moral rather than medical

dilemmas. Goold currently conducts monthly ethical rounds in the high-risk obstetrics clinic, working with the medical staff and their interactions with patients.

“I try to teach them how to recognize moral issues and distinguish them from questions of fact. The tendency is to medicalize everything,” she says.

The new program also will increase the use of standardized, or simulated, patients — individuals trained to portray patients in a clinical setting. They currently are used in the Medical School.

There also will be programs for faculty to develop their teaching skills in the field of ethics. Some faculty are uncomfortable discussing ethics because they received no formal education in the subject themselves, Goold says. The Faculty Group Practice, made up of U-M faculty who provide clinical care, is funding Graduate Medical Education in Ethics.

“You’re excited to deal with it,” Deledda says of the emotional tug-of-war he watched play out. “You’re excited to learn about it because those questions are in your head, and you’re eager to watch the answers unfold.” He admits he does not know if he’s ready to handle such a case on his own. That will be the next frontier, as a resident in an emergency room making quick decisions about life and living. “You never know if you’re ready,” he says. “You find out after your first time.” If his teacher Mel Barclay has his way, those first experiences for John Deledda will make for memories that don’t haunt him years from now. [m](#)

Experimental treatments and hospice care: a new “best of both worlds” opportunity for the terminally ill

A chance to receive experimental treatments for your terminal illness or an opportunity to have the special comforts of a hospice program?

For most terminally ill patients, the choice has been one or the other.

Now, researchers at the Comprehensive Cancer Center and Hospice of Michigan, along with investigators at St. John Health System and Providence Hospital, will begin a 3-year study to see if a new model can’t be developed that won’t force people to make such a difficult choice.

Funded by the Robert Wood Johnson Foundation with a \$1.35 million grant, the Palliative Care Study will challenge the current model of medical care and allow patients the benefits of both hospice care and the most advanced chemotherapy, radiation and other treatments.

Under the current model of care, when terminally ill patients enter an experimental study or receive palliative treatment, they typically spend all but the last week or two of their lives receiving treatment. Then, when all life-prolonging options are exhausted, they are moved into hospice care. The move to hospice care, coming in the final days of the patient’s

life, often is accompanied by feelings of abandonment on the part of patients, families, and those caring for them. Conversely, if patients choose hospice care early, they deny themselves the chance to actively fight the disease.

The Palliative Care research team will evaluate 160 patients in each of four groups, those with advanced breast cancer, advanced prostate cancer, advanced lung cancer and advanced congestive heart failure. Those taking part in the study typically will have a life expectancy of approximately six months.

“Preliminary studies suggest that integrating hospice care with traditional treatment improves quality of life for terminally ill patients and may also be more cost effective than the current system of care,” says Kenneth J. Pienta, M.D., lead researcher and professor of internal medicine and surgery at Michigan. “Under this program you can enter hospice early in the treatment cycle and still receive medicines, such as chemotherapy, that will relieve symptoms and potentially help you live longer.”

Pienta, a nationally recognized prostate cancer researcher, will direct the new program along with co-investigator John Finn, M.D., medical director of Hospice of Michigan, the nation’s largest provider of hospice care, which serves more than 900 patients per day in Michigan communities. “In this study,” Finn says, “we will provide patients with the best of both worlds – state of the art treatment plus the best in palliative care. We think it will significantly improve the quality of end of life care for terminally ill patients.”

Medicare and most insurance companies generally do not pay for hospice services until all life prolonging options have been exhausted or refused. Results of the Palliative Care Project may provide valuable data to regional and national health care planners about costs of merging life prolonging medical care with hospice and palliative care,

The Robert Wood Johnson Foundation is the nation’s largest philanthropy devoted exclusively to health and health care. Based in Princeton, New Jersey, it was founded through a 1968 bequest by Robert Wood Johnson, who built the small but innovative family firm of Johnson & Johnson into the world’s largest health and medical care products conglomerate. To date, the Robert Wood Johnson has given more than \$13 million in gifts to support the work of scholars at Michigan.



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