Physician amplifies complexity of end-of-life ethics decisions

By Jerry Pierce & Tammi Reed Ledbetter
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DALLAS (BP)--Robert Orr expected that some people attending a Dallas bioethics conference might chuck rotten tomatoes at him over his view that end-of-life decisions aren't always as morally clear as some believe.

Bioethics speaker
Robert Orr, a physician and bioethicist at the University of Vermont's College of Medicine and clinical director of the Center for Bioethics and Human Dignity think tank, addresses the "Cutting-Edge Bioethics: Human Life on the Line" conference at Criswell College. *courtesy of the Southern Baptist Texan*

Orr, a physician and bioethicist at the University of Vermont's College of Medicine and "family doctor of the year" in the state in 1995, is a Christian pro-lifer and an outspoken opponent of euthanasia and physician-assisted suicide. He also is an ethics consultant who has been involved in more than 1,400 medical cases and is the clinical director of the Center for Bioethics and Human Dignity, a Chicago-area bioethics think tank and one of the sponsors of the "Cutting-Edge Bioethics: Human Life on the Line" conference at Criswell College.

But his views on artificially administered feeding and hydration -- that such treatment is sometimes inappropriate -- pits him against many pro-lifers.

Orr, referencing the temptation to nap during an after-lunch late-April session, mused, "I'm actually hoping that some of you do fall asleep this hour. Because I'm going to say some things that some of you don't want to hear. In conversations and so on, I've gotten the idea that some of you have already decided on some issues that I think are not necessarily already decided."

In the cases of persons such as Terri Schiavo -- the severely disabled Florida woman who died this year after fluids and nutrition were removed -- Orr said family members nearly always make the right decision on what the patient would have wanted regarding extraordinary life-extending treatment. But such decisions are best made at the bedside, not in the courts, he said.

Removal of artificially given food and water -- with proper family or patient directives -- is appropriate when continued nutrition extends life but does not enhance the patient's recovery chances, Orr stated. Removal of fluids, done with constant moistening of the mouth and with pain relief, is often preferable to extended suffering for terminal patients

and sometimes may be the ethical choice, he said.

Orr used a graph to explain the “trajectory of death.” Some people die suddenly (accidents or heart attacks), some die predictably (terminal illness) and others “dwindle” (as many elderly people do).

But the most complex ethical decisions arise from cases of people with chronic disease, Orr said. They spiral downward, improve, worsen, and improve again. “There’s crisis after crisis -- you never know which one will be fatal,” he said. “And so the uncertainty of how they’re going to do really colors the issue of how you make decisions in these circumstances.”

Because medicine can prolong life far more than in previous generations, new issues arose in the 1970s and ’80s along with a slew of publicized court cases that centered on medical ethics and patient and family rights.

“Some of these media cases resulted in decisions about different types of treatment,” Orr said, citing specific cases such as that of Karen Ann Quinlin, when a ventilator was removed.

“Bottom line is that it’s OK sometimes to use less than maximal treatment even if that means sometimes the patient will die,” Orr said. “This change in approach led to advance directives, hospice, palliative care -- very positive things.”

Orr cited eight ways bioethicists learned from court cases between 1976 and 1990:

1) A competent patient has the right to refuse even life-prolonging treatment.

2) Incompetent patients have the same right and a surrogate may exercise that right.

3) The family is the presumptive surrogate, except in Britain where physicians make the call, sometimes with the family’s influence.

4) Courts are inappropriate places to settle end-of-life issues.

“A judge sitting on a probate bench for 15 years may see one, two, three limitation-of-treatment cases in his or her career,” Orr noted. “They’re not used to this. They’re not up for this. They’re not prepared. They would much rather prefer these decisions be made at the bedside.”

5) There is no specific diagnosis or treatment that must be taken to court for legal approval.

6) There is no difference between withholding and withdrawing of treatment.

“That was a tough pill for some people to swallow -- old folks like me,” Orr said.

7) Artificially administered fluids and nutrition are treatment.

8) Physicians or hospitals acting in good faith and without negligence will not be held civilly or criminally liable for limitation of treatment at the surrogate’s request.

“It was painful learning those eight lessons but those are pretty well accepted in North American bioethics are this point,” Orr said.

The limitation of treatment, he said, may involve such things as cardiopulmonary resuscitation, ventilators, chemicals to maintain blood pressure, artificially administered hydration and nutrition, radiation and chemotherapy -- even transfer from emergency to intensive care.

“I’ve got some news for you. When a patient dies in the hospital, 70 percent of the time the timing of death is a matter of choice,” Orr said. “Not the fact of death but whether the patient dies now or three days from now or three weeks from now is often dependent on whether or not we try to resuscitate, give one more blood transfusion, another round of antibiotics, chemotherapy, so on.”

Withholding treatment, Orr said, is usually an advance decision on a specific remedy; withdrawing treatment is to stop something already begun.

“There’s really no professional, moral or legal difference between those two,” Orr said. “... However, there may be a significant psychological difference. It’s harder to go into the ICU and turn down the dials on the ventilator knowing that the patient almost certainly will not survive than it was to not start the ventilator in the first place.

“Why might we consider limiting treatment in certain circumstances?” Orr asked. “Well, if the patient doesn’t want it -- that’s reason to consider it. Or if it’s not going to work, or if it’s outside the burden of care, or if the burdens of risk of treatment outweigh the benefits. And can we say it out loud -- if the cost outweighs the benefits?

“I’m not saying these are definitive answers but these are considerations we must bring onto the table when we’re talking about limitation of treatment,” Orr said.

When making ethical calls, Orr said he relies on four factors -- medical indications, patient

preference, quality of life and context. He said the first two factors rely on facts; the other two are not so clear.

"What is the condition of the patient? What was the baseline condition a week ago before he had this stroke and is in this condition now? And a big question is, 'What's the likelihood of getting him back to an earlier condition?'

"Prognosis is not a fact, it's a guess," Orr stated.

Orr said a patient's preference might be discerned from the values he expresses, whether he was coerced or pressured by family, finances or physicians. Also, one must consider whether an advanced directive or living will exists or the context in which he expressed his wishes. "The piece of paper is much less important than having a conversation with the family to know their goals and values.

"Sometimes there's a very poor prognosis and you have no idea what the patient wants," Orr said. That's when he considers quality of life for the patient in the context of his or her life prior to medical treatment.

"Christians get very nervous when I mention the phrase 'quality of life' because human life is sacred. I'll be at the head of the line preaching the sanctity of life, but life does have its quality. We have a stewardship of life and resources," Orr insisted.

Sometimes, monetary considerations should inform whether one should pursue extraordinary means in terminal cases, Orr said.

As for quality of life, Orr said doctors and nurses are bad at assessing it. Their perspective of a paralyzed patient who can't breathe without a machine contrasts with the patient who seems more functional.

Orr told of being called to an ICU to decide whether to put a 53-year-old man on a ventilator who had severe cerebral palsy and mental retardation.

"My knee-jerk response was that this is a pretty poor quality of life."

But after talking with the man's mother, who was across the country for a family reunion, Orr said the picture changed.

"For 50 years she had taken care of him at home. When she was in her 80s she could no longer lift him and admitted him to a nursing home where she fed him twice a day." Orr speculated the nurse didn't know the eating habits of the man as his mother did, prompting

a perceived swallowing problem.

“She said, ‘Do whatever you need to do, put him on a machine and I’ll be on the next plane.’”

A few days later Orr returned to find the mother at her son’s bed where he was communicating with her. “I could not understand one syllable, but I noticed he was looking at me and talking. She said he wanted to know what kind of car I drive.”

After Orr told the man he drove a Saturn, the man went into a monologue about the vehicle’s specifications since this was his particular interest.

“I had no idea there was anybody home. I knew that, first, I was a stranger and, second, he was sick and had a certain level of function, then got a fever and was functioning at a lower level.

“So don’t be so quick to judge the quality of life, especially when dealing with strangers,” Orr said.

Although healthcare originated as a religious service with hospitals and hospices begun by religious orders, the secularization of healthcare is nearly complete, Orr said.

“We still have chaplains, but don’t let them get in the way. God talk is excluded,” he warned.

A revival in spirituality in healthcare may open the door to talk with a patient about his spiritual life although “a lot of things under that umbrella are spirits that are not the Holy Spirit,” he said.

Orr said four non-intrusive questions help a person have a conversation about a patient’s relationship with God: Do you belong to a faith tradition? How important is your faith to you? Do you belong to a faith community? How does your faith affect your life and how I should take care of you?

The “Cutting-Edge Bioethics: Human Life on the Line” conference on “end-of-life issues, reproductive technologies, stem cell research and beyond” at Criswell College, April 29-30, was cosponsored by Trinity International University, the Center for Bioethics and Human Dignity, Christian Medical & Dental Associations, The American Academy of Medical Ethics and Baylor Health Care System of Dallas.
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Jerry Pierce is managing editor and Tammi Reed Ledbetter is a contributing writer for the

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[Back to Previous Page]

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901 Commerce Street
Nashville, TN 37203
Tel: 615.244.2355
Fax: 615.782.8736