



CASE OF THE MONTH

THE CAREGIVER'S JUDGMENT VS.
REGULATIONS TO PROTECT THE PATIENT:

Weighing “clear and convincing evidence”

CASE

Miguel is a 44-year-old man with Down's syndrome and Alzheimer's disease. He was transferred from a state-run nursing home to the hospital when he developed pneumonia. His condition rapidly worsened, and he was emergently placed on a mechanical ventilator. TPN was started to maintain his nutrition, and when Miguel had not improved in seven days, a surgical consult was obtained to place a permanent feeding tube.

Miguel had lived in the nursing home since age 23, when his parents died in a car accident. His older brother John visited Miguel weekly, taking him to ball games and fishing. John took Miguel to doctor's appointments and consulted with nurses about level of care and whether or not to give Miguel medicines to deal with his anxiety. Over the last year, because of Miguel's advancing dementia and fear of new places, he and his brother stopped going on outings. John still visited weekly, but Miguel no longer recognized his brother and could no longer speak.

John was out of town and could not be reached when Miguel was transferred to the hospital. When John returned, he immediately went to the hospital. The doctor told John that his brother had a small chance of recovering enough to come off the ventilator in the next week or two. Miguel was heavily sedated because of anxiety triggered by the ventilator and the ICU environment. John refused to sign the surgical consent for the feeding tube, and asked that the ventilator be withdrawn, arguing that this was “torture” for Miguel, given his limited understanding, recent poor quality of life, and rapidly progressing Alzheimer's.

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Bioethics *in* *brief*

ETHICS COMMITTEE

Bioethics in Brief is a newsletter of University Hospital's Ethics Committee, produced in cooperation with the Center for Bioethics and Humanities. Opinions expressed in *Bioethics in Brief* are those of the authors and should not be taken to represent the position of University Hospital or the Center for Bioethics and Humanities.

Questions, suggestions, or comments? Would you like to be added to our mailing list? E-mail us at ethics@upstate.edu.

Have a question about an ethical issue you're dealing with? We are always happy to talk in confidence about ethical concerns; you may reach us through the Center for Bioethics and Humanities at 464-5404. Ethics consultations are available by calling the hospital operator (464-5540) and asking for the ethics consultant on call, or by contacting any of the senior ethics consultants directly (Robert Daly, MD, 464-3104; Kathy Faber-Langendoen, MD, 464-5404; and Joel Potash, MD, 634-1100).

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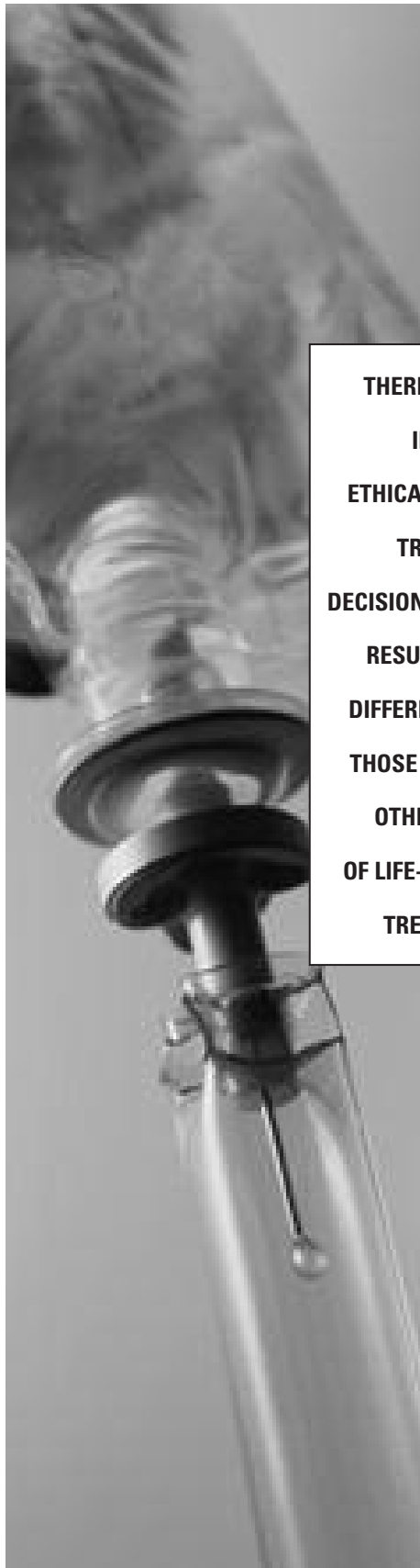
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Clear and convincing evidence, *continued*

DISCUSSION

This case raises the question of whether family ought to be entrusted with making decisions to limit treatment. This is one of numerous ethical issues at the end of life, many of which have played out in

New York State in the courts. Through a series of appellate level court cases in the 1980s, New York State asserted a "clear and convincing" evidentiary standard for decisions to limit life-sustaining treatment. This means that life-sustaining treatments, particularly artificial nutrition and hydration, cannot be withheld legally unless there is "clear and convincing" evidence that the patient would not want such treatment in the particular

clinical circumstance.

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THE STANDARD ARTICULATED

This standard was most clearly articulated in the 1988 case of Mrs. O'Connor, a 77-year-old retired hospital administrator who had watched both her husband and a friend die lingering, painful deaths from cancer. According to her daughters, Mrs. O'Connor said that it was "monstrous to keep someone alive by machinery" and that she would find it intolerable to lose control of her bodily functions. Mrs. O'Connor suffered a series of strokes and was left so debilitated

that her daughters could no longer care for her. She was admitted to a hospital for treatment of pneumonia, and physicians recommended feeding tube placement. Her daughters refused, based on their knowledge of their mother’s wishes. The New York State Court of Appeals ruled that there was no “clear and convincing” evidence of what Mrs. O’Connor would have wanted in this situation, as her previous statements were made in reference to people with cancer, not strokes.

HEALTH CARE PROXIES

Appointment of a health care proxy allows a patient to choose, in advance, someone to make medical decisions on his or her behalf if the patient loses decisional capacity. However, health care proxies are not allowed to make decisions to withhold artificial nutrition or hydration, unless there is “clear and convincing” evidence that this follows the patient’s wishes. Only a minority of adults have designated health care proxies, and patients like Miguel may never have had the mental ability to choose a proxy. A specific DNR law in New York allows families or other substitute decision makers (“surrogates”) to refuse to allow attempts at CPR if the patient is terminally ill, permanently unconscious, or has an incurable condition and treatment would be inhumane or excessively burdensome. However, there is no similar provision for decisions regarding limiting other forms of life-sustaining treatment, including artificial nutrition and hydration. There is little, if any, ethical basis for treating decisions regarding resuscitation differently from those regarding



IN GENERAL, WHEN PHYSICIANS BELIEVE A LAW IS UNJUST, THEY SHOULD WORK TO CHANGE THE LAW.

other forms of life-sustaining treatment. While there is broad ethical consensus that families or other loved ones generally are best able to make health care decisions on behalf of incapacitated patients, New York, Missouri, and (to some extent) Michigan are the only states without legal provisions for allowing such decisions in the absence of a health care proxy.

PROPOSED LEGISLATION

The proposed Family Health Care Decisions Act would allow Miguel’s brother John to make decisions

THE LACK OF LEGAL RECOGNITION FOR FAMILY SURROGATE DECISION-MAKING IS AN IMPEDIMENT TO GOOD, COMPASSIONATE CARE OF THE ILL AND DYING.

about Miguel’s ventilator or feeding tube (for more information on the bill, see www.familydecisions.org). Like the previous DNR legislation, this proposed law would allow such decisions to be made only if the patient is terminally ill, permanently unconscious, or has an incurable condition and treatment would be inhumane or excessively burdensome. This bill has its advocates and its opponents and made little progress during the last legislative session.

ETHICAL VS. LEGAL

Sometimes the law reflects ethical consensus. At other times, it is out of step or represents only a minority view. The lack of legal recognition for family surrogate decision-making is an impediment to good, compassionate care of the ill and the dying. Health care professionals have a responsibility to navigate these difficult decisions as they arise in clinical practice. They should also consider carefully whether they can support the current legal restrictions and, if not, what they might do to change them. As the Council of Judicial and Ethical Affairs of the American Medical Association wrote in 1996:

“Ethical values and legal principles are usually closely related, but ethical obligations typically exceed legal duties. In some cases, the law mandates unethical conduct. In general, when physicians believe a law is unjust, they should work to change the law. In exceptional circumstances of unjust law, ethical responsibilities should supersede legal obligations.”
 ■ *K. Faber-Langendoen*



Human eggs for sale

There has been a surge of requests for human eggs online and in newspaper and magazine ads—many aimed at college age women with particular assets (tall, athletic, high IQ, blue eyes, etc.). Money paid for the time and inconvenience of egg donation (not the product itself) is currently legal in the United States. However, since ads target specific qualities, many argue that the payment offered is not merely for the donor's time and inconvenience. Donors with some highly desired qualities are paid up to \$50,000 for eggs. The "body-as-one's-own-property" view is the strongest argument for allowing people to sell human eggs. On the other hand, some argue that there is something inherently different about the moral intrinsic value of an egg, which can become a human being if fertilized. As such, it is dangerously close to selling a person. Continue to watch for this topic to be hotly debated as reproductive technology continues to expand. ■

Cloning Recommended for "Therapeutic Uses"

The Chief Medical Officer in the United Kingdom has proposed approving limited forms of human cloning for growing organs for transplants and other forms of therapy. In August, the National Institutes of Health in the US issued regulations allowing federally funded scientists to work on stem cells derived from human embryos. These proposals would only allow the use of early-stage embryos from which stem cells could be harvested. These stem cells have the potential to develop into any kind of tissue. This is different from reproductive cloning, which seeks to copy actual human beings. The obvious scientific benefit of cloning organs from one's own stem cells is that it dramatically reduces the likelihood of rejection. Pro-life groups oppose this idea, arguing that abortions might increase to create tissue for these causes. Over 50,000 embryos are frozen in the US, left over from fertility procedures. However, few opponents of the use of these embryos for stem cell research have suggested practical ideas as to what the fate of these embryos ought to be. The President's National Bioethics Advisory Commission has been reviewing these moral issues. Their report, *Ethical Issues in Human Stem Cell Research*, can be found at www.bioethics.gov/pubs.html. ■



Completion of Human DNA Mapping

On April 13, 2000, Celera Genomics, a private Maryland company, announced that it has identified almost all three billion components of the 80,000 genes it takes "to make a human being." Shortly thereafter, the NIH also announced their progress in detailing the human genome. Many people are elated as the prospect of treating hereditary diseases through gene therapy looms larger. Others are concerned about how this information could hurt certain groups of people. For example, could employers find out about someone's genetic code and use that information in hiring decisions? Increasingly, public policy will need to deal with how to regulate the use of genetic information, balancing patients' protection with the financial interests of genetics technology companies, insurers, and employers. ■ *K. Kurtz and K. Faber-Langendoen*



What does an ethics consult look like?

University Hospital, through the Hospital's Ethics Committee, provides ethics consults for situations arising both in the hospital and outpatient settings. Ethics consults provide information and recommendations regarding ethical dilemmas in patient care. Examples of ethical dilemmas addressed in consults include disagreement over continuing or ending treatment, conflicts between patient's rights and family considerations, and questions of who ought to be the decision-maker. The general rule is to follow the patient's wishes. Sometimes, however, a patient's wishes are unclear, inconsistent, unknown, or seem harmful. In such cases, an ethics consult may help untangle the options.

An ethics consultant has advanced training and experience in the field of bioethics. This person is often a clinician, such as a physician, nurse, or social worker. At University Hospital, the Ethics Consult Service is run by Kathy Faber-Langendoen, MD and includes three other senior ethics consultants: Robert Daly, MD, Wendy Edwards, MD, and Joel

Potash, MD. The senior ethics consultants often include other members of the interdisciplinary Hospital Ethics Committee in the consult for additional perspectives.

An ethics consult may be requested by anyone with a moral connection to the dilemma who is experiencing uncertainty or concern about what is happening or not happening in a particular case. This means that family, patients, and any health care professional involved in a case have the right to question something that does not feel "right" to them. Often, these parties resolve such dilemmas on their own. If they cannot, an ethics consult can be useful. The consultant will identify the moral questions and work through an analysis of the ethical issues, offering morally appropriate choices to the decision-maker. This process involves identifying relevant values among the parties, seeing how these values might be at odds, assessing pertinent medical information, and clarifying treatment goals.

Using this model, the ethics consult often helps those persons involved in the dilemma understand who the decision-maker is and what the choices are for resolution. Also, the consult can be helpful to bring a "neutral" third party into a situation in which there is disagreement. This third party can assist those involved in seeing other points of view and learn how we arrive at ethical recommendations. The ultimate goal of an ethics consult is to effect an outcome that reflects the patient's wishes as closely as possible.

The Ethics Consultation Service is here for you, for patients, and for families. We have a brochure for patients and families about ethics consultation; if you would like copies for your area, call 464-5404 or e-mail us at ethics@upstate.edu. If you would like to request an ethics consult or informally discuss an ethical concern, call the hospital operator at 464-5540 for the ethicist on call or Dr. Faber-Langendoen's office at the Center for Bioethics and Humanities at 464-5404.

■ *M. Thompson*

Protecting Basic Human Rights: The Baby vs. The Mother vs. The Judge



A recent court case in Montana is a telling example of one court's willingness to limit a woman's ability to become pregnant, given concerns about the baby's welfare.

In 1998, a 29-year-old woman gave birth to a baby boy who tested positive for amphetamines. District Judge Dorothy McCarter gave the woman a three-year deferred sentence and required her to complete drug treatment. However, she failed to do so and continued to test positive for drug use.

The judge then sentenced the woman to boot camp, ordered her not to get pregnant for ten years, and required that she have a pregnancy test every two months. A positive pregnancy test could result in subsequent jail time. The ten-year prohibition against pregnancy was intended to span the woman's most reproductive years. Judge McCarter announced, "I don't want another damaged baby born because we didn't do enough to supervise that woman. If she wants to drug herself to death, fine. But we can't have her taking drugs when she's pregnant."

The judge's order has raised eyebrows among constitutional scholars and civil libertarians, who argue that the order intrudes on the right to privacy, is discriminatory in its application, and violates basic civil rights.

The ethical questions raised by the judge's order and the significance of potential outcomes are complex. Furthermore, there are strong arguments and emotions on both sides of the debate concerning what is fair and just in dealing with a drug abuser and her fetus. What if we ignore the judge's warning and do not act to protect a future child? A society wants every baby to have a healthy start. But, what if the woman turns her life around and remains drug-free? Is it ethical to imprison her solely because she conceives a child? In such a case, does the threat of prison and separation from her baby make it likely that she would flee and never seek any prenatal care?

In this particular case, the woman did not comply with the regulations of boot camp and is now in prison. Her sentence is being appealed.

■ *L. Baum*

Web Site of the Month

If you want to track down more information about a recent ethical issue in the news, check out www.bioethics.net, a web site produced by the University of Pennsylvania's Center for Bioethics. It also includes basic information on the field of bioethics, a calendar of conferences, and information about formal training programs in ethics. ■

bioethics.net where the world finds bioethics

Bioethics - the moral implications of science, medicine and research.

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Grass Roots Seeded by Drugmaker
Washington Post
Sept 13 - Showing all the signs of a thriving grass-roots movement, a host of new health-care groups are drawing attention to the perils of a contagious, sometimes lethal virus called hepatitis C.

Hundreds of doctors, community leaders and public-health officials have volunteered for the hepatitis C coalitions in 11 states. Members distribute thick information packets to educate the public about what they term the "silent killer" and the "millennium epidemic." Organizers have begun pressing state legislators to spend more to fight the disease, which attacks the liver and affects about 4 million Americans.

'Biological Insurance' for Your Baby
Washington Post
Sept 13 - Lori Lange was pregnant with her first child when she started browsing the Internet for deals on strollers and bassinets. Instead, she came across information about a baby accessory that caught her by surprise: her own child's umbilical cord blood.

Penn Gazette on McGee British Experience

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U.S. to Issue New Rules for Research on Embryo Cells

LA Times on Haselting, Ego, and the Science of Youth

New: Center for Bioethics and Humanities

Under the leadership of Kathy Faber-Langendoen, MD, SUNY Upstate Medical University has developed a new division, the Center for Bioethics and Humanities. The Center brings together the work of the Program in Medical Humanities, the Program in Bioethics, and scholars in the humanities

from the College of Health Professions. The Center will develop research, educational and clinical programs in bioethics and the humanities as they relate to health care. Efforts range from required ethics courses in the colleges of Medicine, Nursing and Health Professions to educational programs at University

Hospital; from research into perceptions of quality of life among the seriously ill to poetry reflecting on medicine; from ethics consultation to creative writing workshops for children with cancer. For more information, call 464-5404. ■



Ethics Committee

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