

Welcome

to the first edition of *Bioethics in Brief*, a newsletter of University Hospital's Ethics Committee, produced in cooperation with the Program in Bioethics and funded by University Hospital. *Bioethics in Brief* will explore ethical problems that arise in caring for patients and families and keep you up-to-date on local bioethics happenings. Let us know what issues you'd like to see addressed. You may contact us at ethics@upstate.edu or by calling Kathy Faber-Langendoen, MD, at 464-5404. ■



Can she handle the news?

CASE

Mrs. McIntosh is a 41-year-old woman with breast cancer that has spread to her liver, intestines and bones. Her past history was notable for depression, which was somewhat improved with medication. She received morphine for the bone pain and lived at home with her husband.

Mrs. McIntosh was admitted to the hospital with abdominal pain and confusion. She was diagnosed with an ileus secondary to morphine. A brain CT showed that the cancer had spread to her brain. Mrs. McIntosh's mental status fluctuated between confusion, clarity and agitation. Her physician decided that further treatment would be pointless, given the rapid progression of her disease. The attending recommended to Mr. McIntosh that his wife have a "Do not resuscitate order," and Mr. McIntosh agreed. However, the physician advised the husband that telling Mrs. McIntosh of the DNR would be "as cruel as pulling the wings off a fly." The husband agreed, saying that his wife might give up if she knew she was dying imminently. The consulting neurologist was uncomfortable with this, because she saw Mrs. McIntosh during a period of lucidi-

ty and felt it inappropriate that she was not being told the truth. The neurologist called an ethics consult.

QUESTIONS

- Should Mrs. McIntosh be told about the DNR?
- Is her history of depression relevant to this decision?

DISCUSSION

In general, we advocate for truth telling in our culture, valuing patients' autonomy and their right to understand what is happening to them. In this case, it would be useful to know several things, such as:

- Has Mrs. McIntosh ever said she does not want to know details of her treatment and prognosis?

continued, next page

Bioethics *in brief*

UNIVERSITY HOSPITAL OF SUNY UPSTATE
MEDICAL UNIVERSITY ETHICS COMMITTEE

Bioethics in Brief is a newsletter of University Hospital's Ethics Committee, produced in cooperation with the Program in Bioethics. 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 Program in Bioethics.

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 Program in Bioethics 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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Can she handle the news, *continued*

- Has she always turned over medical decisions to her husband?
- Recently, has she been asking staff how she is doing?
- Is she from a culture that has specific beliefs against truth telling?

There are many reasons to presume that Mrs. McIntosh has a right to know her prognosis and participate in treatment decisions. First of all, Mrs. McIntosh has a right to know she is dying, as there may be important things she wants to do before she dies. She may want to undergo treatment that has only of temporary benefit if she had a specific short term goal, such as seeing a grandchild born or a child married. Mrs. McIntosh may also want to make peace with her life from an emotional and religious perspective. Not telling people when their lives are ending is harmful because it prevents them from doing important end-of-life "work."

In this case, we would want to know more details about the patient's history of depression. Having a mental illness does not necessarily mean that a patient cannot understand her care or participate in decisions, either on an ethical or legal basis. The only issue that should sway us toward not telling the truth would be if we had evidence that Mrs. McIntosh

would likely cause harm to herself if she found out this news.

The issue of truth-telling is not just a problem for Mrs. McIntosh's physicians. Nurses, social workers and other staff caring for Mrs. McIntosh have an ethical responsibility to question a practice of not telling the truth, because if the truth is not told, they will be part of the deception. Some physicians have trouble giving bad news to patients and others equate emotional outbursts with the inability to hear bad news. However, it is normal for some people to react with tears, anger, and even emotional outbursts to news that one is dying. It is quite normal to be sad about such news. We cannot assume that any of those things render one incapable of hearing the news, however. So, although we would want to understand why the physician thinks telling Mrs. McIntosh the truth would be cruel, his decision might reflect his own difficulty telling bad news, rather than the patient's ability to hear bad news.

In this case, then, absent any clear evidence from Mrs. McIntosh herself that she does not want to know her prognosis or to participate in medical decisions, I would recommend that she be told as compassionately as possible that her disease had progressed and that a DNR order was an appropriate medical decision. (K. Kurtz) ■

Supreme Court agrees to hear case of drug testing pregnant women

The U.S. Supreme Court has agreed to hear a case regarding a South Carolina hospital's policy of testing pregnant women's urine for cocaine without their consent. The hospital argued that they had a responsibility to protect the fetus and had a policy of informing the police if women testing positive for cocaine refused drug treatment. Arguments about similar cases have centered on issues of the woman's privacy, society's responsibility to prevent harm to the fetus, and whether fetuses should be protected if they don't have legal status as "persons." The Supreme Court is expected to rule in the case early next year.

Gene therapy experiments halted

Last fall, Jesse Gelsinger, an 18 year old with a mild case of a rare enzyme deficiency, died during a gene therapy experiment at University of Pennsylvania. The FDA has been investigating this and other experimental gene therapy trials. At issue is whether it was ethically appropriate for Jesse to participate in the trial, which was designed to find out whether gene therapy was safe and effective

for infants with a fatal form of the enzyme deficiency. Much of the discussion has been around what constitutes informed consent, and whether patients enrolling in this trial were told of the potential risks of this unproven therapy. Although research trials are already heavily regulated, the FDA is concerned that oversight needs to be tightened even further. While these issues are sorted out, Beth Israel voluntarily suspended their gene therapy trials on February 7th.

Cable television station airs "how to" suicide video

A Eugene, Oregon cable television station aired a "how-to" video on suicide in early February. Oregon is the only state that has legalized physician assisted suicide. Oregon law requires that patients be terminally ill, able to request suicide themselves, and that physicians must document two requests over a 15-day period before prescribing lethal doses of medication. Derek Humphry, author of *Final Exit*, produced the video, which gives details on specific methods to end one's life. The head of Compassion in Dying, the organization which led the fight to legalize physician-assisted suicide, has criticized the video as being "injudicious, irresponsible, and potentially dangerous." (*K. Faber-Langendoen*) ■

UB Center for
Clinical Ethics
and Humanities
in Health Care



The Center for Clinical Ethics and Humanities in Health Care is an interdisciplinary academic center of the University at Buffalo. The Center draws upon a wide range of individuals from the School of Medicine and Biomedical Sciences as well as various health care and academic institutions in the Buffalo, N. Y., area.



IMPORTANT: www.familydecisions.org
Family Health Care Decisions Act

25245 hits since 7/7/98

Web Site of the Month

The ethics program at SUNY Buffalo has a terrific website at <http://wings.buffalo.edu/facu/ty/research/bioethics>.

If you go to their home page and click on "Ethics Committee Core Curriculum," you will find a wealth of information about common ethical issues such as forgoing treatment, brain death, futility, and artificial nutrition and hydration. It also has a good discussion on how New York state law impacts on health care ethics.

Minding the Gap

Ethical dilemmas in medicine would be less complicated if what we believed to be ethical was, by definition, always legal. For better or for worse, it is not. Actions based upon the principles of bioethics and actions mandated by law are sometimes at odds with another. For example, consider a child with severe, permanent brain damage and intractable seizures. Despite the severity of the child's condition, the parents refuse to allow the physician to write a "do not resuscitate" order. The physician may argue from an ethical standpoint that to prolong this child's life would only make him suffer longer, and that aggressive treatments would only harm the child. Nonetheless, the law may

still require physicians and nurses to abide by the parents' wishes.

This concept, that an action may be lawful yet unethical or, conversely, that a desirable action is ethically justified yet outside the bounds of the law, is distressing. The reason for this gap between law and ethics is partly because law and ethics serve different functions. Laws are created to direct the conduct of many diverse people within a community who may not share common moral values and beliefs. Bioethics attempts to resolve dilemmas confronted so often in health care by means of discussion, analysis and consideration of those moral principles to which every person is entitled. In

addition, as health care professionals consider the ethical issues of specific patient's case, they can do so in a manner tailored to that patient's experience. The practical application of bioethics may be more flexible and dynamic than the application of the law. Laws change and adapt through a slower process.

It is often frustrating when ethical and legal choices conflict. In this column, we will regularly discuss how bioethics and law intersect in specific cases, teasing out where they converge and where they diverge. If you have specific issues you'd like to see addressed, e-mail us at ethics@upstate.edu.
(L. Baum) ■



Ethics Committee

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