Bioethics *in brief*

November 2001

UNIVERSITY HOSPITAL OF SUNY UPSTATE MEDICAL UNIVERSITY ETHICS COMMITTEE

CASE OF THE MONTH

Can patients refuse a transplant once they have given informed consent?

If a patient refuses to be discharged but no longer needs acute care, what is the hospital's responsibility?

CASE *Mr. Marcose* is a 38-year-old man, admitted to the local county hospital for congestive heart failure. He is first on the waiting list for a heart transplant at Woodland Lake Hospital. On the day Mr. Marcose is to be transferred to Woodland Lake, he complains of being very weak and refuses to leave. He now says he is not sure he wants a transplant; the doctors and nurses are concerned about his condition deteriorating so much that he will no longer be able to undergo a transplant, and they want to transfer him as soon as possible. Mr. Marcose also refuses to go home, even with full nursing care, saying he is too weak.*

DISCUSSION

Any competent patient may change his or her mind and withdraw consent for a procedure. In supporting patient autonomy, we do not give a person one chance to decide and preclude a future change of decision. The clinicians should ask the patient to explain why he changed his mind, ensuring that this was an informed choice. In the end, Mr. Marcose has the right to refuse treatment, regardless of his previous decision.

This broader issue of the hospital's responsibility to keep patients in the hospital despite lack of medical justification arises often. With families spread apart geographically and community-based social service programs lacking, hospitals are finding more patients unwilling to leave the hospital when the physician deems the patient no longer in need of acute care.

Some of the reasons for a person not wanting to leave are good

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**names and other identifying details have been changed.*

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Bioethics in brief
ETHICS COMMITTEE

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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; Wendy Edwards, MD, 464-5404; Kathy Faber-Langendoen, MD, 464-5404; and Joel Potash, MD, 634-1100).

SUNY Upstate Medical University
University Hospital
MEDICINE AT ITS BEST®

—*continued from page 1*

May patients refuse a transplant once they have given informed consent?

ones. If they live alone with no family support and do not feel they are well enough to care for themselves, they may be frightened to go home. If they have become used to the nurses and surroundings at the hospital, they may be afraid of the changes they will face when they go home. However, from the standpoint of fairly allocating limited resources, neither the hospital nor the patient has the right to squander resources. If a person does not medically need the services a hospital provides and can be cared for in a less acute facility or at home, it is ethically justified to discharge the patient.

> **FROM THE STANDPOINT OF FAIRLY ALLOCATING LIMITED RESOURCES, NEITHER THE HOSPITAL NOR THE PATIENT HAS THE RIGHT TO SQUANDER RESOURCES.**

Most hospitals, including University Hospital, have an appeal process in place for patients who feel they are being discharged prematurely. Patients who disagree with a physician's discharge decision should be informed of that process and assisted with it. Social work or continuum of care personnel provide this service.

In Mr. Marcose's case, the physicians or nurses should find out why he no longer wants the transplant and why he does not wish to return home even with adequate nursing care. They could call on social work to help them flesh out his reasoning. If Mr. Marcose decides that he does not want to go through a transplant, the physicians should ensure he understands what his quality of life would be like without the transplant. However, absent any acute care need, the physician is not only allowed, but obligated to discharge him with appropriate medical care services at home. ■

—*Kathy Kurtz, Maxine Thompson, Sara-Lee Cleveland*

Fertility Society Moves Toward Approving Sex Selection

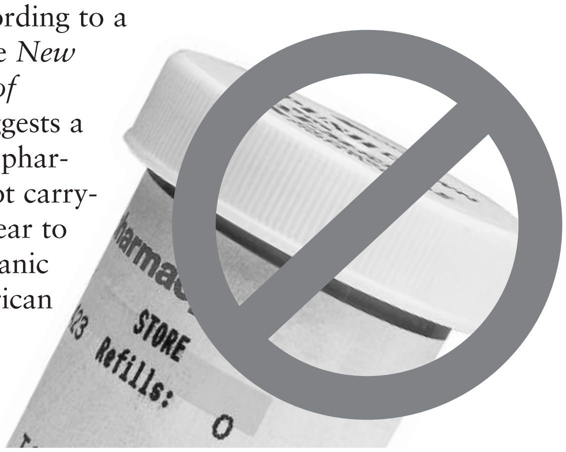
John Robertson, acting chair of the ethics committee for the influential American Society for Reproductive Medicine, made a statement supporting sex selection of embryos for implantation. This method allows prospective parents to selectively choose embryos of the sex they prefer. The technique of sorting embryos by sex, based on the composition of X and Y chromosomes, has been available for more than a decade; its use, however, has been restricted to cases in which embryos are at risk for sex-linked diseases. The Society has discouraged sex selection as recently as 1999, and Robertson's letter has elicited great controversy. Many fertility specialists and others argue that allowing for sex selection will reinforce sex discrimination. In India, many obstetricians provide ultrasounds for sex determination (although this is strictly illegal). A large number of female fetuses are aborted; in one Indian province, only 83 girls are born for every 100 boys. ■

—based in part on

The New York Times *reports, 28 September 2001*

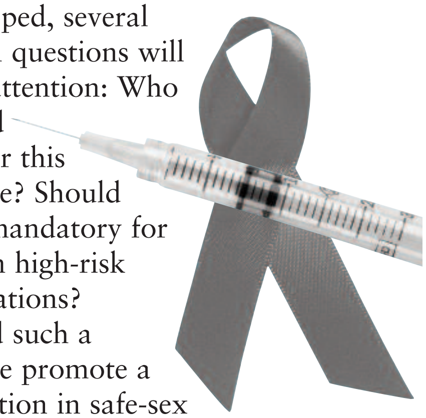
No Pain Meds Here

More pharmacies in low-income neighborhoods are not carrying opioid analgesics, according to recent studies. Pharmacists' fear of theft means that those with legitimate prescriptions for the medications sometimes must travel by bus to suburban areas that carries the medications. According to a recent study in the *New England Journal of Medicine*, this suggests a racial bias, as the pharmacies that are not carrying the drugs appear to be mostly in Hispanic and African American communities. ■



AIDS Vaccine: Who Pays, Who Gets, What If?

Researchers at Merck and Company have confirmed that safety tests for an experimental AIDS vaccine have begun in conjunction with Wyeth-Lederle Vaccines. If an AIDS vaccine is developed, several ethical questions will need attention: Who should pay for this vaccine? Should it be mandatory for certain high-risk populations? Would such a vaccine promote a relaxation in safe-sex practices that might result in other sexually transmitted diseases increasing among those who had only been worried about contracting HIV/AIDS? ■



—Kathy Kurtz, K. Faber-Langendoen

UPCOMING LECTURE:

Ethics in a Short White Coat:

MORAL CONFLICT AS PERCEIVED BY 3RD YEAR MEDICAL STUDENTS

presented by

Kathy Faber-Langendoen, MD and
Catherine Caldicott, MD

Presented will be real-life cases "from the trenches" and dilemmas that arise for third-year medical students during their required clinical clerkships. The students have identified these cases as containing ethical issues and write about them for their required course, "Bioethics at the Bedside."

Department of Medicine Grand Rounds

Thursday, December 6 • 8:30 a.m.

Medical Alumni Auditorium

NYS Task Force: Genetic Testing

It is hard to read a newspaper or listen to the news and not hear something about genetics. How will this age of genetics personally affect us? Should you have genetics tests done to find out your risk for certain diseases? If you do, should your employer be able to access the results?

The State of New York has provided some direction with the latest report from the New York State Task Force on Life and the Law: Genetic Testing and Screening in the Age of Genomic Medicine. This comprehensive report includes an introduction on genetic screening and testing and discusses concerns that most people may not consider in relation to what genetic testing could mean for them, including the potential harms of "predictive" genetic testing. The report also discusses whether and when employers ought to be able to obtain and/or use genetic information about you.

The report contains recommendations for legislative and regulatory action. Among the recommendations are calls for repeal of mandatory sickle cell screening for some couples seeking marriage licenses, amendment of New York's genetic confidentiality statutes to protect the confidentiality of all genetic information, and the creation of a process for state certification of genetic counselors. Copies of the report are available from Health Education Services, PO Box 7126, Albany, NY (518-439-7286, www.hes.org). A summary of the report is available at the Task Force website at: http://www.health.state.ny.us/nysdoh/taskfce/index.htm ■

—Samuel Gorovitz, Task Force member and Dearing-Daly Professor of Bioethics and Humanities

FAITH AND ETHICS

EDITOR'S NOTE: This new feature highlights religious perspectives on various bioethical issues. Each column addresses the teachings of one particular faith regarding one or more specific questions, in an effort to help clinicians understand the religious beliefs of patients and families. We strive to provide the most accurate information, realizing that members of a given faith often have a variety of beliefs. —*K. Faber-Langendoen*

Q. Why do Jehovah's Witnesses refuse blood? What legal and ethical concerns does this raise?

A. Jehovah's Witnesses believe blood transfusions and the use of blood products is Biblically forbidden: "Only flesh with its soul – its blood you must not eat" (Genesis 9:4). "Keep abstaining from… blood and from things associated with such… (Acts15:29). While these verses are open to other interpretations, Jehovah's Witnesses view them as ruling out transfusion of whole blood, packed red blood cells, platelets, and plasma (albumin, immunoglobulins, and factor preparations are accepted by many Witnesses). They believe acceptance of such products eliminate any hope for eternal life.

Many medical personnel have a difficult time acquiescing to Jehovah's Witnesses' refusal of blood, given our desire to preserve this life. However, our culture also gives great weight to individual freedom, and forcing transfusions is a violation of that freedom. Both bioethicists and lawyers generally agree that a competent adult patient ought not be compelled to receive transfusions over his or her religious objections. Deeply held religious beliefs are to be respected whenever possible. If a competent adult is also a Jehovah's Witness, his or her refusal of transfusion should be honored, as we grant autonomy to make decisions to all competent adults.

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…OUR CULTURE ALSO GIVES GREAT WEIGHT TO INDIVIDUAL FREEDOM, AND FORCING TRANSFUSIONS IS A VIOLATION OF THAT FREEDOM.

Children, however, pose a different concern. The question becomes: should children be put in potentially life-threatening situations when religious beliefs are their parents, and perhaps not yet their own? Courts have said no in several cases. Factors such as age, understanding of decisions, and participation in the faith should be given consideration if a child (or the parents of a child) who is a Jehovah's Witness refuses blood products. As one court explained, a child should not become a martyr for his or her parents' beliefs.

However, from an ethical standpoint, as the child nears the age of majority and articulates his or her own religious views, the adolescent's views should be considered. For example, if a 17-year-old young man who was a full participant in his faith refuses blood products, great moral weight should be given to those beliefs in considering medically necessary transfusions. While the 17-year-old is not legally an adult, a court might be convinced to honor his beliefs and treatment refusal.

The resource, *Family Care and Medical Management for Jehovah's Witnesses,* is available in University Hospital's Chaplains' office. It answers many other questions that could be useful to health care providers about this faith. A Hospital Liaison Committee, comprised of Jehovah's Witness elders and other persons experienced in the Jehovah's Witness faith, can assist clinicians with understanding health care issues from the vantage point of Jehovah's Witnesses. The person to contact for assistance in Syracuse is Mr. John Huckabee, 475-2858. ■

—Father Al Bebel, Kathy Kurtz

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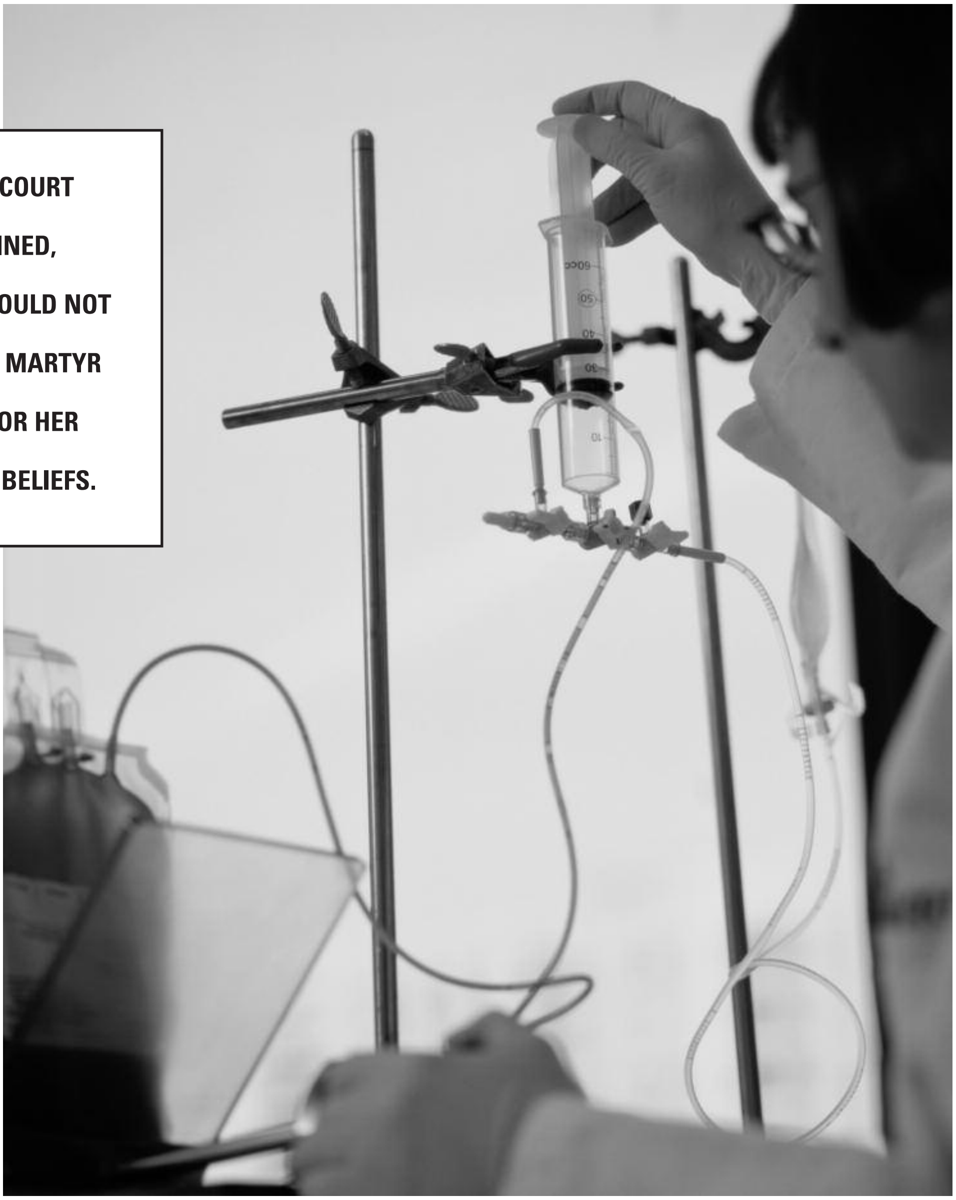
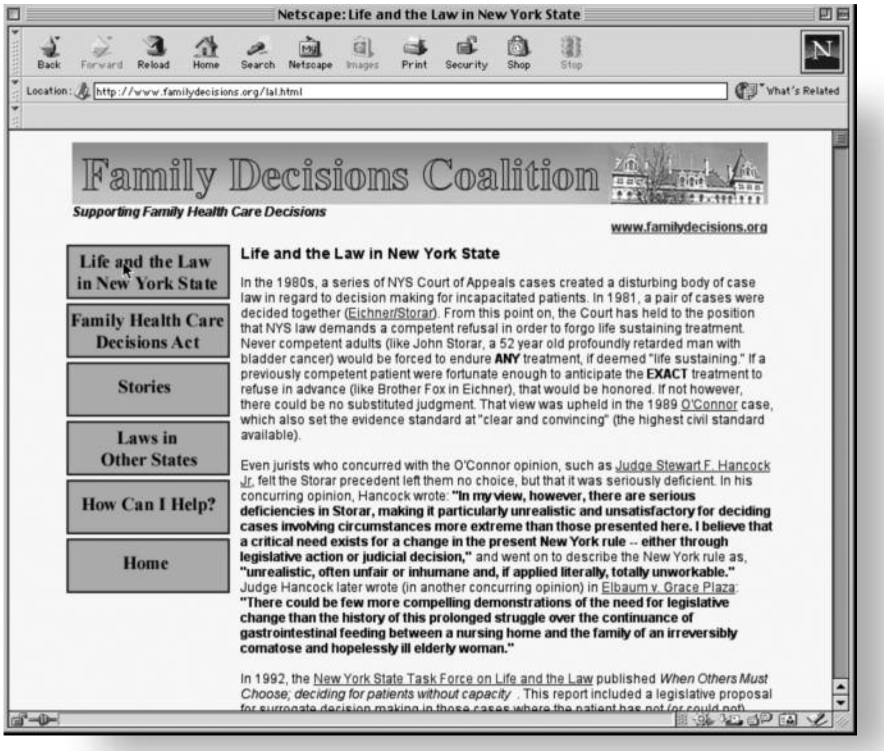


Web Site of the Month

www.familydecisions.org



Life and the Law in New York State

In the 1980s, a series of NYS Court of Appeals cases created a disturbing body of case law in regard to decision making for incapacitated patients. In 1981, a pair of cases were decided together (Eichner/Storar). From this point on, the Court has held to the position that NYS law demands a competent refusal in order to forgo life sustaining treatment. Never competent adults (like John Storar, a 52 year old profoundly retarded man with bladder cancer) would be forced to endure **ANY** treatment, if deemed "life sustaining." If a previously competent patient were fortunate enough to anticipate the **EXACT** treatment to refuse in advance (like Brother Fox in Eichner), that would be honored. If not however, there could be no substituted judgment. That view was upheld in the 1989 O'Connor case, which also set the evidence standard at "clear and convincing" (the highest civil standard available).

Even jurists who concurred with the O'Connor opinion, such as Judge Stewart F. Hancock Jr. felt the Storar precedent left them no choice, but that it was seriously deficient. In his concurring opinion, Hancock wrote: **"In my view, however, there are serious deficiencies in Storar, making it particularly unrealistic and unsatisfactory for deciding cases involving circumstances more extreme than those presented here. I believe that a critical need exists for a change in the present New York rule -- either through legislative action or judicial decision,"** and went on to describe the New York rule as, **"unrealistic, often unfair or inhumane and, if applied literally, totally unworkable."** Judge Hancock later wrote (in another concurring opinion) in Elbaum v. Grace Plaza: **"There could be few more compelling demonstrations of the need for legislative change than the history of this prolonged struggle over the continuance of gastrointestinal feeding between a nursing home and the family of an irreversibly comatose and hopelessly ill elderly woman."**

In 1992, the New York State Task Force on Life and the Law published *When Others Must Choose; deciding for patients without capacity* . This report included a legislative proposal for surrogate decision making in those cases where the patient has not (or could not)

This website explores the limitations on families' legal standing to make health care decisions for loved ones who cannot speak for themselves. Includes case studies, updates on recent legislative initiatives in New York State, and a discussion of the use of artificial nutrition and hydration. ■

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