



Who has the final say regarding a patient's fate?

If a patient's health care proxy does not represent the true wishes of the patient, what can be done?

CASE OF THE MONTH

Miss Cobb* is a 56-year-old with advanced rheumatoid arthritis. Because of her disease, she is in a wheelchair. Three years ago, she appointed her twin sister, Elaine, as her health care proxy. She was admitted to the hospital in severe respiratory distress. *Pneumocystis pneumonia* is diagnosed and antibiotics are begun. Despite this, her condition worsens, and she is placed on mechanical ventilation after two days.

Miss Cobb was employed as a hospice nurse prior to becoming disabled. Fiercely independent and increasingly unhappy about her physical limitations, she moved in with Elaine within the last year because she could no longer maintain her own home.

After a week on the ventilator, Miss Cobb shows no improvement. Now she has a superimposed fungal pneumonia. She is sedated and unresponsive. The critical care attending discusses Miss Cobb's prognosis with Elaine, saying that it is increasingly

unlikely that she will survive. Elaine insists that "everything be done" to save her sister and declines to agree to a DNR order.

The next day, Miss Cobb's brother, Tom, visits and asks to speak with the attending. Since being widowed a year ago, Tom had become quite close to Miss Cobb. He says that they had long discussions about her advancing disease and increasing dependence and he is certain that Miss Cobb would want to be made comfortable and taken off life support. Elaine becomes angry and she insists that, as the health care proxy, it is her decision to make.

QUESTIONS

- What standards should a health care proxy use when making decisions for a patient?
- What accounts for the conflict between Elaine and Tom?
- How should the final decision be made when family members disagree about what the patient would want?

*all names are pseudonyms

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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? We are always happy to talk in confidence about ethical concerns; you may reach us at 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 at the center (Wendy Edwards MD; Kathy Faber-Langendoen MD; and Joel Potash MD).

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Who has the final say regarding a patient's fate?

DISCUSSION

A health care proxy allows patients to designate someone to make medical decisions on their behalf, should they become unable to do so on their own. Health care proxies are supported by law in over 40 states, including New York. As Miss Cobb's health care proxy, Elaine has the responsibility to make health care decisions for her sister.

However, Elaine is not free to make any decision she wants. Her role is to make decisions based on what she knows about Miss Cobb's wishes. Thus, the first question the critical care physician should ask is not "What do you want us to do for your sister?" (or, worse yet, "Do you want us to do everything?"), but "What would your sister want done, if she could speak right now?" Elaine could best answer this question if she and her sister had discussed Miss Cobb's *views and preferences in the past*. Although written evidence of the patient's wishes may be useful, it is not required. Kitchen table discussions about these issues may provide important insights into what the patient would want.

If Elaine and her sister had never discussed these issues directly (and many of us don't, given our reluctance to talk about illness and death), Elaine may still be able to

figure out what her sister would want based on her sister's values, beliefs, and other life choices. This is called *substituted judgment*. Was Miss Cobb someone who always believed she would beat the odds? Was she willing to undergo aggressive medical care in the past? In the face of relentlessly progressive rheumatoid arthritis, did she talk about what gave her life quality?

Did she talk about dying or what made life worth living?

In most situations, the health care proxy makes medical decisions based on the patient's expressed wishes or by extrapolating from the patient's values and

beliefs. Occasionally, this isn't possible. In such cases, the health care proxy should make decisions based on what the proxy believes is in the patient's *best interests*. The proxy should consider the following: the likely benefit from the proposed treatment, the risks of the treatment, the patient's level of comfort with or without the treatment, and whether or not death is imminent regardless.

While Elaine has the legal authority to make health care decisions for Miss Cobb, she has the moral responsibility to make medical decisions based on what is known about what Miss Cobb would want, were she able to speak on her own. In that respect, their brother Tom seems to have

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important information about Miss Cobb's views. How should the nurses and physicians deal with Tom and Elaine's conflicting views?

- First, both Elaine and Tom should be told that the clinicians are looking for insight into what Miss Cobb would want if she could speak, so the family understands the standard for decision making.
- Second, the clinicians should try to facilitate a conversation with Elaine and Tom together, where the physicians can clearly explain Miss Cobb's disease and prognosis and begin a discussion about the realistic goals of care. In this discussion, each should be asked what he or she knows about Miss Cobb's wishes, in order to redirect the discussion from who gets to decide to what is the best decision for the patient.
- Third, the clinicians should thoughtfully consider and explore

whether the input offered by either Elaine or Tom is colored by their own emotional needs, and find ways to address these issues (social workers can be invaluable here).

- Fourth, an ethics consult could be requested. In addition to being able to analyze some of the ethical concerns, consultants are skilled in resolving conflict and may be able to help achieve common understandings.

Unless there is evidence that Elaine is acting contrary to the patient's previously stated wishes, she has the legal and moral responsibility to make Miss Cobb's medical decisions. As a former hospice nurse, Miss Cobb likely had a good understanding of a health care proxy's responsibilities. Furthermore, as someone with a slowly progressive, chronic illness, she had ample time to discuss her wishes with

Elaine or choose a different proxy (such as Tom).

Ideally, a consensus will emerge among Elaine, Tom, and the clinicians as to the best course of action. As a last resort, if the clinicians or Tom feel that there is substantial reason to believe that Elaine is making decisions that go against Miss Cobb's wishes, the courts are the final recourse. Court action is costly, time consuming, and inherently adversarial. It should only be considered when all other options have been exhausted.

—K. Faber-Langendoen



EIGHT IMPORTANT HEALTH CARE PROXY FACTS

1. You don't need a lawyer to complete a health care proxy. A blank form is available online at www.health.state.ny.us/nysdoh/hospital/healthcareproxy/intro.htm or from any University Hospital unit or clinic.
2. Two people must witness the health care proxy form; the person chosen as the health care proxy cannot also be a witness.
3. Health care proxies don't take effect unless you become unable to make your own decisions.
4. You may state your specific treatment wishes on the health care proxy form (e.g., circumstances under which you would be want to be placed on a ventilator), but you don't have to.
5. Your health care proxy cannot refuse a feeding tube for you unless he or she clearly knows this is your desire.
6. Once you can no longer make your own decisions, no one else can appoint a health care proxy for you. It is too late.
7. Copies of the health care proxy form should be given to your primary physician, the hospital where you receive care, your health care proxy, and another person likely to know if you fall ill. Keeping the only copy locked in a file or jammed in a desk is useless.
8. A health care proxy is not the same as a power of attorney. Appointing someone to sign your checks and take care of legal affairs does not give him or her the right to make your health care decisions.

EDITOR'S NOTE: *In this periodic column, we will address specific hospital policies and practices which raise or address ethical issues. If you have a policy you would like addressed, e-mail us at ethics@upstate.edu.*

—K. Faber-Langendoen

The ethics of “Discharge AMA” forms

Nationwide, hospitals have instituted policies regarding discharging against medical advice (“discharge AMA”). There are several reasons for such policies. One, they force patients to recognize the potential for negative outcomes if they do leave against advice, and that alone may cause patients to reconsider; two, such forms may provide a modicum of legal protection for the hospital should the patient suffer a complication after leaving the hospital.

But why do hospitals expect, and in some cases demand, that AMA

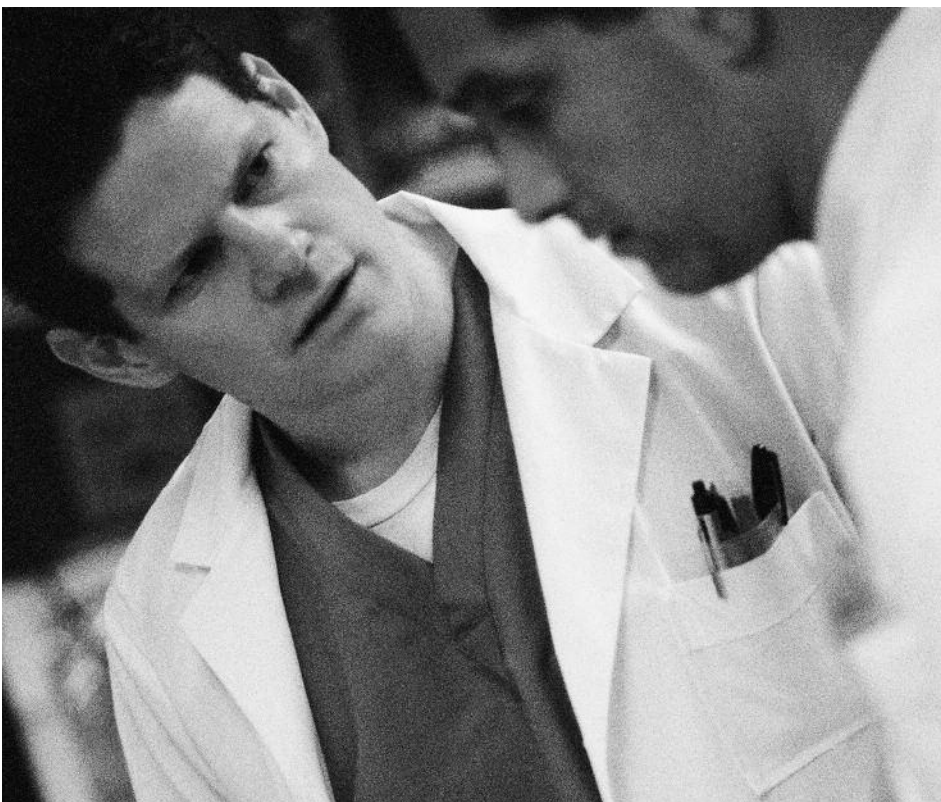
patients sign a release form? In most cases patients enter the hospital on a voluntary basis; why shouldn't they be able to leave in the same way? And why don't we also insist that patients sign a form when they refuse a particular treatment (for instance, chemotherapy)? In fact, we insist that patients sign consent forms for treatment, not for lack of treatment.

Hospitals justifiably do what they can to protect patients from potentially avoidable harm. When a patient leaves AMA, hospital staff are right to be concerned that

patients could fall victim to circumstances of their illnesses or injuries, even suffer fatal consequences, or that they could be mentally incompetent to understand the potential outcomes of their decision. Another concern is that the patient or family member could deny that the patient left the hospital AMA, unless there is a signed form. Even then, however, experience shows that the form doesn't necessarily hold up in court.

It is ultimately the patient's right to refuse further hospital care, just as it is his or her right to consent to a particular treatment. The operative point is this: physicians and hospital staff do not have the right to coerce the patient into signing this form. A competent patient has the right to reject almost any medical treatment, including continued hospitalization; the patient is allowed to leave at any time. While asking patients to sign a “discharge AMA” form may help facilitate discussion of the repercussions of their leaving, patients ought not be coerced to sign the form, and the form should not be used to make the discussion take an adversarial turn. If they sign the form, fine. If they don't, that's their prerogative.

—Melanie Rich



Kissing cousins and genetic risk

A recent issue of *The Journal of Genetic Counseling* contains surprising news: first cousins can have children together without great risk of birth defects or genetic disease. A panel of researchers reviewed six major studies conducted between 1965 and 2000, involving many thousands of births. Although first cousins may be somewhat more likely than unrelated parents to have a child with a serious birth defect, mental retardation or genetic disease, their increased risk only adds 1.7 to 2.8 percentage points to that of the general population's risk.



So, for example, if the general population's risk for having a child with spina bifida or cystic fibrosis is 3 to 4 percent, first cousins would have a 4.7 percent to 6.8 percent risk. Dr. Arno Motulsky, senior author of the report, says even at its worst of 7 percent, this means that "93 percent of the time, nothing is going to happen."

Medical geneticists have known for a long time that there was little harm in cousins marrying and having children, but cultural mores and state laws have had more sway over our behavior. 24 states

forbid first cousins from marrying, but interestingly no country in Europe prohibits this, and in parts of the Middle East, Africa, and Asia such marriages are commonplace.

The guidelines from this report encourage genetic counselors to take a thorough family history as they do for all clients and look for any diseases that might run in the family or ethnic group. No extra genetic tests should be required of cousins who wish to have children together.

While genetic counselors have generally discouraged cousins from marrying, this advice may reflect societal values more than medical risk. Dr. Motulsky said genetic advisers should "give people all the various possibilities and risks and leave it up to them to make a decision. Some people might decide a doubling of the risk is not something they want to face." He also noted that few counselors or others question the right of people with genetic disorders such as Huntington Disease to have children, even though their chance of passing on serious genetic disease greatly exceeds that of cousins.

—based on *The New York Times* report and original article, Deirdre Neilen



Abortion training increases

Abortion training will become a more prominent component of ob/gyn residency training in New York City under a new program backed by Mayor Bloomberg. Previously, abortion training was an elective for Ob-Gyn residents. Now, it will be a planned part of residency training, with an "opt out" provision for residents with moral or religious reasons for not wanting to perform abortions.

The National Abortion and Reproductive Rights Action League praised the decision and agreed with the Mayor's remarks: "These are procedures that are allowed by law, and we're going to make sure that doctors are trained appropriately. You do not want to have second-rate medicine practiced."

The New York State Right-to-Life Committee said it was "horrible" to include abortion as part of mainstream health care. Their spokesperson accused the Health and Hospitals Corporation of "trying to steer the consciences of residents and make it just a normal thing for them to do." Surveys of current residents show that about 90 percent favor including the training in the core curriculum rather than as an elective.

—Deirdre Neilen

The ethics of caring for hospitalized prisoners

All prisoners in New York State and Onondaga County prisons are entitled to medical care. At University Hospital, care is

THE PATIENTS' BILL OF RIGHTS APPLIES TO ALL PATIENTS AT UNIVERSITY HOSPITAL, INCLUDING PRISONERS.

provided to prisoners as both inpatients and outpatients. The inpatient unit for prisoners is a secured, locked unit that opened in 2001, although prisoners may be cared for on other units, such as intensive care. Security is provided for each patient by the state or county.

The patients' Bill of Rights applies to all patients at University Hospital, including prisoners. They have a right to appropriate medical care and information about their conditions. Prisoners must give their own informed consent to treatment. Thus, they may refuse medical testing (including HIV

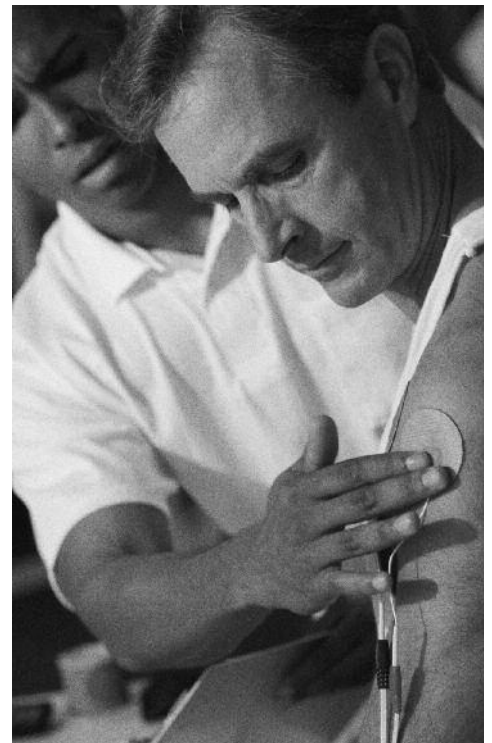
testing) and treatment. Prisoner-patients may sign out of the hospital against medical advice. In such cases, they are returned to prison. Prisoners may not refuse food and fluids to the degree that they cause their own death. In such circumstances, they may be given fluid and nutrition

against their will. Medical information about prisoners is confidential, as it is for all patients of University Hospital. Prisoners may appoint health care proxy agents, who may make decisions for him/her if the prisoner later loses capacity for medical decision-making.

There are some limitations on prisoners' rights as patients in University Hospital. Visitors are limited to immediate adult family members, and hours are limited. Requests to review one's chart or to have copies of it made must go through prison authorities rather

than hospital authorities. An appeals process is available for prisoner-patients who have concerns regarding their rights in the hospital.

—Joel Potash



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These two scenarios remind us that medicine is not an insular profession; rather, the physician's calling is embedded in a larger set of ethical, legal and societal norms. Law, medicine and ethics share commitments to a number of important values at the heart of the physician-patient-family relationship: informed consent,

confidentiality, respect for autonomy, and family authority to decide for incompetent loved ones near the end of life. Often to act ethically is to act legally. At the same time, significant challenges arise when the ethically appropriate response is not clearly supported by—or is contrary to—the law; and when legal compliance

is not synonymous with morally acceptable behavior. Health care professionals whose knowledge base includes familiarity with the connections between ethics and law will be better able to deal with the complex problems faced in health care.

—Robert S. Olick

EDITOR'S NOTE: *This new feature for Bioethics in Brief will focus on the tension between ethics and law in the practice of medicine. Future columns will discuss more fully particular dilemmas at the intersection of ethics, law, and medicine.*

—K. Faber-Langendoen

It's ethical, but is it legal?

CASE 1: *A patient with HIV/AIDS refuses to tell his spouse of his condition. His physician feels morally bound to warn her, but is directed by law to stringently safeguard confidentiality.*

CASE 2: *A physician calls the patient's health plan to complain that its refusal to authorize a longer hospital stay will be harmful to the patient. The health plan remains steadfast, the patient is discharged and subsequently is readmitted for emergency surgery which results in loss of a limb.*

Physicians are increasingly called upon to examine both the ethical and legal dimensions of patient care and to ask, "It's ethical, but is it legal?," or conversely, "It's legal, but is it ethical?" Each question draws our attention to the ways that these two closely related disciplines offer guidance to physicians and other health care professionals.

The patient who refuses to inform his spouse of his HIV-positive status presents the physician with both an ethical and legal dilemma. Most clinicians conclude that the magnitude of potential harm to the wife, together with the possibility of preventing transmission or initiating early testing and intervention, justifies breaching the duty of confidentiality owed the patient, even at the expense of the patient's trust. However, if the state statute

governing HIV/AIDS imposes a strict duty of confidentiality (as it does in some states), "acting on one's ethics" invites legal risk. Furthermore, a physician who does not tell a spouse about a patient's HIV status may risk legal action by the spouse, based on a duty to warn. In short, the physician may well confront a crisis of conscience and conviction. Physicians may be less willing to act on their convictions in the face of the law's command. New York carves out a permission (not a duty) to warn at-risk third parties—sending the message that physicians may notify others at risk if they believe it ethically justified.

The second case of conflict between the physician and insurer travels into new territory where ethics, and to a greater extent law, are relatively undeveloped. Ethical guidelines from the American Medical Association and other professional organizations urge physicians to be vigorous patient advocates in the face of the new demands of managed care. Yet, to follow this advice may run afoul of the health plan's expectations, putting the physician at risk of "retaliation," and raising institutional concerns about who will pay for continued hospitalization. How vigorous must physicians be to satisfy what the law expects? State laws offer only a patchwork of

protections for physicians in managed care contracts, and the law has barely begun to address the bounds of advocacy. How should physicians respond in the face of significant legal uncertainty? To discharge the patient may be legal—if consonant with medical norms at the time of discharge—but there is no clear legal trend to rely upon. The example also opens a window on a larger set of important questions, including the continuing evolution of the patients' rights movement in the laboratory of the states (congressional action is again stalled), and the role of organized medicine in translating ethical norms into legal rules for a changing health care system.

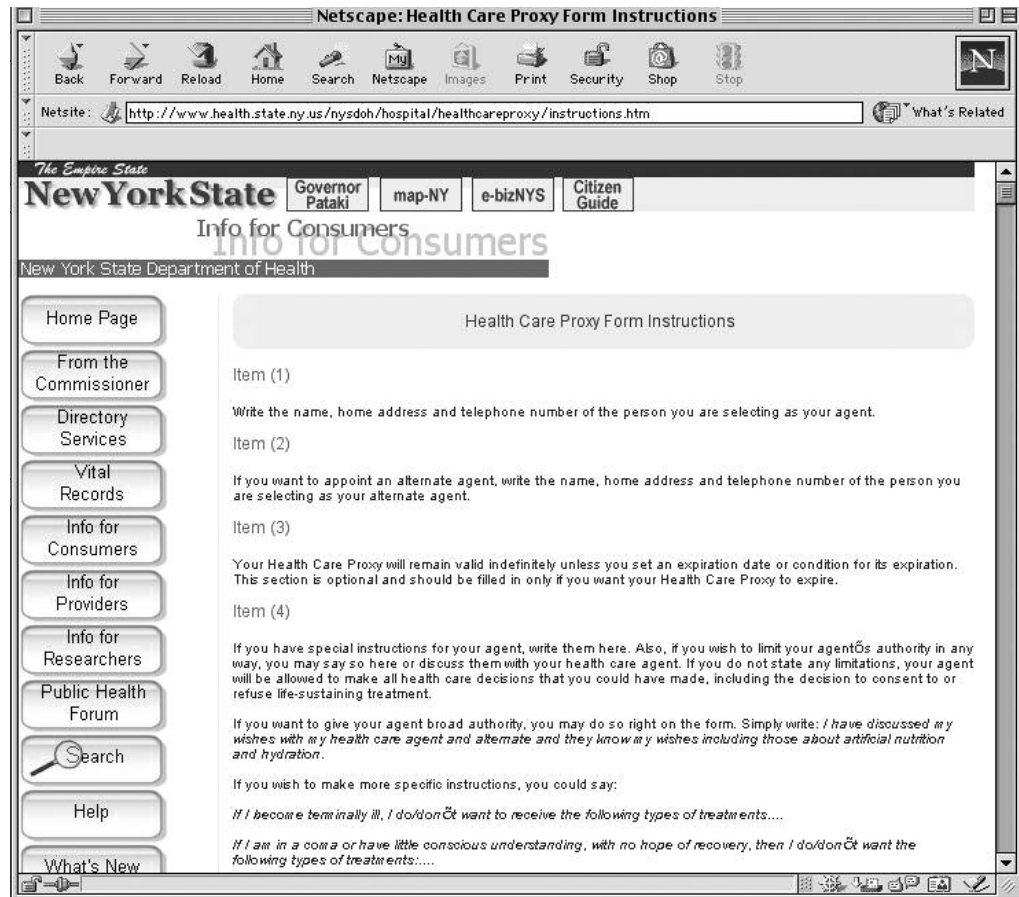
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Web Site of the Month

www.health.state.ny.us/nysdoh/hospital/healthcareproxy/intro.htm

Health care proxy forms can be downloaded from the New York Department of Health's web site (www.health.state.ny.us/nysdoh/hospital/healthcareproxy/intro.htm). The web site also contains useful information about a variety of public health issues. ■



Ethics Committee

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