



“I don’t believe in brain death.”



THE CASE

Mr. Jones, age 52, was admitted with a large bleed into his brain. He was put on ventilator support before surgery, which involved removing blood to release pressure in the brain and repairing the vessel that had bled. After surgery, Mr. Jones remained comatose and dependent on the ventilator for breathing. In addition, he had a rapid heart rate, which concerned his wife. Dr. Wilson, the neurosurgeon, explained that the rapid heart rate was related to further build-up of pressure in Mr. Jones’ brain.

On reexamination, Dr. Wilson noted the absence of brain stem reflexes and suspected brain death. He proceeded with clinical tests to determine death and confirmed that Mr. Jones was brain dead. Mrs. Jones refused to discuss withdrawing the ventilator and insisted that Mr. Jones receive brain surgery to relieve the built-up pressure. “I don’t believe in brain death,” she stated. “Our religion says he’s alive if his heart is beating and he’s breathing. Until it stops, the spirit’s there; it hasn’t left the body.” There was no health care proxy and no do not resuscitate (DNR) order. Dr. Wilson requested an ethics consultation.

THE LEGAL CONTEXT

Throughout the United States, the irreversible loss of all functions of the entire brain, including the brain stem (neurologic death or brain death) is a legal standard for determining death. In 1987 New York became the first state to legally establish a physician’s obligation to reasonably accommodate a patient’s religious or moral objection to the concept of brain death. Department of Health (DOH) regulations mandate that hospitals have written policies for determining brain death. However, the regulations do not spell out what constitutes “reasonable accommodation.” In contrast, New Jersey specifically requires continuing life support until irreversible cessation of heart and lung function occurs, if the patient’s objection to neurologic death is reasonably known.

Pandemic Flu Preparedness and the Problem of Rationing

The fall 2004 flu vaccine shortage, outbreaks of SARS, avian flu and other threats have compelled federal, state and local governments nationwide to develop and update plans to respond to the possibility of *pandemic* flu or mass outbreaks of other contagious agents. Each year flu-related illness causes more than 36,000 deaths and approximately 200,000 hospitalizations in the U.S. alone. If pandemic flu strikes and vaccine supply is limited, morbidity and mortality could far exceed that of the average flu epidemic. Who should be vaccinated when not all can be? Who among those afflicted should be treated when resources are in short supply?

DISTRIBUTIVE FAIRNESS

The call to craft a policy to *ration* the flu vaccine presents a classic problem of distributive justice. On one widely accepted account we should start by affirming equality for all, and strive to treat like cases alike and different cases differently in proportion to their relevant differences. Known as the “formal principle of justice” this starting point does not tell us what differences among persons should count as a basis for deciding who should be vaccinated. We also need a “material principle of justice” that defines

Bioethics *in brief*

ETHICS COMMITTEE

Bioethics in Brief is a newsletter of the Center for Bioethics and Humanities, in cooperation with University Hospital's Ethics Committee.

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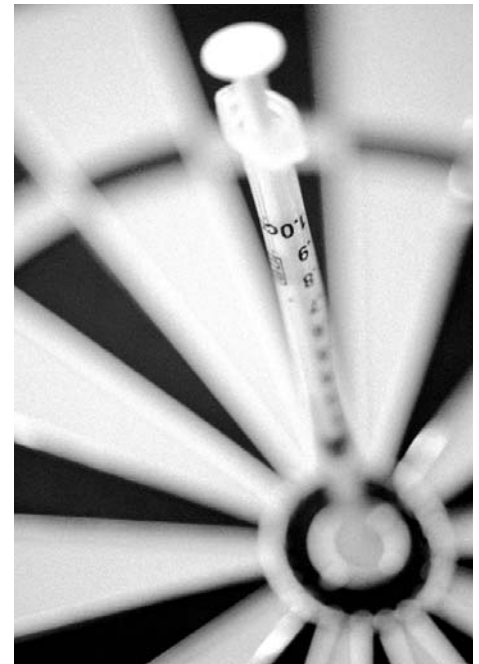


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Vaccine Rationing

what differences among persons count as morally relevant to justify vaccinating some but not others. The same approach can be applied to rationing of other resources in the face of pandemic, such as hospital beds or medical equipment. Identifying *morally relevant* factors that justify differential treatment is the most challenging and potentially controversial ethical problem for any rationing scheme.

CDC's Advisory Committee for Immunization Practices (ACIP) identified risk of infection, risk of serious illness, and risk of spreading infection as the overriding factors to decide who should get the flu vaccine during the 2004-05 shortage. Is this same ranking justified under conditions of pandemic? Giving priority to the elderly, the very young, those with chronic conditions, pregnant women, and healthcare workers was widely embraced as an ethically sound response to the flu epidemic threat of several years ago. But for many the threat of pandemic makes maintenance of the public health infrastructure imperative. Thus, the list of priority groups developed by the DHHS National Vaccine Advisory Committee (NVAC) and the ACIP places vaccine and antiviral manufacturers, and public health emergency response personnel (e.g., persons who manage and monitor pandemic response, vaccinators) in high priority groups, along with healthcare workers with direct patient care, and populations at higher risk for hospitalization and death. The NY State Pandemic Influenza Plan (February 2006) embraces these recommendations, but also notes that the critical issue of priorities in vaccine distribution should be the subject of continuing



discussion. The plan's guidance should be reassessed, and may need to be modified, should a specific pandemic virus with a known epidemiology strike.

The thorny problem of rationing vaccine and antivirals to combat pandemic flu departs in important ways from more familiar discussions of rationing in health care. Access to scarce health care resources, such as organ transplants, frequently includes consideration of such factors as ability to pay, and the fairness of queuing and random selection as methods for ranking groups and individuals. Still the flu preparedness plan's apparent rejection of these factors may be less tidy than it appears. Asking us to pay for our flu shots is rarely even mentioned as a possibility. On the other hand, as in 2004-05, the tasks of implementing distribution and establishing priorities among individuals within high-risk groups, concerns not addressed at the federal and state levels, would again fall to local officials. At the local level the principle of first-come, first-served was frequently invoked for vaccination within particular risk

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Vaccine Rationing

groups, such as public clinics for the elderly; others invoked a lottery system. And some public health officials faced a different sort of (re)allocation question as we went deeper into the flu season: How to transfer delivered supply among providers, even across state lines, to adequately reach underserved high-risk groups and avoid wasting important resources.

BEYOND RATIONING

Other ethical concerns may also emerge. In a flu pandemic who bears (or shares) responsibility for making best efforts to procure additional vaccine, or to create incentives to boost manufacture and supply of vaccine — the federal, state or local authorities? Global scarcity is not always local scarcity. Should supply be moved from lower to higher incidence populations? Or should those further down the priority list (e.g., presently healthy adults under 50) in a better-supplied region be offered vaccine first? What if we had to choose between giving vaccine to the very young or the very old? Finally, an ongoing concern is how closely plans and priorities for pandemic flu anticipate outbreaks of other contagions (such as SARS, other flu strains) or agents of bioterror? Fortunately the flu season of 2004-05 turned out to be far less serious than predicted. Some truly difficult choices did not have to be made. The lessons of the experience have been and will continue to be tremendously instructive as we look to the future.

—Robert S. Olick

Portions of this essay are adapted from Robert S. Olick, "Rationing the Flu Vaccine," *Journal of Health Management, Policy and Practice* II (July/Aug. 2005):373-74.

HOT TOPIC:

The "Ashley" treatment

One of the most recent bioethics cases to receive media attention is that of the "Ashley treatment." A pediatric endocrinologist and bioethicist from Seattle recently published an article in a medical journal detailing this controversial treatment given to a 6-year-old girl who was severely developmentally disabled due to a rare condition, static encephalopathy. Ashley, cared for by her parents at home, is unable to sit, walk, or speak. She does recognize family members, smiles, and vocalizes. Her parents, concerned that Ashley would eventually grow so large that they would be unable to safely move her or physically care for her on their own, asked physicians whether there was a treatment that would stunt her growth.

After considerable discussion and approval of the institution's ethics committee, doctors gave Ashley high-dose estrogen to age her bones quickly and cause them to stop growing. Surgeons removed her uterus (because of parents' concerns about her potential response to having periods) and her breast tissue (to prevent breast development, reportedly because of potential discomfort down the road). Her father explained their experiences and decisions in a web blog; with this treatment, he said, Ashley "can continue to delight in being held in our arms and will be taken on trips more frequently and will have more exposure to activities and social gatherings."

Ashley's parents and physicians maintain that this approach was carried out with Ashley's comfort and best interests in mind, maximizing the possibility that she could remain at home, cared for by her family. Ashley's parents refer to her as their "pillow angel," because she is "sweet" and stays where she is placed (usually on a pillow).

The treatment effectively de-sexualizes and infantilizes Ashley; one pediatric bioethicist, Norman Fost, argued that there is an "aesthetic disconnect" in "profoundly retarded adults," and that this is lessened in Ashley's case by stunting her growth and sexual development. But others argue that this is precisely why the treatment is unethical; infantilizing developmentally disabled people, they counter, is a step backwards in societal acceptance of difference.

Many disability rights groups, including ARC, United Cerebral Palsy, L'Arche, and Not Dead Yet, have condemned the treatment. Others argue that this treatment ought only be offered as part of a research trial, noting that risks are undocumented (e.g., the estrogen could increase risk of blood clots or cause cancers), as is the hoped-for benefit of easing family burden. Still others argue that even consideration of such dramatic treatment belies the inadequate support given to families who care for disabled loved ones at home.

While Ashley's underlying condition is rare, the number of children for whom this treatment might be considered is likely substantial, suggesting that this issue will merit continued reflection by parents, pediatricians, and others interested in the care of disabled individuals.

—K. Faber-Langendoen

Brain Death

ETHICAL CONCERNS

The case raised a number of concerns regarding the wisdom of maintaining ventilator support for a dead patient, as well as the appropriateness of further surgery, since the doctors believed that further treatments would be futile. Mr. Jones' doctors and family clearly reached different conclusions about the goals of care.

Other questions raised by the case include: May the doctor write a DNR order for the brain dead patient, even if the patient's spouse objects? Is it fair, given limited resources, to use an intensive care bed to maintain a person who is legally dead? Is it emotionally harmful to staff to care for a dead patient? If brain dead patients are truly dead, who should pay for continued medical treatment demanded by the family?

REASONABLE ACCOMMODATION OF RELIGIOUS BELIEFS

To respect the patient's autonomy, the doctor should try to learn what Mr. Jones would have wanted. Mr. Jones, however, had left no written instructions. The doctor should consider whether Mrs. Jones' objections to brain death were based on *her* religious beliefs or her husband's. One might also consider whether these beliefs were grounded in an established religion's doctrine or whether they were one person's own perspective. Sometimes patients make claims about religious doctrine that don't actually reflect the official viewpoint of their religion. Consulting with clergy can correct these misconceptions. In other cases, however, patients may willfully deviate from their religion's doctrines while continuing to call themselves and their beliefs "Jewish," "Catholic," "Buddhist," etc. Thus, although most religions recognize neurologic criteria for the determination of death, individual patients may disagree. Abiding by its commitment to patient-centered care, the medical team should assess these beliefs for their sincerity, not for their conformity with established doctrine.

Besides religious objections, opposition to brain death may stem from a family's belief that the loved one, against all odds, will actually recover. The warm body of a brain-dead patient on a ventilator can reinforce this illusion. Although New York's reasonable accommodation clause relates only to religious and moral objections and not to objections based on denial or grief, it may be appropriate to continue supportive care for a short time to allow the family to come to terms with the death.

The medical team should not offer additional tests or operations if a patient has no prospect to benefit.

If the patient is indeed brain-dead, the physician should inform the family of the results and significance of the certifying examinations. Even while preparing to remove intensive care, the medical team should display compassion for the (now dead) patient and the surviving family.

HOSPITAL POLICY

In December 2005, the New York State Department of Health issued a report on certifying brain death and directed all hospitals to review and, if necessary, update their policies.

University Hospital revised its policy to state that families unable to accept brain death should be allowed a "reasonable" amount of time before supportive care is discontinued; the length of time that would be "reasonable" is not defined. The Ethics Committee, Social Services, and Spiritual Care are available to families and to members of the medical team for support in reaching a resolution, as well as to staff who may struggle with caring for a brain-dead patient or who question whether this is a proper use of ICU resources.

—Eli Braun, Joel Potash, Robert S. Olick

**CAN A HOSPITAL
SUBMIT A MEDICAL
BILL FOR CARE OF A
DECEASED PATIENT?**

Should the Government Set the Menu?

Autonomy, Public Health, and Trans Fats

Do you have the right to smoke cigarettes in public or drive without a seat belt? How about a right to eat trans fats? In the case of cigarettes, numerous city and state governments have passed laws mandating that workplaces, restaurants, and bars be smoke-free. The idea is that an individual has every right to make unhealthy choices or lead an unhealthy lifestyle, but not at the expense of others. For similar reasons, SUNY Upstate Medical University has banned smoking from campus and hospital grounds since 2005. While these public health interventions may seem paternalistic and imposing at times, restrictions on personal autonomy are ethically defensible so long as they are necessary to maintain the health of the population.

In December 2006, the New York City Board of Health took a step beyond banning smoking in restaurants and banned trans fats from restaurants as well. Trans fats are created by chemically adding hydrogen to liquid vegetable oils. Unfortunately, trans fats raise an unhealthy form of cholesterol and pose an increased risk of cardiovascular disease. Food manufacturers use trans fats in baked goods, margarine, and salad dressings in order to give these foods a solid texture and long shelf life.

Health advocates praised New York City's ban while restaurant owners criticized it. The restaurant industry contends that the ban could upset the texture and taste of food, thereby driving away customers and cutting profits. Recognizing that it would take time for restaurants to prepare new foods and remove trans fats from their menus, the New York City Board of Health granted restaurants until July 2007, to comply with the ban. At that time, the health department's restaurant inspectors will check the amount of trans fats in the packaging of ingredients, but will not routinely test prepared foods. Violators will face a minimum fine of \$200.

Other critics see the ban on trans fats as "a misguided attempt at social engineering," a move tantamount to "legislating lifestyle." The government, they claim, should work only to make consumers aware of the risks, not to determine what risks individuals may



take. In their view, to ban a food product constitutes an intrusion into free enterprise and personal liberty.

The trans fats ban may seem similar to New York City's ban on smoking in restaurants. But in fact, the trans fats ban is more similar to laws requiring drivers to buckle up. Smoking bans rely on a "prevention of harm to others" strategy, while seat belt laws stem from a more paternalistic motivation: protecting people from their own poor judgments.

It is a time-tested principle of public health that public authorities may limit individual liberties to prevent serious harm to others. This principle justifies automobile speed limits as well as prohibitions on toxic pollutants. But the government's rationale for restricting choices that do not harm others, such as eating trans fats, stands on shakier ground. Nevertheless, New York City's trans fats ban will not be the first time that the government has taken such initiatives. Consider, for example, fluoridation of the water supply or laws requiring motorcyclists to wear helmets. Noting these successful health measures, supporters of the trans fat ban argue that the government has wide authority to curb dangerous lifestyles. It remains an open question, however, just how far the government should go to save us from ourselves.

—Eli Braun

Witnessing Consent

From time to time health care professionals are called upon to witness the patient's or family's consent to a treatment or procedure. What does it mean to sign as a witness to consent? University Hospital's Informed Consent/Refusal policy (C-07) states the following:

- Consent forms must be signed by a witness.
- Witnesses attest that the patient or authorized decision maker is the person who signed the consent.
- Any of the following individuals may serve as a witness: house staff, medical student, nurse, family member, or other hospital staff.
- The health care practitioner who obtains consent may not serve as a witness.
- These requirements apply to both written consent forms and verbal consent that is documented in the medical record, and to less common documentation of consent given by telephone, fax or other means (such as eye blinking).
- When consent is obtained by telephone the witness must listen in on the conversation and document the time and nature of the consent given.

Provisions for witnessing consent also appear in other UH policies, including those governing DNR orders and end-of-life decisions, but neither of these policies sets forth the requirements in the detail found in the consent policy. Other instances of witnessing arise with respect to the execution of a health care proxy and the MOLST (Medical Orders for Life-Sustaining Treatment) form. Each should be read carefully. The health care proxy contains somewhat broader language that calls on witnesses to attest that the individual signed the document willingly and free of duress.

It bears emphasis that in the above situations witnesses serve a narrow function: they attest that those giving consent are who they say they are, and sometimes (with the health care proxy) that they give their consent freely. When you witness a signature you are not attesting that an appropriate



consent process has occurred, nor that the patient's consent was *informed*. Occasionally health care professionals asked to serve as witnesses may have concerns about the nature of the consent process; for example when the patient has questionable decisional capacity

or there is disquiet regarding the appearance of family pressure or conflict. Being mindful of the narrow legal role of the witness may offer some comfort, but it does not obviate the ethical issues raised by such concerns. Before signing on

the witness line health care professionals should consider further discussion with the health care team. Unresolved disagreement may warrant a call for an ethics consult.

CONCERN MAY ARISE WHEN
"... THE PATIENT HAS QUESTIONABLE DECISIONAL CAPACITY OR THERE IS DISQUIET REGARDING THE APPEARANCE OF FAMILY PRESSURE OR CONFLICT."

Nursing: In Need of a Core Identity?

Nurses comprise the largest profession in the field of healthcare, numbering 2.6 million in the United States. It would seem logical that nurses would have a powerful voice in decisions about the delivery of healthcare, yet nursing representation is often absent in the decision making process. Nurses often complain that they are inadequately represented at the leadership level, where important decisions that affect health care delivery are being made.

LACK OF UNITED FRONT

One of the reasons for this is the profession's lack of a uniform, singular program of entry. Unlike physicians, nurses receive basic nursing education from three different types of programs: an RN diploma school, an associate's degree from a community college, or a baccalaureate BSN. Any one of these allows the graduate to take the licensing exam and begin a career in nursing. This variety means nurses enter the profession with various levels of education, perspective, and expectation, and some feel this fragmentation within nursing has kept a powerful, united nursing voice from rising.

The nursing profession has resisted upgrading education for entry into practice as other professions have done even as health care has become increasingly complex. Individual nurses tend to choose sides on

this issue based on their own circumstances. The inability to establish a single minimum level of education for entry into nursing has often meant that nursing is not seen by other health care professions as a fully credible profession.

BSN: ENTRY LEVEL

Many health care experts both inside and outside of nursing now advocate for the baccalaureate degree in

nursing as the entry level as the best way to increase the "professionalization" of nursing. It is difficult to employ nurses from the varying educational programs interchangeably and expect the same level of expertise. Proponents of the initiative to raise the educational

requirement point to other health care professions such as physicians, social workers, pharmacists, physical therapists, and dieticians, professions which all require a bachelor's degree at a minimum.

Currently only about 30 percent of new nurses have a bachelor's degree, but because many nurses, once in practice, realize the importance of further education, about 25 percent of those who enter nursing with an associate's degree eventually complete a baccalaureate degree. That the technical part of training plays an important role in patient care is undeniable, but increasingly professionalism demands knowledge of psychology, sociology, and the liberal arts as preparation for nursing practice.

ADVANCED SKILLS REQUIRED

Patient education, health promotion, and utilization of evidence-based practice are increasingly part of the nurse's job, and they require advanced skills. The complexity of modern nursing practice and the demands of highly technical care also demand critical thinking, a strong scientific knowledge combined with ability to integrate research and clinical practice, as well as leadership and managerial skills to coordinate care for patients and communication between patients and physicians. An expanded knowledge base can prepare nurses who are more likely to demonstrate higher levels of problem-solving, to have better interpersonal communication skills, and to perform the complex functions so necessary in today's health care environment.

The current proposal by the New York State Board for Nursing would require future nurses to obtain a bachelor's degree within 10 years of graduation from a nursing associate degree or diploma program; it does not affect current registered nurses. The proposal would not eliminate either the diploma or associate's degree education programs. Is this finally a plan for nursing entry into practice that will benefit the profession and provide improved care for patients? Will individual nurses unite behind it? In a future issue of the newsletter, we'll examine some of the ethical issues raised by this tiered-education profession.

—Barb Fero

A new feature of this newsletter offers excerpts from Upstate's latest issue of *The Healing Muse* published by the Center for Bioethics and Humanities. These pieces speak to the ongoing and dynamic relationship between medicine and ethics.



Even In Summer, Fibromyalgia

—Laurie Suzanne Lessen-Reiche

I don't know what to say
about the body and muscles
that give way, the nerves turned to fire
in my feet and hands, how the knees
scream with the indecency
of bones bent in pain.

This is an August night with my body:

pelvic bone throbbing
like a little caught fish, mouth
opening and closing in disbelief,
and the small broken voice of my heart
crying at all these failures;
a skewer of lightning shooting

in one ear and out the other, neck
not a flower's stem but wrecked
barbed-wire, intestines writhing
like underfed serpents, the ghost
of my colon trapped inside the abyss
of my hips.

This too is August, deep summer:

evening under aching stars,
another end of a day like all others,
and the dark silence
behind my closed lids
saying all that's left to say.

Laurie Suzanne Lessen-Reiche, a widely published poet living in Petaluma, CA, is the recent winner of *Lilith Magazine's* 2006 Charlotte Newberger Award for Poetry.

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