



CASE OF THE MONTH

Determining Patient Capacity For Making Medical Decisions

Mrs. Camel* is a 45 year-old woman admitted to the hospital with pneumonia and a large mediastinal mass, diagnosed as inoperable lung cancer. She is a heavy smoker and drinker and experienced a 20 pound weight loss and progressive weakness over the last 6 months. Palliative radiation therapy is recommended to prevent post-obstructive pneumonia and to improve breathing. A stomach feeding tube (PEG) is recommended because swallowing difficulties may arise from radiation treatments. Mrs. Camel denies that she has cancer and refuses further workup and treatment. She is confused and agitated and has to be restrained at times. Her confusion and agitation may be dementia or delirium related to alcohol abuse or brain metastases. During a lucid period, she appoints her husband of 20 years as her health care proxy.

A psychiatric consultation is called to evaluate the patient's capacity. Mrs. Camel refuses to talk with the psychiatrist but is found to be incompetent based on history and behavior. The patient's proxy verbally consents to placement of a PEG tube and radiation treatment, but the patient refuses both of these. An ethics consultant is called and meets with the patient, her husband, and the oncology resident. The ethics consultant believes that the patient has the capacity to make medical decisions and understands that she is dying from lung cancer, but in the role of ethics consultant does not make a formal determination in the chart. The patient states that she will accept radiation treatment, but she is uncertain about a PEG tube placement. On the following day the patient is again agitated and delusional. The patient's husband is asked to sign a permit for PEG tube placement, which he does.



WHAT IS THE DIFFERENCE BETWEEN INCOMPETENCE AND INCAPACITY?

Many use these terms interchangeably. Incompetence is a legal determination by a judge that a person is unable to take care of him/herself. Typically a broad-based determination, a person who is incompetent loses a range of legal rights, such as the right to vote or hold a driver's license. Decisional incapacity describes the inability to understand and reason about information relevant to a

Bioethics in Brief is a newsletter of the Center for Bioethics and Humanities, in cooperation with University Hospital's Ethics Committee. 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. Information about sources used in the newsletter can be obtained by calling the Center for Bioethics and Humanities, 464-8463.

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 (Robert Daly MD; Kathy Faber-Langendoen MD, Robert S. Olick JD, PhD; and Joel Potash MD).

© 2004 Center for Bioethics and Humanities. Permission is granted to make up to 20 copies for institutional use.

Editorial Board

Editor-in-chief: Deirdre Neilen PhD
Managing Editor: Robert S. Olick JD, PhD
Consultant: Kathy Faber-Langendoen MD
Writers: Barbara Fero RN, NP; Melissa Freeman MA; Joel Potash, MD
Design and production: Marketing and University Communications, Melanie Rich, Director

The Center for Bioethics and Humanities at SUNY Upstate Medical University, established through the generous support of the Medical Alumni Association, is committed to promoting clinical health care and health policy which is patient-centered, compassionate, and just. We accomplish this through educational initiatives in bioethics and the medical humanities, clinical ethics consultation, and multidisciplinary research and scholarly writing.

—continued from page 1

decision, such as a medical decision, and may be based on immaturity (children), developmental disabilities, or illnesses such as dementia, psychosis, or brain impairment from tumor or infection. Determinations of incapacity usually are decision specific: “Should we allow this person to make this decision at this time?”

Often physicians suspect a lack of capacity when the patient refuses a recommended treatment known to benefit the patient. What if Mrs. Camel had consented to all recommended tests and treatments? Perhaps neither a psychiatric nor an ethics consultation would have been requested. But physicians should be as wary of a consent for treatment as they are of treatment refusal when patients cannot understand information or reason about their choices. Capacity is not necessarily reflected by what is rational to the clinician. Patients should not necessarily be judged to lack capacity merely because they are minors, very old, in severe pain, or on medications such as narcotics or sedatives.

WHY IS IT IMPORTANT TO SEARCH FOR AND PROMOTE CAPACITY?

We ought to recognize an autonomous patient's right to refuse treatment, if it is informed. We should respect the uniqueness of each person, and demonstrate this by seeking their participation in decision-making and honoring their wishes. If a patient lacks the

capacity to collaborate in decision-making, we should look for any window of opportunity where capacity shines through. One such opportunity may have been Mrs. Camel's conversation with the ethics consultant, even though previous and subsequent interviews with the psychiatrist demonstrated “incompetence.” Sometimes treatments such as radiation therapy or placement of a PEG tube may have to be delayed while narcotics are cut back or psychotropic medications are started in hopes of restoring capacity. Mrs. Camel may have capacity to consent to an IV, but may not be able to adequately understand more complex choices about radiation therapy or PEG tube placement.

HOW DOES ONE GO ABOUT DETERMINING CAPACITY?

First we should see if the patient has made a choice: look for consent or denial. Is there a reasonable outcome of choice? How likely is it that a feeding tube would benefit Mrs. Camel, given her poor overall condition and fatal illness? Does radiation therapy have clear palliative goals, or is it “grasping at straws” to prolong life? Can the patient give a rationale for her choice? Mrs. Camel felt that if she was dying, she mostly wanted to avoid terrible suffering. When told that radiation might do this, she agreed to try it. However, a comfort care plan might have accomplished the same end by consultation with the palliative care service. Her refusal

of the PEG tube may have been reasonable, if she weren't interested in prolonging her life or if she rejected the technology that such an intervention requires. Does the patient understand her situation and planned treatments, and to what degree? Perhaps high benefit and low risk treatment such as IVs or antibiotics require less understanding than lower benefit, higher risk treatments, such as radiation therapy, in this case.

WHO CAN DETERMINE CAPACITY?

A psychiatric consultation is often called when there is a need to assess a patient's capacity. However, the second opinion of any physician may be sought if the necessary time is allowed to meet with the patient to assess the patient's individual abilities, the requirement of the task at hand, and the patient's understanding of the consequences of the decision. In most situations, determining capacity is a common-sense judgment, made by the treating physician. Psychiatrists are particularly helpful when lack of capacity may be due to psychiatric disorders.

MAY A PROXY OVERRIDE THE PRIOR WISHES OF A PATIENT WHO LACKS CAPACITY?

The role of a proxy is first, to carry out the patient's wishes if they are known and second, to seek the patient's best interests if the patient has not clearly expressed her wishes. Mr. Camel should have been instructed about his responsibilities as the patient's proxy. An ethical dilemma exists when the proxy wishes the patient to undergo treatment (which may be life-saving) that the patient rejected when she

"CAPACITY IS NOT NECESSARILY REFLECTED BY WHAT IS RATIONAL TO THE CLINICIAN..."

had capacity. If the proxy knows anything about the patient's values and life choices, these should be weighed in decision-making, to reflect what the patient might choose. Mr. Camel heard his wife say no to a PEG tube placement when she had capacity to make an informed refusal. As a legally appointed proxy, he should carry out his wife's wishes. ■

—Joel Potash

Bodies for Sale

People who will their bodies to science do so in the belief the body will be used in either the education of medical students or in research and will always be treated with respect. A recent scandal at UCLA's medical school, however, reveals the existence of a shadowy world that deals in sawing corpses and selling body parts to middlemen who in turn sell them for use in medical research, such as orthopedic knee reconstruction, or in various surgical training seminars.

UCLA immediately suspended its Willed Body Program and arrested the program's director and the middleman who picked up and transported cadavers from the university reportedly to as many as 100 research institutions and private companies. The university denies his allegations that they had full knowledge of what he was doing.

The facts behind this ghoulish trafficking bear an unsettling resemblance to Frankenstein stories: people waiting until nightfall to appear at morgues and crematories and university labs; money exchanging hands, and corpses taken away for destinations their "owners" and loved ones never would have imagined or condoned. Yet the use of cadaver body parts in research without the consent of the

—continued on page 7

Botox

When does a medicine make some physicians uncomfortable about its use? In the case of botulin toxin A (Botox), one of the world's deadliest poisons, it begins when non-therapeutic use of the drug highlights the inequities in the American medical system.

By now, the miraculous effects of Botox are common knowledge: smooth skin, disappearing wrinkles, years seemingly stripped away. Less known, however, are Botox's benefits with movement disorders such as multiple sclerosis or epilepsy and the troubling fact that if patients are uninsured or underinsured they cannot get access to this drug. Thus, physicians like Michael Chancellor MD, professor of urology and gynecology at the University of Pittsburgh School of Medicine, who is researching the drug's use as a treatment for overactive bladder conditions, have sounded a note of caution:

"I take care of a 45-year-old woman with MS who can't urinate because of nerve damage. If I inject Botox she won't have to use a bag. But because she's not wealthy and on Medicare she can't get it. It upsets me that someone who's 35 but wants to look 25 can get it because they have the money."

Another aspect troubling some health professionals is the phenomenon called the Botox party: 15 or more people gather



for cocktails, hors d'oeuvres, and a 'shot' of Botox. Questions abound regarding hygiene, safety, and what John Grossman, MD, a plastic surgeon from Beverly Hills, calls the "trivialization of aesthetic medicine." Other medical professionals disagree. As long as the person doing the injections is a licensed physician, where the injections occur (in a home or in a physician's office) should not cause alarm.

Between 1997 and 2003, the number of Botox injections rose from 65,000 to over 2.2 million, a 30 fold increase. With numbers like these, manufacturer Allergan, Inc., is only too happy to pump up advertising to convince more baby boomers to believe a wrinkle-free face is a happy face. In September

2001, however, the FDA told Allergan that its ads were misleading and ordered them to pull the ads because they did not indicate that the drug's effects are temporary and that its cosmetic use is approved only for people between 18 and 65 years of age. Allergan appealed that order. However, again in 2003, the FDA warned Allergan, stating that their advertisements were misleading consumers and violating federal law.

In summer of 2002, Johns Hopkins Medical School changed its institutional policy in response to criticism of a planned campus seminar on Botox that promised a live demonstration and on-the-spot treatments with the toxin. Critics had called the seminar "a Botox party" unworthy of a reputable academic institution. Nonetheless, manufacturers continue to employ surgeons as "Botox instructors" to lead informational sessions (at a hotel ballroom) where interested people can see a live demonstration and sign up for their own treatments thereafter.

Once again, science and medicine are at the forefront of a new technology. Ironically, its success depends upon convincing patients that another natural (however unappealing) aspect of aging is to be recognized as a "medical disorder." If you have the money, that is. ■

—Deirdre Neilen

NURSING ETHICS:

When the nurse's values are at odds with the physician's values

Q. A patient under my care was not being told his diagnosis of cancer because the family persuaded the attending that the patient "couldn't handle" the information. I disagreed. What should I have done?

A. A common issue in the nursing profession is the perception by many nurses that basic nursing values sometimes conflict with the rapidly evolving health care system. For example, when nurses, acting as advocates for patients, question or disagree with physicians, they may be accused of not following doctor's orders. If required to adhere to policies or procedures instituted by an employer to improve efficiency and cut costs, nurses may fear negative effects on their patients, yet they are reluctant or constricted from taking action. The competing values of advocacy for patients and loyalty to coworkers and employers, as well as personal integrity, may cause frustration. That feeling of powerlessness, of being caught in an uncomfortable predicament with conflicting loyalties is known as moral distress. Moral distress arises when a nurse knows the morally correct action and feels a responsibility to the patient, but institutional or other constraints

make it nearly impossible to follow through with appropriate action.

The ethical obligation of each nurse is always to each patient in the nurse's care. Good nursing care involves more than clinical competency and knowledge of technological advances and techniques; it is the concern for the well-being of every patient, based on respect for patient rights.

"THE ETHICAL OBLIGATION OF EACH NURSE IS ALWAYS TO EACH PATIENT IN THE NURSE'S CARE."

if and when there are conflicting loyalties, the rights of the patient and the nursing obligation to protect those rights are primary. The nurse must recognize that the



obligation to ensure that the patient can make a fully informed decision about health care takes precedence over competing obligations to the physician and to the hospital itself.

Unresolved or ongoing situations that compromise nursing values and cause moral

distress for nurses often lead to decreased morale and burnout. Moral distress can undermine personal integrity if it is easier for the nurse to comply rather than pursue the best outcome for patients. When a nurse faces conflicting obligations, the goal for the nurse is to resolve the conflict in such a way that the patient's best interest is served. Updated versions of the basic tenets of nursing practice listed in the Ethical Code for Nurses emphasize not only the traditional responsibility to each patient's needs but also the role that nurses and nursing play in the health care community. Nurses must be vigilant to protect the patient, the public, and the nursing profession from harm. ■

—Barbara Fero

Hospital Policy Watch

NON-PARTICIPATION IN PATIENT CARE: BALANCING STAFF RIGHTS WITH PATIENT RIGHTS

What happens when a health professional's religious beliefs or moral convictions clash with the patient's request or need for a certain procedure, such as an abortion, a vasectomy, a circumcision, or organ donation? University Hospital has established policies designed to respect the patient's wishes while acknowledging a staff member's right not to participate.

The hospital's policy considers three key components to the exercise of professional conscience:

1. the patient's care and treatment will not be adversely affected;
2. the staff member's beliefs must be sincerely held;
3. the hospital has been notified prior to the onset of an actual clinical situation.

Other factors, such as whether the employee has participated in the same or similar procedures in the past are considered as well.

PRIOR NOTIFICATION

In general, a staff member wanting not to participate in a procedure or treatment based on moral or religious grounds must notify the appropriate supervisor or administrator, in writing, at the earliest possible moment (e.g., upon employment or reassignment or

when the professional's conflict first becomes evident). The administrator will then consult with employee relations and others to determine the validity of the request and any potential negative impact on patient care, *which is the primary determining factor.*

A written decision will be made within 48 hours, but a request will not be granted if it is determined that it may negatively affect patient care or treatment. The employee has the right to seek a predetermination by submitting a written request to the chief operating officer or medical director. In the meantime, staff members must provide the required care and will face disciplinary action if they refuse, which could include reassignment, loss of privileges, or termination. The hospital policy does not allow employees and medical staff members to refuse to treat patients based on ethnicity, religion, age, disability, gender, or sexual orientation.

In some situations, a particular treatment may precipitate an unanticipated conflict. In these cases, the employee or medical staff member must notify his or her supervisor immediately. An attempt will be made to find alternative arrangements, but in the meantime, the individual must



provide the required patient care. It may turn out that reasonable alternative arrangements cannot be made, e.g., for reasons of limited staffing, in which case the employee must participate or face disciplinary action. As soon as possible following the case in question, the employee must submit in writing his or her request for non-participation.

PREGNANCY TERMINATION

Staff members are expected to participate in procedures which are medically necessary for patients who have miscarried. Staff are not required to directly participate in an induced abortion, regardless of the reason for the abortion, as long as staff have notified the hospital, in writing, of their unwillingness to participate. In all cases, however, staff are expected to participate as usual in preparing the OR suite, admitting the patient, providing pre-procedure as well as post-op and post-delivery care, cleaning equipment and room and providing follow up patient care. ■

—Melanie Rich

New Guardianship Law Benefits Some Patients/Families, Leaves Others at Sea

In September 2002, New York enacted the “Health Care Decisions Act for Persons with Mental Retardation” (HCDAPMR). The new law, which took effect in March, 2003, establishes a procedure for appointment of a guardian to make health care decisions in the best interests of a person who is unable to make his or her own decisions due to mental retardation. As defined in the mental hygiene law, mental retardation means “subaverage intellectual functioning which originates during the developmental period and is associated with impairment in adaptive behavior.”

Under the HCDAPMR, court-appointed guardians may be given authority to make decisions to forego life-sustaining treatment in the best interests of the patient and based on the patient’s wishes, including moral and religious beliefs, to the extent reasonably known or ascertainable. The law establishes a process for determining that the patient lacks decisional capacity and for making decisions in consultation with the attending physician, relying on courts to resolve disputes that arise between families, guardians and health care professionals.

The HCDAPMR fills an important void. Guardians (often, but not always family members) and surrogate decision-making panels have for many years made various health care decisions on behalf of mentally retarded patients, but have not had authority to stop or refuse life-sustaining treatment, including feeding tubes.

The HCDAPMR does not, however, protect the majority of incompetent, seriously ill and dying patients in New York — those whose current mental incapacity is due to the assaults of illness or injury. For this much larger group of patients, New York law allows families to stop life-sustaining treatment only if there is a formal proxy appointment, if the decision concerns a do-not-resuscitate order, or if families can show “clear and convincing evidence” of the patient’s wishes — a difficult standard to meet. This often means that loving families at the bedside cannot direct withholding or withdrawing of life-sustaining treatment, even when they know their spouse or parent would want to be allowed to die comfortably without aggressive interventions.

For more than 10 years New York has struggled to enact The Family Health Care Decisions Act (FHCDA), a comprehensive approach to end-of-life decisions for incompetent patients without health care proxies that would

establish clear legal authority for families to make these (and other) decisions in consultation with physicians, in accordance with the patient’s wishes and best interests, and with appropriate procedures and safeguards. The FHCDA would also recognize guardianship appointments for patients without close and caring family who face decisions near the end of life. The FHCDA, first proposed by the New York State Task Force on Life and the Law in 1992, is currently pending before the New York Legislature. Enactment of the FHCDA would recognize the proper role of families at the bedside of their dying loved ones. ■

—Robert S. Olick

Bodies for Sale — *continued from page 3*

deceased or family appears to be both widespread and profitable. Reports of scandal such as occurred at UCLA are rare, but may spur legislative interest in this largely unregulated arena.

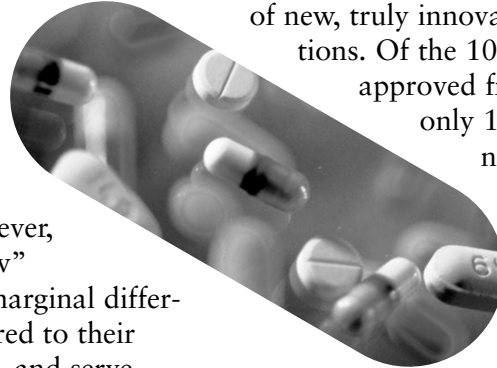
The UCLA story damages the tradition of anatomical gift-giving. It also creates opportunities for all medical schools to examine their treatment of these important gifts and for the public to be more aware of the potential for abuse. ■

—Deirdre Neilen

Variations On A Theme

The National Institute of Health Care Management has reported changing patterns of pharmaceutical drug innovations from 1989-2000. Their results showed a disturbing influx of “incrementally modified drugs (IMDs),” accounting for two thirds of the drugs approved by the Federal Drug Administration. IMDs are line extensions or variations of approved products containing the same active ingredient. For example, manufacturers make changes in routes of administration or dosage forms under the heading “new formulations”; one example is the new once-weekly form of Prozac.

What does this mean for the consumer? Drug alterations can make the original medications safer, more effective, or more convenient. Additionally, drug companies have combined active ingredients to provide a single new product. However, many of these “new” medications have marginal differences when compared to their parent medications, and serve primarily to continue the manufacturer’s profit margin, when the parent drug is about to lose patent protection. Such marketing efforts, when successful, place further strain on the health care dollar, as real needs continue to be unmet.



In addition, some are concerned that drug companies will focus their resources on modifying their old drugs and decrease production of new, truly innovative medications. Of the 1035 drugs approved from 1989-2000, only 15% contained new active ingredients and provided better results than current therapies.

Consumer, beware! Your new pill may not be as innovative as you thought. ■

—Melissa Freeman



Center for Bioethics and Humanities
750 East Adams Street
Syracuse, New York 13210