

Bioethics *in brief*



May 2009

SUNY UPSTATE MEDICAL UNIVERSITY • CENTER FOR BIOETHICS AND HUMANITIES

SYRACUSE, NEW YORK



When May Parents Say “No”?

We asked three of our Center faculty to look at some recent cases involving parents’ refusal or unwillingness to seek medical treatment for their sick children. We were interested in learning more about the intersection of law and medicine, and the ethical dimensions of autonomy and beneficence when minors are involved. We present the cases first, follow with a general overview, and then conclude with the panel’s discussion.

Discussion with Amy Campbell, Tom Curran, and Joel Potash.

CASE I When Faith Supercedes Medicine

Kara Neumann, 11, was dead on arrival at a Wisconsin hospital, due to ketoacidosis from undiagnosed juvenile diabetes (*New York Times*, January 21, 2009, “Trials for Parents Who Chose Faith Over Medicine”). Kara was progressively ill at home, and on the day before she died could not walk or speak. A relative

finally called an ambulance. Her parents were followers of an online faith outreach group, Unleavened Bread Ministries, which calls for healing by faith. David Eels, who runs the ministry, is quoted as saying: “Jesus never sent anyone to a doctor or a hospital.”

CASE II When Religion Forbids

Pediatrician Dr. Ryan calls County General, the tertiary referral hospital, about a 36 hour old newborn under his care at a small, rural hospital. He explains that baby William Rubin was born yesterday to a loving family after an uncomplicated full-term pregnancy. William is the Rubin’s third child, and Dr. Ryan takes care of his two healthy older siblings. While making patient rounds this morning, Dr. Ryan noted that William was jaundiced and ordered a bilirubin level. He was quite surprised to discover that the bilirubin level was 21, with the normal level being <10.

Further testing revealed that Mrs. Rubin has type O blood; William’s blood is type A and shows evidence of maternal antibodies that are destroying

his red blood cells, raising the bilirubin. Dr. Ryan has already started phototherapy but believes that an exchange transfusion, a therapy only provided at the regional center County General, will ultimately be needed. He has talked to the Rubins and explained that left untreated, the high level of bilirubin will likely lead to permanent brain damage.

Although the Rubins appreciate Dr. Ryan’s medical advice, they refuse transport to County General. They remind Dr. Ryan that, as Jehovah’s Witnesses, they reject blood transfusions based on their interpretation of the Bible. They believe allowing William to receive blood transfusions could eliminate any hope for his eternal life.

CASE III Taking a Holistic Approach

Jessica is a 3-year old brought to the hospital by her parents with headache, vomiting, and loss of balance. An MRI reveals a mass; biopsy shows an aggressive brain tumor, a high-grade ependymoma. The pediatric oncologist, working with other physicians, recommends standard care, which is a combination of neurosurgery, radiation therapy, and chemotherapy. Given the difficult location of the tumor, she has a low likelihood of complete resection of the tumor in surgery, leaving her a 5-year survival rate of 25 percent.

Jessica’s parents favor holistic, natural approaches to care. However, they are not against all traditional treatment. Jessica’s pediatric oncologist

sits down with her parents. They are open to surgery only, without radiation therapy or chemotherapy — which they see as toxic — but are told that is not an option. So, given the extent of treatment, possible side effects, and what the parents see as poor odds for long-term survival, Jessica’s parents tell the physician they want to take her home to die peacefully.

The neurosurgeon and Jessica’s primary nurse are concerned that the parents are making the decision too quickly, and letting Jessica die. However, the oncologist feels the parents should be able to make the decision, viewing the available treatment as offering only a “marginal benefit.”

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CENTER FOR BIOETHICS AND HUMANITIES

Bioethics in Brief is a newsletter of the Center for Bioethics and Humanities.

Questions, suggestions, or comments?
Would you like to be added to our mailing list?
E-mail us at cbh@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 315-464-5404. Ethics consultations are available by calling the hospital operator (315-464-5540) and asking for the ethics consultant on call, or by contacting any of the ethics consultants at the Center (Catherine V. Caldicott MD; Robert Daly MD; James Dwyer PhD; Kathy Faber-Langendoen MD; Robert S. Olick JD, PhD; and Joel Potash MD).

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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.

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The Analysis:

GENERAL PRINCIPLES:

Adults who have the capacity to make decisions may do so based on a variety of beliefs---in religion, in holistic approaches to health, in philosophical understandings of what's essential, in science's ability to overcome disease---and they have both the ethical and legal right to refuse medical care, even if doing so leads to their death.

Parents also have broad discretion to raise and make a variety of decisions for their children. Parents can choose what school to send their children to or to home-school their children (although they may not refuse to educate their children at all). Parents are given broad discretion to determine a child's diet and how the child spends his or her time. They also are empowered to make health care decisions for their children, based on the parents' understanding of the child's best interests.

This parental authority, however, is not absolute, and refusing medical interventions has repercussions. For example, parents may refuse immunizations for their children, but the children may not then be allowed to enter public schools or enrolled in some colleges.

In general, the ethical principles for medical decision making for children follow the norm for informed decision-making. Parents and clinicians should consider carefully the clinical picture: the various options for therapy, the consequences of not treating the illness, the risks and benefits of each approach, the odds of success, and a clear picture of what "success" looks like.

The child's ability to participate in making decisions generally increases with advancing age. However, in general (apart from reproductive health decisions), minors do not have

the legal authority to make their own medical decisions.

Because children depend on others for their welfare, the government has a variety of mechanisms to try to ensure that children do not, as one court opined, become "martyrs" for their parents' beliefs and refusals of treatment.

Exact numbers are difficult to know, but approximately 300 children in the US have died in the last 25 years when parents withheld treatment on religious grounds. All 50 states allow social service authorities to petition for removal of children in such cases, but they can do so only if they become aware of the particular situation.

Specific laws vary from state to state. In Wisconsin (site of Case 1), state law exempts parents and guardians who treat children with prayer alone from charges of criminal negligence, but only in cases which are not life-threatening. Courts have been known to order treatments for children over parental refusal. In some cases, parents are charged with criminal neglect, or even homicide, when they refuse or fail to seek proper medical attention for their children. New York law mandates physicians and clinicians report suspected abuse/neglect of any child in their care. But is refusal of medical treatment properly understood as "abuse" or "neglect"? And in what circumstances should a parent's decision to refuse treatment for a child be overridden?

Where Do You Stand?

APPLICATION TO THE THREE CASES

Our three panelists had a lively give and take on these cases, and a summary of their thoughts follows below.

The panelists had the most agreement about the first two cases, Kara (whose parents did not seek medical attention as she died from diabetes), and William (whose Jehovah's Witness parents refused exchange transfusion for hyperbilirubinemia). It is ethically wrong to allow a child to suffer permanent injury or death if a reasonably effective treatment is available, and it does not cause disproportionate harm or suffering to the child.

Kara's death was avoidable. If clinicians had been aware of Kara's illness and her parents could not be persuaded to allow treatment, they would have been obliged to call Child Protective Services to work towards getting a court order to treat the child. Adults may make decisions that go against established medical advice and treatment, but they may not put their children's lives in jeopardy merely to satisfy the tenets of their faith.

William's case illustrates what happens when "the child is on the clock." The panel agreed that while they appreciate the religious beliefs of the parents, they would advise Dr. Ryan to request emergency transport and a judge to issue permission to treat the child immediately. In this case, there is a treatment with a very high benefit and a low risk for the child, and delay puts the child at risk for life-altering brain damage, a serious harm.

However, the third case of Jessica (the girl with a brain tumor) provoked the most disagreement, in that the recommended treatment arguably had a very different benefit-burden ratio.

Jessica's parents have to contemplate arduous treatment for their daughter, including surgery, radiation, and chemotherapy. Even if everything possible is done, the oncologist believes that there is only a 1-in-4 chance that Jessica will be alive in five years and considers this "marginal." And, if only surgery is done (the parents' preference, given their belief in holistic healing and belief that radiation and chemotherapy involves administering toxins to their child), humanly speaking Jessica has no chance of surviving.

Panelists disagreed as to whether treatment really was of "marginal benefit," and at what point (1-in-3? 1-in-2?) Jessica should be treated over her parents' objections. When medicine can only offer a treatment with a high risk and low benefit, parents are usually supported if they decide against it.



Panelists all agreed it was essential that the oncologist talk to the parents not only about survival rates, but also about Jessica's possible quality of life during and after treatment. The panelists split on this case, with JP wanting more information on "the harms of treatment," while TC and AC thought the facts given supported the parents' decision to forgo treatment. JP also wondered if the physician could find parents whose child had undergone treatment of this sort to provide an alternative view.

Reasonable people can reach different decisions when the long-term benefit of therapy is uncertain, and one cannot confidently predict whether a court would order treatment over the objection of Jessica's parents, given the uncertain outcomes.

These cases highlight the difficult ethical decisions that parents and clinicians face when children become ill, and their illness is seen in a religious or philosophic context that conflicts with a medical context. Medicine, ethics, and the law would seem to agree that the primary focus should be and remain on the welfare of the child.

Ethics Consult FAQs

Selected faculty members from the Center for Bioethics and Humanities provide ethics consultation at University Hospital and Crouse Hospital. Here are answers to some frequently asked questions about our services.

WHEN MIGHT AN ETHICS CONSULT BE USEFUL?

The purpose of ethics consultation is to help those who must make an ethical decision think through their options and the possible consequences of their choices. We provide information, education and perhaps another perspective about the ethical considerations related to a health care situation or decision.

We field questions about a wide range of issues, including:

- who should make the final decision about what is the best medical treatment
- treatment recommendations that don't seem right
- starting and stopping life support equipment
- a Do-Not-Resuscitate order (DNR)
- refusal of treatment
- Living Wills and Health Care Proxies
- ethical disputes about organ transplantation
- patient confidentiality

WHAT DOES AN ETHICS CONSULT INVOLVE?

One or more members of the Ethics Consultation Service will review the case and discuss the issues with the concerned patient, family, and/or staff. If it would seem useful, a sit-down meeting or conference call between the relevant parties is arranged. A written note is generally left in the patient's chart, or a letter is mailed to the requesting health care professional.

WHO CAN REQUEST A CONSULT?

Anyone directly involved in the particular issue may call a consult. This includes nurses, attendings, house staff, medical students, social workers, patients, and family members. We generally encourage a staff person requesting the consult to first speak with the attending, when appropriate, rather than calling a consult without the attending's knowledge. However, the attending's permission is not necessary for a consult.

WHAT HOURS ARE YOU AVAILABLE, AND HOW DO I REQUEST A CONSULT?

Ethics consultations are available 7 days a week, 8 a.m. to 5 p.m.

Patients may request a consult by contacting their doctor, a nurse or social worker, or by telephoning the hospital operator (University Hospital, 315.464.5540; Crouse Hospital, 315.470.7111). Hospital staff should contact the operator directly. Alternatively, between 8 and 4:30, you may call the Center directly at 315.464.8464. We try to provide input within 24 hours and if necessary, sooner.

DO THE ETHICS CONSULTANTS DECIDE WHAT HAPPENS?

No, the Ethics Consultants do not decide for you or direct medical care. A consult can, however, help everyone involved to better understand ethical issues and questions and to reach consensus on the best course of action. We may provide you with hospital policies or journal articles that shed light on the situation. We often help people think through the consequences of the possible choices.

WHO PROVIDES THE CONSULT?

We have a team of bioethics experts with backgrounds in medicine, law, and philosophy. Dr. Kathy Faber-Langendoen directs the service; other consultants include Catherine Caldicott MD; Thomas Curran MD; James Dwyer PhD; Gregory Eastwood MD; and Robert Olick JD, PhD. We also have available to us the expertise of other members from each hospital's Ethics Committee and hospital attorneys.

Our call schedule is posted at <http://www.upstate.edu/bioethics/ethicsconsult.php>

Reflections on Upstate's Code of Conduct

The Code fundamentally is a code of ethics. It calls for right behavior in all interactions and transactions at Upstate and promotes the expectation that all members of the Upstate community are “to maintain the highest level of professional behavior, ethics, integrity and honesty.” Two questions arise about Upstate’s code: Why do we need it? And is there evidence that taking such a pledge improves behavior? Most of us know how to behave appropriately and despite the fact that we are engaged in an endeavor that espouses the highest ethical and professional conduct — caring for others, educating people to care for others, and discovering new knowledge in an open, verifiable manner — occasionally we do not behave in a respectful or trustworthy manner. Still, despite the fact the Code reminds us of both our high calling to ethical behavior and our right to be treated in an ethical manner, regardless of our position or status at Upstate.

Regarding the second question, a study that compares behaviors in people who took such a pledge versus those who did not would be extraordinarily difficult to conduct and interpret. Nonetheless, health care organizations, professional societies, and corporations commonly have such codes of ethics and individuals typically take an oath of ethical behavior upon entering a profession. Codes and oaths clarify the ambiguity of individual ideas about right behavior and create a collective understanding and endorsement of right behavior. They are explicit declarations for all to see of the high standards of conduct that are expected and to which we aspire.

Although codes, policies, and guidelines are of the institutional community, Upstate is a community of individuals. What happens here, for good or ill, happens as a consequence of individual actions. The culture at Upstate — its collective attitudes and behaviors — is not something that is separate from us and beyond our control, but rather is a consequence of our individual thoughts and behaviors. Each of us has an obligation to foster a climate that promotes honesty, respect, and tolerance. The responsibility begins with our own actions but also includes open discussion of this issue with our co-workers and colleagues, and if we are in a supervisory position, with those we supervise.

The Code has ample provisions for addressing and reporting infractions. These will be useful both in the enforcement of the Code and in the improvement of individual behaviors. However, ethical behavior at Upstate Medical University will come not simply because we have a Code but because the people at Upstate, individually and collectively, create an environment in which ethical behavior is celebrated and unethical behavior is not accepted.

— Gregory L. Eastwood

You can read the Upstate Pledge by going to www.upstate.edu/hr/document/upstate_pledge.pdf

**THE CODE REMINDS US
OF BOTH OUR HIGH
CALLING TO ETHICAL
BEHAVIOR AND OUR
RIGHT TO BE TREATED IN
AN ETHICAL MANNER,
REGARDLESS OF OUR
POSITION OR STATUS
AT UPSTATE.**

FROM THE PRESIDENT'S COUNCIL ON BIOETHICS

Establishment of a Presidential commission or council charged to study, deliberate and advise on matters of bioethics and public policy has become a familiar province of each new administration. In December

2008, perhaps anticipating its sunset, the President's Council on Bioethics issued two reports. We summarize key provisions of these reports below. For the full text of the reports and more about the Council and its work, go to www.bioethics.gov.

Controversies in the Determination of Death

The report of the first President's Commission, *Defining Death* (1981), was instrumental in the widespread adoption of the Uniform Determination of Death Act (UDDA), or some variant of this model law. State laws nationally embody the medical-ethical-legal consensus that a patient is dead when s/he has irreversibly lost (1) all cardio-respiratory functions, or (2) all functions of the entire brain, including the brain stem (also known as whole brain death or neurological death). Nonetheless, continuing confusion and controversy surrounding whole brain death prompted the President's Council to undertake a re-examination of neurological criteria for determining death. For example, most of us believe that a patient who has irreversibly lost all brain function but who still breathes on a ventilator is *dead*; but for others neurological death is not synonymous with death of the human being and the patient may be *barely alive*. The President's Council's review concludes that the whole brain death standard remains valid. But the Council observes that the prevailing language of "whole brain death" or simply "brain death" contributes to confusion as it improperly suggests the absence of cellular activity, when in fact it is the irreversible loss of function, of

the ability "to carry out the fundamental work of a living organism," that marks the death of a human being. The report offers a sustained argument for defining death as "total brain failure" and discarding the established language of whole brain death. Some Council members argue instead that the vital signs of ventilated patients cannot be assessed with certainty; therefore, such patients should be considered "severely injured," but not dead. It is the Council's view that as technology advances, ideas and practices regarding human death should be periodically re-examined with a focus on preserving human dignity.

The Changing Moral Focus of Newborn Screening

Since the physician Robert Guthrie first developed a blood test for phenylketonuria (PKU) in the mid-1960s, newborn screening has emerged as an essential tool of neonatal and pediatric medicine. Today, all states have newborn screening programs. Programs vary regarding the metabolic and genetic conditions on the screening list; it is common for states to test for twenty or more diseases and disorders. The traditional and time-honored approach has been newborn-centered and has only tested for conditions that meet the following criteria: the condition is

- 1) an important health problem;
- 2) well understood; and
- 3) medicine can offer effective and beneficial early intervention and treatment for the newborn. For example, children with PKU are treated with a strict dietary regimen, and children with congenital hypothyroidism must take a daily thyroxin tablet. In the vast majority of states, screening is mandatory. Information is provided to parents, but parental consent is not required.

In 2005, the American College of Medical Genetics (ACMG) released recommendations for expansion of newborn screening programs to include some genetically-associated conditions for which there is presently no effective intervention or treatment. The core rationale for this paradigm shift is that knowledge of a genetic condition that may develop in the future is beneficial to newborns and their families, and that screening for these conditions is an important research tool for the benefit of society. Many states have followed the path urged by the ACMG and have expanded the number of targeted conditions for which testing is mandated.

The President's Council report offers a cogent discussion of the history of newborn screening and the ACMG position. The Council argues that the ACMG recommendations represent a radical shift from the traditional justifications for screening. The

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Newborn Screening

Council warns that the ACMG approach can be used to justify screening for virtually any genetic

defect, and could bring medical, psychosocial and financial harm for all parties involved. In the face of predictable rapid expansion of individualized, genomic medicine, the Council recommends a model

that serves to protect the child, preserve informed participation, and allow for voluntary participation in biomedical research.

—Andrea Asprelli & Robert S. Olick

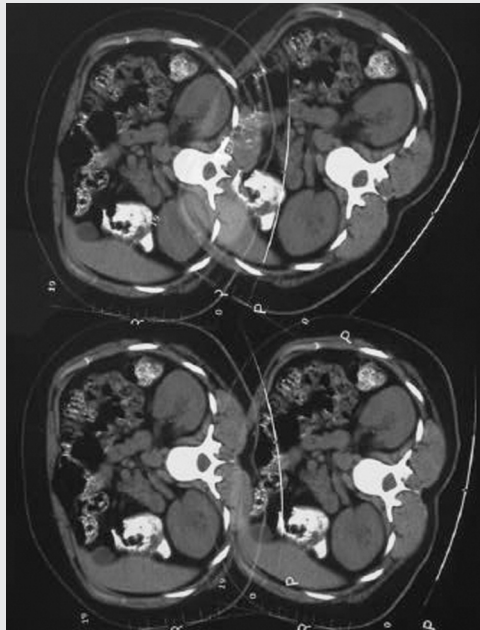
Bioethics Ballot Measures Approved in November 2008

MICHIGAN

Proposition 1:

Allow Medical Marijuana

- This measure allows the medical use of marijuana. It limits use to registered patients with certain debilitating medical conditions including cancer, glaucoma, HIV, hepatitis C, epilepsy and multiple sclerosis. However, the measure also allows unregistered patients and primary caregivers to assert medical reasons for using marijuana as a defense to any prosecution involving marijuana.



WASHINGTON

Initiative 1000:

Allow Doctor-Assisted Suicide

- This measure allows terminally ill, competent, adult residents of the state to request and self-administer lethal medication prescribed by a physician. The person requesting to end his or her life must be medically predicted to have six months or less to live.



Proposition 2:

Allow Stem Cell Research

- This measure amends the state constitution to permit human embryonic stem cell research with certain restrictions. The embryos must have been created for fertility treatment purposes; they must have been otherwise discarded; and they may not be used more than 14 days after cell division has begun.



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.



The Other Mothers

— K. B. Kincer

They arrive in uniforms of grey,
pink and blue, the colors of dusk, of dawn,
patterned like flocks of birds lifting
from water to sky, rustling about the room
straightening sheets, plumping pillows,
untangling tubes hanging from IV poles
that chirp, whir, and tether the bed, a boat floating,
trying to drift from this pastel shore.

A blur of movement, they bob and turn
in short, swift steps, check the charts,
temperature, administer meds, and let
his mother brush Vaseline over cracked,
swollen lips, let her comb his hair,
massage cream into his hands, his feet,
let her stay at the foot of the bed.

They wash his body, but cover him
as they go, before and after, to expose
nothing to janitors swabbing floors,
removing trays, emptying trashcans.
They support his head, his arms and legs
with pillows and blankets, just so,
for they've practiced at home sprawling for hours
on couch cushions and foam bolsters.

Slats of sunlight enter the room, row
slowly across the floor, fade. At night,
his mother watches them lift and turn her son
to face the window, always east.

K.B. Kincer is in the graduate program at Georgia State University working toward an MFA in creative writing with a concentration in poetry.

You can order copies of *The Healing Muse* for \$10 each by calling 315-464-5404 or by going to the website: www.thehealingmuse.org. Or you can purchase a copy at the HealthLink/OASIS site in ShoppingTown Mall (lower level).

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