

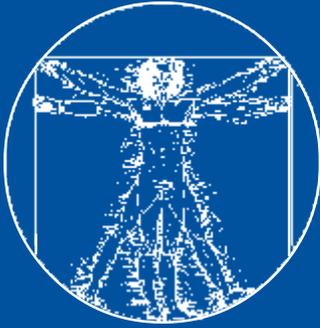
Health Care Law

Mid-Atlantic Ethics Committee Newsletter

University of Maryland Francis King Carey School of Law *Year 2005*

Mid-Atlantic Ethics Committee
Newsletter, Spring 2005

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MID-ATLANTIC ETHICS COMMITTEE

N E W S L E T T E R

A Newsletter for Ethics Committee Members in Maryland, The District of Columbia and Virginia
Published by the Law & Health Care Program, University of Maryland School of Law
and the Maryland Health Care Ethics Committee Network

Spring 2005

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WE COULD . . . BUT SHOULD WE? POSTMORTEM SPERM RETRIEVAL

“I would like my husband’s sperm saved so I can use it to have his baby.”

The request is from the wife of a patient involved in a multi-car collision. Physicians are evaluating him for brain death. Regardless, he is not expected to survive. The organ transplant liaison requested the ethics consult after discussing organ donation with the patient’s wife. The patient’s driver’s license indicated he had elected to be an organ donor. The wife, numbed by the shock of her husband’s impending death, agreed to organ retrieval for donation, and then requested that his sperm also be retrieved and stored for her future use. The wife is aware of other cases in which sperm were retrieved after a man had died and used to impregnate his partner. She believes if her husband’s organs can be used for the benefit of others (which she approves of), his sperm could also be used to create a child as a legacy to him. You, a member of the ethics consult team, are responding to this ethics consult request. How do you proceed?

Can sperm retrieval be done?

Your first question may be a logistical one. Putting aside the question of whether it’s morally OK to retrieve and store a man’s sperm after he dies, *can* it be done?

The Mid-Atlantic Ethics Committee Newsletter is a publication of the Maryland Health Care Ethics Committee Network, an initiative of the University of Maryland School of Law’s Law & Health Care Program. The Newsletter combines educational articles with timely information about bioethics activities in Maryland, D.C., and Virginia. Each issue includes a feature article, “Network News,” a Calendar of upcoming events, and a case presentation and commentary by local experts in bioethics, law, medicine, nursing and related disciplines.

Diane E. Hoffmann, JD, MS
Editor

While it has already been done elsewhere (Batzer, et al., 2003), can it can be done at your facility? Tash and colleagues (2003) describe minimally invasive techniques such as sterile vasotomy and vasal aspiration (transecting the vas deferens and irrigating it and the epididymis using a liquid medium to extract sperm), as well as microsurgical epididymal sperm aspiration or testicular sperm extraction. Few urologists are well-practiced in these techniques, and locating one who knows what to do and is willing to do it may be a tall order when time is limited. (Retrieval

NETWORK NEWS

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MARYLAND HEALTH CARE ETHICS COMMITTEE NETWORK (MHECN)

THE METROPOLITAN WASHINGTON BIOETHICS NETWORK

typically needs to be done no more than 24 hours after death.) Tash and colleagues recommend that a male infertility specialist comfortable with these techniques be identified in advance of such requests. Another critical consideration is whether there is a suitable cryopreservation facility nearby that will be able to properly process and preserve the specimen.

Should sperm retrieval be done?

This question can be broken down into two parts:

- (1) is retrieving this patient's sperm morally permissible?
- (2) if permissible, *should* the health care team facilitate making this happen?

Those who have written about the ethics of postmortem sperm retrieval have described three general areas of concern: protection of the rights and dignity of the patient, protection of the bereaved family (for example, the patient's wife who makes the request at a time of emotional turmoil), and protection of future offspring.

Unlike other organs or tissues in the body that can benefit others who are already living, sperm retrieval does not benefit another living person. Rather, it is extracted with the intent of creating another person. If we queried people who had signed up to be an organ donor, most would likely not equate donating their gametes to create a child as being the same as donating an organ so that another might live. We recognize that a man has the right to participate in decisions about fathering a child, particularly a child who will never be able to know him (e.g., sperm donation). Few men have given explicit consent for postmortem sperm retrieval, which would be the gold standard to ensure protection against unconsented paternity. Ethicists, however, have accepted the substitute of "reasonably inferred consent," in which a wife (or committed partner) provides evidence that her husband was pursuing fatherhood with her, as being ethically acceptable. Tash, et al., write, "[O]nly men undergoing fertility treatment, actively attempting conception, or who had

specifically expressed their plans to attempt conception in the immediate future would be suitable candidates for retrieval" (p. 1923). These authors believe that the wife should be the only person eligible for impregnation with the sperm.

The other consideration in responding to a request for postmortem sperm retrieval is to protect the bereaved family members from making irrational and uninformed decisions. Establishing a wait time of at least 6 months to 1 year before sperm may be used for procreation is standard among those who have studied this issue ((Batzer, et al., 2003). The wife should be the designated surrogate decision-maker, and should be encouraged to undergo counseling before proceeding with impregnation attempts to ensure that she is pursuing pregnancy with the right motives (for example, that she is not giving in to pressure from in-laws to "replace" their son). Because time is obviously limited when these requests arise, it's recommended to develop or have access to a document ahead of time that covers various contingencies (e.g., agreed-upon wait time, requirement for counseling, that the wife can be the only recipient of the sperm, etc.), although it's doubtful these agreements are legally enforceable.

The patient's family should also be informed about costs of sperm retrieval, cryopreservation, and ensuing fertility treatments. Because the number of sperm retrieved are less than that contained in a normal ejaculate, in vitro fertilization using intracytoplasmic sperm injection (ICSI) is recommended. Out-of-pocket costs for all of these procedures can run into tens of thousands of dollars or more. The grieving family may be at risk of incurring burdensome debt by disregarding "details" surrounding costs, but in order for them (or more specifically, the wife) to make an informed choice, the range of possible costs should be disclosed.

The third area of concern is for the future child who may be created. Some argue that creating a child using sperm from a dead man precludes the two having any relationship, and thus may cause psychic harm to the child. But it's difficult to argue that such harm rises to

the level of justifying that the child should never have been born. While research has shown that children do better in two parent households, no one suggests that single parenting is immoral, and certainly plenty examples exist of harm done to children living in two parent households. The main concern is that a child may be created solely for the purpose of assuaging the grief caused by the father's death, and thus be treated merely as a means to an end rather than as an end in him/herself. While there likely are couples who currently have children for selfish motives, the fact that creating a child using postmortem sperm retrieval must be facilitated by health care providers removes it from the realm of privately made decisions. However, in the highly charged atmosphere of recent or impending death, it's unlikely that the ethics consult team can tease out whether a wife has the right motives for having a baby with her dead husband's sperm. This is the reason for separating the decision to retrieve sperm from the decision to use it to try to get pregnant. Hopefully, if the wife comes to a point of deciding to use cryopreserved sperm to achieve a pregnancy, she will have moved beyond the acute bereavement stage and received adequate counseling and support to ensure that her decision is best for herself and any future child that might result. In addition to emotional support, the wife should also be informed that any child produced using retrieved sperm will not be recognized as the legal child of the patient and thus not entitled to inheritance or other legal paternity-based entitlements (Strong, et al., 2000).

While infrequent, requests to retrieve postmortem sperm are likely to increase as more individuals become aware of this possibility. In addition, more couples (including older couples) are using artificial reproductive technology (ART) to reproduce. Such individuals must decide what happens to cryopreserved embryos in the event of death or divorce of either partner, so it's more likely that they will have discussed the possibility of "posthumous procreation." Preliminary consensus among ethicists is that, in rare situations (i.e., requests made by a wife

Cont. on page 4

with explicit or inferred consent by her husband and where the means to retrieve and cryopreserve sperm are available), postmortem sperm retrieval is ethically permissible. But just because an act is ethically permissible doesn't mean that health care providers have a duty to take part in or facilitate it. While those with personal moral objections to postmortem sperm retrieval have a right not to participate, those who do not should actively decide whether they are willing to help in the rare cases where valid requests arise. A good test of one's convictions in this regard can perhaps be revealed by imagining the day when you are called to sit with the wife of a dying or dead patient and respond to her request to retrieve and save her husband's sperm. How is it that you have the right to ask her such personal questions? Is your reason for denying her request justified? Some may say having a policy in place for these rare requests may make such conversations easier, and for that reason alone, a policy is worth having. At the very least, we should think about, and at best, prepare in advance for how to respond to such requests. While we may not be obligated to facilitate posthumous procreation, we will likely be obligated to answer the question, "If we can ... why shouldn't we?"

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INTERVIEW WITH AN ETHICS COMMITTEE CHAIR

by
Samantha Freed
Third Year Law Student
MHECN Research Assistant
(edited interview)

Hebrew Home of Greater Washington, located in Rockville, Maryland, has been serving the elderly for over 90 years. Home to 1,000 residents, the Hebrew Home campus includes two apartment communities for independent living, the Hirsch Health Center, and the Research Institute on Aging, which develops and conducts research projects that benefit the field of aging. Hebrew Home's ethics committee, which is supported by the Department of Spiritual and Pastoral Care, formed over 20 years ago. Rabbi James Michaels was asked by the staff liaison to chair the board-appointed committee. Joel Bressler joined the committee about 7 years ago. Both men sat down with Samantha Freed recently to talk about Hebrew Home's ethics committee.

SF: What prompted Hebrew Home to form its own ethics committee?

HH: We were one of the first nursing homes in the county and perhaps the state to have an ethics committee. There was a lot of community interest from citizens of the surrounding area because ethics in medicine was becoming a hot topic. There wasn't a crisis that prompted it, but Hebrew Home just felt it was better to be proactive and felt there was a need for education in this area. As part of the mission of Hebrew Home, we were educating the community in issues of ethics. At the time, the meetings were in the evening and 10-15 people came each time. The meetings were comprised of more community members than staff. But as people became more aware of the issues from our literature and the media, the need for the education of the community dropped off and the focus of the ethics committee has changed to a more staff-based and committee-based function, no longer playing to the needs

of the community, but geared towards the needs of the residents and staff.

SF: How many members does your ethics committee have?

HH: 9 members. It's not a static number and it could be expanded.

SF: What is the professional background of the committee members? Does the committee consist only of employees of Hebrew Home or are some members solely members of the community (with no employment connection to Hebrew Home)?

HH: Official members are community members but we do invite staff members. We have a retired pharmacist, a lawyer, a physician, a retired nurse and two rabbis [not including Rabbi Michaels]. Hebrew Home's policy requires that there be a lawyer on the committee, but the lawyer need not be an expert in ethical issues. There are social workers who attend the committee's meetings, but their membership is not required by our charter.

SF: How does one become a member of the committee?

HH: We find people that are interested. Then we submit their names to the chairman of the board of Hebrew Home, who writes a letter of invitation.

SF: How do the staff and families know about the ethics committee?

HH: Because of the turnover of staff, there is always a need to educate the staff. We've spent the past year educating our staff on what the ethics committee is all about. In the August meeting, we invited the medical staff. In the November meeting, we invited the nursing staff, etc. We will continue to do this to give them the opportunity to find out the workings of the ethics committee and to help them answer any questions they may have.

As for informing families of our existence, Our social workers, nurses and doctors are supposed to inform the family members of the ethics committee's

existence, especially when we get to critical issues of life support. That's the main way. I'm hopeful about getting a brochure printed that would be part of the admission packet to let them know about the ethics committee. But often, ethical issues are not identified until a crisis situation arises. Putting a family member in a nursing home with or without their consent is often traumatic for families. There may be denial issues on the part of the family that may cause them to avoid addressing ethical issues. In those cases, it may not be until the patient is dying, when hospice is called in, that the ethical issues become apparent. We would hope that the staff will do their job of educating families about the role the ethics committee can play, but our presence in the nursing home may not become apparent to the family until an issue actually arises.

SF: Do you educate employees about the ethics committee when they first begin working at Hebrew Home?

HH: I don't remember getting information about the ethics committee at my orientation. There is so much in the way of educating that they get at their orientation that if it's mentioned, I'm sure it's forgotten.

SF: Does the committee perform consults with patients and families or just with the facility's doctors?

HH: More with families than with patients, and the consult often includes the doctors.

SF: How are the consults conducted? Does the whole committee perform consults or just a sub-committee? Or one person?

HH: We only meet quarterly on a regular basis. We have the possibility of creating a case consultation committee which can be formed in 24 hours. The committee consists of at least 3 people. Once the sub-committee is created, we ask all affected and interested parties to present their case. Then the committee retires and discusses and announces its opinion for this particular case. There are occasions

when Rabbi Michaels alone will be asked to consult, but then it's a matter of resolving conflict within a family. It's more about facilitating their decision making. It's only when we reach an impasse when the ethics committee might get involved. In 2004, we only had two ethics consults with the sub-committee.

SF: Are patients and/or family members typically included in ethics consults?

HH: Yes, in the consults conducted in 2004, family members were included in the ethics consults along with the patients.

SF: What are the most common reasons why or issues for which the ethics committee is contacted?

HH: In one case a resident was in a persistent vegetative state (PVS) and there was conflict within her family about whether to discontinue her life support. And because of the family's conflict, we needed to determine Hebrew Home's policy for this specific situation and couldn't allow the case to hang in limbo. We have a policy to follow the patient's interest, but there was confusion as to whether there was a living will and if so, whether we should abide by it. In another case there was confusion about a resident's end-of-life wishes. She had requested a full code status, and yet she had indicated that she didn't want excessive pain if she had a heart attack. There was a question as to whether she was mentally able to make a decision. She didn't speak English so this further complicated things. After getting an interpreter involved and speaking with her family, we determined that she was competent to make the decision herself, and we were able to figure out her particular needs and wishes.

SF: Given that Hebrew Home is a religious institution, what role does religion play in the functioning of the ethics committee?

HH: Many of the staff are not Jewish and they wonder what Jewish ethics are. There are many questions they need to ask and we give them a forum to ask them. They in turn address these issues with family members.

SF: How do you deal with patients and family members who aren't Jewish?

HH: We have to be sensitive to everyone's religious and cultural beliefs and practices. Even within the Jewish community there are differences. We called in one of the primary authorities in Jewish medical ethics, who explained that the common misunderstanding is that there is one approach, but in fact, this authority explained, there are many approaches. The Jewish approach is to preserve life but also to relieve suffering, and this is where the conflict often arises. There are different approaches depending on the Rabbi's denomination. One of the misconceptions about Orthodox Judaism is that removal of life support is not permitted. However, there are situations that do allow the removal of life support in order to relieve suffering. Even in the more liberal movement, there are different opinions about when removal of life support is permitted. But you have to be careful in order to avoid a slippery slope.

One patient's daughter, both of whom were not of the Jewish faith, told her mother that I (RM) was the elder in the Jewish Church "You listen to him," she said. And right there we created a committee, and walked into one of the big rooms near the lobby and sat down to talk. But the patient wouldn't listen to her daughter or the social worker. It speaks to the issue that people from other cultures or religious traditions may do things differently from us. We understand and respect that.

SF: If the ethics committee does meet on a regular basis, what do you do at your meetings?

HH: Recently we've been doing staff education. If there are pending cases we discuss them. Occasionally we'll ask one of the members to make a presentation. A year ago, Florida's "Terri's Law" was prominent in the news and we asked Dr. Wilks to make a presentation about this. Because of this presentation, we were able to make a more informed decision when consulting about the case involving the woman in a PVS.

SF: Is a portion of your meeting dedicated to education? If so, what percentage of the meeting?

HH: We don't formally educate the staff. But by bringing up these cases, we educate members on how we deal with these issues. So I'd say probably 75% of our meeting time is spent on informal education.

SF: What would you say is the most satisfying work of the committee? What has been a challenge for you? What would you like to improve?

RM: Personally as a Rabbi, I've never dealt with issues of such true life and death magnitude as I do with the ethics committee. As a staff liaison and a member of the ethics committee, it's extremely satisfying to get involved. The biggest challenge has been educating the staff. We'd like to keep on the cutting edge as issues develop. It was the Terri's Law debate that prompted us to discuss in our own consults the issues presented in PVS, and by doing so, we became aware of the complex issues involved. They are not as simple as the news media makes it sound. And the other thing of course is that I'd like our staff and residents' families to be aware of our work so they know we are here to help them.

JB: Resolving issues is more satisfying than the education piece, but in a broad sense, ethics consultation and ethics education are both aimed at resolving ethical issues or conflicts. Blessed are the peacemakers who resolve issues.

For more information about the Hebrew Home of Greater Washington, please visit <http://www.hebrew-home.org/site/PageServer>.

COMMUNICATING WITH MECHANICALLY VENTILATED PATIENTS

Health care providers (HCPs) and ethics consultants can face challenges when communicating with ventilator-dependent patients. Contrary to what is portrayed in the movie "Million Dollar Baby," patients on mechanical ventilation (whether via an endotracheal tube or tracheostomy) cannot vocalize without assistive devices, and the use of such devices requires training and a degree of strength. Nevertheless, being nonvocal does not make a patient non-communicative. If a patient *can* participate in health care decision-making, attempts should be made to communicate with the patient. Indeed, studies of vent-dependent patients in ICUs have associated increased stress, sleep disturbance, panic, and insecurity with the inability to speak. Some studies have shown that ICU patients have impaired reasoning or poor recall because of their critical illness (e.g., those with a Glasgow Coma Scale score under 13), and thus caution HCPs to distinguish between substantive communication and the "appearance of communication." However, vent-dependent patients shouldn't be deemed non-communicative without first trying to establish communication. This can be accomplished in a number of ways. In a literature review summarizing the state of the science in communicating with mechanically ventilated patients, Happ (2001) offers the following suggestions for facilitating communication:

- Gestures are the most frequently used method of nonvocal communication among intubated ICU patients, but can be impeded by wrist restraints. Whenever possible, remove wrist restraints and other impediments to gesturing.
- Offer visual aids (glasses) and hearing aids if patients use them but aren't wearing them.
- For conscious patients who can read and write, consider using a

dry erase board or "magic slate" (for short messages that can be readily erased).

- Try a picture board, which consists of icons representing basic needs such as pain, fear, hot/cold, thirst, and can include either alphabets or words/phrases that patients can arrange or point to. These have been positively evaluated by ICU patients.
- Determine the patient's ability to read and understand English. If the patient does not speak English, consider whether language cards may be helpful.
- Be aware that an eye blink system can be used (i.e., "no" = 1 blink, "yes" = 2 blinks, "I don't know" = 3 blinks), but is time-consuming and may be tiring.
- Consider electronic voice output communication aids (VOCA), which can be attached to bedside poles. These match voice messages with labeled icons or pictures that the patient can choose by touching a dynamic display screen or touch-sensitive keyboards. The message "I am worried" might then be linked with other icons depicting common concerns of ICU patients, such as family, finances, or prognosis. These are more often used for long-term communication disorders, but if available, might be appropriate for some ventilator-dependent patients in an acute care ICU.
- Understand the options for assisted vocalization. This involves the use of one-way speaking valves (e.g., Passy-Muir) or trach capping, and is typically for patients who have been on a ventilator and receive training in the use of these devices. Sufficient muscle strength, gas exchange, and ability to manage secretions is necessary, but some ICU patients may be able to succeed

PHILOSOPHER'S CORNER—MORAL PSYCHOLOGY AND THE ROLE OF EMOTIONS

with nursing, respiratory, or speech therapy supervision.

- Assess for pain and treat it. Pain is under-recognized in nonverbal patients, and can impair other communication attempts. Signs of bracing, grimacing, or restlessness may indicate a need for pain relief rather than cognitive impairment. Sometimes the need for paralytics may be eliminated if pain is better managed, and this can increase the patient's communicative ability.
- Consider asking someone who knows the patient well (such as a family member or primary nurse) to interpret for conscious nonvocal patients. Such individuals are often better able to understand nonverbal cues. However, a family member should not be asked to do this if there are concerns about familial bias or privacy violations.
- Invite a speech-language pathologist to assist with communication attempts if having difficulty communicating with a nonvocal patient who appears to have communicative potential.

Although some of these strategies require a relatively high degree of cognitive function, there are patients who have that cognitive capacity. For others, cognitive functioning may fluctuate throughout the day, so it might be necessary to assess the patient at different times. Also, ICU patients may only be able to participate in communication for short intervals, so this should be kept in mind.

Happ, M.B. (2001). Communicating with mechanically ventilated patients: State of the science. *AACN Clinical Issues*, 12(2), 247-58.

Many of us have heard people talk about the "Yuck Factor." I heard the term used to belittle a philosophy described by Leon Kass, MD, Ph.D. in his essay "The wisdom of repugnance" which argues that if a person's first reaction to a biomedical breakthrough (cloning humans could be one) is repulsion, then maybe there is a good reason for it and a reaction to be seriously considered.

Needless to say, Kass is not the first person to point out the role of the emotions in moral and ethical deliberation. One need only look at the battle lines that are drawn between the supporters and detractors of *Roe v. Wade* to see the role of emotion involved in important moral issues. Some might say that issues heavily laden with emotion are less likely to be rationally resolved. But could it be the other way around? Because there is no rational resolution available (or so it seems), emotion has nowhere else to go but be felt.

Try out this scenario: *The enemy has taken over your town and you, your infant, and ten other townspeople are hiding in the basement of a building. You can hear the enemy soldiers outside of the building looking for townspeople to slaughter. Your baby begins to cry and you cover its mouth. If you remove your hand the soldiers will hear you all and kill everyone. If you keep your hand over the baby's face it will suffocate. Is it appropriate to suffocate your child in order to save yourself and the other townspeople?*

Simple utilitarian math says to sacrifice the child for the wellbeing of the rest because if the child isn't sacrificed then all will die. A principle- or deontologically- based ethic may say that killing is never justified. A simple gut decision may indicate something else entirely. How did you, the reader, react to the scenario? Did you make a snap judgment or did you need some

time to think things through? Did you imagine the child in the scenario as being your own child, and if so what difference did that make?

Some interesting work is going on by a philosopher and psychologist at Princeton University that is taking a look at the role of emotion in ethical decision making. Joshua Greene and colleagues are posing the above scenario and others to research subjects as they are being monitored by a functional magnetic resonance imager (fMRI). What they are finding is that three areas of the brain are activated when a scenario such as the crying baby are presented:

- (1) the hippocampus, an area associated with emotion
- (2) the anterior cingulate cortex (ACC), an area associated with monitoring conflict
- (3) the dorsolateral prefrontal cortex (DLPFC), an area associated with abstract reasoning.

These researchers found that an increase in the activity of the ACC signals a conflict between an emotional response and higher processes, which may incline the individual to respond differently from what may be expected. What these researchers conclude is that emotion may be a very important evolutionary (both genetic and cultural) adaptation, however, there's also a more unemotional and rational process that needs to be monitored. In short, it is not that emotional responses are bad responses: they just are not the final word in every situation. The research seems to point to the inseparability of emotions, behavioral responses, and rational decision-making.

Before anyone calls upon Hume to counter what may be perceived in Greene *et al* as making the naturalistic fallacy (one cannot derive an ought from an is), let me assure you that they are well aware of the criticism. They nonetheless want to argue that knowing something about the process of how we make moral decisions can be enlightening.

Understanding where our moral instincts come from and how they work can, I argue, lead us to doubt that our moral convictions stem

from perceptions of moral truth rather than projections of moral attitudes. Some might worry that this conclusion, if true, would be very unfortunate. First, it is important to bear in mind that a conclusion's being unfortunate does not make it false. Second, this conclusion might not be unfortunate at all. A world full of people who regard their moral convictions as reflections of personal values rather than reflections of 'the objective moral truth' might be a happier and more peaceful place than the world we currently inhabit. (Greene, et al., 2003, p. 850)

That philosophers are interested in emotion and the passions comes as no surprise to those who study the classics. That philosophers as early as Plato referred to themselves as *tes psukhes iatros* or 'healers of the soul' (revealing the philosophical roots of the term *psychiatry*) has not been lost on one of our most respected classic philosophers in our contemporary times. Martha Nussbaum, in her work *The Therapy of Desire: Theory and Practice in Hellenistic Ethics*, makes the case that philosophy-as-therapy deals not only with cognitive but also with affective issues: not just with 'invalid inferences and false premises' but also with 'irrational fears and anxieties ... excessive love and crippling angers' (p. 37). A key aspect of this is the Hellenistic assessment of the emotions as 'not blind surges of affect' but 'intelligent and discriminating elements of the personality that are very closely linked to beliefs, and are modified by beliefs' (p. 38). Philosophy-as-therapy is a process of increasing happiness and well-being through an appreciation of the potential truth value of desire, as well as a respect for rationality in the face of blind prejudice.

This gets us back to the 'Yuck Factor.' There are no doubt levels or modes by which we make moral decisions. There is a basic way that involves self-interest (i.e., ethical

egoism); there is the human empathic way through identification with others; there is the way of cultural norms; and there is the way that comes from 'philosophizing,' the conclusions of which may be largely independent of those of the local culture. Each of these modes involves different measures of rationality and emotion influencing our moral judgments and behaviors. While traditional ethics views rational decision-making as being morally superior to "Yuck Factor" responses, Greene and colleagues see more overlap than separation among these processes. We humans are indeed psychosomatic creatures and it matters to us when we face moral dilemmas that affect us emotionally. The 'Yuck Factor' just may be a signal to be aware and examine our intuitions, presuppositions, and even prejudices as well as a call to re-read the *Nicomachean Ethics* just one more time. Who was it that said that an unexamined life was not worth living?

Brian H. Childs, Ph.D.

Green, J. et al, "An fMRI investigation of emotional engagement in moral judgment" *Science*, Vol 293, September 14, 2001, pp. 2105-2108.

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CASE PRESENTATION

One of the regular features of the Newsletter is the presentation of a case considered by an ethics committee and an analysis of the ethical issues involved. Individuals are both encouraged to comment on the case or analysis and to submit other cases that their ethics committee has dealt with. In all cases, identifying information about patients and others in the case should only be provided with the permission of the individual. Unless otherwise indicated, our policy is not to identify the submitter or institution. Cases and comments should be sent to: Diane E. Hoffmann, Editor, MAEC Newsletter, University of Maryland School of Law, 500 W. Baltimore St., Baltimore, MD 21201, or dhoffman@law.umaryland.edu.

MARYLAND PEDIATRIC CASE STUDY

A 10 year old girl ("Joyce") who suffered brain trauma in an automobile collision is referred for rehab after acute treatment. Joyce has significant cognitive impairment from traumatic brain injury. Rehab after such an injury is a slow process, and includes attempting to regain function while also adapting to physical and cognitive limitations. Yet, Joyce's parents only want to pursue treatments they think will get her back to her baseline level of functioning—they refuse to consent for treatments that acknowledge any level of disability. For example, Joyce has spoken one intelligible word and no others. Thus, an alternative communication system was recommended temporarily to enable her to communicate. However, her parents are unwilling to permit this and want

only treatment aimed directly at regaining speech. Joyce has a tracheostomy, which normally requires family members to be trained in its care, but the parents refuse to learn because they say she won't need it when she goes home. Joyce's damage is mostly on her right side, but standard therapy includes improving left-sided abilities as well. However, her parents only want to focus on treatment to improve her right side, specifically, movement of upper extremities. The parents sharply rebuked staff members who tried to communicate with them about their emotional response to their daughter's injury. A frustrated staff member requests an ethics consult, concerned that Joyce is receiving sub-standard care due to her parents' imposed therapy restrictions.

RESPONSE FROM TWO PEDIATRICIANS & ETHICS COMMITTEE MEMBERS

The unfortunate story of Joyce and her parents raises issues commonly encountered when patients, their families and a medical team have to negotiate what is "best" for a patient. The ethical principle of autonomy underlies the usual practice of allowing patients to decide what therapies they will or will not undergo. An adequately informed patient should be able to accept or reject medical recommendations based on what risks he or she is willing to take and what potential benefits are important.

Things change when a patient is unable to make a decision on her or his own. This can happen when a formerly autonomous patient becomes incapacitated, or, as is often the case in pediatrics, when a patient has not yet reached a cognitive stage of being able to make a rationally informed decision. We are therefore accustomed to letting parents make decisions for their children, both medical and non-medical. We let parents decide, for example, what school to send their children to, what cultural and religious values to expose them to, and what decisions the child is allowed to make on his or her own.

In the vast majority of cases, this includes letting parents decide what medical care their children will receive. But what are the ethical justifications for the usual practice? One argument holds that the family is in the best position to know what the patient would want if she could tell us herself. This "substituted judgment" standard attempts to approximate autonomy by letting those who are closest to the patient and most likely to share her values decide. In theory the surrogate should voice what the patient would want, rather than what the surrogate thinks. Another approach is the "best interests" standard. This approach is the most common in pediatrics; we presume that the parents care deeply about their child, want what is best for their child, and are the agents in the best position to decide what that is. Yet another rarely voiced ethical justification for letting parents make decisions for their children is that they, as a family unit, will be the most affected by these decisions. The burdens and joys of caring for the child for the rest of her life are their responsibility.

Still, parents do not own their children. We do not give them absolute power to make any decision whatsoever for their children; healthcare providers are constantly balancing what they see as the child's best interests with how the parents see it. The most extreme examples of overriding a parent's wishes are in child abuse and neglect situations. In these cases the best interests of the child are so obviously violated that the parents lose their authority to make any decisions for their child. There are other more subtle cases, however, where the parents truly believe they are acting in their child's best interests but the medical team disagrees. Such cases include court-ordered chemotherapy for a child with treatable leukemia whose parents want to pursue alternative therapies alone, or the current common practice of giving children of Jehovah's Witnesses life-saving transfusions if needed over their parents' objections.

Where does Joyce's case fall in that spectrum? It seems that no one thinks that Joyce's parents are trying to harm her; they are simply worried that the parents' misconceptions will lead to suboptimal care. It might be helpful to

have the parents sit down with the member of the healthcare team who has the final authority over what treatments are recommended, perhaps the attending physician or nurse manager. He or she could begin by listening to the parents' assessment of how their daughter is doing and asking what their goals are for her. Nurturing an alliance with them, so that they can see the staff's common purpose of caring for Joyce, is important. The team leader should let them know that other children in Joyce's condition have made tremendous strides and give them examples of things other families have done in similar situations to help their children. Acknowledging the stresses they are under may help; almost all parents in their situation carry a huge burden of guilt for what has happened to their child (whether they are conceivably at fault or not). They are probably terrified, and their current coping mechanism is denial. It has been my experience that even an angry and belligerent parent may break down into tears when asked if they have been able to sleep or eat.

Explore with the parents which treatments are essential and which are merely the way things are usually done at the institution. Some of the therapists may be surprised to learn that some common practices have little hard evidence to support them. The team leader may decide to insist that Joyce receive proven therapies but allow some compromise on others. Show the parents the evidence in published papers if need be.

If the team reaches an impasse and the parents continue to refuse therapies which are felt to be essential to Joyce's recovery, someone needs to sit down with them and calmly explain that their choices might be harming their daughter. If negotiations continue to fail, it would be appropriate for the team leader to state that he or she is unwilling to participate in providing substandard medical care and to offer the option of a second opinion or transfer to another institution.

It would be rare for a conflict to reach this stage. Time and a steady emphasis on the family's and healthcare team's common goals is usually enough. Perhaps interactions with her family will never become easy. They may negotiate a workable plan with the team leader but

Case Study

Cont. from p. 9

continue to make daily care difficult for the nurses and therapists. But hopefully both they, and Joyce, can begin to make some small steps towards healing. We should never presume to understand everything a family is going through in their situation; they are in the trenches of the battle in a way that most of us never will be. We can only try to help them through it using knowledge gained from helping many others face similar challenges.

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An ethics consult has been requested in this case because of a staff member's concern that Joyce is receiving sub-standard care due to her parents' imposed therapy restrictions. Just on the basis of this expressed concern, the possibility that Joyce is being medically neglected must be considered. Neglect is defined in Maryland Family Law 5-706 as: "... failure to give proper care and attention to a child by any parent ... under circumstances that indicate that the child's health or welfare is harmed or placed at substantial risk of harm." While "proper care" is not further defined in the law, it would appear that this could be questioned in this case.

Before concluding, however, that Joyce is being neglected, it would be necessary to consider all of what went into her parents' thinking leading to their restriction of care to her. How long has it been since the original injury? Has there been enough time for the parents to get past the initial emotional trauma of having

their daughter so severely injured? What efforts were made to inform and educate them as to the options for care of their daughter? Were these efforts truly successful and were the parents able to emotionally deal with the realities of their choices so that their decisions truly considered the implications of possible harm to their daughter? It appears clear from their having "sharply rebuked staff members who tried to communicate with them about their emotional response to their daughter's injury" that the parents are very much in need of mental health intervention themselves to assist them in dealing with the situation they face. Without such intervention, it would be inappropriate to consider them neglectful with respect to their daughter's care, although the effect is the same on Joyce in that she doesn't get the care she needs. Creative efforts would need to be made to find ways to provide the assistance these parents clearly need so that they can truly provide consent (or not) for their daughter's care.

Additional issues that would likely have to be dealt with in this case include the social situation the family is in (family make-up, including siblings, the home environment, the family's economic circumstances, the parents' educational background, their cognitive abilities, any other medical or health issues in family members, etc.) and the medical insurance coverage the child has (commercial, managed care plan, medical assistance, Medicare, or none). Any plan for future care for Joyce will require consideration of all of these issues, and developing open communication with the parents is critical for this to happen.

Clearly, Joyce's situation as portrayed in this case study presents many challenges to her family and her providers. Hopefully her primary care pediatrician has a close enough relationship with her and her family to be able to assist in developing the communication link that must be in place before decisions can be made about this child's care.

While, as initially discussed above, this child could be considered medically neglected and therefore reportable to the local social services agency for investigation, the perspective presented above would indicate that further involvement with the parents needs to occur before they might be considered neglectful. One way or another, for Joyce's sake, her best interests have to be pursued, hopefully with her parents' involvement and agreement, but if necessary, through the local social service agency and juvenile court.

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We welcome comments to this case study, including how cases such as this are handled at your institution. Please e-mail your comments to MHECN@law.umaryland.edu.

CALENDAR OF EVENTS

APRIL [old stuff from last newsletter below]

- 9-10 The President's Council on Bioethics Meeting, Washington, D.C. Contact: <http://www.bioethics.gov/meetings/>.
- 23 Portrayals of Physicians in Art and Literature: From Hippocrates to the House of God, Rhonda L. Soricelli, MD, The University of Maryland Medical Systems' Medical Humanities Hour, UMMC Shock Trauma Auditorium, 4PM. Contact: hsilverm@medicine.umaryland.edu.
- 23-24 African American Perspectives in Bioethics, Georgetown University Medical Center, Research Building Auditorium. Contact: <http://clinicalbioethics.georgetown.edu/calendar/index.html>.
- 30 – Oct. 2 Creating Pathways For Care at the End of Life, 19th Management and Leadership Conference, Washington, DC, USA. Sponsored by the National Hospice & Palliative Care Organization. Contact: <http://www.nhpco.org/MLC2004>.

MAY

- 1 Futile Care: When & How Can Healthcare Providers Say 'No,' sponsored by Sentara Center for Healthcare Ethics, Norfolk, VA. Contact: jmwest@sentara.com or (757) 668-4263.
- 5 "I'm demented and I want to vote," addressing the ethical, legal and social issues raised by voting by persons with dementia. Speaker Jason Karlawish, MD. The Emanuel & Robert Hart Lecture Series, sponsored by the University of Pennsylvania Center for Bioethics, 3401 Market St., Ste. 320, Philadelphia, PA. (12N-1PM). Contact: 215-898-7136 or visit: <http://www.bioethics.upenn.edu>.
- 14 Talking to Patients/Surrogates about Dying: Clinical Approaches, Ethical Obligations, and Maryland State Law. Evan DeRenzo, PhD, Steve Selinger, MD, and Jack Schwartz, JD. The University of Maryland Medical Systems' Medical Humanities Hour, UMMC Shock Trauma Auditorium, 4PM. Contact: hsilverm@medicine.umaryland.edu.
- 14-16 Humanity, Technology, and Perinatology: Good Ethics Based on Good Information. A conference on perinatal ethics, including palliative care, pain and symptom management. Sponsored by the National Perinatal Association. La Jolla Marriott Hotel, San Diego, CA. Contact: Anita Catlin, catlin@sonoma.edu, or visit <http://www.nationalperinatal.org>.
- 17-20 Spotlight on Quality, Focus on Residents, sponsored by Last Acts and the National Citizens' Coalition for Nursing Home Reform (NCCNHR), Hilton, Crystal City, Arlington, VA. Contact: Jennifer Hirsch, 202-332-2275, jhirsch@nccnhr.org, or visit <http://www.lastacts.org>.
- 22 WV Center for End-of-Life Care Bi-Annual Summit - Ethical and Legal Issues in Respecting Patients' Choices at the End of Life. Speakers include Jack Schwartz, JD, Maryland Attorney General's Office, and Bud Hammes, PhD, Gundersen Lutheran Medical Center. Marriott Charleston Town Center, Charleston, West Virginia. Contact: Cindy at 877-209-8086.
- 28-31 6th Annual Meeting of the American Society for Bioethics and Humanities, Marriott Philadelphia, Philadelphia, PA. Contact: <http://asbh.confex.com/asbh/2004/>.

JUNE

- 10 Georgetown Fall Bioethics Colloquium, Sponsored by the Center for Clinical Bioethics, Warwick Evans Conference Room, Building D at Georgetown University. (4:30PM). Contact: Marti Patchell, 202-687-1671.
- 17 Speaker Dominick L. Frosch, PhD, Robert Wood Johnson Health and Society Scholar, University of Pennsylvania (topic TBA), The Emanuel & Robert Hart Lecture Series, sponsored by the University of Pennsylvania Center for Bioethics, 3401 Market St., Ste. 320, Philadelphia, PA. (12N-1PM). Contact: 215-898-7136 or visit: <http://www.bioethics.upenn.edu>
- 18 Medicine in an Unjust World: Neglect of Easily Preventable Diseases as an Abuse of Human Rights. David Hilfiker, MD. The Dr. and Mrs. Howard B. Mays Lectureship in the History of Medicine and Ethics. University of Maryland Medical Center, Shock Trauma Auditorium, 4PM. Contact: hsilverm@medicine.umaryland.edu.

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- * The 7th Annual Lecture Series in Palliative Care begins September 27th, and is held every Monday and Thursday until November 4 at Johns Hopkins Hospital, Hurd Hall, 5-6PM. Visit www.hopkinscme.net for a list of topics and CME registration information.

