

## Quote to note

“Are you afraid that you will look like another person?”

— Surgeon to candidates for world's first face transplant

*The Boston Globe*  
September 18, 2005

## Inside

### Ask the ethicist

Does anyone actually invoke their hospital futility policy?  
By Jeffrey Burns, MD, MPH

3

### The legal column

Who should capture the value of donated tissue?

By Robert A. Katz, JD

4

### A medical ethics forum from Harvard Medical School

Soliciting organs on the Internet

Robert D. Truog, MD  
Jeremiah Lowney, MD  
Douglas Hanto, MD, PhD  
Arthur Caplan, PhD  
Dan Brock, PhD

5

### Ethics and the humanities

Million dollar booboo

Review by David Goldblatt, MD

9

### Dialogue

The politics of embryo transfer

By Mary Anderlik Majumder, JD, PhD  
Sarah-Vaughan Brakman, PhD

10

A question of status

Michael W. McDonald, MD

11

The opinions expressed in the journal, *Lahey Clinic Medical Ethics*, belong to the individual contributors and do not represent the institutional position of Lahey Clinic on any subject matters discussed.



in collaboration with  
Dartmouth-Hitchcock  
Medical Center

# Medical Ethics

Fall 2005  
Vol. 12, Issue 3

## Transgenderism

**Norman Spack, MD**

*Assistant Professor of Pediatrics, Harvard Medical School  
Clinical Director, Endocrine Division, Children's Hospital, Boston, MA*

**T**ransgendered individuals are people who, by all known biologic measures, are male or female, yet feel like a member of the opposite sex. The discomfort they suffer is called gender dysphoria. There is a relatively rare condition and cannot be explained by factors such as chromosomes, prenatal hormones or toxin exposure, genital variability, postnatal circulating hormone levels, gender of rearing, birth order, or the presence or absence of same-sex siblings.

Is it possible that the brains of the transgendered are uniquely “wired”? Subtle differences between female and male brains have been reported for decades in research studies that identify gender-related size differences between specific brain nuclei by staining slices of post-mortem specimens.<sup>1</sup> One recent study showed that the nuclei of transgendered male-to-females (MTFs) are the size of the nuclei of genetic females.<sup>2</sup> An earlier study revealed that males dying of prostate cancer who had been treated for years with female hormones, and females dying of virilizing adrenal tumors, had nuclei consistent with their genetic sex.<sup>3</sup> Their hormonal exposure did not affect the gender-specific nuclei of their brains.

Gender dysphoria is listed as a psychiatric condition in the psychiatric diagnostic coding manual DSM-IV. I believe that the psychiatric manifestations are a reaction to the situation, not the underlying condition. A transgendered individual who has not had hormonal therapy or surgery may require psychopharmacologic medications, but after a patient receives medical and/or surgical treat-

ment, psychotropic medicines are often unnecessary.

Nearly all transgendered adults recall feelings of being in the wrong body early in childhood. Patient histories resonate with the common theme of dressing secretly in the clothes of the opposite gender during childhood. However, the age at which a transgendered individual fully acknowledges his or her gender identity varies from mid-childhood to middle age. Delayed acknowledgment can usually be traced to a fear of stigmatization and rejection by family, friends and employers.

The majority of children who express recurrent interest in being the opposite sex are not transgendered, although many become homosexual.<sup>4</sup> A small percentage of children who are emphatic and consistent in their desire to be the opposite gender (less than 20% of the above) prefer to be called by a pronoun and name consistent with their gender identity. Their friends, dress and activities correspond with that identity. Their greatest fear is puberty because of the irreversible changes that threaten how they are perceived (their “gender attribution”). During adolescence, when unwanted and permanent secondary sexual characteristics transform the patient’s body into an adult form that is asynchronous with the brain, depression and anxiety are typical reactions. When menses become a monthly reminder of femaleness in a teenager with a male identity, self-abusive behavior is common. The incidence of suicide among transgendered youth is high.<sup>5</sup> Adult transgendered individuals who find it

*Transgenderism — continued on page 2*

threatening to acknowledge their gender identity publicly may adopt a lifestyle of marriage and parenthood that matches their genetic sex. Inevitably, maintaining this charade takes its psychic toll.

Who is qualified to assess a patient's condition for referral for endocrine treatment and ultimate surgery? "Standards of care" have been created by the Harry Benjamin International Gender Dysphoria Association, a professional society that includes mental health professionals, endocrinologists, internists and surgeons ([www.hbigda.org](http://www.hbigda.org)). The standards define stages of treatment, beginning with "extensive exploration of psychological, family and social issues" by a mental health professional who has abundant experience working with this population, and only then moving to physical intervention, which should take place in stages, from reversible to irreversible interventions.

Physicians may be uncertain how to address transgendered patients who have not legally changed their name and gender but have transitioned to a gender role consistent with their gender identity. Some states require reconstructive surgery—genitoplasty or mastectomy—before allowing name and gender changes on documents such as driver's licenses and health insurance cards. Whether or not patients have made legal changes or undergone surgery, they are entitled to the dignity of being referred to by the name and pronoun of choice. Male-to-female patients should be offered a gown in the exam room, and female-to-male (FTM) patients should be asked what they prefer to wear during the exam. No assumption should be made about the patient's sexual orientation. Like anyone else, a transgendered individual may be straight, gay or bisexual. Sexual orientation reflects physical attraction, not gender identity.

The labeling of transgenderism as a psychiatric condition has the ironic effect of inducing psychological problems in transgendered individuals. This fuels the notion that a psychiatric disorder is at the heart of the condition, which influences the diagnostic coding and billing structure. Under the DSM-IV code, few health insurers in the United States cover the cost of hormonal replacement therapy. Mastectomies in FTMs, which cost \$6,000 to \$10,000, and genitoplasties (sex reconstructive

surgery) in MTFs, which cost \$15,000 to \$25,000, are considered by almost all health insurers to be cosmetic surgeries on patients with a mental illness.

To enable patients to transition physically, endogenous gonadal sex steroid output must be lowered to levels consistent with the gender of choice, which may not be easy. Both MTFs and FTMs require suprphysiologic doses of "cross-hormones": estrogen for MTFs, testosterone for FTMs. High dose estrogen poses a risk of blood clots, which can be fatal if they travel to the lungs (pulmonary embolism) and doses of testosterone sufficient to prevent menses can induce hypertension, cystic acne and excess red blood cell production with the risk of blood flow "sludging." Alternatively, endogenous sex steroids can easily be suppressed by GnRH analogues, which block pituitary gonadotrophin (LH and FSH) release, enabling cross-hormone treatment to be accomplished with safer physiologic doses of estrogen or testosterone. Unfortunately, GnRH analogues are prohibitively expensive in the US, and patients are forced to take the higher doses of sex steroids until they have their gonads removed. Genitoplasty in MTFs and reduction mammoplasty in FTMs are not covered by most health insurers, and patients may have to wait years saving for it.

In the Netherlands and Belgium, national health insurance covers all costs related to evaluation and treatment of transgendered individuals, including children.<sup>6</sup> Interdisciplinary gender teams evaluate patients psychologically, and patients become potential candidates for sex reconstructive surgery at government expense after living for at least a year in the gender of choice (the "real-life experience") while taking corresponding sex steroid hormones. This discrepancy in coverage across nations raises questions about US health insurance policy decisions.

Because treatment with cross-gender hormones has irreversible effects, challenging choices inevitably arise. For the MTF, estrogen produces breast enlargement and diminished sperm production. Some MTFs request sperm banking before estrogen treatment or gonadectomy just to maintain their reproductive capacity, regardless of who will receive that sperm. For the FTM, testosterone produces a deeper voice, facial hair, temporal balding. Loss of ovulation and menses ensue, and the

ovaries become polycystic while retaining retrievable ova. When cryopreservation of ova becomes technically routine and successful, some FTMs will request the procedure to serve as egg donors for their partner or surrogate.

A significant ethical question in transgender care concerns potential intervention with children. Should transgendered children who have had a careful and protracted evaluation by a skilled gender specialist be compelled to complete puberty before being offered the same therapy used for adults? No national or international protocol exists, and there are opposing views on how to proceed. One side argues that physical intervention should be delayed until the completion of puberty because teenagers are more likely than adults to change their minds about their gender identity. The opposing view, with which I concur, argues for early endocrinologic intervention to prevent the severe depression that accompanies the onset of an unwanted puberty and to avoid the physically and psychologically painful procedures required to reverse puberty's physical manifestations.

A model protocol currently employed in the Netherlands begins with a lengthy screening process in gender-variant pubescent teens at the "Tanner 2" stage of pubertal development: breast budding in girls and testicular enlargement in boys. At this stage the pubertal manifestations are reversible. GnRH analogues are given for at least two years, potentially until age 16, when adolescents in the Netherlands are capable of giving informed consent to receive cross-hormones. By blocking puberty, GnRH treatment buys time for FTMs to achieve a height more typical of males and for continued assessment of all patients' desire to transition. If the Dutch clinical trial proves medically and psychologically safe, it will become the standard of care in the Netherlands, and treatment will be covered by the government health insurance.

Adoption of such therapy in the US, except by a research protocol, is unlikely to be reimbursed by most health insurers as long as transgenderism continues to be coded and billed as a psychiatric condition. The only alternative drug capable of achieving comparable gonadotrophic suppression is high dose progesterone, which has effects similar to high dose

## Ask the ethicist:

# Does anyone actually invoke their hospital futility policy?

**Question:** The clinicians in the Intensive Care Unit (ICU) seek to invoke the hospital futility policy over demands for treatment by the parents of a patient in their unit and ask the advice of the hospital ethicist. The ICU clinicians believe that the parents are insisting on interventions that will merely prolong the dying of their child and seek consultation and assistance from the hospital ethicist in overriding the parents' authority to make medical decisions about life-sustaining treatments.

The child is 14 months old, was delivered prematurely at 24 weeks and now has multi-organ failure. He has MRI findings of extensive hypoxic-ischemic brain injury, dependence on inotropic support for biventricular insufficiency, dependence of mechanical ventilation for chronic respiratory failure from hyaline membrane disease, dependence on parenteral nutrition and a colostomy for short gut syndrome from necrotizing colitis, and dependence on dialysis for chronic renal failure. The clinicians believe the toddler demonstrates evidence of feeling pain and discomfort. However, they have been hampered in their ability to provide complete symptom relief by the parents who believe narcotic analgesics interfere with the child's cognitive development. In multiple family meetings the parents have been told by the ICU attending physician that their baby cannot survive and the interventions he is getting now are simply prolonging his dying. The ICU nursing staff members uniformly support this assessment and have consistently relayed the same prognosis at the bedside. All clinicians agree that the toddler's parents are rational, loving and very devoted to their son whom they visit for 5 or 6 hours every day. The parents both work in the health care field. This is their first child. They remain hopeful and are willing to take their little boy home "in any shape."

**Response:** The late Supreme Court Justice Potter Stewart once remarked of pornography, "I shall not today attempt further to define the kinds of material I understand to be embraced within that shorthand description; and perhaps I could never succeed

in intelligibly doing so. But I know it when I see it..."<sup>1</sup> So too with futility. It is difficult to define but we know it when we see it. But how should ethics consultants respond when they "see it"?

Helft and colleagues noted that discussions of futility can be grouped into four categories: attempts to define medical futility, attempts to resolve the debate with the use of empirical data, discussions that cast the debate as a struggle between the autonomy of patients and the autonomy of physicians, and attempts to develop a process for resolving disputes over futility.<sup>2</sup> Our Ethics Committee long ago abandoned definitional attempts at futility and instead adopted a procedural approach to futility cases. We agree with others who see attempts to define futility as illusive, for such attempts only expose and exacerbate a clash of values and fail to provide an ethically coherent ground for limiting life-sustaining treatments.<sup>3</sup>

Our institution has adopted process over definitional attempts to address concerns about futility. This approach is backed by our hospital policy on futility that was developed over a year long process in 1997, with broad input from the community and with attention to the diversity of individual values and goals. The futility policy is disclosed in the public record and outlines a series of steps in dispute resolution, as well as a mechanism to assist a patient or their family in an appeal process before the court if necessary, and leaves open the possibility of transferring the patient's care to another physician or institution. These features of a futility policy have been deemed essential by other institutions as well.<sup>4</sup> Our futility policy culminates in the institution sanctioning "...the unilateral foregoing or removal of life-sustaining treatments" if all previous steps fail to resolve the conflict.

Yet, despite an increasing number of ethics consults on questions of futility we do not invoke our own futility policy. Why? We have concluded that our hospital futility policy is sound in theory but less so in actual practice. First, not placing our futility policy formally in motion on these consults allows a more flexible ad hoc process in dispute resolution.

The absence of a formal document that outlines the crescendo in the dispute resolution process when performing a consult on futility, in our experience, paradoxically seems to avoid the aura of an inevitable path to confrontation and thus mitigates a polarization of positions. If the parties are not aware of the trajectory of the formal policy, more room for common ground appears to be preserved. Second, the simple fact is that the mission of a large, academic pediatric medical center does not align with a public confrontation with parents over the benefit of life-sustaining treatments for their child. Third, the low key, ad hoc process outlined above eventually gets us to a point of mutual acceptance by all parties in the dispute. At the end of the day a consequentialist rather than Kantian approach to ethics case consultation on issues of futility is most effective.

**Jeffrey Burns, MD, MPH**

Chief, Division of Critical Care Medicine

Co-Chair, Ethics Committee

Children's Hospital

Associate Professor of Anesthesia (Pediatrics)

Harvard Medical School, Boston, MA

**Outcome:** After more than a dozen meetings with the hospital ethicist and ethics consult team, the parents and caregivers reached agreement on decision-making about analgesia, concluding that narcotics would be given if the clinicians or parents felt that the child was experiencing discomfort. The parents and caregivers also reached agreement on an order to withhold specifics steps in resuscitation and to withhold further escalation in life-sustaining treatment. The clinicians reported that being able to provide symptom relief to the infant removed enough of their reservations about burdensome treatments to continue to support the parents' medical directives. □

<sup>1</sup>*Jacobellis v. Ohio*, 378 U.S. 184 (1964).

<sup>2</sup>Helft PR, Siegler M, Lantos J. The rise and fall of the futility movement. *N Engl J Med* 2000;343:293-296.

<sup>3</sup>Truog RD, Brett AS, Frader J. The problem with futility. *N Engl J Med* 1992;326:1560-1564.

<sup>4</sup>Haley A, Brody BA. A multi-institution collaborative policy on medical futility. *JAMA* 1996;276:571-574.

## Who should capture the value of donated tissue?

By Robert A. Katz, JD

Associate Professor of Law and Philanthropic Studies,  
Indiana University School of Law – Indianapolis

**W**hen implanted into another person, human organs and tissues can significantly enhance or even save a recipient's life. Yet unlike solid organs, most tissues undergo substantial change in their journey from donor to recipient. In recent years, scientists have increased their ability to manipulate or "process" tissues to increase their therapeutic value. Bones can now be demineralized and made into a putty or gel; when packed or injected into bone voids, this material can stimulate the formation of new bone.<sup>1</sup> Skin can be decellularized while preserving its biological framework; then it can be absorbed by the body without rejection and promote the regeneration of new skin.<sup>2</sup> These and other technologies have been pioneered by several for-profit, publicly-traded corporations that sell tissue products and related services. In 2004, the four leading for-profit tissue processors had combined revenues of over \$300 million.<sup>3</sup>

Tissue processors obtain raw tissue from nonprofit tissue procurement organizations or "tissue banks." Some tissue banks are also organ procurement organizations (OPOs), while others recover only tissues. As with organs, tissues are voluntarily supplied by altruistic donors and next-of-kin. Most tissue banks do not inform potential donors that for-profit firms may process donated tissue. The concern is that such information might discourage donations, as in "I'm not donating my loved one's tissues in order to make money for some corporation's investors." It is also feared that such disclosures might spur donors to restrict for-profit entities from processing their donations. Accordingly, many leaders in the tissue industry oppose a federal proposal to require tissue-procuring OPOs to tell potential donors whether for-profit firms will be involved.<sup>4</sup>

Public relations aside, is anything wrong with involving for-profit firms in tissue processing? In theory, no, as federal law bans the commodification of donated tissue as such. The National Organ Transplant Act of 1984 (NOTA) prohibits the purchase or sale of body parts for use in transplantation.<sup>5</sup> At the same time, NOTA recognizes that participants in the transplantation process must be compensated for their expenses and efforts. To this end, NOTA permits "reasonable payments" for goods and services rendered in connection with transplantation.<sup>6</sup> Under NOTA, industry participants wouldn't actually sell donated

tissue; they would simply ask a fair price for the value they add to the tissue.

In practice, however, NOTA does not and likely cannot achieve its aims. Although federal law bans the transfer of tissue for "valuable consideration," it does not render such tissue valueless.<sup>7</sup> The economic value of donated tissue originates in the willingness and ability of would-be recipients to pay for it. Under NOTA, recipients should pay nothing for the tissue itself—only the value added by tissue banks, tissue processors and other intermediaries. This is precisely what would happen if the tissue industry was perfectly competitive: Intermediaries would earn at most a market rate of return (a.k.a. "normal profits") for the value they add, and recipients would enjoy all the value embodied in the tissue itself.

Among the various intermediaries in the tissue industry, tissue banks follow NOTA's commands most closely: They generally sell tissue for no more than the cost to procure, handle, inspect and ship it, plus normal profits (5–10%) for overhead, capital improvements, etc.<sup>8</sup> For-profit processors are not as scrupulous. By design, such enterprises aim to maximize their net profits and so price their products accordingly. This profit imperative weakens the link between what processors charge for tissue and the value they add to it. If the market will bear it, processors will seek "super-normal profits," i.e., more profit than necessary to keep them in the processing business. Moreover, some processors earn super-normal profits, either because their name recognition and brand loyalty enable them to charge more or because their lowered production costs enable them to earn more profit with each sale. These processors appropriate some of the tissue's inherent economic value for themselves, instead of passing it along to recipients. They then distribute the value of donated tissue—a charitable resource—for the private benefit of their investors.

If not processors, who should capture the economic value of donated tissue? If the free market prevailed, donors and their next-of-kin would do so, but society is not ready to let this happen. If NOTA were effectively enforced, recipients would obtain this economic value. But how to make that happen? One way might be to appoint regulators to set reasonable rates of return for for-profit processors and restrict prices to keep firms from exceeding these rates.

Another approach requires a modification in NOTA. Under the current regime,

tissue banks generally earn no more than normal profits, even if processors are willing to pay more. This arrangement enables—if not invites—processors to appropriate the tissue's economic value and so earn super-normal profits. This appropriation can be stopped, however, by letting tissue banks earn super-normal profits. This change would effectively redistribute the tissue's economic value from processors to tissue banks. Because the market for processed tissue still functions reasonably well, these processors might settle for smaller profits (but not less than normal profits), rather than pass on their increased costs to recipients.

Transferring tissue's economic value to tissue banks could have significant and beneficial consequences. Because tissue banks are organized on a nonprofit basis, they must use any new income to advance their charitable missions and to finance their services, rather than enrich private parties. They would thus have more resources to educate the public about donation and transplantation, provide counseling and bereavement for donor families, improve the quality of their facilities and subsidize transplants for people who need but cannot otherwise afford them. They could also direct the development and production of tissue-based products based on medical need and social concerns, rather than profit. Granted, donors might prefer recipients to capture the tissue's value. If this option is not feasible, however, donors would likely prefer that it go to nonprofit tissue banks rather than for-profit tissue processors, a result more consistent with the altruism that motivated their decision to donate.

Before making any changes, however, we should consider the advantages of the current arrangement. By letting processors capture the economic value of donated tissue, they have more incentive and resources to develop new therapeutic uses for it. And though the status quo does not stop the commodification of donated tissue, it partly conceals it from public view by interposing a nonprofit entity between altruistic donors and profit-maximizing processors. If tissue banks could earn super-normal profits from their activities, the commodification inherent in the tissue industry would become harder to hide. This might deter people from becoming donors. On the other hand, a conscious policy of

*Legal Column* — continued on page 9

## Soliciting organs on the Internet

*This is an edited transcript of a forum presented by the Harvard Medical School Division of Medical Ethics in May 2005.*

**Robert D. Truog, MD, Moderator,**  
*Professor of Medical Ethics & Anaesthesia (Pediatrics), Harvard Medical School, Children's Hospital Boston*

Suppose you need a kidney transplant. You will probably be put on the waiting list at your local transplant center and maybe the waiting lists in some other regions as well. But the waiting times are long, you are impatient and you want a kidney soon. So, you think about asking others to see if there might be someone who is willing to undergo major surgery and to give up one of their kidneys on your behalf. You start by

---

*All of these options are equally legal, but they don't strike everyone as being equally ethical.*

---

asking your close family members if they would be willing to give you a kidney. When that doesn't work out, you begin to widen your search. You ask members of your extended family and acquaintances, but still without success. And then you learn that there is a Web site, [www.MatchingDonors.com](http://www.MatchingDonors.com), where for a fee you can advertise your need all over the world and hope that a generous stranger will read about your plight and come to your rescue.

All of these options are equally legal, but they don't strike everyone as being equally ethical. In general we are most comfortable when the donor and recipient share a strong relational bond, as

with a family member or a close friend. As we move outside of that circle, however, we become increasingly concerned that the donor's choice may not be sufficiently autonomous or motivated by altruism. We also worry that these practices might undermine one of the most important principles of organ transplantation—the premise that organs are a gift of life—by tempting patients who are desperate for organs and those who are desperate for money to turn organs into mere commodities that can be bought and sold.

**Jeremiah Lowney, MD, Medical Director of MatchingDonors.com and internist in private practice in Hyde Park, Massachusetts**

I have been involved with MatchingDonors.com since its beginning. Over the course of time, I have developed a deep compassion and understanding for what people go through who are waiting for organs. I got involved in this Web site because a patient of mine, Paul Dooley, came to me. His father was very ill and was in need of a kidney transplant. He was told by his physician, however, that by the time a kidney became available, his father probably would be dead. Obviously this disturbed not only Paul but also his dad. His dad eventually died. Paul runs a Web site that matches employers to employees. He has been doing this for five or six years, and he said, "You know, I have this Web site. I understand how matching Web sites work. Is there a way that we can match people who are in need of an organ transplant with people interested in being live donors?" I told him that I wasn't sure. I didn't know how many people would be willing to be live organ donors for complete strangers, but I told him I would look into it. I did some research and discovered that the National Kidney Foundation had done a survey of about 1,000 people.<sup>1</sup> They were asked, "Would you be willing to donate a kidney to a

complete stranger?" Almost 25 percent of those who responded said yes. So, I called Paul and said, "You know, your idea actually may end up helping a lot of people."

That conversation took place in October 2003. We have learned a lot over the course of the last year or so. We have learned a lot about the patients and, although you never really know what they are going through unless you have lived through it, we have learned a lot about how they feel and how difficult it is to be someone waiting for an organ. We have learned a lot about transplant hospitals and how difficult it is for them. We have learned a lot about the United Network for Organ Sharing (UNOS) and their waiting list. We have learned that there are now almost 89,000 people waiting for an organ. In 1993, just 31,000 people were on those waiting lists. So, over the course of 12 years, we have almost tripled the number of people waiting for an organ.

I am proud of what we do at the Web site. I am proud of the people who work for it. To date, we have had seven people who have been successfully matched with immunologically compatible kidney donors through our Web site and who have had successful surgeries. As of yesterday, we have 22 people who have been matched on our Web site and who have gone through their preoperative evaluations and are waiting for their surgical dates.

This Web site raises many ethical questions, and I will try to give my best answers for them. First, is it ethically acceptable not to allow a person in need of an organ transplant to actively search on his or her own for one? Is it ethically acceptable to allow patients to receive an organ from family members or friends, but not to allow patients who may not have a brother or sister or close relative to receive an organ from another? Is it

*Soliciting organs — continued on page 6*

ethically acceptable to allow someone to announce at their place of worship or a community center that they are in need of an organ transplant but not allow them to use the Web, as a larger community, to search for that organ? And is it ethically acceptable to allow 17 people a day to die while waiting for an organ transplant, while there are potentially thousands of people out there willing to help them? My answer to all these questions is no.

*Douglas Hanto, MD, PhD, Professor of Surgery at Harvard Medical School, Chief of the Division of Transplantation at Beth Israel Deaconess Medical Center, Chair of Ethics Committee of the American Society of Transplant Surgeons*

I can't imagine a more difficult situation than being on the transplant list waiting for an organ transplant, or having a loved one suffering on dialysis or in liver or heart failure waiting for an organ transplant. As a surgeon, my career has been devoted to improving the health of patients with organ failure. Nothing hurts more than seeing patients chronically ill or dying on the waiting list.

What is the history behind our current system of allocation? When I was a surgical resident at the University of Minnesota, before UNOS was established, individuals were soliciting organs publicly. Charlie Fisk went on national TV to find a donor for his daughter, Jamie, who needed a liver transplant and was hospitalized at the university. Who could blame him for doing so? Did it work? Yes, absolutely it worked for his daughter. But what about all the other patients like Jamie, whose fathers did not have the energy or resources that Charlie Fisk had. Clearly it was not fair to them. This is what led to the formation of UNOS. As a community we all have to face up to the fact that we have to make choices about allocation. They are tough choices, but they must be made in a way that is fair to all. The problem is that we don't have enough organs. The problem is not how they are allocated.

For these reasons, I believe that solicitation by individuals or families for deceased donor organs and directed

donation to specific individuals will undermine the trust and fairness on which UNOS currently exists. I believe that solicitation of organs from living donors is just as wrong.

What about the arguments in favor of bypassing the UNOS system? One argument is that the living donor or deceased donor family should be able to give their gift to anyone of their choosing, just as we might donate food, clothing or money to a charity of our choice. This view is flawed, however, in that organ donation is not a purely personal transaction but occurs within the context of a transplant team and a public institutional structure. Directed donation ties donation to the emotional appeal, public relations skills, photogenicity and financial resources of the patient, family and others involved in the campaign. It assumes that the person soliciting for the organ is ethically special because of some characteristic that allows an exemption from criteria that apply to everyone else.

The principle of autonomy does not mean that we have an unqualified right to self-determination. Rather the donor's action is subject to the competing and legitimate rights of others, specifically all of the patients on the waiting list. If the individual choice infringes on equality and justice, it is not a legitimate exercise of autonomy and must be rejected.

If altruistic donors understand the fair policies of organ allocation, they will

---

*"...the donor's action is subject to the competing and legitimate rights of others..."*

---

be willing to donate their organs to the neediest recipient, as a non-directed donation. In the case of deceased donors, this will be according to the established allocation policies. In the case of living donors, I would argue that this would be according to the transplant center's waiting list, to which the donor has volunteered.

Let me review more briefly some of the other problems of directed dona-

tion, most applicable to either deceased or living donors. In the 1980s several prisoners volunteered to be organ donors. When they were released from prison, they sought out the recipients and tried to extort money from them. The experiment was ended. There have been documented instances where potential recipient family members have solicited donor families in waiting rooms and intensive care units. In other cases, families have monitored police and ambulance communications to identify hospitals where potential donors were being taken. The family members of potential recipients then approached the family of the victim, seeking directed donation to their loved one.

In conclusion, directed donation, except in the context of relatives or friends, unfairly directs organs away from the neediest patients on the waiting list and bypasses approved allocation policies. New England transplant programs and other programs across the country have been performing non-directed transplants from volunteer donors for many, many years. These programs need to be expanded by educating the public more about the options for voluntary living donation. If altruistic donors understand the fair policies of organ allocation, I believe they will be willing to donate the organs to the neediest recipient as a non-directed donation. It is already being done effectively in New England and elsewhere and needs to be expanded.

*Arthur Caplan, PhD, Professor of Bioethics, Chair of the Department of Medical Ethics and Director of the Center for Bioethics at the University of Pennsylvania*

Transplantation was what got me interested in bioethics, and I have been working in this field since it began. I believe that transplantation is a worthwhile and good thing. All that said, I have had, and continue to have, a lot of doubts and reservations about living donation and so, part of my problem with Web brokering or solicitation of strangers to act as living donors is not just linked up to the Web. After all, the Web is just a tool. It is just one way for people to find one another. But I have some reservations on ethical grounds

more generally about the practice of living donation.

Let me present to you something I have labeled Caplan's paradox. Caplan's paradox relates to a spectrum. At one end is the voluntary, altruistic, well-informed person who freely decides to choose to donate an organ to a family member. I doubt we are going to hear anybody on the panel, except maybe me, say that they are very worried about a brother who gives a kidney to his brother, who understands what is going on, who knows the risks that are involved, who is not being paid any money under the table, who has a reasonably good idea that the brother will benefit and goes into it eyes open. But at that end of the spectrum, we must recognize that it is obviously difficult emotionally to disassociate yourself from the fact that it is your brother. An old friend of mine once told me, "I don't know why you bioethicists spend so much time on the informed consent issues with living donors." When I asked her what she meant, she said, "Because when we ask people whether they are going to give bone marrow or a kidney to someone, they make up their mind in a second. 'That is my brother. Of course I will give him my kidney or bone marrow.' Or, 'That is my brother. I would never give that jerk my kidney or bone marrow.'" So, you can see the emotional pull that we associate with family roles correlates very strongly with their emotional ties. These ties might even extend to my buddies in the firehouse. They might extend to my fellow members at my church. The closer you are emotionally related, the harder it is to say that your choice is based on careful deliberation and reasoning. Some of what you do is simply because you think your role as parent, brother, friend or close associate makes the choice for you. In other words, it may be acceptable to act out of a love for one's family member to give up a kidney, but it isn't a voluntary choice in the purest sense of that term.

At the other end of the spectrum, we have people who fly into town and say, "I read in the paper that someone needs an organ, and I am going to give them an organ" or someone who says, "Jesus spoke to me last night, and I am here to give up a piece of my liver today." We recognize that it is possible for someone

to be motivated by regard for one's fellow man or religious motives. Even so, it is impossible not to wonder what sort of person comes in from out of the blue to give somebody an organ. Can we trust someone who says he is responding to

---

*"...it is impossible not to wonder what sort of person comes in out of the blue to give somebody an organ."*

---

voices he has heard in his head? Competency becomes suspect at this end of the spectrum.

In other words, when dealing with close family members or friends, there is voluntary and free choice, but it is clouded by emotion. At the other end of the spectrum, when the participants are strangers, we start to worry about the competency of potential donors who appear out of nowhere and say they want to help. We do not have, by any measure or means that I know, a reliable way of discerning between Good Samaritans and true altruists versus those who have psychological problems or who are acting on impulse.

If you accept this paradox, then you have to be very worried about how to assess competence or motive. Are the donors acting on impulse, because of money, because of psychiatric issues or something else? The problem in the field of living donation is that there is hardly any regulation in terms of how to screen and assess donors. Different programs do different things. Some don't do much at all. I know one or two programs who do no psychiatric, psychological or social work assessment whatsoever. This raises questions about the business side of transplantation. Programs are very eager to get people into their programs, not just to save lives, but because there is a lot of money to be made. But what about looking after the interests of the donor? This is a fundamental weakness in living donation. There isn't much in the way of donor advocacy, and there are not agreed upon

standards for how to assess donors and make decisions about who should be eligible to be a living donor. Without those standards, the whole process of living donation is fraught with danger.

*Dan Brock, PhD, Professor of Medical Ethics, Director of the Division of Bioethics at Harvard Medical School*

I want to look at three ethical issues that are raised by directed donation over the Internet. First, is an organ a private or public resource? Second, is directed contingent donation (that is, naming the recipient of your organ) ethically objectionable in itself, and third, is it unfair to either donate or to get an organ outside of the UNOS system?

Let me start with the first question, "Is my kidney or your kidney a private or a public resource?" The philosopher Judy Thompson once said that, "If I own anything, I own my body." This being the case, a surgeon cannot take my kidney without my permission, even though I can get by without it, and someone else with renal failure would be much better off with it.

In addition to thinking it would be wrong to take an individual's organs without their consent, we also think it is morally permissible for individuals not to donate, even to others who are in great need. We don't criticize people for not donating, at least absent some special obligation to the potential recipient.

All this suggests to me that a kidney is a private resource. Now, if one of you donates your kidney to UNOS to be allocated by a fair system such as the one used for deceased donor organs, then I think it becomes a public resource. I don't think this is true, as Dr. Hanto argued, because it takes a social network to get a kidney from one individual into another. If I want to help people who are starving in Bangladesh, I can't do that by myself either. The fact that it requires that social network doesn't transform my resources into public resources. I think the same thing is roughly true in the transplant context. If the organ is donated to UNOS, it then does become a public resource, to be used according to the rules of that system. If the organ is instead donated to a specific individual, then I think the

*Soliciting organs — continued on page 8*

organ becomes the property of the intended recipient.

Second, what about directed donation? Is it wrong to name whom the recipient will be? Well, as several have pointed out, we already do accept this and it is a common practice. It is done in families. Why do we think it is okay there? One reason is that we believe that individuals have specific obligations to other family members that they don't have to others. This could show why someone might be required to donate to a family member, but I do not think it can show that it would be wrong to donate to a stranger. So, the fact that we have a reason for accepting directed donations to specific family members does not give us a reason for rejecting donation in the case of strangers.

If we assume that the organ would not be donated unless it went to a specified individual, then notice what happens. Someone is better off, namely the recipient of the organ, and no one is worse off as a result of this, because the organ would not have gone to anyone else. This is what typically happens in family donation. Someone is willing to donate to their brother but not to just anyone. But this could also be true with regard to direct donation to a stranger, that is, that I would donate to this specific person because I was moved in one way or another by this individual's plight, but I wouldn't just donate to anyone. So, why might it be wrong to donate to a stranger? Well, one worry here is the possibility of payments under the table. For that, we need to put practices in place that give us reasonable assurance that this is not taking place, because we don't want these resources to be auctioned off to the highest bidder. In addition, we worry about other objectionable motives. There was a case in Florida, for example, where the family of a brain-dead man found Ku Klux Klan membership cards in his wallet and insisted that his organs

go only to white recipients.<sup>2</sup> The transplant team was reluctant to participate in this expression of racism and should have been entitled to refuse, but in that case the team did ultimately take the organs, and, as a result, Florida passed laws against that kind of donation. Despite these legitimate concerns about racism, however, it is worth adding that even if an offer to provide something to someone else is done from a bad motive, it doesn't simply follow from this that the offer should not be accepted, especially if some great good will come of it, such as saving a life or improving the quality of someone's life substantially.

Is it wrong if I am giving to someone who is not the person in greatest need? This is often the case in directed donation. Well, we certainly accept this possibility in a wide variety of other circumstances. Consider, for example, donations to the United Way. For those donations, you have the capacity to say, for example, that you want your entire donation to go to one organization or you want it to go to three organizations. I doubt that, when people pick those organizations, they have even thought about whether they have picked the organizations that meet the greatest needs. So, when we are engaging in charity we have some discretion over where we want our resources to go.

The third issue is fairness. Is it unfair to others, in need of a transplant, to direct a donation to a particular patient, who presumably isn't at the top of the waiting list? Notice that unfairness arises even in directed donation among family members, because some people don't have families and so don't have this option.

In considering the fairness issue, it is important whether we think that directed donation increases the supply of organs or merely reallocates a fixed supply of organs. So let's consider each case separately. Take first the case where the donor would only donate to an identified recipient and, if this is not permit-

ted, won't donate at all. First, notice that no one is made worse off by this practice, as I have already pointed out. Those above that individual on the waiting list are just as well off as they were before. Those below that person on the waiting list are actually better off than they were before because there is one less person in front of them. So no one is harmed. Now, I do think there can be harmless wrongs, so I don't think this argument is decisive, but it is worth noting that in this case no one is made worse off by allowing directed donation to happen.

Now, suppose instead that the donor might have donated to UNOS, if he or she couldn't direct the donation to a particular individual. Then those above that individual on the waiting list are in fact worse off because an organ that would have gone to one of them now doesn't go to one of them. In this case, I think there is at least an argument that the practice may be unfair. This argument would be stronger if there were not some features of the UNOS system that I think are themselves unfair. For example, individuals can get on multiple waiting lists around the country, increasing their increases chances of getting an organ. Since this privileges those with the resources and the savvy to game the system, there are aspects of the existing system in need of some correction before these concerns about fairness can be adequately addressed.

My conclusion is not to endorse donation over the Internet without any regulation. I think that would be a mistake. But I do think that several of the central arguments that are made against directed donation and solicitation of organs are weaker than they are sometimes supposed to be. □

<sup>1</sup>Spital A. Public attitudes toward kidney donation by friends and altruistic strangers in the United States. *Transplantation* 2001; 71(8):1061-1064.

<sup>2</sup>Veatch RM. *Transplantation Ethics*. Washington, D.C.: Georgetown University Press; 2000.

# Ethics and the humanities: Million dollar booboo

**M**illion Dollar Baby, a movie based on a short story by a former boxer and cut man, won four 2005 Academy Awards, including best picture, actress, supporting actor and director (Clint Eastwood). I will discuss the ethical dilemma presented in the film. If you don't know the plot, you should decide whether you want to read on.

Maggie, a boxer, has been sucker-punched in a title fight. She has high cervical, ventilator-dependent quadriplegia. She transfers to a rehabilitation facility, all expenses paid by the Boxing Commission. Despite competent care, she loses a leg to infection. With her career at an end and no other interest in life (she has at last rid herself of her cartoonish trailer-trash family, and she has no desire to pursue an education), she asks her devoted manager and trainer Frankie, played by Eastwood, to help her to die. She does *not* have that discussion with her doctor, whom we see only briefly.

When Frankie tells Maggie he can't do what she wants him to, she tries, twice, to kill herself by biting deeply into her own tongue. Her doctors respond by keeping her under sedation.

Frankie, a questioning Catholic, goes to his priest, who says that if Frankie does help Maggie to die, he will be irredeemably "lost." Nevertheless (in a strategy that works on the screen but would cause a patient suffering in real life), Frankie, in secret, first disconnects the ventilator, then administers a large dose of epinephrine through the IV.

This depiction of mercy killing has evoked much discussion, from persons partisan to the sanctity-of-life concept and from advocates for the disabled, some of whom believe that the able-bodied are plotting to do away with the disabled by discounting their lives, failing to acknowledge that it's "all right" to be that way. Both factions appear to have accepted the film's tacit assumption: Maggie's doctor, who has kept her alive even at the cost of a leg, and has kept her from taking her own life even at the cost of her alertness, would, if he

were to abandon the fight and let her have her wish, be no different from Frankie. He would be killing his patient. Because he can't do that, it's up to Maggie and Frankie.

Because I don't buy the story's premise, I don't—how else can I say it?—buy the punch line.

Euthanasia, suicide and assisted suicide remain choices, legal or not, for persons who have the capacity to decide whether or not to live with either disability or illness. As a person who has undergone chemotherapy, I think about decisions I may or may not act on if my illness progresses despite treatment. These choices are important, but, in Maggie's situation, *they should be irrelevant.*

Persons who retain the capacity to make decisions on their own behalf and who are receiving any form of treatment have the right to refuse it. That remains true even when foregoing treatment will surely result in death. When a person who is receiving life-sustaining treatment (usually, artificially administered hydration and nutrition, hemodialysis or mechanical ventilation) has firmly made the decision not to "live this way," euthanasia or suicide, assisted or not, is neither appropriate nor required.

As a clinical ethicist, I have talked with competent, ventilator-dependent patients who had traumatic quadriplegia or amyotrophic lateral sclerosis, to help them decide about foregoing life-sustain-

## Review by David Goldblatt, MD

Professor Emeritus of Neurology and the Medical Humanities  
University of Rochester School of Medicine and Dentistry

ing treatment. As an attending physician, I have withdrawn ventilatory support. Those experiences were difficult and deeply moving. My skills in both roles improved with experience. I do not regret my participation.

Maggie, as she was portrayed, had the capacity to make a valid refusal of treatment. Once she had made her decision, her doctor should have been the one to stop the ventilator, in accordance with a tested protocol. No physical suffering. No horrible self-mutilation. No clandestine, illegal mercy killing.

Whether or not good ethics and attention to established legal precedent could have made a good short story or a good movie is a question I shouldn't try to answer. Nevertheless, the movie had the opportunity to inform the public that, when a treatment is life-sustaining, another choice exists. Passing up that opportunity was a booboo.

As we were about to get into our cars outside the theater where we had just watched *Million Dollar Baby*, a man who recognized me and knew I am a doctor remarked on the ending. I gave him the 30-second version of this article. "That's good to know," he said. □

## Additional reading

Bernat JL, Cranford RE, Kittredge FI Jr, Rosenberg RN. Competent patients with advanced states of permanent paralysis have the right to forego life-sustaining therapy. *Neurology* 1993;43:224-225.

---

### Legal Column — continued from page 4

concealing commodification from donors may itself raise ethical problems. □

<sup>1</sup>See, for example, the Grafton® line of demineralized bone matrix (DBM) products made by Osteotech, Inc. (<http://www.osteotech.com/prodgrafton.htm>).

<sup>2</sup>See, for example, AlloDerm, an acellular dermal matrix made by LifeCell Corp. (<http://www.life-cell.com/products/95/>).

<sup>3</sup>For 2004, Osteotech and CryoLife, Inc., reported revenues of \$89 million and \$62 million, respectively. LifeCell reported "product revenue" of \$59 million, and Regeneration Technologies, Inc. (RTI) reported "net revenues" of \$93 million.

<sup>4</sup>This proposed rule, written by the Department of Health And Human Services (HHS), sets forth conditions for tissue-procuring OPOs to participate in Medicare and Medicaid programs. See 70 Federal Register 6086 (February 4, 2005) (discussing section 486.342).

<sup>5</sup>42 USC § 274e(a).

<sup>6</sup>Id. § 274e(c)(2).

<sup>7</sup>Pinkdyck RS, Rubinfeld DL. *Microeconomics*. 4th ed. Upper Saddle River, NJ: Prentice Hall; 1998:298.

<sup>8</sup>Anderson MW, Schapiro R. From donor to recipient: the pathway and business of donated tissues. In: Youngner SJ et al., eds. *Transplanting Human Tissue: Ethics, Policy, and Practice*. Oxford: Oxford University Press; 2003:12-13.

## Dialogue:

# The politics of embryo transfer

I will examine aspects of the current embryo “adoption” controversy introduced by Sarah-Vaughan Brakman (*Lahey Clinic Medical Ethics*, Spring 2005) through the lens of law and policy. I will begin by looking at possible legal and policy responses to the concerns of those who regard an embryo as morally equivalent, or nearly morally equivalent, to a child.

## Legal and Policy Responses

Our society is sharply divided over the moral status of a human embryo. If the segment of society committed to full(er) moral status for embryos is given some policy space, at least three options are possible: 1) avoid any public expenditure that supports or promotes embryo destruction, 2) expend public funds to promote the use of embryos for purposes of reproduction or 3) require implantation of all viable embryos and/or prohibit embryo destruction.

The first option is the compromise enshrined in federal law since 1995 through a rider to an appropriations act and known as the “Dickey Amendment.” This legislation prohibits the use of appropriated funds for the creation of a human embryo or embryos for research purposes or research in which a human embryo or embryos are destroyed, discarded or knowingly subjected to risk of injury or death above the threshold set for research with fetuses in utero.<sup>1</sup>

Using the second option, the Bush administration has spent over \$1 million of public money to promote embryo “adoption.” Although this outrages some commentators, it is, in general, considered legitimate for the majority to use public resources to advance its agenda, even if others believe a particular expenditure is wrongheaded or foolish.

Bioethicist Arthur Caplan does not share the view that a human embryo is the moral equivalent of a human infant. He also makes the argument that paying for the promotion of embryo adoption is a relatively ineffective way of helping infertile couples have babies. Caplan writes that “most frozen embryos are not healthy enough to ever become babies,” because the highest quality embryos are usually used first by the generating couple, and because over time frozen

embryos degrade.<sup>2</sup> But if the goal of President Bush and his supporters is to help save embryos with the potential for becoming children from destruction as well as to help the infertile, this objection is unlikely to change minds or policy.

The third option is the most draconian. A number of countries have laws that limit the creation and destruction of embryos in ways that impinge quite significantly on the use of assisted reproductive technologies. For example, Italy limits fertilization to three eggs at a time and requires implantation of all resulting embryos. Last year, an Italian judge ordered a couple to transfer all the embryos produced with their eggs and sperm to the woman’s womb, despite the fact that both the man and the woman carried the recessive gene for beta-thalassaemia, wanted preimplantation genetic diagnosis and would not keep a child born with the condition.<sup>3</sup> Of course, this is an unlikely scenario in the US given the current state of constitutional law. Yet Louisiana law declares a viable in vitro fertilized human ovum to be a juridical person “which shall not be intentionally destroyed.”<sup>4</sup> While the goal of reducing the number of excess embryos is arguably a worthy one, such laws seem at odds with recognition of moral pluralism and with respect for privacy and the intimate nature of procreation.

## Terminology

Brakman notes that debate exists over the terminology that should be used to describe the transfer of an embryo from the progenitors to others and states her own position in support of the use of the word “adoption.” My ambivalence is reflected in my repeated placement of that word within quotation marks. Brakman links her position to information on how participants feel about or regard what is going on. Others accept or reject the use of the word “adoption” according to how they stand on the question of moral status. Nightlight Christian Adoptions, which runs the Snowflakes Embryo Adoption Program, describes embryos as “pre-born children” of the “genetic parents” and uses the word adoption to describe the transfer to another couple, because it reinforces the view that an embryo is just like a

baby in all important respects.<sup>5</sup> Caplan sees the use of adoption language as a rear-guard attack on human embryonic stem cell research.

Caplan also believes that the rhetoric of adoption is deceptive given the low odds that a frozen embryo will become a baby even where every effort is made to realize that end. The National Embryo Donation Center notes that “only about two-thirds of embryos survive the thawing process” (other *advocates* say only half), and the “chance of pregnancy after transfer of frozen embryos is currently 20–25%.”<sup>6</sup> The statistic that likely matters most to prospective recipients is the chance of bringing home a baby, often referred to as the “take-home baby” rate, which tends to be considerably lower.

Does use of the word “adoption” imply that prospective parents should be subjected to background checks to assure that the gestational couple will be good parents? In unassisted reproduction, restraints based on evidence of unsuitability to parent are rare and controversial. In assisted reproduction, assessment is much less systematic than in the case of adoption, though clinics appear to do some screening.<sup>7,8</sup> While I believe that professionals involved in aiding conception have a responsibility to attend to the welfare of future children, the challenge in assisted reproduction is distinguishing between standards based on reasonable evidence-based consensus about characteristics likely to be inconsistent with good parenting and standards based on unreflective prejudice.

Finally, as even the National Embryo Donation Center acknowledges, “[b]ased on current law, adoption only refers to the placement of a child after birth.”<sup>6</sup> “Regardless of what terminology is used to explain the procedure, adoption law does not and cannot apply to donating embryos because many state statutes specifically invalidate biological parents’ consent to adoption that is given prior to childbirth.”<sup>9</sup> In short, state adoption laws are not currently being applied to embryo donation. If embryo transfer were to be subsumed under the law of adoption, donors would retain the power to assert parentage throughout the pregnancy, and if a donated embryo

results in a child, the gestational mother might have to return the baby to the genetic parents.

The Uniform Parentage Act, a model act offered as a guide to state lawmakers, creates certainty about assignment of parentage in the context of assisted reproduction. The Act states: "A donor is not a parent of a child conceived by means of assisted reproduction."<sup>10</sup> (The definition of assisted reproduction expressly includes donation of embryos.) Rather, a birth mother who intends to parent the child is the legal mother, and if she is married, her husband becomes the legal father. The Uniform Parentage Act approach is commendable for its clarity, but it has been adopted by only six states to date; however, more states have laws that declare that embryo donors do not have parental rights and responsibilities.

A pragmatic resolution of the terminology debate might consist of allowing Nightlight/Snowflakes and others who prefer the language of adoption for a variety of reasons to use it in peace and to make contracts that accord embryo donors some of the choices now offered to parents surrendering a child for adoption (such as playing a role in the selection of the adoptive parents), while favoring the intent-based approach that makes no distinction between gamete and embryo donation for purposes of determining legal parentage.

**Mary Anderlik Majumder, JD, PhD**  
Assistant Professor of Medicine  
Center for Medical Ethics and Health Policy  
Baylor College of Medicine  
Houston, Texas

<sup>1</sup>The original version, introduced by Representative Jay Dickey, was in § 128 of the Balanced Budget Downpayment Act, I, Pub. L. No. 104-99, 110 Stat. 26 (1996). The most current version (identical in substance to the rest) is in § 509 of H.R. 3010, the appropriations bill that, as of the writing of the commentary, has passed the House and is pending in the Senate in the 109th Congress.

<sup>2</sup>Caplan A. "The problem with 'embryo adoption': why is the government giving money to 'Snowflakes?'" <http://www.msnbc.msn.com/id/3076556>.

<sup>3</sup>Turone F. New law forces Italian couple with genetic disease to implant all their IVF embryos. *BMJ* 2004;328:1334.

<sup>4</sup>Louisiana Revised Statutes (2005), §§ 9:121, 9:124, 9:129.

<sup>5</sup>Nightlight Christian Adoptions, "Message to Genetic Parents," [www.nightlight.org/message\\_genetic.asp](http://www.nightlight.org/message_genetic.asp).

<sup>6</sup>National Embryo Donation Center, "Embryo Adoption Information," <http://www.embryo-donation.org/adoptions.php>.

<sup>7</sup>Gurmankin AD, Caplan AL, Braverman AM. Screening practices and beliefs of assisted reproductive technology programs. *Fertil Steril* 2005;83:61-67.

<sup>8</sup>Stern JE, Cramer CP, Green RM, Garrod A, DeVries KO. Determining access to assisted reproductive technology: reactions of clinic directors to ethically complex case scenarios. *Hum Reprod* 2003;18:1343-1352.

<sup>9</sup>Kindregan CP, McBrien M. Embryo donation: unresolved legal issues in the transfer of surplus cryopreserved embryos. *Vill L Rev* 2004;49:169-206, at 175.

<sup>10</sup>National Conference of Commissioners on Uniform State Laws, Uniform Parentage Act (2002), §§ 102, 702. For information on state legislative action with regard to the Uniform Parentage Act, see [http://www.nccusl.org/Update/uniformact\\_factsheets/uniformacts-fs-upa.asp](http://www.nccusl.org/Update/uniformact_factsheets/uniformacts-fs-upa.asp).

**R**esponse: Professor Majumder's reply enriches our appreciation of the political and legal difficulties regarding embryo adoption. Those like Caplan who assume "adoption" terminology necessarily implies a moral status claim about embryos, however, are mistaken. Pets are adopted, so are laws and highways. I readily agree that some may in fact use the term to draw the connection between infants and embryos, but logically there is no direct implication from one to the other.

I do not argue for the use of the word *adoption*, but rather for the use of the *adoption paradigm*. Though some law at present equates gamete donors and embryo donors for the purposes of determining parentage, there is a distinction of note here. Gamete donors never intended to actively parent. Embryo "donors" originally intended to be parents. To equate couples' interests in the disposition of their embryos to those of gamete donors (as most fertility centers do when denying couples the ability to choose the gestational couple or to know the outcome of the "donation") is to gravely mistake the reality of these families' lives and to inappropriately conflate the two practices.

Professor Majumder asks if "adoption" implies screening for the gestational couple. The answer is yes. While legally pre-adoption screening may represent the state's interests in ensuring the welfare of its most vulnerable citizens, birth parents who place their infants with adoptive parents expect, indeed demand, that adoptive couples have undergone such screening. From the data I found, screening would increase the availability of embryos for adoption. Perhaps what is troubling is

that it seems like these "fertility patients" would be treated unequally compared to other patients at the clinics who are not subject to any screening. While this may be, they would not be treated unfairly, because the situation by definition would be different than all others; the "gestational" couple would be choosing to bear and rear children from another couple's once valued embryos. No such prior interest in genetic material exists for any other assisted reproductive technology alternative.

Finally, Professor Majumder correctly worries that applying current adoption laws to embryo adoption would have disadvantages making the practice unattractive. Surely laws may be amended, or new regulations proposed specific to embryo adoption that acknowledge its unique place in the spectrum between the donation of genetic material and the gift of a born child. □

**Sarah-Vaughan Brakman, PhD**  
Director, Ethics Program  
Villanova University

## A question of status

**T**he Medical Ethics Forum from Harvard Medical School in the Spring 2005 *Medical Ethics* begs an important question by granting prisoners at Abu Ghraib and Guantanamo status under the Geneva Convention. Actually, Article 4 of the Geneva Convention delineates persons covered by its provisions as consisting of armed forces, as well as irregular forces, such as militias, provided that such irregular forces fulfill certain conditions, including: 1) having a fixed distinctive sign recognizable at a distance (uniform), 2) carrying arms openly and 3) conducting their operations in accordance with the laws and customs of war. Obviously, clandestine individuals involved in a campaign that features suicide bombers and the beheading of civilian non-combatants do not fulfill these conditions and, therefore, are not subject to the provisions of the Geneva Convention. The Presidential Directive acknowledged that Abu Ghraib and Guantanamo prisoners (with some exceptions) are not covered by the Geneva Convention but still called for humane treatment of detainees, because such treatment is in accord with our American tradition.

**Michael W. McDonald, MD**  
Natick, MA

prednisone or cortisone and can produce ACTH suppression, fluid retention, “moon face,” central obesity and insulin resistance.

“Precocious puberty” is the only approved indication for pediatric use of GnRH analogue therapy in the US. For a patient’s insurance to pay for this drug a physician would have to use this diagnosis for an 11-year-old FTM or 12-year-old MTF, even though the patient hardly meets the age criteria of sexual precocity. If the Dutch protocol is approved by the Harry Benjamin Society, would it be right for US health insurers to withhold payment for GnRH in properly screened transgendered teens?

Transgendered individuals have long faced discrimination in medical institutions, including physicians’ offices and hospitals.<sup>7</sup> Reminiscent of the medical/psychiatric approach to homosexuality not so long ago, some physicians and psychologists maintain that the goal of psychiatric treatment is to convince transgendered individuals to remain in the gender role of their genetic sex, which is an impossibility for most patients. Everyone involved in patient care should have some awareness of gender identity disorders, however rare they may be. Primary care physicians interested in providing hormonal replacement therapy for transgendered patients should consult the Harry Benjamin Society Standards of Care. Physicians and mental health professionals who are neither comfortable nor sufficiently knowledgeable to treat transgendered patients should refer them to more experienced colleagues. □

<sup>1</sup>Woodson JC and Gorski RA. Structural differences in the mammalian brain: reconsidering the male/female dichotomy. In Matsumoto A (ed.) *Sexual Differentiation of the Brain*, New York and London: CRC Press, 2000.

<sup>2</sup>Kruijver FP et al. Male-to-female transsexuals have female neuron numbers in a limbic nucleus. *J Clinical Endocrinology & Metabolism*. 85(5):2034–41, 2005.

<sup>3</sup>Zhou JN et al. A sex difference in the human brain and its relation to transsexuality. *Nature*. 378(6552):15–16, 1995.

<sup>4</sup>Zucker KJ and Bradley SJ. *Gender Identity Disorder and Psychosexual Problems in Children and Adolescents*, New York and London: The Guilford Press, 1995

<sup>5</sup>Kreiss JL and Patterson DL. Psychological issues in primary care of lesbian, gay, bisexual, and transgendered youth. *Journal of Pediatric Health Care*. 11(6):266–74, 1997

<sup>6</sup>Cohen-Kettenis PT and Pfafflin F. *Transgenderism and intersexuality in childhood and adolescence. Making choices*, Thousand Oaks and London: Sage Publications, 2003

<sup>7</sup>Feinberg L. *Transgender warriors*, Boston: Beacon Press, 1996

## Additional readings

Boylan JF. *She’s not there*. New York: Broadway, 2003

Brown ML and Rounsley CA. *True Selves: Understanding transsexualism—for families, friends, coworkers, and helping professionals*, San Francisco: Jossey Bass, 1996

Israel GE and Tarver DE. *Transgender Care*, Philadelphia: Temple U. Press, 1997



**Lahey**  
CLINIC

**Medical  
Ethics**

[www.lahey.org/ethics/](http://www.lahey.org/ethics/)

41 Mall Road  
Burlington, MA 01805

# Medical Ethics

*Lahey Clinic Medical Ethics* encourages reader participation. We welcome comments for our “Dialogue” column and invite submission of ethical dilemmas for “Ask the ethicist.” Send correspondence and requests for complimentary subscriptions to David Steinberg, MD.

**David Steinberg, MD, Editor**  
Lahey Clinic Medical Center  
41 Mall Road, Burlington, MA 01805  
david.steinberg@lahey.org

**James L. Bernat, MD, Assoc. Editor**  
Dartmouth-Hitchcock Medical Center  
One Medical Center Drive, Lebanon, NH 03756  
bernat@dartmouth.edu

## EDITORIAL BOARD

**Nancy Knoblock Hunton**  
Managing Editor

**David M. Gould, Esq.**  
Legal Editor

**Susan M. Donovan**  
Circulation Manager

**Daniel Callahan, PhD**

**Allan M. Brandt, PhD**

**Dan W. Brock, PhD**

**Diane M. Palac, MD**

**Thomas J. Prendergast, MD**

**Paul Reitemeier, PhD**

**James A. Russell, DO**

**Andrew G. Villanueva, MD**

Generous funding for *Lahey Clinic Medical Ethics* is made in memory of Harold Karp by the Karp Family Foundation.

*Lahey Clinic Medical Ethics* can be found on the Lahey Clinic Medical Ethics Web site at [www.lahey.org/ethics/](http://www.lahey.org/ethics/).



**Lahey**  
CLINIC

Nonprofit Organization  
U.S. Postage  
PAID  
Boston, MA  
Permit No. 9