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Medical Ethics

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Quote to note

"The bird flu threat is getting worse."

— Bui Ba Bong
Deputy Minister of Agriculture, Vietnam
Viet Nam News, January 11, 2007

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Ethics at the limits of viability

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The field of newborn care encompasses unique ethical problems that occupy the attention of clinical practitioners and bioethicists. Which infants should we try to save and at what costs to families and society are problems requiring constant reexamination. They are problems that also have drawn political attention.

The fairly young field of neonatology, working in relative obscurity with limited technical tools, gained the public spotlight in 1973 when two physicians at Yale-New Haven Hospital reported that neurologically impaired babies were being allowed to die. But it was the case of Baby Doe in the early 1980s that changed neonatology from a low-profile subspecialty of pediatrics to one worthy of public scrutiny.

Baby Doe, born with trisomy 21 (Down syndrome) and esophageal atresia, with the advice of the physicians caring for the infant and the agreement of the family, did not undergo a repair of the interrupted esophagus and thus could not be fed. Community members went to court to override the decision, but the Indiana courts upheld the family's right to decide about their infant's health care. Baby Doe died before the U.S. Supreme Court could hear the appeal, and the Court chose not to accept the case. The response of the federal government was first to issue regulations, tied to civil rights law and later to child abuse statutes, that forbade neonatologists from making life-and-death decisions based on the possibility of disabilities.[1] The path from there to the present is long and complex but, in 2007, we have come no closer to consensus on a number of complex ethical issues.

What are these issues? The most basic one is our understanding of the lower gestational age (or weight) limit for viability. This is not the "viability" discussed in *Roe v. Wade* but the practical viability in 2007. At less than 23 weeks of gestation (or 18 weeks before term), survival is about 5%–8%, while between 23 and 24 weeks, 15%–30% of babies can be saved with aggressive neonatal care. At 24 to 25 weeks (still exceedingly premature) 40%–60% of the infants can survive. An argument could be made for trying to save any baby that might live with our intervention. Would we not provide any and all intensive care to an adult who expresses the wish to continue despite the odds? So what is the difference? Obviously, the adult "expresses a wish" and the infant cannot. We have either to follow the desires of the family or attempt to understand what would be in the best interest of the child. These are not easy tasks.

At all these gestational ages, a future with mental and physical challenges is likely for 50% or more of the infants. These challenges range from learning problems and attention disorders to significant mental retardation, cerebral palsy, blindness and deafness. In general, the more premature the infant, the more likely there will be disabilities. But the data are flawed by the lack of certainty of the exact gestational age of such small infants and a number of other confounding factors such as socioeconomic status (babies from lower socioeconomic homes have more problems) and gender and race (Caucasian

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males do worst and African-American females do best) that can influence the outcome. Our ability to predict an accurate outcome at the time of delivery is poor. Thus for a particular baby being delivered at a particular time, we do not know if that baby can survive and, if it does, whether it will be normal, mildly abnormal, or have severe lifelong problems.

Some people feel strongly that our degree of medical uncertainty about survival and long-term outcome obligates us to manage aggressively all potentially viable infants despite the wishes of the family, while others (including the vast majority of neonatologists) believe that parents are best poised to decide whether their child should risk having a life with little or no conscious interaction with the environment.[2] With no ability to know the child's wishes (or for the child to have any true wishes), someone must make these decisions. We give parents considerable latitude to raise their children, but not total freedom. As a society, we accept that some parents, in some situations, might put their children at too great a risk of serious physical or mental harm. To allow that harm would degrade our fundamental respect for human life.

I apply the same analysis to the neonatal intensive care unit. When the chances of survival are low and the risk for a future of severe handicaps and a lack of connection to one's environment is high, parents should be able to decide that their child need not be aggressively resuscitated and managed in the NICU. Subjecting the majority of very premature infants to aggressive and invasive care that may be painful, despite our attempts to prevent pain, can be viewed as a form of torture when we know most will die. The process of including parents in these difficult decisions both respects human life and properly cedes to the family a role they are best suited to embrace.

In practice, that has meant that families faced with the possible birth of a baby (or babies) at less than 25 weeks of gestation are offered the option of providing comfort care rather than endotracheal tubes and respirators. For those who choose aggressive care, the chance to reconsider should be discussed again when evidence accumulates that the infant is extremely likely to have suffered neurological and physical damage that will place it in the most disabled category. I believe that such a choice should not be offered for infants at less than 23 weeks since that really is experimentation, not medical care, and should be part of a protocol. This is a category in which independent existence and meaningful interaction with one's surroundings are very unlikely, and creates an enormous burden for a family in a society where support is weak at best. This seemingly rational and ethically defensible approach has become a lightning rod for those who hold the view that preserving life at all costs is a fundamental function of society.[3]

But neonatology is not only about trying to save one-pound infants. Incredible advances in medical and surgical care allow for attempts at repairing defects that could only be imagined 25 years ago. Our definitions of viability for these infants are constantly in flux. Nevertheless, trying to provide medical care that is not "an experiment in disguise" is a challenge we face. It is not unusual to have a baby born with a constellation of severe birth defects that may or may not include neurological abnormalities. Each of the defects may have the potential for palliation or incomplete repair, and a number are fatal if not medically/surgically approached. The outcome from each "repair" might allow the child existence out of the hospital, but each includes the potential need for future surgery and the likelihood of pain and greatly decreased activity.

The neonatologist occupies the position of gatekeeper—a primary care intensivist. The easiest course is to consult specialists, tell the family each problem should be fixed, and that it is difficult to predict the future. Once the medical/surgical facts are established, the harder course is to consider whether beginning down this path makes ethical sense or whether not beginning is an option. How could that be a realistic option?

It is ethically justifiable to consider the above scenario as one in which the medical system is not providing good health care for the infant. High-technology rescue therapy resembles superior, cutting-edge medicine, but is it really something everyone (and therefore every infant) must choose? I do not believe an intervention that places a child on a course inevitably filled with prolonged hospital stays, pain and future suffering with little likelihood of any kind of a reasonable life is one that is either good health care or required. Well-intentioned, ethical families and society should allow us to withhold aggressive care in such situations. That is not the scenario of spina bifida, where the odds for a meaningful and productive life are high. The line is quite hard to draw (and it will move as medicine improves), but that does not mean that we, as a society, should not have these discussions or that we should not accept that there are limitations to what we can or should do.

At the limits of viability, whether because of gestational age or multiple medical problems, neonatologists are faced with profound ethical decisions. In our present political environment it seems easier to attempt to save every baby rather than face the difficult task of analyzing alternative approaches. I believe that an ethics that balances the family's wishes, the future for the child and our role as doctors (not technicians) is the one most suited to neonatology.[4]

To apply this approach in clinical practice requires a willingness to invest great time in dialogue with families. These discussions challenge one's ability to listen carefully to a family before introducing the medical perspective. This approach often requires delaying final decisions for days while questions are answered and understanding on everyone's part is increased. When disagreements between the family and the medical staff appear irresolvable, it may be helpful to consult either an ethics committee or respected outside "experts" such as members of the clergy. Regardless, time and careful listening can go a long way toward settling these complex issues. □

[1]Kopelman L. Are the 21-year-old Baby Doe rules misunderstood or mistaken [commentary]? *Pediatrics* 2005;115:797–802.

[2]Peerzada JM, Richardson DK, Burns JP. Delivery room decision-making at the threshold of viability. *J Pediatr* 2004;145: 492–498.

[3]Sayeed SA. Baby Doe redux? The Department of Health and Human Services and the Born-Alive Infants Protection Act of 2002: A cautionary note on normative neonatal practice. *Pediatrics* 2005;116:e576–e585.

[4]Richards N. Life or death decisions in the NICU. *J Perinatol* 2006;26:248–251.

Ask the ethicist:

Is HIPAA in the room?

Question: A 24-year-old construction worker became agitated and sleepless. He accused his wife of plotting with her parents to kill him. The wife convinced him to go with her to the emergency department of the local hospital. After accepting admission for psychiatric treatment, he refused to list his wife or her parents as persons with whom the attending psychiatrist could communicate. His wife felt frustrated because of her lack of understanding of her husband's illness and because she could not talk with her husband's doctor about how to deal with him even when she was notified that her husband was being discharged.

After a few days at home, the husband again became agitated and threatened to kill his wife. She called the police. He was readmitted, held and treated against his will under a court order. During this entire process, which included a court appearance by the wife, the patient continued to deny the psychiatrist permission to speak with her.

Is the psychiatrist's decision not to communicate directly with the wife legally and ethically supportable?

Response: First, the psychiatrist needs to be satisfied that the patient is, indeed, deluded. (Hitler may have been paranoid, but his generals really did try to kill him.) If he concludes that the wife is not plotting against her husband, he still has to decide whether to talk to her against his patient's wishes. When the patient appears to be ready for discharge, the psychiatrist must also consider whether he can release him safely: if he poses a foreseeable danger, the psychiatrist has a duty to warn third persons who are at risk of being harmed.[1]

Persons suffering from a major psychosis are not automatically deemed to lack capacity to make medical decisions in their own behalf. They may understand their situation, their choices and the probable outcome of any choice. An element of capacity that medical ethicist Bernard Lo considers important may be lacking: the decisions of a person who has become mentally ill may not remain consistent with choices and personal values previously enunciated and displayed.[2] A family member may aid in assessing this element of capacity.

A psychotic person's decision may seem irrational because, although it was reasoned plausibly, the reasoning proceeded from a false premise. (It was reasonable for the husband to keep his wife in the dark about his condition and at bay, as long as he believed she intended to kill him.) Faced with a patient's irrational decision, a psychiatrist may declare the patient incompetent in order to override it, although the practice is questionable.[3] I can only guess at the reasons behind the behavior of the psychiatrist in this case. He may simply have followed an institutional privacy rule against disclosing information without the patient's authorization. By so doing, he could avoid nettlesome questions of competency and rationality.

Utilitarian arguments can be adduced both for and against the psychiatrist's talking with the wife against his patient's wishes. One might argue that more good than harm will come from overruling the patient: with more information, his wife will understand and manage him better at home. When the patient recovers, he will likely be grateful that the psychiatrist talked with his wife.

If the psychiatrist refuses to talk to the wife, in accordance with his patient's demand, it may be because he believes that ignoring that demand, even though it is based on a delusion, will do more harm than good: his patient will not trust a doctor who talks behind his back.

There is a problem with these analyses: it is challenging to assign proper weight to each positive and negative factor in consideration, to see which way the balance tips. Another approach may be more fruitful.

Doctors are obliged to tell the truth, but they do not have to tell everyone everything. The wife has a need to know some but not all details of the case.If she is worried that her husband may harm himself or others, or doesn't know how to respond to him when he expresses "crazy ideas," she needs professional guidance *for her husband's sake.* She appropriately regards his physician as the best, most trusted source of that information.

The psychiatrist should tell his patient, "You can't go home until I talk with your wife, but I will tell her only what she needs to know." The subsequent conversation would best be held with the patient present and when a home visit seems feasible.

Unlike the "elephant in the room," the "hippa regs," as they are familiarly called, cannot be ignored; but the HIPAA Privacy Rule will not crush the physician who needs space for professional decision-making. It states that if an individual is incapacitated but disclosure to another person is in his or her best interests, it should be limited to "information that is directly relevant to the person's involvement with the individual's health care."[4]

The Health Privacy Project at Georgetown University labels as "myth" the belief that the Privacy Rule prohibits a hospital from sharing information with the patient's family without the patient's express consent. "If the patient is unable to agree or object to disclosure because of incapacity or an emergency circumstance, the covered entity [hospital or physician] may determine whether the disclosure is in the best interests of the patient. The professional judgment of the health care provider should inform any decision regarding disclosure of protected health care information to a family member or friend who is involved in the patient's care, as these disclosures are permitted but not mandatory."[5] Some state laws explicitly declare that a treating professional who, in good faith, decides to release or withhold treatment information is *not* subject to civil liability for the decision.[6]

Federal or state law did not prevent the psychiatrist from doing the right thing in this case, but he did not do it.

Outcome: The patient was eventually discharged to the care of his parents. Later, he returned to his wife. He continued on court-ordered treatment. The wife dealt with his residual paranoia by limiting her contact with her own parents and telling them little about her husband's condition. □

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The legal column:

*Do tissue banks have a First Amendment right **not** to tell potential donors about for-profit processors?*

By Robert A. Katz, JD
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Following the death of a loved one, grieving families are sometimes asked to donate the decedent's tissues for use in transplantation procedures. Donations of cadaveric tissue—bone, skin, eyes, heart valves, etc.—are solicited and recovered by tissue procurement organizations or "tissue banks," most of which are set up as nonprofit organizations.[1] Outside the occasional scandal, the public is generally less familiar with the recovery and transplantation of tissues than of organs. As a result, some families agree to donate tissue without the benefit of information that might affect their decision-making. Most notably, they may be unaware that both nonprofit and for-profit firms process raw tissue into implantable therapeutic tissue (aka "allografts"). Although donor families can permit only nonprofit firms to use their donations, this right means little if the families do not know about for-profit processors.

Since 2003, two states—California and Wisconsin—have enacted laws that require tissue banks to inform potential donors that for-profit firms may process donated tissue, and to obtain their approval for such use.[2] On first view, these mandatory disclosure rules are attractive because they seem to promote more informed charitable giving. From a legal perspective, however, they are problematic because they encroach upon the free speech rights of nonprofit tissue banks.

The First Amendment protects both the positive freedom to say what one wants and the negative freedom *not* to say what one does *not* want.[3] In *Riley v. National Federation of the Blind*,[4] the U.S. Supreme Court extended this freedom from compelled speech to charities and their for-profit fund-raising solicitors. In the Court's view, charitable solicitations involve high-value speech because they typically inform, discuss and advocate on matters of public and social concern. They thus warrant the most rigorous First Amendment protection.[5] The *Riley* Court struck down a North Carolina law that required professional solicitors to tell potential donors the percentage of contributions they typically remit to their charitable clients, and to do so prior to or while requesting funds, i.e., at the point of solicitation.

Nonprofit tissue banks solicit charitable contributions when they ask bereaved families to donate their loved ones' tissue for use in life-saving or life-enhancing procedures. The California and Wisconsin rules require tissue banks to disclose certain information to potential donors at the point of solicitation. Under *Riley*'s standard, they will only survive if they are *narrowly tailored* to achieve a *compelling* government interest.[6] They will not survive, by contrast, if they serve merely a *legitimate* (but not compelling) government interest, and/or use means that unnecessarily burden speech. If challenged, the California and Wisconsin rules would likely fail in the face of such strict scrutiny.

The government has an interest in stopping the sale of donated tissue. Such sales contravene both law and policy: the National Organ Transplant Act of 1984 (NOTA) prohibits the sale of body parts for use in transplantation.[7] Such sales also violate the manifest intent of tissue donors: just as these donors "sell" tissue for nothing, they undoubtedly want its ultimate recipients to "pay" the same price for the tissue itself. Although the government has an interest in NOTA compliance, it can advance that interest through means that are more straightforward and less burdensome on speech. Most notably, the government can prosecute industry actors that violate NOTA by selling tissue.[8] This approach respects speech more than a rule that compels every tissue bank to repeat a government-approved speech at the point of solicitation.

The government also has at least a legitimate interest in helping people make informed decisions on a host of matters. In the context of charitable solicitations, some states try to advance this interest by requiring charities or their for-profit agents to disclose potentially unflattering information to potential donors. In *Riley*, for example, North Carolina unsuccessfully argued that its mandatory disclosures "inform[ed] donors how the money they contribute is spent in order to dispel the alleged misperception that the money they give to professional fund-raisers goes in greater-than-actual proportion to benefit charity."[9]

In a similar vein, the California and Wisconsin rules provide more information to families asked to donate a loved one's tissue. According to a California legislative report, "unless [donor] families are made aware [that a for-profit organization may be involved in the tissue industry], it may be difficult to assert that genuine informed consent was obtained."[10] Mandatory disclosures may narrow the gap between how some people expect the tissue industry to operate (e.g., driven by altruism and selflessness) and how it actually operates (i.e., by relying on for-profit firms to process some tissue). Even so, these rules may violate the First Amendment because the government can promote informed charitable giving through means less burdensome to speech. For example, it can require tissue banks to publicize in their annual reports the entities that they supply with tissue. Also, it can require them to disclose this information if asked.

Although mandatory disclosure of for-profit involvement in the tissue industry may advance some government interests, it works against others. If widely adopted, these rules will likely increase the number of donors who deny for-profit firms access to their donations.[11] Yet the government has no obvious interest in reducing these firms' supply of cadaveric tissue. No law prohibits for-profit firms from processing donated tissue, and NOTA expressly permits them to earn a reasonable rate of return from this activity.[12] Moreover, for-profit involvement promotes public health by infusing the tissue industry with entrepreneurial energy and fresh capital for research and development.

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Ethics and the humanities:

Middlesex: A novel

By Jeffrey Eugenides
New York: Farrar, Straus & Giroux, 2002

Review by Stephanie Brown Clark, MA, MD, PhD
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"**I was born twice:** first as a baby girl, on a remarkably smogless Detroit day in January 1960; and then again as a teenage boy, in an emergency room near Petoskey, Michigan, in August of 1974." Cal Stephanides, born Calliope Helene Stephanides, is a hermaphrodite. At the age of 41, Cal "feels another birth coming on." He finds himself thinking about his own history, both genealogical and genetic, and wanting to tell the story of his sprawling, multigenerational Greek-American family and "the roller-coaster ride of a single gene through time." Jeffrey Eugenidies made the main character of *Middlesex* a hermaphrodite as "a correlative for the sexual confusion and identity that everyone goes through in adolescence."

Beginning in 1922 with his grandparents, Desdemona and Eleutherios "Lefty" Stephanides, Cal imagines their exodus from the village of Bythinios—and their forced migration to America during the Greco-Turkish war. The family business for generations has been the raising of silkworms. When they leave they carry two suitcases, books of Ancient Greek and a box of silkworm eggs, and the same last name. They are a brother and sister in love—with each other. Fabricating memories Cal's grandparents manage to "recreate themselves" among 500 perfect strangers sailing across an ocean. In a kind of metamorphosis, they emerge at Ellis Island as husband and wife.

Cal points out, "Without their knowing, my grandparents on their way to America were each carrying a single mutated gene on the fifth chromosome," specifically, a gene that codes for 5-alpha reductase deficiency. This enzyme converts testosterone to dihydrotestosterone (DHT) and its deficiency results in ambiguous exter-nal genitalia at birth. Because the gene is recessive, Cal remarks that it "goes underground for decades only to reappear when everyone has forgotten about it." Cal does not learn the secret of his grandparents' consanguinityuntil the novel's end.

What follows is the history of the second Stephanides generation and the journey of the mutant gene through bodies and through time. The couple conceive a child, Milton; on the same evening their cousin's daughter, Tessie, is conceived. The two children grow up in the same house together, fall in love and marry. Cal is their child. After the Detroit race riots in 1967, the family moves out of the city and into the exclusive suburb of Grosse Pointe to a house on Middlesex Boulevard.

Cal's metamorphosis from girl to man through adolescence is funny, sad, poignant and sharply observed. Cal sees two images, "the dark-eyed pretty little girl I used to be, and the severe, aquiline-nosed, Roman-coinish person I am today." In seventh grade, Callie's previously frozen body sprouts "with the velocity of the mung bean we studied in Earth Science." A year later, Callie falls in love with one of her classmates, a red-haired girl whom Callie calls the Obscure Object of her affections. Callie is approaching the moment of discovery about her sexuality "which is something I knew all along and yet didn't know." Her first sexual experiences are with Jerome, the Obscure Object's brother. In the confusing welter of innocence, ignorance, pleasure and exploration, Callie's attractions for Jerome's sister are stronger and they begin a sexual relationship of sorts. And through all this, Cal remembers," I made no lasting conclusions about myself…. The mind self-edits. The mind airbrushes. It's a different thing to be inside a body than outside. From outside, you can look, inspect, compare. From inside there is no comparison…. What I saw looking down at myself was only the dark triangular badge of puberty…. True, my chest was completely flat. But there were other ironing boards at my school…. Why should I have thought that I was anything other than a girl? Because I was *attracted* to a girl? That happened all the time."

When Jerome discovers Callie touching his sister, a fight ensues. Callie is injured and brought to the hospital; the attending physician observes her ambiguous genitalia and recommends a consultation with Dr. Peter Luce at his Sexual Disorders and Gender Identity Clinic in New York. After a psychological assessment, Dr. Luce determines that Callie's sexual orientation and gender are female and recommends "a simple surgery and some injections would end the nightmare and give my parents their daughter back, their Calliope. No one would ever know." However, Callie disagrees: "I am *not* a girl. I am a *boy*." She runs away to San Francisco, where the flamboyant owner of a sex parlor befriends her. Arrested during a police raid, Cal is allowed one phone call. He calls home and returns as a prodigal son. The final chapters of the book raise provocative questions about identity in America in the 21st century when immigration, globalization and genetics have blurred the boundaries of ethnicity, race and sexuality. Cal muses that:

"As my first barber put it, everybody wanted to go unisex [in the 1970s]. The consensus was that personality was primarily determined by environment, each child a blank slate to be written on…. For a little while during the seventies it seemed that sexual difference might pass away. But then another thing happened…. evolutionary biology. Under its sway, the sexes were separated again…. Nurture no longer formed us; nature did…. This is where we are today…every newborn had been inscribed by genetics and evolution."

Cal contends it's not as simple as that:

I don't fit into any of these theories…. My psychological makeup doesn't accord with the essentialism popular in the intersex movement, either…. I never felt out of place being a girl. I still don't feel entirely at home among men. Desire made me cross over to the other side, desire and the facticity of my body. In the twentieth century, genetics brought the Ancient Greek notion of fate into our very cells. This new century we've just begun has found something different. Contrary to all expectations, the code underlying our being is woefully inadequate…. And so a strange new possibility is arising…. free will is making a comeback. Biology gives you a brain. Life turns it into a mind."

***Humanities**—continued on page 8*

Dialogue:

Another view on ethics and politics

Madison Powers begins his essay "The relationship between ethics and politics" (*Lahey Clinic Medical Ethics*, Fall 2006) by asking, "Why do we focus on 'ethics' when the grist for the bioethics mill is overwhelmingly a political or juridical event?" He answers, "I think that the answer lies in looking more closely at the relationship between ethical theory and political theory." Unfortunately, Powers looks at the wrong ethical theory. Later, he says, "The stuff of such methodologies (for example, that of the dominant bioethics model of balancing among competing principles) remains quite mysterious." He is quite right that principlism is mysterious, but quite wrong in his account of what morality is. Powers follows Aristotle in regarding the question "what is the best life for man," as the basic moral question. He also follows Aristotle in claiming that good moral judgment is the judgment of the man of mature practical judgment. But that is not what we now mean by "moral judgment," for that would result in judgments about what to eat, how much to exercise and when to brush your teeth being moral judgments.

Powers also follows Aristotle in recognizing, "The main justification for the rule by rules is that social relations so organized contribute great value to our moral life that is not attainable otherwise. It means that social life itself is possible only if some important parts of our moral relationships are governed by general rules known to and applicable to all."[1] Hobbes, who puts forward a remarkably similar view, realizes, as Aristotle and Powers do not, that the most important of these common rules are not rules of law but moral rules that apply to all those who can understand them and guide their conduct by them.[2] Indeed, these moral rules are used to critique those rules of law that are in conflict with them. Powers does not realize that these common rules are part of our common moral system. He mistakenly takes the Beauchamp and Childress account of common morality (to which they have recently been converted) as a correct account of what is meant by that phrase.[3] That leads to his criticizing common morality as an inadequate account of morality.[4]

Powers seems to hold that the common moral rules are the result of political deliberation, as if different societies could come up with completely different sets of moral rules. But there is no society that does not prohibit killing, causing pain, disabling and depriving of freedom and pleasure, unless one has an adequate justification for violating these prohibitions. Similarly, every society prohibits deceiving, breaking promises, cheating, violating the law and neglecting one's duties without an adequate justification.[5] Political deliberation determines the interpretation of these rules and what counts as an adequate justification for violating them. Different societies, indeed, even different groups and individuals within a society, can disagree about the interpretation of a rule and about what counts as an adequate justification for violating it. Common morality sets limits to legitimate moral disagreement, but within those limits, common morality allows considerable disagreement.

Most moral disagreement is due to disagreement about factual matters, including predictions of the consequences of various alternatives, but even with complete agreement about factual matters, there is no way to resolve many of the most controversial moral disagreements. The four primary sources of unresolvable moral disagreements are disagreements concerning (1) the ranking of the evils or harms, e.g., is death worse than living with an extremely painful terminal illness; (2) who is protected by morality and how much are they protected, e.g., fetuses and animals; (3) what would be the consequences of everyone knowing that they are allowed to violate a moral rule in the same morally relevant circumstances, e.g., doctors granting patients' requests to be killed; and (4) the interpretation of a moral rule, e.g., does turning off the ventilator of a ventilator-dependent patient who refuses continuing ventilation count as killing the patient?[6] It is in these cases that political deliberation has its proper place, deciding what to do when there is an unresolvable moral disagreement.

The first sentence of the abstract to Powers's article, "Bioethics as politics: the limits of moral expertise," is, "The increasing reliance upon, and perhaps the growing public and professional skepticism about, the special expertise of bioethicists suggests the need to consider the limits of moral expertise." Powers is too timid in his questioning of moral expertise. If a bioethicist is supposed to be related to bioethics as a physicist is related to physics, someone whom we should accept as an authority on the subject, then there are no bioethicists. No one is an authority on ethics; we should not accept any ethical judgment based on the authority of anyone, including any religious figure, in the way that we must sometimes accept the authority of historians or scientists in their fields of expertise.

Every normal adult has the ability to make moral decisions and judgments; otherwise, they could not be subject to moral judgment about their actions. No one who is legitimately ignorant of what they morally ought to do can be held morally responsible for his actions. That is why we do not make moral judgments on the actions of infants, small children, the severely retarded or any nonhuman animals.

Although very few people can explicitly formulate the moral rules, moral ideals and morally relevant features that are part of this system, they use it in making their considered moral decisions and judgments. Of course, morality being intimately involved with matters about which we have strong emotions, people sometimes make moral decisions and judgments that upon reflection they later realize are mistaken. But everyone agrees that morality is universal in the sense that it applies to everyone who understands it and can guide their behavior by it. There is also universal agreement that what counts as an adequate justification for one person counts as an adequate justification for anyone else in a similar moral situation. Although there is disagreement about what can serve as the basis of morality, as stated earlier, everyone agrees that no one who is legitimately ignorant of what they morally ought to do can be held morally responsible for his actions. That means if there is a universal morality it cannot be based on religion, for no religion is known to all those whom we hold morally responsible for their actions.

Here is an example of doing bioethics. Everyone agrees that a physician ought to tell patients all the informa-

tion relevant to their making rational decisions about treatment. It is also universally agreed that information about significantly lessening the risk of death, pain and disability is relevant to making a rational decision. Thus, everyone who thinks about this matter knows that a physician morally ought to provide this kind of information to her patients. Powers is correct that it was only when the courts held that patients must be informed of the significant risks associated with an operation or procedure that this became the standard practice. However, the courts have not yet ruled that physicians must tell patients that their chances of dying of a given operation, e.g., the Whipple procedure for pancreatic cancer, are almost ten times higher at some hospitals than at others. Nonetheless, it is clear that physicians morally ought to provide this information to their patients.

Although loyalty to one's colleagues and various economic considerations often lead physicians not to provide this information to their patients, it is clear that morally, they ought to provide it. At some point, there will be a court decision to this effect, but until that time it will not be standard practice. So Powers is correct if he means that physicians' behavior, like most people's behavior, is more importantly influenced by political and juridical decisions than by moral considerations. However, that does not mean that reaching the correct answer to a bioethical matter is a political and juridical matter. Of course, on controversial matters, bioethics or moral theories cannot provide unique correct answers, for on most controversial matters, those on which "Expert panels and advisory councils are convened"[7] there are no unique correct answers; political and juridical decisions are needed. However, the legislators and judges are not providing unique correct answers to the questions under consideration, they are merely providing acceptable answers, ones that are within the limits provided by common morality.

In the abstract of his article in the *Kennedy Institute of Ethics Journal*, Powers talks about the current situation in bioethics. Of the "attempt to develop a decision-making procedure in ethics that would operate on a plane above politics," he correctly says, "The risk…is that we will fail to appreciate the wide range of reasonable disagreement that will remain past the point of extended reflection and discussion." That is one of Power's central points and on it I completely agree.

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[1]Powers M. The relationship between ethics and politics. *Med Eth.* 2006;13:1–2.

[2]Gert B. Definition of morality. *Stanford Encyclopedia of Philosophy*, http://plato.stanford.edu/entries/morality-definition. For a more detailed discussion, see Gert B. *Common Morality: Deciding What to Do.* New York: Oxford University Press; 2004; paperback ed., 2007; and Gert B. *Morality: Its Nature and Justification.* New York: Oxford University Press; rev. ed., 2005.

[3]Beauchamp T, Childress J. *Principles of Biomedical Ethics.* New York: Oxford University Press; 1994. "Common morality" makes its first appearance in their index in the 4th ed., published in 1994.

[4]Powers M. Bioethics as politics: the limits of moral expertise. *Kennedy Inst. of Ethics J,* 2005; 15:305–322.

[5]See the books cited in note 2.

[6]Gert B. Moral arrogance and moral theories. *Philosophical Issues* 2005;15:368-385; and Gert B, Culver CM and Clouser KD. Moral disagreement. Chapter 3 in *Bioethics: A Systematic Approach.* New York: Oxford University Press; 2006.

[7]Op. cit., Powers, 305.

Response: There is much in Professor Gert's comments with which I agree, indeed, a great deal more than he imagines. The most telling point of genuine disagreement, however, lies in his claim that I have put forward the wrong ethical and political theories as the basis for my discussion; Hobbes, rather than Aristotle, would have been the better choice on his view.

I agree that it would be a mistake to hold "that the common moral rules are the result of political deliberation, as if different societies could come up with completely different sets of moral rules." Neither Aristotle nor I make that mistake. I concur with Aristotle's account of "natural justice," which holds that some basic elements of human well-being are sufficiently similar that some core of morality (and law as well) must necessarily be much the same everywhere.

One of Aristotle's central claims, which Hobbes denies and I endorse, is the view that the content of moral norms and laws meant to regulate our mutual association can be worked out

***Dialogue**—continued on page 8*

***Legal**—continued from page 4*

For-profit firms have pioneered some of the industry's most important technological advances and helped fuel its rapid growth.

In sum, requiring tissue banks to disclose for-profit involvement in the tissue industry at the point of solicitation may be both unconstitutional and bad policy. These disclosures unduly infringe upon the tissue bank's freedom from compelled speech. They may also mislead potential donors who do not understand the difference between nonprofit and for-profit processors and who lack significant reasons for preferring the former. Mandatory disclosure of this information may influence decision-making by potential donors in ways that may be ill grounded—if not irrational—and harmful to public health. □

[1]For convenience, I use the terms "charitable" and "nonprofit" interchangeably.

[2]Cal. Health & Safety Code 7158.3(b)(1) (West 1970 & Supp. 2006); Wis. Stat. § 157.06(6m) (2006).

[3]See, e.g., *West Virginia State Board of Education v. Barnette,* 319 U.S. 624 (1943), (state cannot force students to salute the flag and recite the Pledge of Allegiance).

[4]487 U.S. 781 (1988).

[5]Id. at 800.

[6]Id.

[7]42 U.S.C. § 274e(a) (2003).

[8]Persons who violate NOTA by selling tissue may be fined up to $50,000 or imprisoned for up to five years. Id. at § 274e(b).

[9]487 U.S. at 798.

[10]Sherry Agnos, California Senate Office of Research, *Tissue Donations: Issues and Options in Oversight, Regulation, and Consent* 11 (2003), http://sinet2.sen.ca.gov/sor/reports/reports_by_subj/health/tissuedonationsreport.pdf.

[11]E-mail from Karen Richards, program manager, University of California San Francisco (UCSF) Tissue Bank, to the author Aug. 15, 2005, 16:16 EST; on file with author. ("In 2004, approximately 13% of our families opted out for profit and 15% in 2005.")

[12]42 U.S.C. § 274e©(2).

Ask the ethicist—*continued from page 3*

[1] *Tarasoff v Regents of the University of California*, Cal Supreme Ct (17 Cal 3rd 425, July 1, 1976).

[2] Bernat JL. *Ethical Issues in Neurology*, 2nd ed. Boston: Butterworth-Heinemann 2002:30.

[3] Ibid., p. 32.

[4] www.hhs.gov/ocr/privacysummary/pdf.

[5] www.healthprivacy.org/.

[6] www.azleg.gov/ars/36/00517-01.htm.

Humanities—*continued from page 5*

Eugenides writes convincingly and evocatively about adolescence in the character of Cal as a kind of metamorphosis into an identity that is bound by complex threads of environment, biology and culture. At 41, Cal Stephanides is a cultural attaché, living in Berlin. "This once-divided city reminds me of myself. My struggle for unification…. Coming from [Detroit] still cut in half by racial hatred, I feel hopeful here in Berlin." □

Dialogue—*continued from page 7*

using only rather modest premises regarding the nature of human well-being. The Hobbesian assumption is that relatively little agreement about the ends or purposes of political association is necessary in order to establish the basic terms of our common moral life. I follow Aristotle in supposing that the differences in judgment are chiefly differences in underlying value judgments regarding ends to be achieved. Professor Gert, by contrast, seems to think that mere factual disputes account for a larger share of unresolvable moral disputes. Where Professor Gert thinks that the core of common morality is made up largely of prohibitions of the Stone Tablet variety, I agree with Aristotle—and with Beauchamp and Childress—in supposing that the common morality involves much more than mere prohibitions.

Even if we focus primarily, as Professor Gert does, on predicable forms of harm that seem everywhere restrained by prohibitive rules (both moral and legal), the main issues that divide most societies cannot be resolved without additional evaluative premises regarding the ultimate point or ends of such rules. That killing of other humans is among the harms everywhere prohibited tells us remarkably little unless we suppose, contrary to the weight of human experience, that all killings everywhere are viewed on a moral par. The interpretation of such prohibitions, and whether they apply to abortion, embryo research, the death penalty and so on, depends crucially on an account of the more fundamental goods such prohibitions ought to serve. This claim, I think, is what distinguishes Aristotelians and Hobbesians most fundamentally. □

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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.**

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