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Quote to note

It is the mark of an educated mind to be able to entertain a thought without accepting it.

— Aristotle

Inside

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What information should be disclosed to patients?

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Most people agree that patients should be given adequate information about their health and any planned medical interventions. The difficulty is defining what constitutes adequate information. Three standards of information disclosure have traditionally been used. All of them are flawed.

The professional standard requires disclosure consistent with the standards of other professionals in the same community acting in the patient's best interest. Standards defined in this manner risk disproportionately reflecting the values of professionals, not patients. Also, the question of how professional standards were justified in the first place is left unanswered.

The reasonable-person standard calls for the provision of information that a reasonable person would want. This standard suffers because of the difficulty gauging the needs of a hypothetical reasonable person; also, reasonable people may differ in their information needs.

The third standard — and my preference of the traditional models — is the subjective standard, which calls for information to be tailored to the needs of each patient. Physician and patient engage in dialogue; if more information is requested, it is given. The subjective standard is, however, fragile because it depends on the skill and willingness of the physician to engage in this sort of information exchange and on the ability of the patient to ask the right questions.

The existing disclosure standards are based on what professionals, reasonable people and individual patients choose to know or disclose. Little attention is paid to the characteristics of information itself. Why should a physician decide to disclose certain information and not other information? Why should a patient want certain information and not other information? A challenging case illustrates the inadequacy of the currently used standards and will serve to demonstrate a different way of analyzing disclosure decisions that considers the characteristics of information.

The American Red Cross notified a hospital blood bank director that a unit of blood shipped to his hospital a year earlier and transfused to a patient came from an apparently healthy donor who subsequently developed Creutzfeldt-Jakob Disease (CJD). Because CJD has a long incubation period, the donor probably harbored the causative agent at the time of donation. The letter noted that the American Red Cross, the Centers for Disease Control, and the New York Blood Center "strongly discouraged" sharing this information with the recipient of the blood transfusion because there was no screening test, no treatment and the information would cause the patient "tremendous stress." The letter also noted that representatives of the hemophilia community, a highly transfused group, disagreed with this position and at public meetings expressed their

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expectations that recipients of possibly tainted blood be notified.

CJD is a rare, rapidly progressive fatal brain disorder that has been transmitted to humans by hormones derived from cadaveric pituitary glands, corneal transplants, dura mater grafts, and reusable deep brain electrodes. A variant of CJD has been transmitted with the ingestion of beef and is popularly known as "mad cow disease."[1] The transmission of CJD by blood transfusion is theoretically possible but there have been no documented cases.[2] We might expect the increased use of blood products in recent decades to be associated with an increase in CJD if CJD were transmitted by blood; but that has not been the case. Confounding this reassuring data is CJD's long incubation period, which can be decades; heavily transfused people may not survive long enough for us to observe manifestations of the disease. The rarity of CJD limits our ability to obtain a reliable number of observations and there is no laboratory test to determine whether the causative agent has been transmitted. It is not likely we will have a definitive answer to whether CJD is transmitted by blood in the near future.

There is reason for the blood bank director not to notify the recipient of the CJD blood. There is no proof that blood transmits the disease, there is no test similar to HIV testing that would indicate whether the agent has been transmitted, there is no treatment for CJD, and notification could be psychologically devastating to the recipient. However, CJD might be transmitted by blood, the illness is horrendous, the patient might want this information, and although there is no treatment for CJD, it would be prudent for the recipient to know he should avoid donating any of his tissues or organs.

How should the blood bank director analyze this case? The traditional disclosure standards are not helpful. Decisions concerning the notification of CJD blood recipients are so unusual — and there are no clearly analogous situations — that no community professional standard exists. In several informal surveys, about half of the presumably reasonable people I questioned would want to be informed if they had received blood from someone who developed CJD and half would prefer they not receive this information. In the wake of a CJD scare in Canada involving the transfusion of albumin from a donor who subsequently developed CJD, 68 percent of presumably reasonable Alberta residents favored notification of recipients and 32 percent did not.[3] Because some reasonable people favor notification and others do not, the reasonable-person standard is not helpful.

The subjective standard would be difficult to implement because the blood bank director could not call the patient a year after the transfusion without explaining the reason for the call — which would lead to notification of the patient independent of the patient's wishes. If there were a physician who knew the patient, that might to some degree obviate this problem.

Another approach to information disclosure discussions examines eight characteristics.[4] Consideration of these factors may not make the blood bank director's decision easier, but they provide a useful framework for thinking about the problem.

Relevance is a threshold criterion. CJD is an infectious disease and its transmission by blood is theoretically possible; therefore information about the transfusion is relevant to the recipient. If the blood donor had glaucoma, that information would not be relevant because there is no reason to believe glaucoma can be transmitted by blood.

Probability is an important factor because an event that occurs with a probability of one in 10 thousand does not have the same claim on disclosure as an event that occurs with a probability of 10 percent. It is a reasonable guess that the probability of CJD transmission by blood transfusion is very low.

The **significance** of information is important because omitting insignificant information is less ethically troublesome than materially significant information. For example, an evanescent rash does not demand disclosure as strongly as heart or kidney failure. The factor of significance is high in this case because CJD destroys the brain and is fatal.

The **availability of interventions** can in some instances trump all other factors. There is no diagnostic test for CJD and no treatment. The recipient of CJD blood would be well advised not to donate blood, a kidney, a lobe of liver or, when he dies, his corneas. Notification now might be advised so the patient can be alert to tests or treatments developed in the future. At this time the availability of CJD related interventions should be considered relatively low.

Does the patient have a **subjective need** for this information? Faced with the prospect of a fatal illness, even if the probability is low, some people might alter their lifestyle, take a long anticipated trip, or resolve a festering family dispute. We do not know the recipient in this case, therefore his subjective needs must be considered unknown.

The disclosure of information can cause **harms**. The knowledge that you have received blood from someone who developed an awful and ultimately fatal brain disease can cause anxiety and depression. Some Canadian recipients of CJD albumin were "scared silly every time they forgot a number or a key." If you inform a recipient of CJD blood, you may cause considerable harm.

Patient **autonomy** should be respected. If a patient has made it clear that he doesn't want certain types of information that wish should be respected. If a patient has indicated a desire for detailed information about his or her condition, even trivial details, to the extent possible those wishes should also be respected. Clinicians who routinely solicit information preferences from their patients are better equipped to gauge the factor of patient autonomy.

The **decision-maker's perspective** cannot be ignored. A transfusion service director who, in the wake of the AIDS crisis, promised full disclosure in all cases would be under self-imposed pressure to inform the CJD recipient. A decision maker director in a different professional culture that frowns on delivering bad news is likely to be more restrained. When the disclosure decision is difficult, as in this case, my perspective is to err on the side of disclosure. That's why I would inform the recipient of CJD blood.

When there is a substantial probability of a significant future event and beneficial interventions are available, a patient who would want the relevant information and use it to modify his life without suffering mental turmoil should receive it. Of course, difficult cases will not be this straightforward. Information about some of the eight characteristics may be unknown or controversial and it may be unclear how to weigh contradicting factors, which differ qualitatively, one

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Ask the ethicist:

A teenager's refusal of assent for treatment

Question: A 14-year-old boy was diagnosed with early-stage Hodgkin's disease. Two pediatric oncologists recommended aggressive treatment with chemotherapy and radiation therapy, offering a 90 percent probability of complete cure. But the boy obstinately refused to undergo treatment. Counseling sessions with the general pediatrician, pediatric oncologists and nurses failed to convince him to undergo treatment. His parents very much wanted him to be treated but his pediatric oncologists were reluctant to begin treatment without the boy's assent. How would you advise the pediatric oncologists?

Response: Caring for adolescent patients can present serious ethical challenges for physicians especially, as in this case, in determining their appropriate role in difficult and life-threatening decisions. Over the last 30 years, professional groups, national commissions, and judges have expanded the role for adolescents in healthcare decisions.[1] The oncologists in this case are understandably concerned about the significance of this boy's refusal of treatment. Does this teen have the capacity to refuse this potentially life-saving intervention? What is the moral authority of the parents here? What is the doctor's duty? How can the physician help identify the proper balance between parental authority and respect for developing autonomy in a serious medical situation?

The law allows exceptional categories for adolescent health decision making for "emancipated minors" and "mature minors" and under "minor treatment statutes" (typically limited to pregnancy, sexually-transmitted diseases, and alcohol and drug abuse). "Emancipated minor" is a legal term that refers to an adolescent who lives apart from parents because of marriage, military experience, parenthood and often because of the neglect or abuse of parents. "Mature minors" are still dependent on families but have decision-making capacity for particular medical conditions. So, both law and ethics focus on the teen's context and competence for autonomous decisions.

Parents are primarily responsible for protecting and promoting their children's interests.[2] They are granted wide discretion in making decisions for their children. While the literature demonstrates that adults and older adolescents do not differ significantly in their cognitive capacities and decision-making skills,[3] there are still good reasons for parents to limit the autonomy of adolescents, especially in a situation with life-saving potential. These include the need to promote the lifetime autonomy of the teen; the reality that the teen's decisions are based on a limited life experience; the importance of family goals and responsibilities, and finally the need for consistency between health decisions and others, such as smoking or playing competitive sports.[4]

Respect for autonomy is a fundamental principle of ethical practice. For adolescents this means respect for their developing autonomy even as they are dependent on parents for care and support. Physicians encounter adolescent patients in three categories: (1) those younger than 14 years who generally lack decisional capacity; (2) those 14 to 17 who clearly have capacity for making competent decisions; and (3) those 14 to 17 whose capacity is unclear.[5] Where does this teen fit?

The physician has a primary role in assessing the teen's competence for decisions.[6] This competence requires three elements: (1) *information* — Does this patient have sufficient information about the condition and treatments to understand them? (2) *Capacity* — Can he communicate and respond to information? Does he demonstrate reasoning and deliberation, especially regarding the risks and consequences of this decision? Does he show a conception of "the good," i.e., enduring values, with some degree of stability as a basis for the decision? (3) *Freedom* — Is he free from undue influence, fear, guilt and coercion regarding the decision and able to make choices that are meaningful for him?

Is this adolescent capable of making an "authentic choice" and giving an informed refusal? Refusal of a potentially life-saving intervention requires a high degree of certainty regarding competence. If not capable of that degree of decisional maturation yet, can and should he give assent to the treatments?

The concept of assent was developed to respect that intermediate stage in which the parents give permission for the procedure and the not-yet-competent teen gives assent.[7] While there is a certain comfort when the adolescent assents to their parents and caregivers decisions, there is great distress when the adolescent refuses or dissents as this boy does. Do both competent refusal and not-yet-fully-competent dissent mean the treatments cannot be initiated?

More information about this boy's emotional and decisional maturity is essential. What are the real reasons for the refusal? His participation with treatment is essential to its success so, forcing him against his will can be difficult and dangerous. However, the case portrays a refusal that is difficult to take as competent. His best interests seem to be dependent on treatment. The task for the general pediatrician and parents is to find a way forward that has his best interests always in focus and, if possible, gradually allows the teen to actively participate.

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Outcome: With further intervention by family members, the patient accepted treatment. □

[1] American Academy of Pediatrics Committee on Bioethics. Informed consent, parental permission and assent in pediatric practice. *Pediatrics* 1995;95:314–7.

[2] Buchanan A, Brock D. *Deciding for Others: The Ethics of Surrogate Decision Making*. New York: Cambridge University Press, 1989.

[3] Grochowski E, Bach S. The ethics of decision making with adolescents: what a physician ought to know. *Adolescent Medicine* 1994; 5:485–95.

[4] Ross L. Health care decision making by children. Is it in their best interest? *Hastings Cent Rep* 1997;27(6):41–5.

[5] Weir R, Peters C. Affirming the decisions adolescents make about life and death. *Hastings Cent Rep* 1997;27(6):29–40

[6] Kenny N P, Skinner LE. Skills for Assessing the Appropriate Role for Children in Health Decisions. *Pediatric Clinical Skills*. Philadelphia: Harcourt Health Sciences, 2002:349–59.

[7] Bartholome W. A new understanding of consent in pediatric practice: consent, parental permission, and child assent. *Pediatric Annals* 1989;18:262-5.

The legal column:

Governmental bioethics commissions: The nature of the beast

By Alexander Morgan Capron
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Alexander Morgan Capron was the executive director of the President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research during its entire existence, 1979 to 1983.

The topic of governmental bioethics commissions has little to do with the law (except for the statutes or executive orders under which they are typically established) and may seem too commonplace to deserve further thought. Yet many issues are imbedded in each of the topic's three parts: In what sense are such bodies governmental? How do they do bioethics? And what kinds of commissions are they? Let's start with this last question.

Public commissions come in a variety of forms, divided basically between permanent bodies to which Congress has delegated lawmaking functions and ad hoc panels that are convened to provide advice on a particular subject. At both the state and federal levels, panels of the former type have a history dating to the 19th century. Bodies such as the Interstate Commerce Commission and the Federal Trade Commission fill in the details of broad, general statutes that frame their respective fields by issuing rules and applying them in individual or categorical determinations. The members of such commissions are typically appointed by the chief executive and serve as full-time public officials, with expert advice from their staff. The members of ad hoc advisory panels — who may be appointed not only by the chief executive but by other executives or even legislative or judicial branch officials — typically do not enter full-time governmental employ, though they too may be supported by staff. In most cases, they do not issue regulations or adjudicate individual claims but may offer advice to officials who do.

The several dozen federal and state "bioethics commissions" that have functioned over the past three decades have all been of the latter type — ad hoc and advisory. Indeed, most have existed for relatively brief periods, though several were established in a fashion that would have allowed them to continue indefinitely, and at least one specialized board (the Recombinant DNA Advisory Committee, or RAC) has existed for more than a quarter century. Yet being merely advisory is not inherent in the task of doing "public bioethics." For example, the UK's Human Fertilisation and Embryology Authority (HFEA) — a mixed panel of experts and laypersons, like commissions in the US — not only licenses fertility clinics but decides on ethical grounds whether particular assisted-reproductive technologies may be used. The HFEA recently permitted one couple to use preimplantation genetic diagnosis (PGD) to select embryos for implantation which were not only free of the genetic disease that affects the couple's first child but which would make well-matched donors of cord blood stem cells for the existing child. Conversely, PGD was denied to another couple because the condition affecting their existing child was extremely unlikely to recur and thus the only reason to select embryos would be to create a suitable donor.

The second aspect of these commissions is that they "do bioethics." Yet does it seem reasonable for a mixed group of lay persons and experts from a range of fields, meeting for a day or two each month or so, to produce "bioethics"? If it were an academic discipline (a subset of philosophy or theology) or even a professional field, the answer would probably be "no." Committees aren't known for great, original thinking, and the eclectic nature of bioethics commissioners makes that even less likely. But the roots of bioethics as an interdisciplinary field that arose in the late 1960s from collaborations among natural and social scientists, physicians, nurses, philosophers, theologians, lawyers and others, make it an ideal field for a public commission.

Furthermore, while bioethics commissions do undertake or sponsor original studies (which not only influence their conclusions but are published as appendices to their reports), their most important contributions are typically synthetic: having clarified the issues and arguments, they draw together the best current thinking and move the field forward by formulating a new consensus. Two reports by the President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research (1980 to 1983) illustrate this point.[1,2] Among the topics assigned by Congress, the commission decided to start with "the matter of defining death" precisely because it had been debated for more than a decade and a broad agreement existed on how it should be resolved both medically and legally. The commission was able to bring the other groups whose competing statutory proposals had stymied action in most states to agree on a uniform proposal — which was then quickly adopted across the country — and to facilitate the leading medical authorities on the subject to promulgate what was recognized as the accepted medical criteria for declaring death.

As an offshoot to this assigned topic, the commission decided to undertake another large study on the situations in which patients, families, and physicians must decide whether to forgo life-sustaining treatment. Medical thinking, case law, and public awareness on this topic were all rather rudimentary at this time. "Living wills" had been around for about 15 years but few people had them and only 15 states had "Natural Death" statutes authorizing the use of "directives to physicians." Moreover, most people — including many healthcare providers — operated from the assumption that it was wrong (and even illegal) ever to discontinue life-support, perhaps even when the patient's wishes to do so were known. Drawing on the best ethical and legal analysis, the commission articulated why this was not the case, provided a framework for hospital ethics committees (which were just being widely instituted), and urged states to formulate and adopt

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Ethics and the humanities:

Complications: A Surgeon's Notes on an Imperfect Science

By Atul Gawande
New York: Henry Holt and Company Metropolitan Books, 2002

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This delightful and fascinating book gently rolls like a conversation with the author across 14 clinical stories recounting his personal and professional reflections while a surgical resident. The conversation is admittedly one-sided, yet when I wished I could pose a question to him, Gawande seemed to sense it and provided an almost direct response in the next page or two. The surgical cases he describes are fairly common and both public and professional audiences will find much with which to personally identify, cheer and lament.

Gawande's skill at weaving his clinical experiences with their personal meanings provides readers privileged access to poignant, insightful lessons from a reflective healer and astute observer of his profession. The stories' chief value resides not in their content but their role as springboards from which Gawande touches and teaches with patience and empathic identity about fallibility, error, authority and uncertainty in healthcare practice.

Gawande believes that quality healthcare is inextricably held hostage between the twin towers of fallibility and error. When it is rescued, it is through professional dedication more than brilliant skill. "Surgeons," Gawande writes, "believe in practice, not talent." The need for practice is infinite and professional skill accrues slowly, but errors, students are told, are never acceptable. Since trainees must practice on sick people, medicine is inescapably conflicted both in what it teaches students about providing quality care and how the lessons are ethically framed. Recounting a personal error, Gawande describes his reaction as shame rather than guilt; though he was not culpable, it occurred because he was inexperienced. Systems theory, he observes, postulates that errors are more commonly the result of inadequate quality monitoring and control processes than of deficient individuals. But too often personal shame for one's error occurs because collegial support is lacking and a serious and dangerous risk of self-doubt emerges.

Despite self-doubt, trainees need practical experience to develop professional competence. Moreover, patients in the future will receive competent medical care only if patients today agree to be treated by trainees rather than the most experienced and skilled practitioners available. This ethical trade-off sometimes results in lower quality care and increased risk of error, but it is absolutely necessary to accept. What troubles Gawande is that the risks are not equally shared, and they should be. "… the ward services and clinics where residents have the most responsibility are populated by the poor, the uninsured, the drunk, and the demented. … the humblest of patients."

Patients seeking care should not be able to refuse service from trainees, but sometimes they do refuse and, if the patient is a health professional or the child of one, refusal is generally accepted. That version of professional courtesy fills Gawande with moral misgivings for having made such a refusal when his own child needed medical attention. Gawande's candor reveals both his internal tensions and profound respect for patients who courageously agree to acquiesce. Patient confidence in the medical profession is so thoroughgoing that they shop more carefully for a car than a surgeon. Even if the financial investments are sometimes comparable, the risks never are.

Gawande explores how the evolution of medical decision making shifted authority from physicians to patients. He views informed consent as an effective technique for improving understanding about the goals of treatment between patient and practitioner, but neglects to note that its dominant motivation is less often to empower patients than to reduce practitioner liability in the event of adverse outcomes. Informed consent is a significantly progressive ethical step, but it is limited to competent patients facing specified treatment choices. Advance directives further extend patient empowerment to those who have previously exercised, but presently lack, decision-making capacity. The motivation for advance directives is avoiding harm to patients and promoting responsible stewardship of resources, an ethically important focal change.

Like many physicians, Gawande worries about the focus on patient autonomy and empowerment in medical decisions. He confesses that talking patients through their decisions is a delicate dance with its own practiced techniques that aim at providing patients the opportunity to change their mind but stopping short of directly pointing out how wrong they are. For most patients, just feeling heard by their physician seems to be enough and frequently they do not want the freedom and authority that the patient empowerment movement is thrusting upon them. Gawande reconciles his own hesitations about this by noting that the exercise of genuine autonomy includes being able to relinquish it.

Gawande's solution to this paradox is understanding that "There is an art to being a patient, of knowing when to be assertive and when to submit, but always to ask for explanations." Medical ethics fails, he argues, when it insists on an ultimate value like patient autonomy rather than a balancing of competing values. The vexing problem is how to do the balancing, and it remains very much unresolved. Gawande takes the real task to be neither championing patient autonomy nor banishing physician paternalism but rather fostering professional competency and preserving interpersonal kindness.

According to Gawande, the core predicament for medicine is neither universal fallibility nor ubiquitous error but diagnostic and therapeutic uncertainty. Professional wisdom, he concludes, is defined by how one copes with it. Yet coping most commonly is done by the physician relying on his or her ability to negotiate with each patient what is best. This has a certain intuitive reasonableness until one realizes that it results in enormous variation in practice and contributes to avoidable errors. Why not reduce professional uncertainty by using statistical analysis or decision theory for developing practice guidelines, and urging practitioners to agree in advance what to do in uncertain circumstances? The answer, Gawande postulates, is that each physician remains convinced that the best person to work out what should be done for a patient is always the local physician. And that hubris, emanating too often from students' expert role models, is often what leads to complications. □

Dialogue:

Heating up the conversation?

In his new book, *Our Posthuman Future: Consequences of the Biotechnology Revolution*, Francis Fukuyama suggests that there were two great dystopias of the 20th century, Orwell's *1984* and Huxley's *Brave New World*. Of the two, says Fukuyama, only Huxley's vision continues to haunt us. One reason is clear: the effects of the computer revolution and the emergence of the Internet have not had the sinister effect that Orwell might have predicted. On the contrary, if anything, these developments have undermined rather than strengthened totalitarian regimes. But how do we explain the enduring quality of Huxley's vision? According to Fukuyama, one reason that Huxley's vision always was, and continues to be, more worrisome than Orwell's, is precisely that, in Huxley's world, no one is obviously harmed.

I thought of Fukuyama's observations when reading the recent reflections on preimplantation genetic diagnosis (PGD) by Erik Parens and Thomas H. Murray (*Lahey Clinic Medical Ethics Newsletter*, Spring 2002). The authors wish to start a conversation on embryo screening by raising an important series of cautionary questions about PGD. Should decisions about PGD be left exclusively to the marketplace? Do medical professionals have a responsibility to consider the impact of PGD on the lives of the children who will be created using these techniques? Is using PGD to select for so-called enhancement traits ethically acceptable? What kind of society will we create if we allow PGD to become widespread? These are all important questions, but one can almost hear the procreative entrepreneurs of reproductive medicine complaining to Parens and Murray: "But where's the harm?" The children wouldn't exist without *in vitro* fertilization; how is anyone harmed by selecting one embryo rather than another in the lab?

We are indebted to Parens and Murray, not to mention Aldous Huxley, for reminding us that sometimes we are harmed when we least suspect it. That is the real threat of PGD. It is hard to argue that screening an eight-cell organism to avoid the pain and suffering associated with, for example, Tay-Sachs disease is morally wrong. Yet, it is a short step from the paradigm cases that support using PGD to other more problematic cases, so short that we may fail to notice that we have crossed an important moral threshold. Consider, for example, the case cited by Parens and Murray, of the couple who used PGD to screen embryos to create a child who would not carry the gene for early-onset Alzheimer's, a disease from which the mother is likely to die before her made-to-order child is 10 years old.

In one sense, using PGD to screen against the gene for early-onset Alzheimer's is like using PGD to screen against Tay-Sachs disease. Both diseases are devastating and in both cases the motive for screening may well be one of beneficence. Still, as Parens and Murray properly ask: What about the child? Unfortunately, many fail to ask that question — or see it as secondary — when evaluating PGD. For example, writing in *The Wall Street Journal*, Jerome Groopman had little patience with the reservations raised by physicians and ethicists about screening in the case of early-onset Alzheimer's.[1] The fact that we are knowingly creating a child using PGD who will almost certainly have to watch her mother succumb to dementia and die seemed of little concern. To be sure, the couple in this case could have conceived a child without using PGD, so we cannot blame the PGD for the creation of a child whom we know will suffer. Still, the issue here is not merely what responsibility parents have in considering whether to procreate, but what responsibility physicians have in helping prospective parents pursue their desires. According to Groopman, however, only the parents' choice really matters. Those who would oppose the use of PGD in a case like this, Groopman wrote derisively, "do so primarily because of religious beliefs …"

Nowhere in their essay do Parens and Murray appeal to religious beliefs to oppose the use of PGD, but they do raise serious moral reservations about the growing and unqualified acceptance of PGD. Indeed, they seek to draw a line between acceptable and unacceptable uses of this technology. Specifically, they appear to endorse a distinction between using PGD to screen for health-related traits and screening for non-health-related traits.

I agree with Parens and Murray that we need to draw a distinction between treatment and enhancement, but a full moral discussion of PGD needs to be much more expansive than a focus on this distinction will permit. Notice, for example, that screening for the gene for early-onset Alzheimer's is in fact screening for a health-related trait. Yet classifying this use of PGD as treatment related rather than enhancement related is hardly the end of the matter morally.

I am not, of course, suggesting that Parens and Murray would disagree with me about the need for expanding the framework in which we discuss PGD. Indeed, Thomas Murray has recently argued persuasively that almost all of the current debates about the ethics of reproductive technology are too narrowly focused on the theme of procreative liberty.[2] I certainly agree with Murray that, like so many other debates in bioethics these days, the terms of the argument about reproductive technology are too cramped. While autonomy is an important value, it is not the only or even the most important value.

Of course, the specific provenance of the framework of procreative liberty is a commitment to autonomy read through constitutional law. Essentially the reasoning behind the appeal to procreative liberty is as follows. Given that the Supreme Court has recognized a right not to procreate in its decisions upholding a liberty interest in contraception and abortion, it would likely recognize a right to procreate. If there is a right to procreate, the only reason to interfere with the exercise of that right would be to prevent direct harm to another. Because it is nearly impossible to harm someone by bringing him into existence, almost every restriction on reproductive choice, including the choice to use PGD for almost any purpose, is prohibited.

Just how impoverished the framework of procreative liberty is can be seen by considering how it would handle a variation of the second case discussed by Parens and Murray, that of the Nashes. As Parens and Murray explain, Molly Nash inherited Fanconi anemia from her parents. Hoping to avoid the same fate for their second child and seeking a good donor match for Molly, the parents conceived a second child using PGD to screen for embryos that would be HLA compatible with Molly and thus a good cord blood donor.

By all accounts, the Nashes were always committed to their second child and there was every reason to believe that they would love and cherish him. Yet, what if that were not the case? What if the parents decided to have a child merely to serve as a stem cell donor, with no intention to raise and care for the child? How would the framework of procreative liberty approach such a case?

For anyone who has read the work of John Robertson, the most well-known advocate of the procreative liberty approach, the answer is not reassuring. Indeed, recently Robertson and two colleagues, Jeffrey Kahn and John Wagner, have written about precisely this issue.[3] "As objectionable as such an action seems," they write, "… it is not clear that the parents have actually harmed the child, nor that they should legally be stopped from doing so." Although some people may apparently react badly to the prospect of creating children without any thought to their care, there are no moral grounds for opposing this practice and no legal grounds for prohibiting it. After all, nobody has been harmed.

Because I find the analysis of PGD offered by the framework of procreative liberty both wholly inadequate and disturbing, I very much welcome the thoughtful reflection on PGD offered by Parens and Murray. In the final analysis, however, I find their reservations too tepid and too restrained. I suppose that what I would like to hear from them is the kind of alarm Tom Wolfe sounds in his recent book, *Hooking Up*, after exploring contemporary research on brain imaging technology and neuroscience. Noting the uncompromising determinism of the neuroscientific view of life, Wolfe wonders whether the notion of a self can survive in a world in which neuroradiologists can read a random list of words to a patient hooked up to a PET scan and see specific areas of the cerebral cortex light up when the radiologist hits a topic of interest to the patient. Wolfe's essay, entitled, "Sorry, but Your Soul Just Died," conveys the sense of urgency that he believes this technology ought to evoke.

I would not go so far as to say that we are about to lose our souls by embracing PGD. There are clearly uses of PGD that are morally acceptable, and it is certainly the case that most uses of the technology have so far been health related and designed to prevent pain and suffering. Nevertheless, it is perhaps worth noting that even in the highly secularized world of reproductive medicine, the road to hell is still paved with good intentions.

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[1] Groopman J. Designing babies. *The Wall Street Journal* March 4, 2002.

[2] Murray TH. What are families for? Getting to an ethics of reproductive technology. *Hastings Cent Rep* 2002;32(3):41-5.

[3] Robertson JA, Kahn JP, Wagner E. Conception to obtain hematopoietic stem cells. *Hastings Cent Rep* 2002;32(3):34-40.

Moral rules and technology

Paul Lauritzen implies criticism when he speaks of "creating a child who will almost certainly have to watch her mother succumb to dementia and die." He doesn't tell us whether this concern is relevant only when technology is used to make babies or whether he believes that women destined with high probability to have early-onset dementia should also not have children even when that is possible by natural means. If the use of technology produces an undesirable end, should producing the same end by natural means also be considered undesirable? Should the moral rules for having babies be different when technology is used?

The editors

Lauritzen's reply

The editors ask whether my implied criticism of creating a child whom we know will watch her mother die applies only when technology is needed to conceive or whether it also applies to conceiving naturally in such circumstances.

They have properly called me to task on this point because I intentionally attempted to sidestep this question in my response to Parens and Murray by focusing on the responsibility of physicians who assist couples to procreate rather than on the couples themselves. However, having now had my hand forced, my answer is that, of course, couples who conceive naturally must be every bit as concerned about the welfare of the child they conceive as couples who use assisted reproduction. Unfettered autonomy is no more to be encouraged among those who do not use assisted reproduction than it is among those who do. Whether in any individual case a couple should refrain from procreation will, of course, be highly contested, but if procreation is a bad idea when technology such as PGD is used, it is likely to be a bad idea without the technology as well.

Paul Lauritzen

A meaningless implication?

Paul Lauritzen notes that some commentators make claims to the effect that "… it is nearly impossible to harm someone by bringing him into existence." Such claims do not need the qualifier "nearly" because the subject of the act of "bringing someone into existence" cannot already exist. It is impossible to harm an entity that doesn't exist. Moreover, courts consistently dismiss wrongful life suits on the grounds that, while a damaged life has some value, nonexistence can have no value for there is no subject, or value holder. □

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Errata: In "Preimplantation genetic diagnosis: Beginning a long conversation" *Lahey Clinic Medical Ethics Newsletter*, Spring 2002, the author's names were reversed. Erik Parens, PhD, is the first author.

Disclosure *(Continued from Page 2)*

against the other. Despite these limitations, disclosure decisions are best made by including an analysis of the characteristics of the information in question rather than resorting to the flawed traditional professional, reasonable-person, and subjective standards. The identification of eight characteristics: relevance, probability, significance, availability of interventions, subjective needs, harms, autonomy and the decision-maker's perspective will hopefully provide a framework for this analysis. □

[1] Rhodes R. *Deadly Feasts: The Prion Controversy and the Public's Health*. New York Touchstone, 1998.

[2] Dodd RY, Sullivan MT. Creutzfeldt-Jakob disease and transfusion safety: tilting at icebergs? *Transfusion* 1998;38(3):221–3.

[3] Sibbard B. Features. *Can Med Assoc J* 1998;159:829–31.

[4] Steinberg D. Informing a recipient of blood from a donor who developed Creutzfeldt-Jakob disease: the characteristics of information that warrant its disclosure. *J Clin Ethics* 2001;12(2):134–40.

durable power of attorney for healthcare statutes (which nearly all of them did over the decade that followed).

These two reports also help flesh out the significance of the topic's third facet, namely, that the commissions are "governmental." Plainly, nongovernmental bodies also propose legislation as well as changes in professional practices. Governmental commissions — especially those appointed by US presidents — have two advantages, however, one is visibility (and, if they do their work well, a sense of legitimate authority), and the other is that their pronouncements are seen as "official" in a sense that is helpful in getting action from legislators and bureaucrats, even when the commission operates at a federal level and its recommendations are for state action (as was true of the two reports I just described). This is not to say that recommendations are never ignored — especially once a commission's charter has expired and it is not around to pester policy makers for a response — but the governmental commissions still have more leverage than private ones.

At the same time, these commissions are not governmental in the sense a federal agency or Congressional committee is governmental. Indeed, several of the presidentially appointed commissions continued to function after a change of occupants at 1600 Pennsylvania Avenue, certainly straining the sense that they were part of the current administration. Even when they possess something close to decision-making power — as, for example, is true of the RAC for r-DNA research and gene transfer experiments that seek federal funding — bioethics commissions typically operate more like outsiders. Still, by virtue of their official status, they are more open and "transparent" in their processes than private bodies, which is a great virtue for those who favor democracy over rule by experts.

In the 30 years since the first steps were taken — in the wake of revelations of the Tuskegee experiment and other research scandals — to establish what became a succession of bioethics commissions, they have become familiar fixtures (not only in the US but around the world). Individually, they have had hits and misses in helping the public and policy makers understand modern biomedical science and practices and their ethical and social implications. Yet collectively these commissions — both at the national level and in a number of states — have succeeded in building a bridge connecting the legislative and executive branches, experts and academics in science, philosophy and law, and the general public, and in aiding the adoption of better governmental, organizational and professional policies, and the making of more ethically enlightened individual decisions. □

[1] President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research. *Defining Death: A Report of the Medical, Legal and Ethical Issues in the Determinations of Death*. Washington DC: US Government Printing Office, July 1981.

[2] President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research. *Deciding to Forego Life-Sustaining Treatment: A Report on the Ethical, Medical, and Legal Issues in Treatment Decisions*. Washington DC: US Government Printing Office, March 1983.

Medical Ethics

The *Lahey Clinic Medical Ethics Newsletter* 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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