NEWSLETTER ON PHILOSOPHY AND MEDICINE

FROM THE EDITORS, ROSAMOND RHODES & MARK SHELDON

FROM THE CHAIR, KENNETH KIPNIS

ARTICLES

KENNETH KIPNIS
“Pediatric Ethics and Responsibility for Children: Clearing the Ground”

LAINIE FRIEDMAN ROSS
“Adolescent Autonomy in Health Care?”

JOEL E. FRADER
“Commentary: Parental Authority and Health Care Decisions”

F. M. KAMM
“Embryonic Stem Cell Research”

ARTHUR CAPLAN
“Revulsion Is Simply Not Enough: The Impending Culture War over Advances in Genetics”

THOMAS MAY, ROSS D. SILVERMAN, & MARK P. AULISIO
“Do Healthcare Professionals Have an Obligation to be Vaccinated Against Smallpox?”

MICHAEL DAVIS

BOOK REVIEWS

David Kuhl: What Dying People Want: Practical Wisdom for the End of Life and Timothy Quill: Caring for Patients at the End of Life: Facing an Uncertain Future Together
REVIEWED BY MARY DEVEREAUX

Peter Korn: Lovejoy: A Year in the Life of an Abortion Clinic
REVIEWED BY VIRGINIA J. NIMICK
"Richness" and "variety" describe this issue of the Newsletter. Its contents illustrate how interesting topics in applied ethics can be and how philosophically challenging medical ethics issues are. The contributions span the field from discussions of parental authority over health care decisions to stem cell research, from an examination of smallpox vaccination policy to an assessment of a theory of punishment.

At the March 2002 meeting of the Central Division, the Committee on Philosophy and Medicine invited four individuals to focus on the issues of how to resolve the tension between parental rights, children's interests, and physicians' responsibilities. The four were philosophers Jeffrey Blustein and Kenneth Kipnis, philosopher and pediatrician Lainie Friedman Ross, and pediatrician Joel Frader. The specific issue that the four addressed was the age at which children should be allowed to make health care decisions for themselves. Jeffrey Blustein's paper, "Parental Authority, Children's Rights, and Health Care," appeared in Volume 02, Number 1, Fall 2002 of this Newsletter. In this issue, the discussion continues as Kenneth Kipnis, in “Pediatric Ethics and Responsibility for Children: Clearing the Ground,” sketches a broad outline concerning criminal and family law, medical social work, and clinical ethics. He discusses whether the criminal and family law frameworks provide precedents and a model for when physicians should override parental wishes.

Lainie Friedman Ross, in "Adolescent Autonomy in Health Care?" seeks to counter what she perceives as a growing trend to grant to adolescents autonomy to make health care decisions. She particularly questions the effort by the American Academy of Pediatrics to recognize a greater role for children and adolescents in making health care decisions for themselves and the basis for their ascribing an adequate level of maturity when there is no test for maturity. Ross sees no basis for allowing physicians to overrule parental decisions and argues, instead, for the importance of keeping the family at the center of medical decision-making and allowing parents to set family priorities.

In "Parental Authority and Health Care Decisions," Joel Frader (who Chaired the Committee on Bioethics of the American Academy of Pediatrics when it formulated the report criticized by Ross) stresses the practical challenges posed by the real and complicated world in which clinical pediatrics plays itself out. While he acknowledges the usefulness of criminal law for dealing with some pediatric cases, he does not see it in others. Frader questions the appeal to a standard of "rationality" premised on the notion of a “well-reflected” or “well-conceived life plan” that we don’t even apply to adults. Frader also criticizes Ross for failing to appreciate that clinicians sometimes encounter adequately mature adolescent patients, and he maintains that it would be appropriate to let such patients make decisions. In addition, he challenges Ross’s claim that there is no test to determine levels of maturity by pointing to the behavioral scientists who would disagree.

The next two papers, “Embryonic Stem Cell Research” by F.M. Kamm and “Revelation is Simply Not Enough: The Impending Culture War Over Advances in Genetics” by Arthur Caplan, focus on the current controversy concerning therapeutic cloning. Kamm develops a tight and rich analysis of the moral importance of human embryos. Caplan expresses concern about the political and social forces that make the new genetic science and therapeutic cloning into a symbol for their broader agendas and the newest battlefield of the “culture war” to block further advances in the new science. Taking issue with Kass and others who experience revulsion at the thought of creating a cloned human embryo, and criticizing Fukuyama’s argument from the inviolable status of human nature, Caplan argues that turning away from the possibilities afforded by biotechnology amounts to paranoid conservatism. The clear and present danger of these vocal critics is that they would deny the sick or disabled the possible benefits of developments on the horizon of science.

Turning to yet another topic is the timely paper by Thomas May, Ross Silverman, and Mark Aulisio. Focusing on President Bush’s December 2002 announcement of plans to vaccinate up to 500,000 healthcare professionals, they ask whether healthcare professionals have an ethical obligation to submit to vaccination. They examine the issue in light of the Model State Emergency Health Powers Act developed shortly after September 11, 2001, in light of membership in a health profession, and in light of healthcare professionals' obligation to serve national security interests. Ultimately, the authors conclude that there is no professional obligation for healthcare professionals to be vaccinated against smallpox prior to a terrorist attack.

In the final paper of this issue, “Some Problems of Method in Punishment Theory: A Critique of Michael Ridge’s ‘Unfair Advantage, Auctions, and Proportionality,’” Michael Davis responds to Ridge’s criticism of Davis’s own “fairness theory” of punishment. The appearance of this paper in these pages may surprise some readers. Yet Davis’s comments are far more relevant than his title suggests. Punishment, whether it is seen as a part of ordinary morality and integrally related to our assignment of praise and blame, or seen as a piece of a legal system, raises an important topic in medical ethics. It is relevant to our judgments and responses to medical errors and to our stand on the issue of the medical profession policing itself. Davis also offers interesting comments on the use of
intuitions and models in applied ethics. This part of his discussion is apropos because a good deal of the work in medical ethics makes use of intuition as a starting point (for instance, Frances Kamm’s paper in this section). Davis provides a clear account of how intuitions can be misleading. Unless they are clear, shared, and relevant, and unless the inference is appropriate, intuitions are not a useful starting point for ethical analysis. Furthermore, Davis’s discussion of how to use and criticize a theoretical model raises appropriate considerations for addressing the models we find in medical ethics discussion (for example, Kenneth Kipnis’s reference to the dominion model in family law).

This issue of the Newsletter concludes with reviews of three books, each one worthy of library space according to the assessment of our reviewers. In “Patient Perspectives on Dying: A Review of Recent Literature,” Mary Devereaux considers two books, What Dying People Want: Practical Wisdom for the End of Life and also Caring for Patients at the End of Life: Facing An Uncertain Future Together. Virginia Nimick reviews Lovejoy: A Year in the Life of an Abortion Clinic.

As always, please send announcements, letters, papers, poetry, stories, book and film reviews. Contributions and queries should be sent to Rosamond or Mark at the addresses below. For ease of communication, please include your phone and fax numbers and your email address.

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FROM THE CHAIR

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The Business Models of Philosophy

For reasons that are not easy to understand, we philosophers don’t often think about how we earn our livelihoods. Perhaps we are too much the heirs of Socrates, who didn’t seem to have taken the problem seriously enough. Aside from the poverty, Our Founder counted on the informal graciousness of wealthy and powerful friends, connections that may have served him badly toward the end. To his credit, Socrates had regular conversations with a variety of adults who, while neither philosophers nor intent on becoming philosophers, nonetheless pursued lively interests in philosophical questions.

Those dialogues shifted when Socrates’ student, Plato, developed the Academic business model, perhaps his most important contribution to philosophy. In exchange for teaching the sons of the wealthy, philosophers could now subsist on regular tuition payments while continuing their creative professional work between classes. Conversations now occurred between teachers and students and among faculty. For about 800 years—a successful run by any commercial standard—the Athenian philosophy industry flourished, albeit in a non-Socratic, sequestered manifestation; coming to an end only when an ascendant Christianity shut down the schools as hothouses of pagan corruption, an occupational hazard.

Although Dark Ages ensued, new academic institutions eventually re-emerged to support philosophy and other disciplines. While our contemporary colleges and universities are not so different from Plato’s shop, we have come to take the Enlightenment legacy for granted, usually conceiving professional philosophers as academicians.

But other business models have appeared. To be sure, Pierce and Spinoza did estimable work in their spare time. But Nietzsche, Russell, Hume and Copi sought livelihoods in the publishing industry. And still others took up work within non-academic settings: Plato and Aristotle in Syracuse and Macedonia; Aquinas and Confucius most spectacularly within the church and the Chinese courts; and, arguably, Lenin, Leibniz, Trotsky and Jefferson. It is a mistake to think that ‘academic philosophy’ is a redundancy.

Many of us working in medical ethics are now venturing well beyond the walls of the academy and discerning what may be new career paths. But there are perils for professionals who seek work within alien organizations, risks that are well-known to in-house corporate attorneys, doctors in correctional health services and—notoriously—accountants who get too chummy with their clients. Journalists worry about colleagues who board political bandwagons and “drink the Kool-Aid.” You can lose your professional bearings if you aren’t careful.

Having worked as an organizational ethics consultant and as an expert witness in ethics-related legal cases, I have learned to keep my distance, staying away from victory parties, for example. I struggle to avoid referring to my client and myself as “we.” I treasure my day job. I remind myself that I am merely an outsider, offering a judgment within my professional competence and decidedly not a participant in the client’s enterprise. None of these precautions were
covered during my professional training, I have picked them up along the way.

We may need a new business model for this work: something like an ethics consultation firm. The jobs are out there, but not the optimal organizational setting. Such an entity would have a Board with deep roots in professional values. It would have multiple clients with project managers who were primarily accountable to the Board rather than to clients. There would be information management practices that encouraged publication, so work could be judged openly by peers rather than concealed as proprietary. These arrangements and others could protect philosophical practitioners from being overawed by wealthy and powerful clients.

Though more work needs to be done, the idea of a such an entity may hold out the prospect of new career paths for philosophy students. But it also points toward an alternative business model that could end the Academic isolation that has marked too much of our profession’s history since the death of Socrates.

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**ARTICLES**

*Pediatric Ethics and Responsibility for Children: Clearing the Ground*

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What exactly do pediatricians owe to their minor patients—early infancy to late adolescence? And what do they owe to the parents of those minors? While these questions usually lie dormant in everyday clinical practice, they arise as ethical problems in a broad array of cases: vaccinations, clinical research, teen abortions and birth control, circumcision (both male and female), venereal disease, parental refusals of indicated treatment on religious grounds (particularly Jehovah’s Witnesses and Christian Scientists), deafness and cochlear implants, non-treatment decisions in newborn intensive care, child abuse reporting, and so on. Conscientious physicians can experience perplexing ethical conflicts involving duties to children and to parents. Even worse, ethical deliberation is often further complicated by the presence of legal standards and imperatives that add a third vector of obligation to the first two. The field of medical ethics is far from consensus on these problems.

Rather than providing definitive answers to the questions here, my purpose will be to begin to sort them out, narrowing the areas of possible disagreement and sharpening the issues.

I have suggested elsewhere [Kenneth Kipnis and Gailynn Williamson, “Nontreatment Decisions for Severely Compromised Newborns” in *Ethics* 1984, 95:90-111] that the root of our problem is our commitment to two different and incompatible ways of accounting for parental authority: accounts that I have termed *dominion*—with its roots in Roman Law—and *custody*—a more recent idea. Dominion conceives society as composed of families, not persons. Just as I do not have to account to others when I paint my car, so, on this view, parents do not have to justify the religious upbringing they provide to their children. Parenthood consists of a right that certain men and women have *in* certain children. It sets out a domain of privacy—the home as sovereign castle—that neither the state nor other persons can properly violate. Just as it is wrong to mess with Mr. Jones’s garden even though he neglects his flowers, so it is wrong to mess with Mr. Jones’s children even though they may benefit from our attention.

Dominion in family law is most clearly seen in the legal system’s response to actions that would be criminal offenses but for the fact that the “perpetrator” is the “victim’s” parent. If I wreck your daughter’s bicycle, pierce her earlobes, and spank her for misbehaving, those would be very serious legal matters. But if I do the same with my own daughter, there will be no legal charge.

Proponents of dominion can either (1) seek to establish that children are the personal possessions of their parents (strong dominion), or they can (2) concede that while parents don’t literally own their children, things will go better if we acted as if they did, supporting parents in their decisions (weak dominion). It is commonly alleged that parents have a special sensitivity to the child’s interests, while professionals and state officials are clumsily intrusive. In both its strong and weak forms, dominion creates a powerful presumption against interference with the family, providing few tools for child advocates and reformers. As late as 1874, laws prohibiting child abuse were unheard of in the United States. The first prosecution (the New York City case of 10-year-old Mary Ellen McCormack) was famously brought under an animal protection statute. Because dominion offers few internal resources for limiting parental authority (e.g., delinquency and abandonment), its derivative pediatric ethic will endorse strong deference to parents, much as veterinarians are obliged to animal owners.

Beginning in 1874, the view that children are under the sovereignty of their parents has given way to the view we can call *custody*. The term suggests an entrusting of the child to the care of its parents. Custody acknowledges the truism that it takes three to make a marriage: a man, a woman, and a state. This idea is not new; Plato, in the *Crito*, has Socrates argue that the state, acting through its laws, is a third and preeminent parent. On this second account of parenthood, parental authority is a stewardship: a special permission the state bestows and can revoke if certain conditions are not met. Parental powers do not come free.

Society often grants special permission: think of the privilege that ambulance drivers have to sound their sirens, break the speed limit, and oblige others to pull off the road. We expect ambulance drivers to use their special permission to perform an important task. And we will take away their privileges for reasons of abuse, neglect, or inability to meet responsibilities. Important matters of social concern should only be entrusted to persons who are willing and able to attend to them, and who do not abuse the special privileges they are accorded in the light of their responsibilities.

Custody gives parents a revocable possession of the child until it reaches adulthood. Parental authority is both justified and limited by parents’ duties to meet their distinctive responsibilities. In pediatric ethics, the tasks are, first, to define the proper dimensions of the responsibility that the community imposes on parents for the care of their children and, second, to circumscribe the special responsibilities pediatricians have for the health care interests of those same children. To the extent that these boundaries and standards are murky and insecure, dominion may come to be a more accurate description than custody. Here medical ethics can play a role in the creation of socially valuable clarity.

Discussion of the dimensions of pediatric responsibility are often confused by inattention to the context of discussion.
There are at least four contexts within which inquiry can be carried out. We can be concerned about substantive criminal law, family law, medical social work, and—finally—clinical ethics.

**Criminal Law:** Criminal law characteristically includes prohibitions on child abuse, involuntary manslaughter (or negligent manslaughter) and child neglect. Standardly, parents have a legal responsibility to provide appropriate care for their children, including health care. Since they are ordinarily not licensed to do this themselves, they must retain doctors to do this for them. If a parent refuses to seek out appropriate medical care for a child who is obviously and seriously ill, and the child dies, there can be a charge of involuntary manslaughter. Parents do go to jail for this. Although it is not often discussed, there may be situations in which pediatricians serve as instruments of abuse. In one case I know of, the parents of a young child refused on religious grounds to permit the use of pain medications during debridement (the removal of debris and dead tissue following a severe burn). Even with medication, this is one of medicine’s most painful procedures. It seems that anyone inflicting a like amount of unnecessary suffering upon a child would plainly be guilty of abuse. I think health care professionals should have refused to do the debridement in that way. Comparable concerns also arise in connection with circumcision (both female and male), surgical assignments of sex, and when dying minors are “flogged” with burdensome treatments that cannot provide patient benefit.

This context, we might include the deliberate failure to relieve severe pain and the imposition of burdensome treatments—especially those that cause pain or irreversible loss of function—that are not expected to provide compensating benefits. It may be that the concept of abuse is broad enough to prohibit such treatments.

Finally, physicians are routinely assigned enforceable legal duties to report evidence or reasonable suspicions of child abuse and neglect. These legal responsibilities can conflict with ethical obligations of confidentiality and—more importantly—with the duty to make medical services available. Child abusers will be discouraged from bringing injured children to doctors if they know they will face prosecution and punishment as a consequence. Instead of protecting children, reporting laws may substantially increase the danger to them.

**Family Law:** From this point of view, the primary issues are whether and on what basis courts should suspend or terminate some or all parental rights where parents are unwilling or unable to provide appropriately for children. If we have common standards specifying what parents owe to children, and if it becomes clear that some parents are neither meeting those obligations nor delegating the appropriate authority to others who will, then it can fall to a court, acting with ethical obligations of confidentiality and—more importantly—with the duty to make medical services available. Child abusers will be discouraged from bringing injured children to doctors if they know they will face prosecution and punishment as a consequence. Instead of protecting children, reporting laws may substantially increase the danger to them.

**Medical Social Work:** Instead of appointing a proxy decision-maker, it is often possible to mobilize and enhance the resources of the immediate family and community in the interest of ensuring that the minor patient receives indicated care. Almost all parents are, from time to time, unable to manage certain childrearing responsibilities by themselves. Public schools, hospitals, day care centers and preschools, foster homes, juvenile detention facilities, pharmacies, family courts, etc., are all social mechanisms intended to augment the resources of parents in the interests of the community and its children. This point of view inquires about special resources that might provide assurance that the child will be protected. For example, where Christian Scientist parents are conscientiously refusing medical care for a chronic condition like diabetes, one might ask whether a guardian can be appointed on a continuing basis to arrange for and consent to treatment. Can mechanisms be set up to ensure that appropriate parties are notified in the event that the child needs medical attention? Can neighbors, teachers, home visits by social workers, be part of the solution? Much can be gained—especially for the child—if a formula for cooperation can be found.

It was noted earlier that guardians are sometimes appointed—almost as a prosthesis—where parents who are mentally retarded are unable, by themselves, to manage the responsibilities associated with childrearing. In a comparable way, Christian Scientists sometimes cannot be counted upon to provide their children with medical interventions that are necessary in the senses defined above. While there may be no blame in these cases, it is unfair to the children of Christian Scientists for the larger community to undertake to protect all children against unnecessary suffering and untimely death from medical neglect, except for the children of Christian Scientists. The special legal privileges that parents have over their children make sense only in relation to the reciprocal responsibilities parents have to provide appropriate care. When it becomes evident that parents, for whatever reason, cannot be expected to meet the standard, the larger community has a duty either to relieve the parents of responsibility—delegating all or part of it to another—or to augment the family’s resources to the point where the child’s well-being is reasonably assured.

**Clinical Ethics:** A fourth context involves pediatric clinical ethics: specifically, the circumstances under which a physician should act to override a parental decision. We have already alluded to one case in which the parents demanded that a physician administer abusive treatments, treatments that imposed burdens without an expectation of compensating benefits. Here the Hippocratic duty “above all, to do no harm” should suffice. Physicians have a duty to reject such demands. But how physicians and hospitals should respond to refusals of medically indicated treatment by the children themselves or by their parents or guardians is a quite different issue. (A further complication occurs when a mature minor disagrees with a parental decision). Under what circumstances should physicians operating within a liberal society (a society committed to respecting substantial differences in orientation and values) either disregard such refusals, treating the minor directly or, if time permits, seek to have the refusal overturned in court? While the criteria the courts use in deciding to appoint guardians will be relevant to a medical decision to seek a court order, the medical profession, collectively, has an ethical duty to try to get the courts and legislature to adopt criteria that are consistent with medical ethics.

Notwithstanding the central involvement of doctors, it is not the case that physicians have the legal authority to impose...
treatment against the will of the minor’s parents, except under rare, emergency circumstances. At the hospitals at which I have worked the standard procedure is to ask the administration to direct the hospital attorney to petition the family court for a hearing to appoint a guardian. In Honolulu, a family court judge carries a beeper for this purpose at all times. Emergency hearings can be convened in hours. If the motion is granted, the parents’ authority over the child will be partially suspended and delegated to another individual—the guardian—who will then have the authority to give or withhold consent to medical treatment in the interest of the child. Conceived as a problem in medical ethics, the bottom-line issue is when to seek in this way to suspend or terminate a parent’s legal authority to give or withhold consent to a minor’s treatment. While it is not possible to set out a rule here, there are three factors that should generally carry weight in medically honoring a refusal of medical treatment by or on behalf of a minor: the decisional capacity of the minor, the burden and risk of treatment, and the effectiveness of treatment.

The Decisional Capacity of the Minor: The emerging trend, both in law and medical ethics, is to distinguish between mature (i.e., decisionally capacitated) minors and other minors. Minors often have the abilities to understand their diagnosis, the treatment options, and the risks and benefits attaching to each. Their personal values may be stable and well-reflected upon, and not the manifestations of either a developmental phase or a transient or treatable psychiatric condition. There may be grounded confidence that the child will still own the decision later on in life. It is now common for medical ethicists to maintain that a refusal to assent to treatment from such a “mature minor” should be given great weight in medical decision-making and several court cases support the right of mature Jehovah’s Witness minors to refuse blood. [See, for example, In re E.G, 549 N.D. 2d 322 (IL, 1989) and In re W.M. (823 S.W.2d 128 (Mo. Ct. App. 1992). Belcher v. Charleston Area Med. Ctr., 422 S.E.2d 827 (W.Va. 1992) involved a non-Jehovah’s Witness minor.]

One very useful standard is the “rule of sevens.” [See, e.g., Cardwell v. Bechtol, 724 S.W. 2d 739 (TN, 1987).] Below the age of seven years the child is unrebuttably decisionally incapacitated; from seven to fourteen years there is a rebuttable presumption of incapacity; and for fourteen years and above there is a rebuttable presumption of capacity. Accordingly, a Christian Scientist minor, perhaps even as young as seven years of age, could have a refusal of treatment honored, especially if that refusal made sense against a background of what appeared to be reasonably stable personal values. The case for deferring to parental authority (and the withheld assent of a child) would be much stronger if either or both of the next two conditions obtained.

The Burden and Risk of the Treatment: Though medical treatments can be risky and burdensome, many doctors tend to focus on the best outcomes and not on the human costs of getting there. Where treatments carry high prices in this way, that factor can call into question whether treatment is, on balance, a clear benefit. The greater the burden and risk, the less clear it is that the physician is doing a favor for the child in treating and that the treatment is “medically indicated.” The fact that a parent is withholding consent on religious grounds should carry no weight if the treatment being rejected is “elective” on the basis that it is burdensome or risky to the point that it could be plausibly refused on those grounds alone. It is worth noting that there are a number of effective and standard life-prolonging treatments—chemotherapy for cancer, dialysis for end-stage renal disease, and immunosuppressive therapies following transplants—that adults can reject as too burdensome or risky to endure.

The Effectiveness of the Treatment: There is also a need to consider whether the treatment is likely to be effective in securing some significant and subjectively valuable benefit for the child. The strongest case for overriding parental authority will involve treatments that are demonstrably effective—not experimental or investigational—in securing or recovering some very significant benefit that is subjectively valuable to the child (e.g., saving the child’s life with good function). Antibiotic treatment for bacterial meningitis is a clear case. But where a treatment has less than a 50% chance of realizing such a benefit, and where it is burdensome and/or risky, then these two conditions can entail that it is more likely that the child will be harmed by the treatment instead of being helped by it. If, let us say, a certain drug has a side effect which harms everyone who takes it, but provides significant compensating benefits to 30%, then a patient has a 70% chance of ending up harmed by the treatment without any compensating benefit. It would be difficult to argue that parents should have a legal obligation to authorize treatments that were reasonably expected to harm the child without a compensating benefit. In making these calculations, it should not be overlooked that the psychosocial stresses of official intervention in the family and litigation, and the imposition of treatment against the expressed wishes of the parents, may themselves cause significant damage to the child and his or her social support system, and all of these at a time when, because of the illness, the integrity of the family is likely to be critically important to the child.

But where the intervention is virtually without risk or burden, then even a small chance of a significant subjectively valuable benefit might conceivably carry great weight. A treatment’s effectiveness, together with its burdens and risks, are relevant in applying the Hippocratic principles that whatever the physician does shall be for the benefit of the patient and that, above all, the physician is to do no harm.

Being a physician is not like repairing appliances. The doctor has an independent responsibility for the well-being of the minor: he or she is not a mere functionary, beholden to the whims of the parents. There are some things a physician should not do to a minor patient even if the parents ask, and there are other things a physician should do for a minor patient even if the parents object.

— Adolescent Autonomy in Health Care?* —

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Introduction

The physician-patient relationship is often described as fundamental to medicine and medical decision-making. The relationship is being stretched at both ends. The doctor is now represented by physician-extenders (e.g., nurse practitioners, physician’s assistants) or by a health care team. And the patient is no longer viewed in isolation because 1) changes in medicine, most obvious in such fields as genetics and transplantation, have blurred the individual line of who is the patient; and 2) a recent movement within the Bioethics community seeks to promote an increased role for the family in the decision-making process, even when the patient is a competent adult.1 These changes are challenging mainstream contemporary American Bioethics in which the principle of patient autonomy functions as the crux of ethical decision making.
In pediatrics, the doctor-patient relationship traditionally has included three parties: the physician, the child, and his or her parents. Parents are not merely surrogate decision makers on the grounds of child incompetence, but rather, parents are believed to have both a right and a responsibility to participate in their child’s medical decisions. In contrast with the changes in the physician-patient relationship generally, the triadic nature of the doctor-patient relationship in pediatrics is being contracted. Many ethicists and policy makers are seeking to isolate the child and physician by excluding parents from many of their children’s health care decisions, and thereby promote the child’s self-determination. In part I, I examine the current position of the American Academy of Pediatrics (AAP) as a leader in promoting this policy and I argue why it is misguided. In part II, I discuss two controversial issues and the implications of a policy that supports adolescent self-determination versus a policy that requires parental involvement.

Part I: Health Care Decision Making for Children

1. Recommendations of the American Academy of Pediatrics

In 1995, the American Academy of Pediatrics (AAP) published its recommendations for the role of children in health care decision-making. The AAP recommended that the child’s role should depend upon his or her decision-making capacity. The AAP concluded that children who have decision-making capacity should give informed consent for themselves. Although the AAP stated that there were no requirements to obtain parental permission, it tempered this conclusion by encouraging parental involvement “as appropriate.” With respect to children with developing decision-making capacity, the AAP stated that there were certain situations in which their dissent should be binding (e.g., research) and that even in the therapeutic arena, the child’s decision should “carry considerable weight when the proposed intervention is not essential to his or her welfare and/or can be deferred without substantial risk.” For children who lacked decision-making capacity, the AAP deferred to parents unless they (or their decisions) were abusive or neglectful.

The AAP also made specific recommendations about what should be done when parents and children disagree on health care decisions. According to the AAP, if there is parental-child disagreement and the child is judged to have decision-making authority, the child’s decision should be binding. If the child has developing capacity, consensus should be sought. The AAP supported third-party intervention for persistent disagreement between the parent and the child and offered various mechanisms including:

- short term counseling or psychiatric consultation for patient and/or family, case management or similar multidisciplinary conference(s), and/or consultation with individuals trained in clinical ethics or a hospital based ethics committee. In rare cases of refractory disagreement, formal legal adjudication may be necessary.

In part I of this paper, I challenge the AAP’s recommendations regarding 1) the proper role of children and parents in the decision making process; and 2) its suggestions for mediating child-parent disagreements.

2. Are Children Competent to Make Health Care Decisions?

A major problem with the AAP’s recommendations regarding the proper role for children in the decision-making process is that it assumes that decision-making capacity can be defined and measured. In the medical and psychiatric literature, there exist no objective standards that can easily distinguish between a competent and an incompetent individual. Even if an objective test could be devised, individual tests of competency of every potential patient would exact a high price in terms of efficiency, privacy, and respect for autonomy. Rather, adults are presumed competent on the basis of age, and physicians are not allowed to perform any medical procedure without the patient’s “informed consent.” In contrast, non-emancipated children are presumed incompetent and their parents have surrogate decision-making authority. To some extent, the age standard is arbitrary, as there are individuals older than the legal age of emancipation who are incompetent (lack decision-making capacity) and individuals younger than the legal age of emancipation who are competent (have decision-making capacity). But the statutes are not capricious; in general, individuals above the legal age are more likely to be competent than individuals below the legal age.

The AAP offers no guidance as to how to define or test for decision-making capacity, but recommends individual assessment of decision-making capacity on a case-by-case determination. However, since there are no criteria on which to base maturity or decision-making capacity, the decision of whether or not a child has decision-making capacity is dependent upon the judgement of the particular pediatrician—a judgement for which he or she has no training.

Are some children competent to make health care decisions? Although the data support the claim that adolescents and adults make equally competent decisions in medical vignettes designed by psychologists, this competency may not apply to real life. Despite their knowledge regarding automobile safety, adolescents account for a disproportionate number of fatal car accidents. And despite their ability to repeat the facts about the transmission of HIV and other sexually transmitted diseases, adolescents tend to overlook long-term consequences. If competency is understood as the ability both to choose and to act to promote one’s self-interest, then the claim that adolescents are competent is not persuasive.

I will ignore the difficulties in determining whether a minor has decision-making capacity and assume that some minors are competent to make at least some health care decisions. If autonomy is based solely on competency, then competent children should have decision-making authority in the health care setting. My goals will be to argue 1) that even if children are competent, that there is a morally significant difference between competent minors and adults; and 2) that competency is a necessary but not a sufficient condition on which to base respect for a minor’s health care decision-making autonomy.

3. Competency and its relationship to autonomy

If a child is competent, are there any advantages in treating her differently than an adult, particularly with regard to respect for her autonomy? One moral argument to limit the child’s short-term freedom is based on the parents and other authorities need to promote the child’s long-term autonomy. Given the value that is placed on self-determination, it makes sense to grant adults autonomy, provided they have some threshold level of competency. Respect is shown by respecting their present project pursuits. But respect for a threshold of competency in children places the emphasis on short-term autonomy rather than on a child’s life-time autonomy. Children need a protected period in which to develop “enabling virtues” (habits, including the habit of self-control), which advance their life-time autonomy and opportunities. Although many adults would also benefit from the development of their potential and the improvement of their skills and self-control,
at some point (and it is reasonable to use the age of emancipation as the proper cut-off\textsuperscript{1}), the advantages of self-determination outweigh the benefits of further guidance and its potential to improve long-term autonomy.

A second moral argument to limit the child’s present-day autonomy is based on the child’s limited world experience such that her decisions are not part of a well-conceived life plan. Again, there are many adults with limited world experience, but children have a greater potential for improving their knowledge base and for improving their skills of critical reflection and self-control. As Willard Gaylin explains:

Surely, part of what goes into our abridgement of the child’s autonomy is the recognition that although he may be [competent] ... the limitations of his experience distorts his capacity for sound judgement.\textsuperscript{13}

By protecting the child from his own impetuosity, his parents help him obtain the background knowledge and the capacities that will allow him to make decisions that better promote his life plans. His parents’ attempt to help him flourish may not be achieved, but that does not invalidate the attempt.

A third argument why childhood competency should not entail respect for a child’s autonomy depends upon the significant role that intimate families play in our lives. Elsewhere, I have argued that when the family is intimate, parents should have wide discretion in pursuing family goals, even though these goals may compete and conflict with the goals of particular members.\textsuperscript{14} In general, family autonomy promotes the interests and goals of both the children and the parents. It serves the needs and interests of the child to have autonomous parents who will help her become an autonomous individual capable of devising and implementing her own life plan. It serves the adults’ interest in having and raising a family according to their own vision of the good life. These interests do not abruptly cease when the child becomes competent. If anything, parents then have the opportunity to inculcate their beliefs through rational discourse, instead of through example, bribery or force.\textsuperscript{15} While children are still dependent upon their parents for emotional, economic, and material support, parental interest in their children must be balanced against the competent children’s interest in acting autonomously. In contrast, the current movement gives unilateral responsibility to older children who can still benefit from adult guidance, and it denies enduring parental interest in educating and guiding their competent children according to their own values.

If family intimacy is valuable both for what it does and for what it is, then family autonomy should not terminate the moment that a child attains some threshold level of competency. Rather, families can continue to pursue family goals which may compete with the individual goals of family members, even of its competent members. As the ultimate arbiters of intrafamilial conflicts, parents have the right and responsibility to choose these goals. This is not to suggest that parents should not give their child’s opinions serious consideration, particularly if the child is mature; only that parents should retain final decision-making authority until the age of emancipation.\textsuperscript{16} Although the child’s present-day autonomy is overridden, respect for family autonomy serves to promote the direction and development of the child’s lifetime autonomy. As such, respect for family autonomy respects the child’s developing personhood.

A fourth moral argument against respecting the health care decisions of minors is based on placing the notion of health care rights in context. Most individuals who support health care decision making for children view it as an exception and do not seek to emancipate children in other spheres. But why should a child who is competent to make health care decisions not have a right to make other types of decisions? That is, if a fourteen-year-old is competent to make life-and-death decisions, then why can’t this fourteen-year-old buy and smoke cigarettes? Participate in interscholastic football without his parents’ consent? Or even drop out of school?

Child liberation is a radical proposal with wide repercussions.\textsuperscript{17} It would mean that children could make binding contracts, and that child labor laws, mandatory education regulations, statutory rape laws, and child neglect statutes should be overturned. It would give children rights for which they are ill-prepared and deny them the protection they need from predatory adults. It would leave children even more vulnerable than they presently are.

My objection to the child liberation position should in no way suggest that I do not place great value on autonomy. My objection is that respect for an individual’s autonomy means respecting her good and bad decisions. Child liberation requires that I respect a child’s present-day freedom regardless of its long-term impact on her developing personhood. Imagine, then, that a fourteen-year-old with new-onset diabetes refuses to take insulin because she fears needles (or because her boyfriend’s religious beliefs proscribe medical care) even though she understands that she will die without it. Who is willing to abandon her to her autonomy? Not many: the laws that give adolescents the right to consent to treatment often do not give them the right to refuse treatment.\textsuperscript{18}

Child liberationists may object that adults also make bad decisions. Since physicians often challenge adults whom they perceive to be making bad decisions, they could do the same with adolescents. The difference is that the competent adult’s decision ultimately prevails. In contrast, most health care professionals for children would be unwilling to respect the treatment refusal of the fourteen-year-old with new-onset diabetes. More generally, we would be unwilling to respect a competent child’s present-day autonomy whenever she makes a bad decision. But if we are unwilling to respect her autonomy on the basis of content, then we are not respecting her autonomy. To only respect those decisions that a child makes with which we agree is not to show respect for the child’s autonomy, but to make a farce out of what is meant by respect for autonomy.

Finally, there are also pragmatic reasons to justify overriding the present-day autonomy of competent children. First, although it may be desirable to obtain a determination of competency for unusually mature and competent children, no such test exists. Second, it may be best if parents recognize their children’s maturity and treated them accordingly, but deny that this justifies granting competent children legal emancipation. Many parents respect their mature child’s decisions voluntarily, and “[i]t is plausible to think that children’s maturity is not completely unrelated to parental good sense.”\textsuperscript{19} Although child liberationists may object because a voluntary approach only encourages but does not legally enforce respect for the adolescent’s autonomy, such an approach does limit the state’s role in intrafamilial decisions, which is important for the family’s ability to flourish.\textsuperscript{20}

4. The Family as the Locus of Decision-Making

My second objection with the AAP’s recommendations is its willingness to involve third parties in the decision-making process. My concern is that these decisions undermine the family as an autonomous unit. Scant attention has been paid to the family and its children-members by moral theorists.
during the last quarter of the last century. Blustein hypothesized in 1982 that contemporary moral theorists ignore children and the family “because they tend to conceive of ethics as the study of those principles that determine how any two individuals are required to regard, and behave toward, one another.”21 The history of the philosophy of the family shows that this has not always been the case. From Plato to Russell, all moral theorists discussed the family. Although some contemporary moral theorists have recommended empowering children with rights and allowing them to make decisions for themselves,22 classical liberal theorists did not.23 John Locke, for example, specifically stated that it is a failure of parents and society ...

... To turn him loose to an unrestrict’d Liberty, before he has reason to guide him, is not the allowing him the privilege of his Nature, to be free; but to thrust him out amongst Brutes, and abandon him to a state as wretched, and as much beneath that of a Man, as theirs. This is that which puts the Authority into Parents hands to govern the Minority of their Children.24

Locke was quite specific about when a child comes to be free from both his mother and his father: “when he comes to be of age.”25 Locke did not deny the developmental process, but understood that a sharp line needed to be drawn between those who are and those who are not under parental authority.

My concern is that unlike Locke, many of my physician and bioethicist colleagues forget where their professional responsibilities end. Physicians only provide for a child’s transient medical needs; his or her parents provide for all of his or her needs and are responsible for raising the child into an autonomous responsible adult. Goldstein and colleagues at Yale University’s Child Study Center described the harm that health care professionals cause when they think they can replace parents.26 By deciding that the child’s decision should be respected over the parents’ decision, physicians and bioethicists are placing their judgment that the child’s decision should be overridden. This is less of an issue of respecting the child’s autonomy, but rather, in deciding who knows what is best for the child. In general, parents are the better judge as they have a more vested interest in their child’s well-being and are responsible for the day-to-day decisions of child-rearing. It behooves physicians and bioethicists to be humble as they are neither able nor willing to take over these daily tasks.

I do not mean to suggest that children, particularly mature children, should be ignored in the decision-making process. Diagnostic tests and treatment plans should be explained to children to help them understand what is being done to them and to garner, when possible, their cooperation. Parents should include their children in the decision-making process to get their active support, to dispel fears if possible, and to help them learn how to make such decisions. However, when there is parental-child disagreement, the child’s decision should not be decisive nor should health care providers require third-party mediation. The decision belongs within the family.

The idea that parents can be both involved in the parent-child disagreement and the final arbiter represents what would be an unacceptable conflict of interest in most settings. Ferdinand Schoeman explains this on the grounds that parents represent their own interests as well as the interests of the family as an integrated whole.

Though entrusting individuals with the responsibility of making judgments for the common good when their own interests are involved does not accord well with modern constitutionalist conceptions, we should not discount on a priori grounds the prospects for such an arrangement’s being feasible in certain contexts. The context in which such kinds of representation can work are those in which people in fact conceive their roles and their very identity as requiring such an attitude.27

According to Schoeman, parents in intimate families perceive themselves as representatives of the family’s interests, and this identity can be separated from their roles as representatives of their own interests. As such, parents can serve as both moderator and disputant in intimate family decisions. Again, this is not to suggest that parents should not give their child’s opinions serious consideration, particularly if the child is competent; only that parents should retain final decision-making authority until the age of emancipation. Although the child’s present-day autonomy is overridden, respect for family autonomy serves to promote the direction and development of the child’s life-time autonomy. As such, respect for family autonomy respects the child’s developing personhood.

Despite my arguments, I should add that parental autonomy in health care is not absolute and there are cases in which an adolescent’s decisions should be decisive. For example, I argue elsewhere that a child’s dissent should be binding for some cases in which a child is selected to participate as an organ donor, or as a subject of human experimentation.28 But in neither of these areas would I allow the child to consent unilaterally. Rather, the decision to participate would require the consent of both the child and his or her parent(s). But this paper has focused on the question of when, if ever, adolescents should be given sole decision-making authority.

5. Conclusion—Part I

In summary, adults are presumed competent and their autonomy is (should be) respected unless they are proven incompetent. There are, however, morally relevant differences between competent children and adults which justify different treatment with respect to autonomy. A competent child’s short-term autonomy can be morally overridden to promote her life-time autonomy. I base this conclusion on a competent child’s greater potential to improve her decision-making skills, her greater potential to broaden her background knowledge, and her parents’ valid interest and responsibility in supporting and guiding her moral and cognitive development, even though she has achieved a threshold level of competency.

Competency is a necessary but not a sufficient condition on which to base respect for decision-making autonomy in pediatrics. Parents have a valid interest and responsibility in guiding their child’s moral and cognitive development and these interests outweigh the costs of denying the child’s present-day decision-making authority. As such, I believe that the AAP’s recommendation to empower competent adolescents to consent and refuse treatment on their own is misguided.

Part 2: Two Case Studies in Adolescent Autonomy

6. Introduction

In part 1, I argued against granting adolescents sole decision-making autonomy in health care. Here I want to consider the implications of such a policy revision and compare them with the implications of our current policy. To do so, I examine two controversial issues that challenge both processes. The first issue is health care decision making regarding the
withdrawal of life-sustaining treatment. In the November-December 1997 issue of the Hastings Center Report, Robert Weir and Charles Peters argued for the need to affirm the decisions adolescents make about life and death. At its extreme, this raises the question of whether physician-assisted suicide, if legalized, should be extended to adolescents. The second issue is health care decision making regarding contraception. Since the 1970s, all fifty states have specialized consent statutes, statutes which vary in their scope, but which give adolescents some autonomy to seek and consent independently to the diagnosis and treatment of drug and alcohol abuse, contraceptive counseling, and/or the procurement of contraceptives. Some states even allow minors to consent to abortions without disclosure or consent from the minor’s parents.

7. Refusal of Life Sustaining Treatment

In their Hastings’ article, Weir and Peters review the literature of adolescent decision-making and conclude that the data that exist suggest that adolescents over the age of 14 years have decision-making capacity. The data that support their conclusion are scant and are based on hypothetical cases answered in a survey setting. The problem is that most of the studies do not reflect how decision making actually occurs because the studies depict hypothetical situations which may not accurately capture the differences that would be revealed in a more naturalistic setting. For example, it is not known whether the stress of illness has the same influence on the decision-making capabilities of adolescents and adults. There are some who believe the impact may be worse on adolescents, although to be fair, even they have few data to support this.

Weir and Peters distinguish three classes of children with respect to decision making regarding life sustaining treatment: 1) adolescents over the age of 14 years who are capable of making decisions; 2) children under the age of 14 years who usually lack decision-making capacity; and 3) adolescents over the age of 14 years about whom there are doubts regarding their decision-making capacity. Their conclusions are similar to those proposed by the AAP.

If the child is less than 14 years of age, but appears to have decision-making capacity, Weir and Peters argue for including the child to the greatest extent possible—that is to seek parental permission and the child’s assent for end-of-life decisions. This would mean that children would have to be told they are dying. The literature supports this position, but currently there are some parents who are unable or unwilling to do so. Weir and Peters believe they must. I am less adamant: I would encourage it, I would try to explain to parents because the studies depict hypothetical situations which may not accurately capture the differences that would be revealed in a more naturalistic setting. For example, it is not known whether the stress of illness has the same influence on the decision-making capabilities of adolescents and adults. There are some who believe the impact may be worse on adolescents, although to be fair, even they have few data to support this.

What does it mean to be “sufficiently mature”? This assumes that we can determine maturity and competency, despite the fact that no tests exist. My concern is that the finding of “sufficient maturity” may be a euphemism for “the physician agrees with the child’s decision.” This is not respect for autonomy, but the decision by the physician to replace his or her determination of what is in a child’s best interest with the decision made by the parents.

But ignore my cynicism for a moment and ask what would it mean to empower adolescents to refuse life-sustaining treatment? I could envision a scenario in which parents are unrealistic about their dying adolescent’s prognosis and would want aggressive care despite the adolescent’s plea “enough is enough.” Many of the cases of this sort reach consensus—the parents eventually hear the child and understand the “futility” of resuscitation and continued ventilation. But not always, and so some children are forced to bear unnecessary suffering—hopefully tempered by the physician’s obligation to provide sufficient palliative care. This is the sad case and it is the one that draws one to Weir and Peters’ conclusion.

But medical prognostication is not always right and it may be that the child will survive. And it is this doubt which explains why families are given the choice. If we are absolutely certain that treatment X would serve no purpose, treatment X cannot be offered ethically to the family. Imagine, then, a different scenario: an adolescent who refuses life-sustaining treatment because he does not like the side effects of treatment, despite his good long-term prognosis. Such is the case of Billy Best, who made headlines in 1994, prior to Weir and Peters’ article. Billy was 16 years old, had leukemia and an eighty percent chance of cure with conventional chemotherapy. But the chemotherapy made him weak and made his hair fall out, so he ran away to avoid further treatment.

My first reaction to Billy was to ask why or how could anyone judge him sufficiently mature, assuming that the media description of his reasons were accurate? The chemotherapy was temporary and his chance of complete recovery very high. Eventually, however, Billy convinced his parents to support his decision to refuse further chemotherapy, and his physicians acceded to the family’s demand. The physicians could have attempted to seek legal authority to force treatment (because he is a minor and his parents’ decision not to pursue further chemotherapy could be defined as neglect), but chose not to. Billy had completed most of his treatment course, and given the family consensus, the doctors decided that the incremental gains were offset by the harms and costs that judicial restraint would impose.

But imagine if Billy could not convince his parents and the doctors decided to respect his decision anyway. If I were his parent, I would say, “Say that again doctor. You can save my child’s life, and you won’t? Because he doesn’t want to be bald?” I’d find another physician quickly, and call the state board as well.

The easy objection is that autonomy is about the right to make decisions with which others disagree. And, in fact, adults make many bad decisions. But the inadequacy of some adults (or some of their decisions) is not the standard on which respect for autonomy is or should be based. Laura Purdy explains the problem with a least common denominator approach:

“Even liberationists, after all, lament the mistakes and immorality of adults. It seems to be that instead of asserting children’s rights to be equally silly and weak, it would be at least plausible to argue for the overriding importance of helping children develop the
self-control and other enabling virtues necessary for living more satisfying and moral lives.  

Of course, how would life sustaining treatment be administered?  Billy ran away from Boston and was located skateboarding in Texas.  Would I, in my role as physician, place him under house arrest?  Restrain him if necessary?  When I answer yes, this disturbs some of my supporters.  And then I am pushed: Would I be willing to restrain him if the treatment success were only 10% but his parents still insisted and he still objected?  Here I still want to respect the parents’ right to make health care decisions for their child, but I am more uncomfortable that respect for their decision requires that I restrain their child.  I would want more help from his parents: they need to get his cooperation.  But in the end, I might still restrain him.

I raise these hypothetical scenarios to consider the consequences of each policy.  In both cases, problems arise when parents and their children disagree.  If Billy wanted non-treatment and his parents demanded treatment, Weir and Peters would withhold it, even if death were to ensue, and I would force treatment.  By treating Billy, he would have most likely lived to hate me.  And this reminds many of the case of Dax, the 26 year old with severe burns who was treated for 18 months against his will.  But Billy is not Dax.  Dax is an adult and he should have had the right to refuse life sustaining treatment.  If Billy lived to 18 and relapsed, he too would have had the right to refuse further treatment.  All I want is to give him the chance to make this decision with a little more life experience to enhance his judgment skills.

Post script:  Billy Best is alive and well, 8 years later.  After discontinuing chemotherapy, he and his family pursued alternative medical treatments.  I am relieved, as it confirms the physicians’ decision not to seek a court order to impose treatment.  But it does not change my position about what I would have done had his parents demanded treatment.

8. Adolescent Sexuality and the Specialized Consent Statutes

The second issue involves health care practices that fall under the specialized consent statutes.  The statutes were designed to encourage adolescents to seek health care for problems which they might deny, ignore, or delay if they had to obtain parental permission.  Here I will focus on the adolescent’s right to seek contraception without parental involvement.  While the purported purpose of the specialized consent statutes to encourage early responsible sexual health care for adolescents is laudable, I will argue that 1) the empirical data do not support the claim and 2) that the moral and pragmatic arguments do not justify such a usurpation of parental responsibility.

There are several pragmatic and moral reasons to support such statutes.  The pragmatic position is compelling:  Given the fact that adolescents can be and frequently are sexually active even when birth control and other sexual health services are relatively inaccessible, they should be given the opportunity to be responsible for their sexual activity.  The pragmatist does not need to concede or refute whether the availability of such services increases the numbers of sexually active adolescents.  Rather, he or she must argue only that the number is sufficiently large, even when such services are unavailable, as to portend a public health crisis.  I accept the pragmatist’s position thus far.  But the argument makes two other assumptions which must be fleshed out:  1) that adolescents are competent to make these decisions; and 2) that a policy that grants adolescents autonomy will achieve greater sexual responsibility than would a policy that requires parental involvement.

Consider if the two assumption are false.  If the first assumption is false, that is, if adolescents are not competent to make health care decisions, then the statutes are misdirected.  If adolescents are incapable of giving informed consent in the area of sexual and reproductive health services, then the statutes unfairly hold them responsible for such measures.  If the second assumption is false, that is, if granting autonomy to adolescents does not produce greater sexual responsibility, then the argument for extending autonomy fails.  Since parents have, and I have argued, should have presumptive responsibility for their minor children, even if they are competent, legislation should override their responsibility only if it can be shown that the policies will promote adolescent well-being significantly better than a policy based on parental responsibility.  The state should not override parental authority on a single issue in which the state is only slightly more effective unless the state is able and willing to take responsibility for the myriad of other concerns of its adolescent citizens.  The rationale for requiring significantly better well-being is that state intervention inadvertently risks undermining parental authority in other realms—realms in which we both need and want enduring parental commitment.  Unless granting adolescent autonomy will promote significantly better sexual and reproductive health care for adolescents, the state must defer to parental authority.

Again, I will assume that the first assumption is correct and that some adolescents are competent to make such decisions.  Let us examine the second assumption which is that the specialized consent statutes will promote significantly better health care for adolescents in the realm of sexual and reproductive services than if adolescents required parental involvement.  Despite the confidentiality assured by the specialized consent statutes, adolescents typically delay seeking sexual and reproductive health care for almost one year after they become sexually active.  Of course, if parental involvement would cause adolescents to delay such services indefinitely, then the statutes achieve significantly better results.  Proponents of these statutes need to get empirical evidence that adolescents will seek earlier and better care if they are assured complete confidentiality.  Since such data do not exist, the presumption ought to be in favor of parental involvement.

Another pragmatic reason to support adolescent autonomy is that this position avoids conflict.  Some adolescents want to act without their parents’ consent because they know that their parents’ religious convictions condemn premarital sexual activity and birth control.  But why do we permit these adolescents to seek medical help when we do not allow them to get sex education against their parent’s beliefs?  That is, if parents can remove their children from sex education classes because we supposedly respect their traditional lifestyle, then why do we allow physicians to go behind their backs and prescribe birth control to their daughters?  And would anyone suggest that we should not tell parents when their adolescents are failing in school to avoid conflict?  Surely poor grades are common and are a major cause of intrafamilial strife.

The moral argument in support of the specialized consent statutes is based on the moral claim that competency should entail autonomy which I argued is not the case.  It ignores the fact that parents are responsible for responding to the child’s current identity, needs and interests and for shaping the child’s future identity, needs and interests.  To grant autonomy to competent children requires that it serve their current selves and their future identities.  Parents must be able to justify restricting a child’s present day autonomy in order to enhance his or her overall or long-term autonomy.
Consider, then, the moral and pragmatic arguments to rescind the specialized consent statutes. First, parents have decision making authority for their children because parents are best situated to decide and to act upon what is in their children’s best interest, and because parents are financially and socially responsible for them. This is true for their education, health care, and religious upbringing. There are no compelling moral arguments that show why medical care with regard to sexual health issues should be an exception.

Second, we should rescind the specialized consent statutes because they send adolescents the wrong message. They teach adolescents that their decisions regarding sexuality are unrelated to other aspects of their lives. Consider that parents dictate what schools and church their children attend and in which activities their children may participate, but these same children have legal sanction to ignore parental discretion in the area of sexuality. Consider that these children cannot consent to a throat culture without parental permission, but can authorize their physicians to perform a pelvic examination. Third, the specialized consent statutes affirm the adolescents’ attitude that their sexuality is solely a private matter. It is not. Adolescent sexual activity has numerous public consequences for which the adolescent is ill-prepared to accept responsibility. It entails responsibility to themselves (by delaying sexual gratification until they are emotionally and psychologically prepared), responsibility to their partners (by practicing safe sex), and responsibility to their community (by avoiding parenthood until they are both emotionally and financially capable of caring for a child).

By arguing against the specialized consent statutes, I do not mean to deny the need for a public commitment to prevent and treat the unwanted consequences of adolescent sexual activity. In that vein, the specialized consent statutes are on the mark: they affirm the community’s belief that the cost of unwanted adolescent pregnancy and untreated sexually transmitted diseases is too high. But the implementation of these statutes entails moral hurdles for the ethical physician: collusion against parents, disrespect for parental conceptions of the good, and a disregard for the adolescent’s need for further parental guidance. There must be other ways to minimize the negative consequences of adolescent sexuality without the specialized consent statutes which I discuss elsewhere.44

9. Conclusion—Part 2

Health care decisions are one of many decisions that are made by parents for and with their children. As such, who should have decision making authority and who should have the right to intervene must be kept in context. In our culture, we place great weight on the right of parents to raise their children according to their own values. This right is not absolute and we can and must challenge parents who are neglectful even if well-meaning. But in the vast majority of cases, we should leave medical decisions for children within the family. We should do so with our eyes open to its implications for adolescents, their families, health care providers, and society at large.


Endnotes


5. Ibid., p. 317.

6. Ibid., p. 316.

7. Ibid., p. 316.

8. Competency is a legal term that signifies that an individual has legal decision-making capacity for the decision at hand, although it is often used in the medical ethics literature to refer to a person with decision-making capacity, morally or clinically defined. In this paper, I will use “competent” as an adjective to describe someone who has decisions making capacity clinically and morally. I use the terms to refer to capability regarding a particular decision and not to some abstract concept of "global competency" or "global decision-making capacity".


12. The specific age at which emancipation should be granted is a political and not a moral question. Any age cut-off will liberate some immature individuals and will delay the liberation of some mature children. I do not argue for any particular age because I believe that the age should be chosen by societal consensus, and may differ in different cultures and different periods of times.


24. Ibid., Treatise II, p. 63.

25. Ibid., Treatise II, p. 60-61, 67.


36. Ibid., p. 38.

37. Ibid., p. 38.


41. I realize that this is also changing under the mature minor statutes which allow “mature” adolescents to consent to much of their own medical care. (G.S. Sigman, and C. O’Connor, “Exploration for physicians of the mature minor doctrine.” Journal of Pediatrics, 119 (1991): 520-525.) Nevertheless, this freedom is not commonly sought when the issue is not sexual, reproductive, or psychiatric. Rather, in general, parents are an important influence in their children’s decisions and adolescents tend to seek their suport and advice in most other matters. (See, L.B. Hendry, W. Roberts, A. Glendinning, and J.C. Coleman, “Adolescents’ perception of significant individuals in their lives.” Journal of Adolescence, 15 (1992):255-270.) In addition, adolescents are often willing to conform to parental influence (See, Scherer and Reppucci, “Adolescents’ Capacities” op. cit.) particularly female adolescents (See, C. Gilligan, N.P. Lyons, and T.J. Hammer (eds.), Making Connections: The Relational Worlds of Adolescent Girls at Emma Willard School. Cambridge, MA: Harvard University Press, 1989.)


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Commentary: Parental Authority and Health Care Decisions

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Like most philosophers, I am fond of public deliberation and debate. However, I am also a practical person. I seek guidance about how to function in the real world. With regard to parents and health care decisions for their children, real world action takes place in many different contexts. Unfortunately, the papers preceding this commentary, in trying to provide moral insight to suggest correct behavior, do not address context-specific circumstances. In general, their authors make many, many assumptions about different aspects of family, social, and medical situations such that, in the end, the papers provide us with little practical help.

First, I have to disclose an historical conflict of interest and admit a personal failing. As Dr. Ross knows, I and the Committee on Bioethics that I chaired have responsibility for much of the specific language in the published American Academy of Pediatrics policy statement on Parental Permission, Informed Consent, and Child Assent. Some of my reactions to her disagreements with that policy may arise, albeit unconsciously, from a natural inclination to defend the work that went into getting that statement approved—a task that took approximately a dozen years from the time William Bartholeme first drafted it. As Dr. Ross notes, we failed to make the document as clear or practically helpful as we would have liked or as it should have been. Thus, I know full well that providing useful moral guidance is quite difficult. Professor Kipnis begins by warning us he will not provide “definitive answers.” Nonetheless, one can be practical without having to be definitive. Does Kipnis’ conception of the issues help us know what to do? Kipnis reminds us of important historical elements in Western thinking about parental rule over children. He suggests that thinking about decisions for or by children divides among four contextual categories. His sketch does not acknowledge that the categories are not just fluid and indissoluble from one another, but we construct them in changing ways in our society. For example, his scheme reminds us that we are in the midst of a movement to revise how we view child abuse. Society has reclassified many kinds of child abuse...
once seen as requiring social work intervention—with its generally supportive and therapeutic approaches—as now necessitating police responses. We seem to want to use the criminal justice system to extract retribution and provide punishment, rather than reform or rehabilitate those who have hurt or neglected children. This transformation in ways of thinking about parents’ inappropriate actions toward children does not depend on a well-defined body of knowledge about or insight into the motivations of abusing parents, nor reflect strategies which might lead to prevention of future abuse. The changes are political, even ideological. Our moral judgments about parent/child authority thus seem to depend, in part, on the classification schemes we use to characterize adult behavior. This suggests an unsettling ethical shift associated with social attitudes about responsibility for actions rather than nuanced thinking about the morality of action, per se.

In addition, I find some of Professor Kipnis’ classifications rather sweeping and unrefined. He correctly criticizes professional complicity with parental abuse of a burned child when they conspired to deny pain control needed for wound care. He goes on to say “comparable concerns” “arise in connection with circumcision, surgical reassignments of sex, and excessive life-prolonging therapies.” I do not see how it helps to view any of the wrongs as “criminal.” Moreover, withholding needed analgesia has empirical and moral differences from permitting circumcision, accepting sex reassignment, or authorizing overly-aggressive measures to sustain life. The distinctions here require careful explication. Many of us would use another of Professor Kipnis’ categories to analyze these cases, that of clinical ethics. He does not make clear whether he would accept such a reclassification. With regard to his clinical category, Kipnis refers to the need to appeal to the canons of medical ethics in order to see if, in some particular case, professionals should seek court intervention to provide care that parents reject. I am sure Kipnis would agree this invokes a very fuzzy body of work, indeed. Medical ethics may itself qualify as an “essentially contestable” notion, with no singular authority. Bioethics scholars often have little agreement about how to understand, much less solve, a particular problem. Practicing physicians often have even less insight into the “right” ethical or even medical action in a given situation. The canons of medical ethics hold out little promise of help for knowing when to appeal to society for permission to override parental authority.

Finally, Kipnis, as well as his colleagues, refer to the importance of individuals—minors or adults—having a “stable” and “well-reflected” set of personal values or “a well-conceived life plan.” This seems to me an extraordinary—and entirely unattainable—standard. Few of us have well thought-out systems of values. I am not certain my colleagues really mean this should be of great importance. All of them would—perhaps reluctantly—support the “right” of an adult to refuse recommended care, even if the decision to refuse rests on irrational and arbitrary grounds apparently inconsistent with the individual’s other values. (I assume the adult in question shows no other evidence of lacking decision-making capacity.) This gets at a problem in the arguments of each of the philosophers here. It seems unfair to hold minors to a higher standard of decision making than adults. Rather than simply determining if a minor has the cognitive and emotional wherewithal to make a particular choice, the philosophers insist that minors make so-called rational decisions. That it somehow makes sense to apply a standard of rationality until the day of a person’s eighteenth birthday and thereafter a magical transformation occurs, entitling one to foolishness, baffles me. That arbitrariness does not correspond to anything we know about human development and maturation.

Ross suggests that we have to prevent minors from having decisional authority until their ascension to the legal age of majority for two reasons. First, it is the only sensible approach to public policy. Like it or not, policy requires arbitrary standards. Second, we must do things this way to preserve the critically important social institution of parental authority. She supports the former by saying we have no sensitive tests of decision-making capacity. Many psychiatric researchers would disagree with this. Several instruments now in use have been shown to be valid and reliable for indicating capacity to consent. Moreover, Dr. Ross has probably seen a variety of clinical situations in which adolescents exhibit remarkable maturity and judgment, at least about some aspects of their care. Some of these minors surely displayed a large measure of wisdom, even about life and death. Practically speaking, we make clinical judgments about capacity all the time. In critical situations we often put our heads together and make reasonable assessments about whether this teenager in this circumstance should have a great deal—even the last word—in determining the course of his or her care. Arbitrary denial of authority in all circumstances, even to support social policy and preserve social support for families, does more damage to the moral order than allowance for exceptions.

We have good reasons to believe that adolescents, as a group, make less sound decisions than, say, those twenty-five years or older. That said, surely we can agree that an individual younger than eighteen who meets reasonable criteria for cognitive capacity and mature judgment deserves decisional authority. This might well apply commonly to adolescents who have lived with serious, chronic medical conditions, especially when they have experience with proposed invasive interventions, such as surgery, mechanical ventilation, chemotherapy, or dialysis. The use of a sharp chronological threshold discourages young patients from taking on responsibility for managing their medical affairs. Modern developmental psychology suggests a graduated transfer of authority makes more sense. We use such schemes in other situations, including employment, driving, and criminal justice.

Finally, all three philosophers deserve considerable credit for going beyond the medical community’s strict and somewhat mindless “best interests of the child” notion. That mid-twentieth century conception, arising from child custody law and the “discovery” of child abuse, only gets us a little ways down the path of understanding. The interests of children cannot, in all cases, trump the legitimate interests of others: siblings, parents, family elders, and so on. Parents can and should have authority to consider what they and others need, as well. Health care professionals and judges may have to intervene when parents recklessly disregard the interests of particular children. However, actions to override parental authority in such cases must remain exceptional.
Embryonic Stem Cell Research: A Moral Defense *

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Should scientists seeking to cure human diseases be permitted to use stem cells from human embryos in their research? Proponents of embryonic stem cell (ESC) research emphasize that it may help in finding cures for diabetes, Parkinson’s disease, heart disease, Lou Gehrig’s disease (amyotrophic lateral sclerosis), and other devastating disabilities and illnesses. Critics acknowledge the possible medical benefits, but point out that ESC research destroys embryos. Such destruction, they say, shows insufficient respect for the embryo and, more broadly, insufficient regard for the value of human life. Human embryos, the critics argue, are morally important, and that importance imposes substantial limits on permissible research.

Last summer, President Bush came down close to the critics. He announced that taxpayer dollars could be used only to finance ESC research on stem-cell lines that had already been extracted from human embryos; federal money could not be used, he said, to “sanction or encourage further destruction of human embryos.” Interpretation of this policy has softened recently, making it easier for scientists who accept federal funds to use ESCs in their research, but the debate has grown in intensity because of connections between the use of ESCs and the controversial issue of human cloning. Cloning is one possible source of embryos. And with a bill before the U.S. Senate that seeks to prohibit human cloning for all purposes, including biomedical research, and a majority of the President’s Council on Bioethics recently recommending a four-year moratorium on all cloning of human embryos,1 we urgently need to assess the permissibility of using ESCs.

The moral problems with ESC research have been exaggerated, I believe. But to answer the critics, it is not enough to show that many lives may well be saved and much suffering avoided by new breakthroughs from ESC-based research. Critics acknowledge those benefits—although sometimes with considerable hesitation about their likelihood—but rightly deny that the magnitude of the benefits suffices to justify the research. After all, experimentation on infants is impermissible even if it generates socially valuable results. To respond, then, we need to address the moral criticism head-on, either by showing that human embryos are devoid of moral importance—like a human fingernail or an appendix or a small clump of human cells—or that the kind of moral importance they have is consistent with using them in biomedical research.

The idea that human embryos have no moral importance at all strikes me as wrong, so my case for the permissibility of ESC research assumes that embryos are morally important. I will, however, challenge the conception of that importance endorsed by the majority on the President’s Council in their report on cloning and in an earlier government commission report on stem-cell research.2

The Sources of ESCs

When a human sperm fertilizes a human ovum, a single cell is created with the potential to grow into a human person. A few days after fertilization, a blastocyst develops, comprising an outer layer of cells that forms the placenta and other tissues needed for the fetus to develop, and a hollow sphere that contains an inner cell mass. Cells in the inner mass are called “stem cells,” and they can go on to form nearly all tissues and specialized cells in the human body (e.g., organs and blood cells). Because of this unusual potential, stem cells—sometimes called pluripotent cells—may be useful in treating many illnesses. From this early stage in development until it is nine to ten weeks old, the organism is called an embryo. The embryo passes through a pre-implanted zygote stage, which lasts about seven to fourteen days, and the first eight weeks of gestation. Only after significant cell differentiation has occurred does the organism become known as the fetus. Stem cells can be gathered from the embryo’s inner cell mass; thus originates the term embryonic stem cells.

ESCs can be obtained from three sources: aborted embryos and early fetuses that still have some such cells; embryos generated for in vitro fertilization (IVF) but not implanted; and embryos created by cloning. However the embryos are obtained, they die when the stem cells are removed. A 1999 government report on guidelines for federally funded research involving ESCs acquired through abortion or IVF (that is, not through cloning)3 took the view that while human embryos do not have the moral status of human persons, they should be treated with respect. Treating human embryos with respect entails not using them simply as a means for achieving some further goal. I shall call this the Mere Means Thesis. According to the government report, Mere Means has two important corollaries, one concerning the creation of embryos, the other concerning their destruction.

1. Noncreation: Embryos should not be created for the purpose of conducting research that will destroy them. In particular, embryos should not be created for stem cell research because removing stem cells destroys the embryo. An embryo should only be used in stem cell research if it was created for some other purpose. Otherwise, it is treated as a mere means.

2. Alternate Destruction: Even embryos not created for the purpose of conducting research that will destroy them should not be destroyed in research unless they would have been destroyed in any case. Consider, for example, an embryo left over from an IVF project that will be stored in a freezer. Alternate Destruction says that a researcher should not acquire that embryo and use it to acquire stem cells. That, too, would be to treat it merely as a means and would not show respect.

Together, Noncreation and Alternate Destruction very substantially restrict morally permissible ways to acquire ESCs; they should only be obtained from embryos that were not created for the purpose of being destroyed but that will in any case be destroyed.

To appreciate the force of these restrictions, consider how they apply to the case of cloning as a source of ESCs. Many people assume that reproductive cloning—that is, cloning that results in a new human person—should be banned, but suppose we clone embryos. If reproductive cloning is wrong, then we have a duty to prevent the cloned embryos from developing into full human beings. So if a scientist clones ten embryos for the purpose of acquiring ESCs but draws ESCs from only five, then the remaining five must not be allowed to survive and grow into cloned human persons. Unless we can freeze the embryos, we will have a duty to destroy any that can develop further.4 Development of cloned embryos, however, violates Noncreation, and destroying them violates Alternate Destruction. The result closes off the cloning option altogether.

In a recent New York Times interview,5 Harold T. Shapiro, the chair of the federal panel that produced the original report on the use of ESCs in federally-funded research, said that
cloning embryos for the purpose of reproduction poses no unique moral problems. *Mere Means* and *Noncreation*, however, appear in his panel’s report—theses that conflict with cloning for the purpose of obtaining ESCs for research if, as seems to be the case, destruction of cloned embryos will occur and indeed be required.5

Perhaps, however, *Mere Means* does not apply to cloned embryos. How might one arrive at that exemption? One reason for thinking that embryos ought not to be treated as means is that the embryo has the potential to develop into a person. Embryos, however, could be created that lack the genetic potential to develop beyond a few days. Some scientists think that using such embryos for research would obviate many moral problems in using ESCs from cloned embryos. Let us call this the *Non-Potential Solution*. In this scenario, *Mere Means*, *Noncreation*, and *Alternate Destruction* do not apply to embryos with such limited genetic potential, even if they apply to embryos with the genetic potential to develop into a person. After all, by destroying an embryo lacking the potential to develop into a human being, we would not be taking away its future because it could have no future.

An alternative way to reopen the option of cloning as a source of ESCs is to say that an embryo’s potential to develop into a human person depends on its environment. Thus Senator Orrin Hatch, an opponent of abortion, came out in favor of ESC research because “life begins in a woman’s womb, not in a petri dish.” Hatch’s view seems to be that when an embryo is already in a sustaining environment such as the womb, it has the potential to develop into a person. In a petri dish or a freezer, however, it does not have the potential to develop until someone puts it in a sustaining environment. Hence, even cloned embryos that could develop if put in a sustaining environment do not have the potential to develop when they are not, and will not be, placed in such an environment. Creating and using embryos in laboratories (as is done in IVF) would create no problem according to this view because they would not have the potential for further development. Interestingly, bioethicist Arthur Caplan—who is no opponent of abortion—also holds this view.5

Notice that in the view proposed by Hatch and Caplan, we achieve the *No-Potential Solution* without creating embryos that are genetically unable to develop. If ESCs are taken from embryos deliberately created outside a sustaining environment such as the womb, then *Mere Means*, *Noncreation*, and *Alternate Destruction* may not apply. The fact that an embryo will not develop because we never put it in a sustaining environment is crucial. Achieving the *No-Potential Solution* in this way would, it might be thought,9 allow us to obtain ESCs from cloned embryos and from leftover embryos generated for IVF.

Because he is pro-choice, Caplan may also believe that when an embryo is aborted, it may be destroyed for its ESCs. Senator Hatch, however, may not share this view, for he thinks that abortion, which fatally interferes with an embryo that is in a sustaining environment, is morally wrong. He may believe it is impermissible to take advantage of an immorally aborted embryo. Therefore, depending on one’s beliefs, the *No-Potential Solution* may or may not allow us to obtain ESCs from aborted fetuses.

**Problems with Current Policies and Positions**

*Mere Means* and its corollaries impose large restrictions on using ESCs. Unless we endorse some form of the *No-Potential* view, they appear to close off completely the option of obtaining ESCs from cloning. I want now to offer some reasons for rejecting *Mere Means*, *Noncreation*, and *Alternate Destruction* and for thinking that the *No-Potential Solution* is incomplete and even unnecessary. In this section, I will offer some hypothetical cases that suggest that the first three ideas are implausible. In the next section, I will challenge a view that makes the moral importance of embryos depend on their potential to develop into human persons, and I will propose an alternative view of their importance. The upshot is that ESC research is morally much less troubling than much current discussion suggests.

*Mere Means*. The government report that presents *Mere Means* seems to be founded on an idea that traces to Immanuel Kant’s moral philosophy. The second formulation of Kant’s categorical imperative says that we should treat rational humanity, “whether in [our] own person or in that of another, always as an end and never as a means only.”10 The embryo is not rational humanity, however, but pre-rational humanity. A pre-rational embryo may have some moral value, but why suppose that the strong Kantian principle applies to it?

To see the force of the question, consider a couple in an IVF clinic. The couple has produced three embryos for implantation and cannot produce any more. The couple hopes for at least two children. Two of the embryos run into trouble, but both could be saved by sustaining them with parts of the third embryo. The third embryo is not in any trouble, is about to be implanted in the womb and would have developed without problems. Still, it seems permissible to use that one embryo to save the other two, even though it is impermissible to kill one person in order to save two people.11 Thus, the couple may use one embryo to save two, but they may not, for example, take organs from one infant child to save two others. If this is so, it is not true that human embryos should never be used as mere means. Embryos have a different moral status than human persons.

*Noncreation*. According to *Noncreation*, we must not create embryos we intend to destroy.12 But suppose that a woman dying of heart disease learns that if she becomes pregnant and has a very early abortion that kills the embryo, her body’s reaction to the embryo’s death will prompt a cure for her disease. Would it be morally permissible for her to become pregnant with the aim of aborting the embryo immediately? *Noncreation* implies that she should not do it, yet it seems permissible.13 To be sure, the example is very odd, but ask yourself what you think. Now suppose instead that the woman could cure her heart disease by carrying her pregnancy to term and having the infant’s heart valves transplanted into her body. In this case, the woman’s conduct is plainly wrong. Once more, moral thought distinguishes embryos from other living human beings—a difference obscured by *Noncreation*.

Suppose it is permissible for a woman to create an embryo that will be destroyed to cure her heart disease. Why may she not create it in order to give it to a scientist who will destroy it in an attempt to find a cure? Why may she not help create the embryo outside her body, in a laboratory, for the same purpose? If a doctor may help her have an abortion, why may a scientist not help her through ESC research in a laboratory? Perhaps the likelihood of finding a cure is important for assessing the permissibility of these acts, but this should hold whether or not a scientist is involved. Why should it matter that a cure is sought for the very woman whose embryo is donated? Why should she be permitted to help herself but barred from trying to help someone else in the same way?

Another problem with *Noncreation* is raised by the possibility that one might need to create a spare embryo for IVF in order to use it to keep other embryos alive. (This is an
extension of the three-embryo case discussed above). This case reminds us that creating an embryo in order to have a baby does not necessarily mean an embryo must become—or even have a possibility of becoming—a baby. Though Noncreation rules out creating an extra embryo for this purpose, it strikes me as morally permissible.

Alternate Destruction. According to Alternate Destruction, we may not destroy an embryo in research unless it would have been destroyed anyway for nonresearch reasons. Suppose, however, a woman is pregnant and discovers early in the pregnancy that she has fatal breast cancer. She has every intention of going through with the pregnancy, as this is her chance to leave a child behind for her family. She is then told that if she aborts the embryo and gives it to a scientist, a drug can be developed that will cure her cancer. According to Alternate Destruction, aborting this embryo is impermissible because the embryo would not otherwise have been destroyed. But it seems permissible for the woman to save her life this way. It seems permissible, too, for her to abort the early embryo to save someone else's life or to use an embryo in laboratory research even if it would have been implanted had the research not been possible.

The Moral Importance of Embryos

The basic principles underlying the 1999 government report on federally funded stem cell research—Mere Means, Noncreation, and Alternate Destruction—all seem misguided. These principles are founded on the plausible idea that human embryos are morally important, but they misrepresent that moral importance. How, then, should we understand the moral importance of embryos? I will come at this question a little bit indirectly, through a problem raised by cloning.

My criticisms of Mere Means, Noncreation, and Alternate Destruction imply that it is permissible to destroy embryos in more circumstances than if these theses were true. But cloning raises a special problem with these theses. It is widely agreed that allowing a cloned embryo to develop into a human person would be wrong. To avoid that wrong, we would have a duty to destroy any cloned embryo that might develop into a human person. Even if it is permissible to destroy an embryo for research purposes, it might be thought wholly objectionable to produce embryos that we subsequently have a duty to kill. An embryo has the potential to develop into a human person and, it might be said, we cannot have a duty to kill an entity with such potential. Hatch and Caplan deny that an embryo in a laboratory has any such potential. Imagine, however, that this embryo has been mistakenly implanted in the womb (or some external gestation device)—as might happen—and is otherwise fine. Everyone would agree that this cloned and implanted embryo has the potential to develop into a person. Would we nevertheless have a duty to kill it? And is it permissible to start projects that might lead to such mistakes and result in such a duty?

The answer to both questions is “yes” because of the kind of moral importance the embryo has. An embryo is not the sort of entity that can be harmed by the loss of its future. An embryo may have some moral value in the sense that its continued existence, in its own right (even if it is frozen and will never develop into a person), gives us a reason not to destroy it. This value could only be overridden by some good that we can achieve in destroying it, thus ruling out the useless or gratuitous killing of embryos. This is very different from saying that we should not destroy the embryo because that is bad for the embryo.

Consider, by way of analogy, a valuable work of art: say, a painting. A painting is valuable in its own right and therefore should not be wantonly destroyed. But we do not preserve paintings for the sake of the paintings themselves, because their continued existence cannot be good for them. After all, a painting cannot sense, perceive, or experience anything. Likewise, an embryo does not have and never had the capacity to sense, perceive, or experience anything. In contrast, when we refrain from destroying a bird—even if it is less valuable in its own right than a painting—we may be acting for its sake, for it may be good for the bird to continue to exist.

By not destroying the embryo, can we be acting for its sake because it has the potential to become a human person able to think, perceive, and experience? I do not think so, because even if it is good to be a person and even if there is some sense in which the embryo loses out on becoming a person (from which it is very different), I do not think that the embryo itself is harmed by this loss. I do not think that an embryo is the sort of entity that can benefit from transformation into a person or be harmed by not so transforming. This has something to do with its not being (and never having been) capable of consciousness or sentence, and so not capable of being benefited at all, even by turning into the kind of being that can be benefited. Analogously, suppose that a tree has, by magic, been made capable of turning into a person. The tree is not harmed if it is destroyed instead of being allowed to transform. (Harming an entity is not the only way to treat it disrespectfully, of course. For example, overriding a person's will for his or her own good can be disrespectful. But embryos do not have wills, and so cannot be treated disrespectfully in this way either).

Notice that the reasons I have given for the permissibility of destroying embryos for research do not yield a principled distinction between embryos in the first two weeks of life and older embryos. Researchers on stem cells intend to use embryos in the first two weeks, before the “primitive streak” appears and marks the first point at which the clump of cells begins to be an individual coordinated embryo. It is possible that other research might find it useful to use older embryos. Some have argued that because an embryo can split before the primitive streak appears and form the bases of identical twins, it does not merit the same protection as the embryo that is the basis for a definite individual person.

I am not convinced this is a morally crucial distinction. Suppose it were possible for children to split into identical twins before age four. A child who will not split still merits protection against destruction. What justifies such protection are the characteristics of the entity. A person has the necessary characteristics, but embryos before or after the primitive streak may not have them. Nor would it be correct to conclude that a child who will split can permissibly be killed on the grounds that the child will soon be replaced by two other people and thus cease to exist.

For these reasons, I do not think that it would be wrong to involve ourselves in a project that would result in a duty to destroy a cloned embryo with the potential to become a human person. I also think that many of my judgments about the permissibility of killing the embryo in the hypothetical cases I explored earlier can be justified by this understanding of the moral importance of a human embryo.

Let us now consider in more detail the question of what has the potential to be a person and whether creating an embryo without the potential to develop into a person is a plausible solution to the many moral issues that surround ESC research. Is it correct to say that an embryo that is not and will not be in a sustaining environment has no more potential for development than an embryo created with a genetic makeup that prohibits development? I do not think so.
Consider an embryo that could develop if placed in a sustaining environment but will be frozen instead. Even if it never develops, its genetic capacity for development makes it more valuable in its own right than an embryo without such a capacity. The potential for development into a human person counts for something.

Imagine a magic wand, capable of producing a great effect, that is locked in a museum case and will never be used. Compare it with a nonmagic wand in the same case. Though neither will ever produce any great effects, the former wand has greater intrinsic value in virtue of its potential, even though both wands have the same instrumental value. The human embryo that could develop into a human person if it were placed in a sustaining environment is like an unused magic wand.

The difference between embryos with no genetic potential and embryos lacking potential because of their environment can also explain why some antiabortionists object to Hatch’s position. If one believes that the embryo with genetic potential is very important, a possible response is to call for it to be placed in a sustaining environment. This is analogous to how one would treat a child who was in a nonsustaining environment: one would not say that it was permissible to kill the child because the child was in a nonsustaining environment; one would instead try to move the child into a better environment. However, such a position concerning the embryo also implies that frozen leftover embryos from IVF should be adopted and transferred to a sustaining environment at reasonable cost. If this is, in fact, not morally necessary, it is because the value of an embryo with genetic potential does not imply that its potential must be developed or even that it cannot be killed for the sake of an important good. What is most important for the permissibility of using human embryos for biomedical research is not that genetically normal embryos in a nonsustaining environment will not have a chance to develop, but that such embryos need not be placed in a sustaining environment.

Finally, is the creation of human embryos that will die naturally soon after being created a solution to the current controversies? I believe not. The problem here is that we first need to show why embryos can be used in research projects before we can permissibly create entities that are otherwise like human embryos but lack the potential to develop into persons or to live beyond a few days.

To see why, suppose that an embryo already exists with potential to develop, and we seek to take away that genetic potential (without destroying the embryo) in order that we may then destroy it because it lacks genetic potential. Doing this is problematic if we do not first justify our action by showing that embryos are not the sort of entities that have a right to retain their genetic potential or are harmed by having this potential taken away. But if we show these things to be true, we will have gone a long way in proving that it is the sort of entity that can be destroyed.

Now suppose we could create an embryo without genetic potential for continuing life rather than removing such potential. To show that this is permissible, we must first show that it would be permissible to kill the embryo even if it has potential. The following analogy may help. Suppose someone wanted to experiment on human persons but it was objected that this is impermissible because it would lead them to lose the rest of their lives. Creating a human person with a genetic modification that will produce an early death, just so that we could experiment on him without thereby causing him any loss of life, is not a solution, for the sort of entity he would be—a person—would thereby lose out on life, and thus be denied something that is a basic good for him. Hence, it is only permissible to make such a genetic modification to an entity that would not be harmed to a great degree by losing out on more life. If, as I argued earlier, the human embryo is such an entity, then we have already gone a long way in showing that it is the sort of entity that we may destroy even if it has potential for development. To defend the permissibility of creating an embryo without potential, then, we have to defend the very same theses that are crucial to the permissibility of killing an embryo with potential.

In conclusion, I want to recall the context of my argument. The discussion of biomedical research using ESCs begins from two basic considerations: first, that such research may have very large benefits; and second, that the research requires the destruction of embryos. Critics argue that we must forgo the benefits of ESC research because destroying embryos fails to show respect for their moral importance.

I have argued that this conclusion is founded on an implausible view of the moral importance of embryos. A proper understanding of that importance must take seriously the fact that the destruction of an embryo is not bad for the embryo. The grave evil that we associate with the destruction of human life—and more broadly with using people as means to an end—reflects the fact that such destruction—and such use—is either bad for the persons whose lives are destroyed or who are used, or contrary to their will. Embryos, however, have no will, and their destruction is not bad for them. The conclusion is not that we can use human embryos however we want, but that we have no reason to forego the large benefits that doctors and scientists expect will follow from research on ESCs.

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Endnotes

1. President’s Council on Bioethics, “Human Cloning and Human Dignity: An Ethical Inquiry,” available on-line under “Reports” at: http://www.bioethics.gov. [APA editor’s note: HR534, the Human Cloning Prohibition Act of 2003, was passed by the House by a vote of 241-155, on February 27, 2003].


4. Charles Krauthammer—a columnist, M.D., and member of the President’s Commission on Bioethics—points to this as a decisive reason not to allow cloning for research purposes, even though he agrees that the embryo does not have the same moral status as a person. See his “Crossing Lines: A Secular Argument Against Research Cloning,” The New Republic, 29 April 2002. He also supports Noncreation, arguing that we must not create human life while intending to destroy it.


6. Of course, Shapiro may not have agreed personally with the panel’s report, though no dissent was published. Reports by government panels that aim to provide reasons for their conclusions may well be compromises in their conclusions as well as their reasoning. Such reports appear to propose philosophical rationales, but no one on the panel fully endorses the rationale. It is there as window dressing. If this is so, it may not be wise to treat the reasoning in these reports as intended to be correct and so rightly subject to critical examination in the search for truth. On the other hand, such a critical examination is important in order to show that these reports do not embody correct,


11. On why we should not kill one person in order to save two, see my Morality, Mortality, Vol. 2 (New York: Oxford University Press, 1996).

12. I shall assume in what follows that creating embryos by the intention to use them for research with foresight of the fact that they will certainly die from such use is as contrary to Noncreation as is creating embryos while intending their destruction or creating embryos foreseeing that we will intend their destruction.

13. Notice that those who endorse Noncreation and would support its implication for this case could also think that it is, in general, morally permissible to have abortions. For in most abortions, a woman does not get pregnant in order to have an abortion. Furthermore, one of the reasons given to support the moral permissibility of most abortions is that the embryo (or fetus) is imposing on the woman’s body and its presence is presenting some problem for her. In extreme cases, the embryo may pose a threat to her life, just as heart disease does in the case above. So a person may believe, with no inconsistency, that it is permissible to destroy an embryo that presents a (morally innocent) threat to a woman but that it is impermissible to create and use an embryo (that is not itself presenting a threat to her) simply because destroying it will help the woman avoid another threat, like heart disease.

14. Krauthammer also presents such a case. He thinks that it is analogous to what is involved in cloning and that it is clearly morally impermissible.

15. I shall not here try to contest this assumption that reproductive cloning is wrong, though it possibly can be contested.

16. For discussion of the moral relevance of such external gestation devices for the permissibility of abortion, see F. M. Kamm, Creation and Abortion (New York: Oxford University Press, 1993).

17. Notice that even creatures, such as birds, for whose sake we can act in keeping them alive, do not necessarily have a right not to be killed.

18. A being that is capable of sentient experience or consciousness is not one that merely has the capacity to develop into a being that is capable of sentience or consciousness. Also, it is not necessarily a being that has already had sentient experience or consciousness. For example, a being that has never experienced pleasure can still be capable of it, and so it is the sort of being for whose sake I can act in giving it pleasure for the first time and in not depriving it of future life from which it will get pleasure. Here I differ with the view in Bonnie Steinbock, Life Before Birth: The Moral and Legal Status of Embryos and Fetuses (New York: Oxford University Press, 1992), and Mary Ann Warren in Moral Status: Obligations to Persons and Other Living Things (Oxford: Clarendon Press, 1998). They both require that a being have already experienced in order for it to be possible to harm it by killing it.

19. Although it is not a harm to the embryo to lose its potential, it would be an indication of the value of an embryo if we would try to correct a defect in it that interfered with its potential rather than dispose of it and create a new embryo without a defect. Similarly, it can be an indication of the value of a painting if we try to rescue it from damage rather than have an equally good painting created in its stead.

20. I am grateful to Derek Parfit and Jeff McMahan for comments on earlier drafts.

Revolusion Is Simply Not Enough: The Impeding Culture War Over Advances in Genetics

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In April of 2002, when President George W. Bush, Jr. strode into the Rose Garden at the White House to urge a ban on all forms of human cloning including the cloning of human embryos for the purpose of stem cell research he declared, “Our age may be known to history as the age of genetic medicine” (Bush, 2002). In expressing his optimism and awe at the implications of the genetic revolution, President Bush appeared to be echoing the sentiments of former President Bill Clinton, Prime Minister of the United Kingdom Tony Blair and many other world leaders who have also dubbed the twenty first century “the age of genetics.” But, the similarities in the rhetoric between Bush and the views of nearly all other world leaders are deceiving. Something very different and far more sinister and morally wrong was being announced when Bush made his views on cloning known.

Clinton and Blair had made the advance of genetics a core part of their domestic policies. By paying for basic research, most notably the human genome project, they hoped to secure an economic advantage for their nations by making them the world leaders in biotechnology. When Clinton and Blair expressed worries over the future course of genetics it was over whether the science was moving fast enough to address the needs of those afflicted with diseases and disabilities. For Clinton and Blair there was never any doubt about the value of genomics for the future of human prosperity. True, for a short time they indulged in some public rumination about how to divide the profits. But that was about it. Not so for George W. Bush, Jr. The President, responding to the demands of an alliance of old-line prolifers and neo-conservatives, has rejected the idea that with respect to genetics America’s primary duty is to the sick.

President Bush in his Rose Garden speech did acknowledge the power of genetics. He expressed enthusiasm about the potential of genetic technology to cure human ailments and ills. But he also expressed grave concerns about other directions the genetic revolution might take.

He warned that in our zeal to find benefits and cures we could also “travel without an ethical compass into a world we could live to regret.” Throughout the rest of his speech were salted terms such as “products,” “design,” “manufacturing,” “engineered to custom specifications” and others connoting the worry that in addition to using genetics to heal ourselves we could easily run off our collective ethical tracks by using genetics to create and manufacture ourselves and our children (Bush, 2002).

This grave ethical concern about the prospect that genetics could easily run amok was not triggered simply by the specter of human cloning. The same unease over the new genetics was present in an earlier speech Bush gave indicating
his unalterable opposition to human embryonic stem cell research (CNN, 2001). Bush chose stem cell research as the first subject to talk about to the nation in a nationally televised speech, which he gave on August 9th, 2001. Had the tragic events of the destruction of the World Trade Center and the attack on the Pentagon and their aftermath in the war in Afghanistan and the unraveling of peace in the Middle East not overtaken his agenda, it is quite likely that Bush would have made his moral reservations about the future of genetics and biotechnology the centerpiece of his domestic social policy agenda.

What is happening is that bioethical debate about genetics has taken a sudden and drastic turn. Whereas genetics used to be one among a variety of topics that bioethicists might examine or even specialize in as an area of interest, ethical concern about developments in genetics has now become something very, very different. Genetics has moved to center stage as a key battleground in what are sometimes referred to as the “culture wars” where the political left and right fight over the core values of American culture. Genetic engineering is now a slogan meant to rally conservative and neo-conservative forces against the power of Godless and soulless science and the bioethical camp followers who trail after them concocting apologia for their ever riskier experiments.

The President is hardly acting alone in sounding the tocsin of moral concern about the dangers of misapplying the new genetics. He is simply the most prominent among a long list of conservatives, pro-lifers, neo-conservatives and an odd, much smaller smattering of neo-green thinkers who see the genetic revolution as holding the seeds of the degradation and destruction of humanity. Genetics in particular and science in general are the objects of deep distrust on the part of this new band of social conservatives.

Whereas in the 1960s, it was the left who wondered where physics and engineering might take America under the sway of industry and the Department of Defense, it is now the right who wonder into what moral pothole biology might lead us under the sway of industry and the National Institutes of Health. And the new right is just as capable of letting overheated rhetoric substitute for argument as was the old left.

Consider the rhetoric employed by Eric Cohen, William Kristol and other neo-conservatives in response to Stanford University’s announcement this past December that the school intended to create a new research center to conduct studies of stem cells and embryonic development. The University announced that some of the research that would be done involved the creation “... of human stem cell lines.” Stanford insisted that cloning embryos for research is not the same as cloning with the intent to make human beings.

Cohen, Kristol, Kass and many other conservatives, neo-cons and pro-lifers all went ballistic. They insisted that Stanford was lying, intentionally obfuscating and otherwise acting in an irresponsible manner. Cloning embryos, according to the right-wingers, is making people however you want to describe it, and that is that.

Except it isn’t. Making a human embryo in a dish and leaving it there, cloned or otherwise, will never lead to the same outcome as putting a human embryo, cloned or otherwise, into a uterus. Nor is there a lot of reason to presume that cloned human embryos could ever develop into liveborn babies given the dismal track record of cloning in animals. More to the point, it is clear why some pro-lifers want to give full moral rights to embryos from the moment of their creation—it is a matter of religious doctrine. Despite all their talk of dissembling and demands for plain talk, it is not at all obvious how conservatives who self-style themselves as “secularists,” such as Kass, Kristol, Cohen, Charles Krauthammer and many others, can see a person if a cloned human embryo were to be placed before them in a petri dish.

Whether it likes it or not, bioethics now finds itself center stage in the emerging battle over who will set the terms and the values that will guide the use of the most powerful body of knowledge created by science since the splitting of the atom. What has been a relatively small potatoes subject in bioethics—ethics and genetics—is about to become the major topic of the field as human genetics becomes embroiled in a heated social debate that has lots to do with ideology and somewhat less to do with ethics.

The appearance of two new books; Francis Fukuyama’s Our Posthuman Future: Consequences of the Biotechnology Revolution and William Kristol and Eric Cohen’s edited volume, The Future Is Now: America Confronts the New Genetics, a collection of reprinted essays from various magazines and excerpts from Congressional testimonies, constitute a birth announcement of the role genetics is going to play in the emerging culture war over biology. Kristol, editor of the conservative magazine the Weekly Standard and Cohen, who is affiliated with the equally conservative Ethics and Public Policy Center in Washington, D.C., are aghast at the prospect of biological design. The bulk of their anthology consists of a parade of persons who are made morally miserable at the prospect that human beings are on the threshold of designing their own nature by manipulating their genes or the genes of their offspring. The collection begins with the obligatory early twentieth century warnings of Aldous Huxley to the later 1970s morose cautionary sounds of Paul Ramsey, Leon Kass and Gertrude Himmelfarb, right through to the growing list of contemporary conservative catarwalers such as Francis Fukuyama, Gilbert Melllaender, Adam Wolfson, Charles Krauthammer, and Kristol himself. All see nothing but ill in the idea that we would be arrogant enough to think we can design a better body or hubristic enough to want to build one that could last nearly forever. The Kristol and Cohen volume is an unremitting call for a halt to the genetic revolution from the new would-be mullahs of genetic neo-conservativism.

Many in bioethics have tended to dismiss the current debates over the future of stem cell research and the cloning of human embryos for research as simply abortion politics redux. And there is much in the Kristol and Cohen book that makes it very clear that some of the basis for concern about the future directions genetic engineering and biotechnology might take is a worry about the carnage to nascent embryonic life that those advocating progress would unleash.

If embryos are killed, then there are many who would bring any genetic technology that would cause these deaths to an abrupt halt on the grounds that killing to help another is never justified. Robert P. George of Princeton and a member of the President’s National Bioethics Advisory Committee contends that, “Modern science shows that human embryos... are whole, living members of the human species, who are capable of directing from within their own integral organic functioning and development into and through the fetal, infant, child and adolescent stages of life and ultimately into adulthood” (George in Kristol and Cohen, 2002, p. 290.)

Robert P. George is not stipulating, as many do on religious grounds, that life begins at conception. He is arguing, on scientific grounds, that it does. In this he is, as are so many other proponents of the new genetic neo-conservativism (such as Wesley Smith who makes similar claims in his reprinted essay), simply wrong.
Not since the first days of the microscope when early embryologists claimed to see tiny babies contained in the heads of spermatozoa has anyone advanced a theory of preformation akin to that put forward by Professor George. Modern embryology holds that an embryo is absolutely incapable of self-directing its own development. Development requires a subtle and ongoing interplay between embryo and environment. It takes almost nothing for this delicate interaction to go wrong which is why so many conceptions end in spontaneous abortions. It is also why so many embryos lack the potential to develop at all due to either programming errors in their genomes or an inability to process information from outside the embryo correctly. It is why in vitro fertilization is so hard to do. Embryos do not work well. It is certain that some of the difficulty those attempting to clone animal’s embryos have encountered is the result of failures in the interplay between the transplanted genome, the environment of the egg and the environment of the uterus.

George takes the meaning of totipotent—the term scientists use to describe embryonic stem cells, to an entirely new level when he tries to argue that science supports the view that an embryo is simply a self-contained vessel which can, through its own programming, guide development from a blastocyst to the grave. It cannot, and no embryologist would ever make any such assertion—probably accounting for the absence of any invocation of scientific evidence in George’s article and the others that maintain the same flawed position in the Kristol and Cohen volume.

More is going on with neo-conservative and conservative disquiet about genetics than simply a recasting of old pro-life views into new forms that still rest on flawed science. Some of the opponents of the new genetics have little to say about the alleged power of the embryo or even the moral status of embryos. But they have plenty to say about the unnaturalness of intervening in a deliberate way with nature to try and improve ourselves and our children. Usually their arguments begin with some expression of moral revulsion or disgust about genetic engineering of humanity and end up with an invocation of a theory of human nature that makes it immoral to attempt to change or manipulate or modify that nature. But when it comes to ethics, revulsion is not enough. Feelings of revulsion or disgust are superb starting points for a moral argument, but they are hardly an endpoint. And views about the invariable nature of human nature presuppose that human nature is fixed, that it is inherently good as it is and that we are not wise enough ever to try to change it to make it better.

In the works of Leon Kass that Kristol and Cohen selected to include in their book, Kass salts his writings with talk of revulsion, shame and disgust. Nothing disgusts him more than when topics such as embryo farming or the pursuit of immortality arise. Whether they are filled with the revulsion Kass believes any decent person should feel at the prospect of making embryos for research, the neo-conservative writers who accompany Kass in the Kristol and Cohen volume, especially Charles Krauthammer and Kristol, become weak in the knees when admiring the power of Kass’ moral intuitions about the horror of the “designer” become the “designee.” Anyone who is not revolted by the prospect of human beings genetically tampering with their own genetic programs or those of their descendents is written off as simply morally tone deaf.

It is hard to take all this talk of moral sensation seriously. Americans live in a society where most citizens were once utterly revulsed at the thought of interracial sex, disgusted by homosexuality, shamed at the idea that a wife would work outside the home, nauseated at the thought of sharing a public pool with a Jew, repulsed at the notion that immigrants from Southern and Eastern Europe were arriving on American shores in large numbers and downright horrified that anyone would think of freeing their slaves. Professor Kass may possess an exquisitely fine-tuned moral sense but it is not one that all others share and more importantly, without argument and reasoning it is a sense that, used as a detector of moral right by other thoughtful persons in the past, has proven to be notoriously unreliable.

Revulsion is not especially reliable in making assessments in the domain of medicine either. Autopsy, dissection, heart surgery, masturbation, mental illness, vaccination, organ transplantation, birth defects, anesthesia, menstruation, and artificial insemination have all been viewed as repugnant at one time or another by many inside medicine. Charting the future of genetics by using our moral intuitions as our searchlights is as likely to lead us astray as the well-intentioned blunderings of a “value-free” science might do.

The invocation of human nature as a barrier that must not ever be breached by genetic science holds up even less well than feelings of revulsion and disgust as firewalls against the application of genetic knowledge to human beings. Francis Fukuyama is about as clear as the new neo-conservatives get when he argues that:

“Whatever academic philosophers and social scientists may think of the concept of human nature, the fact that there has been a stable human nature throughout human history has had very great political consequences” (Fukuyama, 2002).

Fukuyama then goes on to put down all efforts from the French revolution to the Cuban as utopianism intent on seeing human nature as infinitely plastic when it is not. This argument might score a few points at a luncheon at the Heritage Foundation or the American Enterprise Institute, but bashing the utopian views about human nature of those on the left is not the same as making an argument about what human nature is and why it should never be changed. This argument, which undergirds so much of the neo-conservative agita about genetic engineering and biotechnology, and to some extent some of the Green movement concern about genetics as well, is deeply flawed.

While “academic” philosophers and social scientists may not agree, as Fukuyama says, on what human nature is, I defy him to find any theorist who would maintain that human nature has been “stable” throughout “human history.” Indeed I would also like to see a few citations for the equally unsupported view that human nature exists as a single nature in every member of the human species. This is simply preposterous. It is ideology in pseudoscientific clothing.

As any evolutionary biology text will reveal, human nature has evolved. Partly under the pressure of the environment, and partly as a result of cultural and social evolution, which has completely reshaped our nature from that exhibited by our hairier ancestors. We are not the same as those who have gone before us. We have childhood and retirement and adolescence, not as a function of our nature but as a function of culture and history. Our impulses to rape, exhibit our genitalia, steal, kill, hunt and urinate wherever we please, to adolescence, not as a function of our nature but as a function of culture and history. Our impulses to rape, exhibit our genitalia, steal, kill, hunt and urinate wherever we please, to
manipulating their creation. It is amazing to see that those healthier and happier than we can be by designing and transplanting organs and tissues, to trying to make our children modified foods to efforts to extend our lives through change. 

Which of course leaves the door open to the question of whether we ought to use our emerging understanding of the programming that is partly responsible for the more fixed elements of our nature to try and improve upon them. Improvement here includes making ourselves healthier, stronger, more long-lived, less prone to disease or psychological happier. No doubt there will be plenty of debate about what those concepts mean, how they can be guaranteed to all who might want to pursue them, and what risks are worth taking to attain them. That debate should take place.

To argue as Fukuyama, Kass, Krauthammer, Cohen, George, Kristol and many others do that we have a nature, it is fixed, it has stood us in good stead throughout all of our history on this globe, and thus must not be altered, is most assuredly a conservative contribution to such a debate. It is also most assuredly wrong. None of the above claims against alteration are adequately supported.

It is not clear that we all have a single nature, that it is fixed, that it has worked throughout all of human history to our benefit and that it would be wrong to try and improve upon it, whatever it is. Evolutionary theory, sociobiology, anthropology, history, psychology, the arts and neuroscience have revealed much about our nature, but they have not given us evidence for any of the claims that the neo-conservatives want to use to pull us back from the brink of the moral chaos they are certain must follow all efforts at tampering.

But is all tampering the road to perdition? Should we decide to use genetic engineering to eliminate Tay-Sachs disease, cure Fanconi’s anemia or make astigmatism nothing but an entry in old ophthalmology textbooks? Do we consign our children spared these plagues and woes to a disvalued existence because they are the products of genetic engineering? Is our nature really all that vulnerable?

At most, elements of what we call nature are fixed by our genes. At most, some aspects of our nature were once adaptive for the world our ancestors inhabited. But certainly some aspects of our nature are flawed and wanting. There is nothing admirable about our inherent tendency toward violence or a fear of spiders. We spend vast amounts of our time, energy and resources trying to buffer, ameliorate or improve aspects of our nature through all manner of social, cultural and environmental intervention. Whether genetic intervention is somehow more problematic because its impact is less well understood is a legitimate question. But it is hardly a knock-down argument about why those elements of our nature that lead us to be prone to certain diseases or to engage in behavior that is not adaptive for 21st century urban living should not be made the subject of intervention, alteration, and change.

The battle over the future of biotechnology is hardly confined to cloning and stem cells. It extends from genetically-modified foods to efforts to extend our lives through transplanting organs and tissues, to trying to make our children healthier and happier than we can be by designing and manipulating their creation. It is amazing to see that those who used to worry that the future of America was imperiled most directly by the threat of Communism abroad and socialist thinking at home have now chosen to align themselves against science in the name of the wisdom of repugnance and a blind commitment to a Platonic view of human nature. One would have hoped that the demise of the old enemies of the right would have made them less paranoid. Instead, it has created a burgeoning class of mandarins and pundits who are unable to evince anything but horror at a genetic revolution that holds enormous promise for doing good. Most scientists and doctors see genetics as having enormous potential to do good for those who are sick or disabled. Kristol, Cohen and Fukuyama see genetic engineering as revolting. Bioethics can and should find a lot of attractive intellectual space in between these extremes.*

References


Do Healthcare Professionals Have an Obligation to be Vaccinated Against Smallpox?

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Background: Public Good vs. Individual Risk

Bioterror defense in the aftermath of the Sept. 11, 2001 terror attacks has focused largely on preparation for a biological attack using the smallpox virus. The most visible project designed to prepare for such an attack has been the stockpiling of smallpox vaccine. The threat of naturally occurring smallpox is non-existent at present; however, should a terror-related outbreak occur, it may become necessary to once again distribute the vaccine on a population-wide level. Although the risks of the smallpox vaccine make vaccination of the public controversial in the absence of an immediate threat, the risks associated are low in the face of an epidemic. To wit: routine administration of the vaccine was discontinued in the early 1970s because smallpox was eradicated as a threat, but was widely administered prior to the eradication of this serious communicable disease as the public health threat persisted.

In order to be effective, the smallpox vaccine must be given within 3 days of exposure to the virus. In the aftermath
of a bioterror attack using smallpox, then, there is likely to be widespread demand for immediate access to vaccination. Recognizing this, President Bush announced, in early December 2002, plans to immediately vaccinate up to 500,000 healthcare professionals against smallpox on a voluntary basis (as well as up to 500,000 military personnel on a mandatory basis).\(^1\) These healthcare professionals would act as smallpox response teams in the event of a terror attack using this agent, treating cases and administering vaccinations to the general population. Within days of Bush’s announcement, however, two prominent teaching hospitals refused to vaccinate their employees against smallpox, and several others were leaning toward similar refusal.\(^2\) In addition, several prominent medical associations have expressed concerns about smallpox vaccination prior to an actual attack using this agent, including the American Medical Association, the American Academy of Family Physicians, and the American Academy of Pediatrics.

Refusal by healthcare professionals to be vaccinated against smallpox creates problems for the timely distribution of vaccine in the event of a terror-related smallpox attack. In Sept., 2002, the Centers for Disease Control and Prevention published guidelines for conducting mass smallpox vaccination of the general public within a ten-day period in the event of a smallpox attack.\(^3\) The plan calls for states to collectively run up to 4,844 vaccination clinics, with eight vaccination stations each, for sixteen hours a day. This number of clinics would require as many as 510,000 healthcare professionals to staff.\(^4\) One possible area of delay involves vaccination of healthcare professionals who would staff these clinics: as stated in the CDC guidelines, “Establishment of voluntary clinics may need to be done in a stepwise fashion over 2-3 days to accommodate administration of staff vaccinations prior to opening a clinic.”\(^5\) The pre-event vaccination program announced by the Bush administration is designed to avoid this type of delay. In short, healthcare professional’s refusal to be vaccinated against smallpox presents a classic conflict between individual and public goods: how much risk should an individual healthcare professional be required to assume in order to attain a public good—in this case, creating conditions for the timely distribution of smallpox vaccine should an outbreak require mass vaccination of the general public?

### Political and Legal Context of Professional Obligations

Before examining ethical arguments for a professional obligation to subvert self-interest for the public good, we must first examine the political and legal context of professional obligations in this area. In order to do this, we will consider the justification for the Model State Emergency Health Powers Act (or MSEHPA)\(^6\) developed shortly after the Sept. 11, 2001 terror attacks.

The MSEHPA is perhaps the clearest example of how public good might override the individual interests of healthcare professionals in the context of bioterror. In the Model Act, healthcare professionals can be required by the state to participate in the treatment of patients and containment of an epidemic. As of February 20, 2003, legislation based on the Model Act had been introduced in 36 states, and versions of the Model Act enacted in 21 states and the District of Columbia.\(^7\)

The justification of the Act represents a straightforward balancing of public good and individual liberty. According to MSEHPA author Lawrence Gostin, et al., there “may be a need to exercise powers over individuals to avert a significant threat to the public’s health . . . Although the vast majority of people probably will comply willingly (because it is in their interests and/or desirable for the common welfare), some compulsory powers are necessary for those who will not comply. Provided those powers are bounded by legal safeguards, individuals should be required to yield some of their autonomy, liberty, or property to protect the health and security of the community.”\(^8\) Gostin continues: “Compulsory power has always been a part of public health law, because it is sometimes necessary to prevent or ameliorate unacceptable threats to the common good.”\(^9\)

The required participation of healthcare professionals under the MSEHPA, however, differs significantly from the conditions under which healthcare professionals are asked to subvert their own interests in being vaccinated against smallpox prior to an outbreak. The conditions specified under the MSEHPA represent special circumstances analogous to emergency circumstances. According to Gostin, et al, “The Model Act is designed to be triggered by an extreme public health emergency comparable with the sudden, devastating epidemics of the 19th Century.”\(^10\) Although U.S. common law has a very strong presumption that, in the words of George Annas, supports the rule that “a healthcare professional is not obligated to treat any particular patient in the absence of a consensual professional–patient relationship,” this rule can be defeated in emergency circumstances.\(^11\) Absent emergency conditions or special consensual relationships established with a particular patient, however, healthcare professionals are not obligated to participate in the provision of specific healthcare treatments.\(^12\) Pre-event vaccination of healthcare professionals clearly does not meet the conditions of emergency circumstances, precisely because there is no immediate threat.

If such an obligation exists, a professional obligation to be vaccinated against smallpox to facilitate a public good, then, will be an ethical, rather than political or legal, professional obligation. It will not, therefore, be enforceable through law.\(^13\) This is consistent with the Bush administration’s vaccination program, which makes participation in pre-event vaccination of healthcare professionals voluntary. The voluntary nature of the program, however, does not preclude discussion of whether a healthcare professional has a duty qua membership in the health profession to be vaccinated against smallpox, this professional obligation overriding his or her own self-interest. It is important to note that our focus here is on the obligations derived from membership in a health profession (not on whether an individual has an obligation as a citizen of the U.S. not specifically derived from one’s membership in a health profession). Our concern, therefore, is with a potential obligation as a healthcare professional to subvert one’s own interests for the sake of a public good. It is to this that we will now turn our attention.

### Professional Obligations and Risk

One argument for a professional obligation to assume the risks of smallpox vaccination centers on a more general obligation for healthcare professionals to provide healthcare to patients in need despite some risk to their own health. The clearest analogy for this argument lies in the commonly recognized obligation of healthcare providers to treat patients with communicable diseases, including TB, yellow fever, polio, influenza, and others.\(^14\) Discussions of this type of professional obligation were prominent both in the bioethics and popular literature in the early years of the HIV epidemic, when little was known about the nature of the infection or ways in which it might be spread. Both professional and public opinion condemned refusal to treat HIV-infected patients.\(^15\) The
argument for an obligation to assume some degree of risk as a part of the healthcare profession is perhaps best illustrated by a statement issued by the Committee on Ethics of the American Nurses’ Association concerning the professional responsibility to care for patients with infectious disease: “Nursing . . . creates a special relationship between nurse and patient, with special duties for the nurse. The nurse is not a “stranger” and thus is not at liberty to walk away from those in need of nursing assistance.”16

However, using this approach to establish a professional obligation to be vaccinated against smallpox is fraught with problems. First, the professional obligation to assume risk is normally centered around issues related to providing care in specific (existential) cases, and related explicitly to the needs of a sick and vulnerable population. In contrast, pre-event vaccination involves preparing to treat abstract “possible cases” that cannot be said to be probable or even likely. Related to this, the balance of harms in the case of treating patients with infectious diseases is significantly different than it is for pre-event smallpox vaccination. Consider, for example, the mid-1980s literature related to the professional obligation to treat HIV-infected individuals. That literature points to the serious harms to the patient that would result from a refusal to treat. In the words of John Arras, “If patients suffering from severe or painful maladies are refused care by a physician or clinic and referred elsewhere, their conditions may well be exacerbated by the time they find someone willing and able to treat them.”17 At the same time, the risk of harm to the treating healthcare professional was recognized as relatively low even then: even under the rare worst case scenario of exposure through a “stick” with a sharp object contaminated with HIV infected blood, studies showed only a very remote risk of contracting HIV.18

Pre-event smallpox vaccination, however, poses a significantly different balance of risks. The smallpox vaccine is the most dangerous vaccine approved for large-scale use, resulting in adverse events that include encephalitis, death, and other side-effects requiring a doctor’s care in one of every 10,000 cases. The risks of adverse reactions to smallpox vaccination, then, are not clearly less than the risks posed to the general public by a 2-3 day delay in vaccinating the general public after a terror event using the smallpox virus. In this context, it might be useful to again consider the emergency treatment rules. As George Annas has stated, physicians are not expected to be saints: “If the patient’s medical condition exposed the physician to great risk to life or health, she may be justified in refusing to provide treatment even in emergency situations.”19 Although Annas finds a risk/benefit analysis that focuses on the risk to a treating physician as “strange” in the context of professional obligations to treat HIV-infected patients,20 we believe that in the absence of the types of significant and identifiable harms to patients posed by cases like the refusal to treat HIV patients, the risks posed to healthcare professionals are a necessary component of deliberation concerning professional obligations.

Another argument for the obligation of healthcare professionals to be vaccinated against smallpox is that healthcare professionals represent the “front lines” of national defense against biological terrorism. Thus, healthcare professionals have a national security obligation, as “front line soldiers in the war on terror,” to assume the risks associated with vaccination similar to the obligations of military personnel. The National Intelligence Council of the Central Intelligence Agency, for example, has characterized bioterrorism as not only an issue for public health, but also as a national security concern.21

Establishing a professional obligation on the basis of national security interests, however, requires that we establish a public responsibility for healthcare professionals beyond that of ordinary citizens. Arguments for this type of responsibility have been advanced in other contexts. For example, some arguments for an ethical obligation to treat HIV patients centered around the idea that as members of a healing profession, physicians are obligated to subordinate self-interest to a duty of altruism.22 Others have argued that, as professionals, doctors and nurses have ethical obligations beyond their duties as citizens.23 To some degree, a recognition of such duties can be found in the development of the MSEHPA, which singles out medical professionals as a group that might be required to participate in the containment of a public health emergency. The required participation is clearly linked to professional status, as evidenced by revisions meant to improve and clarify the Model Act: the first draft, issued in October 2001, characterized the failure of a health professional to comply with required participation in treatment of patients following declaration of a public health emergency as a criminal act,24 while the revised MSEHPA from December 2001 no longer treated such failure as criminal, but rather as a violation of professional obligations, with penalties involving professional licensure action, rather than criminal charges.25

However, this approach is fraught with problems too. We can understand the basis of obligation for professional military personnel, for example, to assume risks in order to protect national security in this way. Protection against smallpox might be deemed necessary for military personnel in order to avoid a loss of military defense ability due to the spread of contagious disease among the troops. Several historical examples exist wherein the spread of disease resulted in a significant reduction of military capacity.26 As entrance into the military profession involves the explicit recognition that one’s own welfare (and even life) will be subverted to the interests of national security, the fact that a refusal to be vaccinated might threaten military capacity provides a plausible grounds for a professional obligation to be vaccinated among military personnel.

However, it is unclear that healthcare professionals have the same type of national security duties as the result of their membership in a health profession. While it is true that healthcare professionals possess skills unique to their profession that are vital for the treatment and containment of (natural or terror-related) epidemics, it is unclear that possession of these skills requires that they assume risks beyond those required of ordinary citizens in order to protect national security. Acquisition of these skills through entering a health profession is related to quite different goals: treating the sick. As we examined above, there is a significant difference between the obligation to assume risk in this context and the obligation to be vaccinated against smallpox pre-event. At most, one might argue that a collective obligation exists for the profession as a whole to assume risks to achieve the public welfare goods desired.27 This broad obligation would be difficult to translate to a professional obligation for any particular individual: it is not clear that there will not be enough voluntary participation to achieve the desired goal, and in fact historical examples would suggest that members of the healthcare profession are likely to voluntarily participate despite some health risks to themselves. Even without adequate participation in pre-event vaccination, however, at most refusal to be vaccinated pre-event poses a threat of vaccination for the general public being delayed 2-3 days. It is unclear at this time that such a short delay would represent a significant threat to national security.
Conclusion
In conclusion, we believe that there is no professional obligation for healthcare professionals to be vaccinated against smallpox pre-event. This does not mean, however, that we discourage healthcare professionals from voluntarily participating in pre-event vaccination. Indeed, we believe it would be praiseworthy for healthcare professionals to participate in pre-event vaccination, assuming risk to self in order to facilitate timely vaccination of the general public should a terror event using the smallpox virus occur.

Failure to participate in voluntary pre-event vaccination for healthcare professionals, however, does not constitute violation of a professional obligation. Although healthcare professionals may have an obligation arising from their membership in this profession to assume some degree of “risk to self” in providing care for existent patients suffering from infectious disease, the circumstances surrounding such obligation differ significantly from the nature of risk assumed in preparing for a possible epidemic which cannot even be said to be likely. Likewise, it is unclear that healthcare professionals should be required to assume this particular risk in the interests of national security. In short, we believe that healthcare professionals do not have an obligation to assume the risks associated with smallpox vaccination, prior to a terror event, in virtue of their membership in a health profession.

Endnotes
4. Ibid.
5. Ibid.
9. Ibid. at 627.
10. Ibid. at 626.
12. Ibid.
18. Bell, supra.
19. Annas, Standard of Care, supra, p.122.
20. Ibid., p. 120.


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Michael Ridge’s “Unfair Advantage, Auctions, and Proportionality” is an extended critique of my theory of setting justified statutory penalties (“the fairness theory”). That he rejects almost every element of the theory is, of course, a disappointment. In compensation, he has given me an opportunity to dispose of objections that may have occurred to others. I shall not, however, try to refute Ridge’s objections point by point. Instead, I shall identify the chief errors of method upon which those objections seem to depend. I hope to eliminate the objections by eliminating the errors upon which they seem to depend. While I think that Ridge’s errors are far from being his alone, I shall not argue that here.

1. Intuition
Like many philosophers, Ridge appeals to “intuition” at crucial points in his argument. Intuition, as he uses that term, seems to be a mere feeling or impression that “such and such is so,” a spontaneous judgment having epistemic authority independent of argument. Since Ridge does not seem to believe in a priori knowledge of such matters as whether a criminal deserves less punishment for an attempted robbery than for a successful one (p. 5), any epistemic authority intuition has in his argument must rest on experience. To support epistemic authority, the experience in question must be a reliable indicator of whatever the intuition supposedly reveals. Our intuition of familiar situations, especially if shared by others, should be (relatively) reliable. Experience disciplines intuition. Experience that disciplines everyone’s intuition more or less the same way seems to belong to the same epistemic category as perceptions of color, shape, texture, and so on. We may then distinguish at least four kinds of intuition that lack the appropriate epistemic authority: a) intuitions not resting on the right experience, b) pseudo-intuitions (that is,
mere verbal formulas), c) intuitions not shared (or, at least, not shared widely enough), and d) intuitions open to more than one interpretation. Let us take these in order.

a. An appeal to intuition must rely on the right experience. For example, if asked to consider what we would say if we were in a certain situation, that situation must be enough like what we have experienced for our response to be likely to reflect what we would actually say there. Where we lack similar experience, our response lacks the discipline experience provides and, lacking that, lacks the corresponding epistemic authority.

At several points in his argument, Ridge appeals to an intuition that does not meet this standard. In each case, his purpose is to show that our intuitions are at odds with the results of the imagined auction I use to model fairness. Consider, for example, Ridge’s request that we “[imagine] telling a woman whose son was raped, tortured, and brutally murdered that although we know who committed the crime and can prove it and have him in custody, we unfortunately will have to allow him to go free because he had licenses for all of his crimes.” (p. 8) Imagining such a woman in our own society, I have the same intuition Ridge does: “this is not justice but a mockery of it.” But, of course, this society (the only one of which we have direct experience) does not have the system of licenses I imagined to make an auction possible. Our intuitions, though probably reliable indicators of what we would think if aliens imposed such a system on us tomorrow, are probably not reliable indicators of intuitions we would have if we lived under the system I imagined.

What reason do I have to think our intuitions of what is just might be different had our experience of justice been different? Anthropology and history. Consider the very spot where Ridge had his intuition: Only a thousand years ago, a woman living there, in what was then Saxon Northumbria, would, it seems, have accepted as full justice for the brutal murder of her son a “wergild” (that is, a payment negotiated between the victim’s family and perpetrator’s family). Those who live in a society where murderers must pay blood money rather than suffer the death or imprisonment we consider just will have to allow the intuitions to be about. Where those with experience similar to ours seem to have intuitions that differ from ours, we are not entitled to rely on our intuition. Our intuitions about their practices should yield to those of people more familiar with them. Only our arguments need not yield to their intuitions.

Of course, the intuition that Ridge appeals to is not of any actual system, but of one we merely imagine. We are free to imagine it anyway we like. But we are not free to imagine the intuitions of its inhabitants anyway we like—or, at least, we are not free to imagine them anyway we like if we want them to carry weight in our argument. Any appeal to intuition must (at least implicitly) rely on actual experience, not on ours necessarily but on the experience of those as close as possible to what we want the intuitions to be about. Where those with experience much closer to the imagined society’s experience than ours seem to have intuitions that differ from ours, we are not entitled to rely on our intuition. Or, at least, we are not entitled to rely on it without further argument. Ridge gives none. Hence, we must dismiss the intuition he appeals to, even though we all share it. We must also dismiss any argument that relies on such an intuition.

b. An appeal to intuition is not a mere verbal formula. There must actually be an intuition to appeal to. Where there is no possible experience corresponding to the desired intuition, there can be no reliable intuition. We must, then, always take care to describe the situation about which we are supposed to have a certain intuition in enough detail to know that it is a possible situation (as well as a situation at least somewhat like those of which we have experience). Ridge does not always take care to do that. As a result, he sometimes mistakes a verbal formula for an imaginable circumstance. Consider, for example, Ridge’s terrorist who “masterminds an attack against the United States from overseas which kills several people [but who] (unlike Osama Bin Laden) has never reaped any benefits from the United States and its system of laws nor . . . from international law.” (p. 10) Rice thinks it “very [plausible] the terrorist deserves criminal punishment.” (p. 11) Never having had the benefits of those legal systems, he cannot have taken unfair advantage of them. So, Ridge concludes, deserved criminal punishment cannot be a function merely of the unfair advantage the criminal takes by committing the crime.

The “plausibility” of the terrorist deserving the punishment, that is, the intuitive appeal, presupposes that we can imagine a terrorist who, though not benefiting from international law, can kill people in the U.S. without coming here. I don’t think we can imagine such a terrorist. The very isolation that would eliminate all benefits of international law—including the money, technology, and movement of conspirators necessary for the terrorist act—would, it seems to me, eliminate the terrorist’s ability to strike the U.S. Or, at least, it would unless we are to imagine the terrorist doing his killing by voodoo or some other unfamiliar means not relying on Western technology and institutions.

I do not claim that Ridge cannot fix this example so that we can have intuitions about it. All I claim is that, as stated, even a reasonably charitable reader cannot have the intuition. Unless Ridge can re-imagine the terrorist in a way generating a real intuition serving his argument, he has only a verbal formula, not the terrorist he needs for his argument.

If Ridge cannot fill out his description in a way making it more than a verbal formula, how is it possible for him to think he has an intuition regarding it? Obviously, the intuition must be of something else, something easily mistaken for the desired intuition. My guess is that Ridge’s intuition is actually of a terrorist we can all imagine, a terrorist who, like bin Laden, did benefit from international law. Any intuition about this easily imagined terrorist would, of course, not serve Ridge. He needs to have us imagine the terrorist he described, the one that cannot be understood as a free rider. Ridge therefore needs to state his example in enough detail so that we can be sure his intuition—and ours—is real, not something mistaken for a real one.

c. Having achieved that, Ridge would have another problem. We might not share his intuition. Often, intuitions are not as widely shared as the author appealing to them supposes. Ridge thinks it “plausible” (that is, intuitive enough to need no argument) that his imaginary terrorist deserves criminal punishment. I am dubious. My reason is that I do not feel that way even about bin Laden. If the U.S. government were to ask my advice about what to do with bin Laden should he be captured, I would, I admit, advise trying him in open court under ordinary civilian law. But I would advise that on principle, not because I feel that he deserves such treatment. Criminal justice—as I understand it—is a system of law in which deserved punishment is the normal, and ordained, outcome of criminal wrongdoing, a system that treats people as rational moral agents. What I have heard of bin Laden makes me feel that he is more like one of Locke’s polecatis, a danger rather than a criminal. Hence, my intuition is that punishment is too good for him. We should just shoot him where we find him or hold him in a cage until the flesh falls from his bones. I doubt I am alone in that feeling. The Bush administration’s incarceration of hundreds of “suspected terrorists” without trial seems the natural expression of that
feeling—as is the public’s acceptance of what might otherwise seem an outrage against justice, an outrage without obvious benefit in safety or international esteem.

d. Even if an intuition is clear and shared, it may not be clear about the relevant question. Consider the passage from Prachet’s Guards! Guards! that Ridge quotes. It describes an arrangement between the Guild of Thieves and the government in “Discworld”. The arrangement is a complicated system of vouchers and receipts designed both to keep crime within limits and to distribute crime more or less evenly across the population. The arrangement sounds a lot like the background for the auction I use to model fairness. Ridge concludes—without argument—that the passage is funny “precisely because [the arrangement] is so absurdly unjust.” (p. 9) I share Ridge’s intuition that the passage is funny, but I do not agree that the reason it is funny is the absurdity of the injustice. Good satire is seldom so flat-footed. Indeed, I think the joke is precisely the opposite of what Ridge supposes. As far as I can tell, I laughed at Discworld’s system of crime control for the same reason I laugh at a Rube Goldberg cartoon. Yes, the mechanism performs a familiar function—but in what a fantastic way! Unless Ridge has an independent argument showing Discworld’s system of crime control to be unjust, he has no right to move from our intuition that the arrangement is laughable to the conclusion that it must be unjust. Our intuition, however clear, is not clearly about injustice.

If I strike from Ridge’s paper all passages relying on one of these erroneous uses of intuition, not much is left. Cleaning up his erroneous uses of intuition would, in effect, wipe out his argument against the fairness theory. I might then stop here, but I shall go on. Ridge has committed at least three other serious errors other critics might make as well: a failure to be clear about criteria of adequacy for a theory of punishment; a failure to treat my model as a model; and a failure to understand how the model is constructed. I shall conclude this response by explaining these three additional errors of method.

2. What should a theory of punishment do?
There seem to be two (primary) views about what punishment theory should do. One view, the moralist, assumes that punishment is a widespread social phenomenon of which criminal justice is a special case. We must shape our theory to fit such diverse practices as parents punishing their children, gods punishing humans, humans punishing each other in “the state of nature,” and even children punishing their pets. Punishment is as central to morality as moral praise and blame. A theory that fit only criminal justice would be radically incomplete. That is the moralist view, punishment as part of ordinary morality.

On the other view, the legalist, punishment is primarily a legal concept. Its home is that relatively complex system of rule and penalty we call criminal justice. What a parent does with a child—say, deprive of some privilege for misbehaving—is a mere analogue, lacking some or most of the features of punishment strictly so called (rational agent, rules announced in advance, set penalties for violation, and so on). One cannot argue against a legalist theory of punishment (a theory of criminal justice) by appealing to such marginal cases. Their marginality disqualifies them from serving as counter-examples. For legalists, a theory of punishment that fit only criminal justice would be quite good. Any failure to deal with marginal cases, even as analogues or metaphors, would be no worse than an absence of frosting on an already rich cake.

These two views might live side by side in relative peace, much as moral theory and legal theory do, did the moralists not regularly criticize the legalists for (in effect) not being moralists. The moralists have some justification for their criticism. Early work in criminal justice, that is, its foundational literature, tended to take moralism for granted. Why that was so is a question for historians. Perhaps the analogy between morality and law, the extreme form of which is natural law, made it easy to think of morality as a natural legal system. Perhaps the practice of most of Europe’s legal systems contributed, since they then generally accepted natural law as (in some sense) part of positive law. Legalism is a recent break with the philosophical literature.

But legalists have at least three justifications for that break. The first is etymological. All the terms central to punishment theory (“penalty”, “crime”, “condemnation”, and so on, as well as “punishment” itself) have their origins in systems of public justice. Etymology warns us that we are not entitled to assume that children punishing their pets, parents punishing their children, or even God punishing his people, is the older or more central form of punishment. Second, there is context. Very little writing on punishment is about justifying private or divine “punishment”. At least since Beccaria (1764), the focus of punishment theory has been the practice of relatively complex legal systems. Third, while legalism shares with legal positivism an awareness of the differences between law (in which there are authoritative decision-makers) and morality (in which there are none), legalism does not depend on legal positivism for its defense. All it depends on are the obvious differences between law and morality.

One obvious difference between law and morality concerns punishment. Legal systems have relatively complex procedures for setting and evaluating penalties in advance of wrongdoing. Morality does not. Morality falls far short of containing a natural system of criminal justice. While I believe that Ridge would, or at least should, agree with this abstract statement, he often argues as if it were false. Consider, for example, Ridge’s claim that I “[allow] that we can make reliable moral judgments about what the maximum penalties appropriate for forms of wrongdoing other than free-riding but [deny] that those intuitions are relevant to determining the maximum criminal penalty.” (13) His only evidence for this interpretation of me is a footnote: “This seems implicit in his discussion of non-criminal punishment in extra-legal settings, such as punishment of someone in a concentration camp by his fellow prisoners.” Ridge cites two pages in To Make the Punishment Fit the Crime as the authority for this claim of implicitness—without quoting either. The relevant passage on the first of those pages seems to be this:

“We could, I agree, talk of deterrence, revenge, training, condemnation, and perhaps even education. Since each of these categories includes a principle of proportion, we could find a use for “deserved punishment” even in a concentration camp—just as we can find a use for “deserved punishment” when explaining why we kicked a dog. But such uses are easily distinguished from the use of “deserved punishment” characteristic of criminal law.” (237)

As I read this passage, it allows for moral uses of “deserved punishment” that are analogical or metaphorical rather than literal. On the second page, I add (in part):

“... even if I agreed that we could find in a concentration camp a use of “deserved punishment” much like that characteristic of the criminal law, that would show only that a concentration camp is still enough like ordinary life for ordinary moral categories to apply. Our judgments of desert there would be judgments of simple moral desert, not of criminal desert.” (238)
Note that I did not actually agree that we can find such a use of “deserved punishment” in a concentration camp. My reasoning is counterfactual: Even if we could find such a use, the use would be the analogical or metaphorical use of ordinary morality, not the literal use characteristic of the criminal law. True, I do not explicitly say there that ordinary morality lacks a literal use of “deserved punishment”. But the preceding chapter does criticize von Hirsch’s moralism; and other chapters include such statements as the following: “Punishment [as I define it] cannot be conceived apart from the criminal law (or some close analogue).” (71)

To me, my position is as clear as desert air. “Deserved punishment” in its literal sense has no use in a concentration camp or in any other radically unjust institution. Whatever one prisoner might say to justify harming another in response to a moral wrong is better put in terms other than “deserved punishment”. Morality may limit our response to wrongdoing, even in a concentration camp, but those limits are not enough to justify the claim that the resulting response is literally “deserved punishment”. The problem is as much “punishment” as “desert”.

Alas, whenever a writer fails to make himself clear to a reader, especially as earnest and intelligent a reader as Ridge, the fault is the writer’s. When I wrote those passages, I did not appreciate how strong a hold moralism would have on many of my readers or how hard it would be for them to understand my view that punishment, literally understood, is a legal, not a moral, term. So, at the risk of seeming to some reader, especially as earnest and intelligent a reader as Ridge, to misunderstand my view that punishment, literally understood, is a legal, not a moral, term. So, at the risk of seeming to some to repeat the obvious, let me repeat the point I think Ridge missed: morality as such does not require punishment—though it may have much to say about deterrence, reform, education, incapacitation, and so on. Only when morality is brought into a legal system, as a side constraint, does speaking literally of morally deserved punishment become possible. Anyone who understands this will, I think, have no trouble reading as I intended the passages Ridge cites as implicitly showing that I accept a literal sense of “deserved punishment” in “nature” (that is, in morality operating outside the criminal law).

Having read those passages my way, the same reader will have no trouble dismissing a number of Ridge’s criticisms that depend on assuming a natural scale of punishment. For example, it is not true (as Ridge claims) that any disagreement we may have about the outcome of an auction for licenses is no easier to resolve than disagreements about how to determine the relative overall moral wrongness that moralists take to be the first step to determining the morally deserved punishment. (p. 14) Determining the outcome of an auction for licenses of the sort I imagine is a relatively well-defined task, one about which there has, as far as I know, yet to be any disagreement in print. In contrast, the moralist’s task is so ill-defined that more than two centuries of work by philosophers, lawyers, and social scientists has so far failed to produce agreement even on such a simple question as whether attempts doing no harm deserve less punishment than the corresponding complete crime.

3. Using the model

That Ridge is a moralist may explain other features of his argument. Consider, for example, his “small fishing tribe” with only a “rudimentary system of law”. Ridge supposes that practice there provides an interesting counter-example to a theory that (as he admits) fits (reasonably well) the actual practice of fully developed (reasonably just) legal systems. Since I am legalist, my first response to such an example is to dismiss it as irrelevant. Ridge owes us an explanation (other than morality) of why a theory of criminal justice should concern itself with an example so far from the central cases of punishment. Though entitled to dismiss Ridge’s fishing tribe in this way, I shall not do that here. The fishing tribe embodies another error of method, one that we have yet to consider, a misunderstanding of how to use my model.

Ridge’s fishing tribe is a thought experiment, not an actual case. It purports to undermine the fairness theory by showing that the market analogy itself yields results independent of unfair advantage. The tribe is supposed to embody a relatively simple situation in which the public goods at stake are all that distinguish one crime from another. The two crimes in question are moral wrongs only because prohibited, not moral wrongs whether prohibited or not. The unfair advantage taken—what Ridge prefers to call “free-riding”—is supposed to be the same. Yet, according to Ridge, the crime involving the more important public good (“staple”) deserves a punishment greater than the crime involving the less important public good (“caviar”). If he is right, we must conclude that what is deserved here, though criminal punishment, is independent of the unfair advantage the two crimes take. The unfair advantage theory must be incomplete.

If this argument were an appeal to intuition, it would commit an error already discussed. The appeal would be to our intuitions, not to those of the fishing tribe. Since our intuitions about which crime should be punished more seem an unlikely indicator of what would be punished more in a primitive fishing tribe, I think charity requires us to interpret Ridge’s claim that over-fishing staple is morally worse than over-fishing caviar as having some basis other than our intuition. Unfortunately, he does not say what that other basis is—and I have no guess. So, for purposes of argument, let us suppose we somehow know that over-fishing staple is morally worse than over-fishing caviar. What follows about deserved punishment?

Nothing—unless my theory, or rather the auction model embedded in it, yields a result inconsistent with the comparative moral judgment we just supposed. Does it? Ridge claims it does. But his only argument for that claim is a single sentence: “It may well be that a license to catch extra caviar would fetch much more on an auction than a license to catch extra staple—caviar is very, very tasty and 5 fish is easily enough to keep one from going hungry (change the number if 5 doesn’t sound compatible with this, but I am assuming that staple are big fish!).” (p. 16) “It may well be.” The argument seems to have this form: since our ignorance does not rule out X’s being true, X is true. The argument seems to be a non sequitur.

Underlying the non sequitur seems to be a misunderstanding of how to use the auction as a model. In the unfair advantage theory, the auction is not an appeal to intuition. It is, instead, a way to transfer methods from economics, methods allowing us to deduce a (partial) ordering of crimes from greatest to least. But the auction will allow that only if we construct the model so that economic theory applies to the questions we put. There must, for example, be a common medium of exchange. Without that, we cannot compare one sale with the next. Ridge’s fishing tribe, however primitive in other respects, will have to have money, whether denominated in dollars, shells, or the like. Barter will not do. The auction will also have to have enough licenses and enough bidders to avoid collusion, to cancel the effects of individual idiosyncrasies, and otherwise to make the tribe’s market behave (more or less) like a perfect market. That is not possible in a small tribe. Ridge’s fishing tribe is going to have to be much larger than he supposes and, given the...
sophistication running a large auction presupposes, much more sophisticated as well.

Ridge will have to make a number of choices as he constructs this large tribe, choices that might beg the question with which he began. So, for example, he must decide whether the tribe will trade with others for staple. If the tribe can trade caviar to other tribes and receive staple in return, the caviar will, in effect, be equivalent to staple for purposes of feeding the tribe. There will be one public good rather than two. Even morality will have to treat them as (qualitatively) the same. To get the result he wants, Ridge must imagine his tribe isolated. Any decision concerning the relative size of staple and caviar will also threaten to beg the question.

I could go on. But I think you get the idea. Ridge has so under-described his fishing tribe that nothing follows from it. Some more fully described version of it might yield the result that he claims for it, but some will not. He must carefully construct his model to find out what is possible. To avoid begging his question, he will have to justify the assumptions on which that construction relies. Among the relevant considerations will be preserving the market he wants to study and not begging the question he set out to answer.

4. Between the horns of Ridge’s tri-lemma

It was such considerations that led me to decide to assume that poaching would be possible in my model, but dealt with in a way separate from the system of licenses. I did not, however, face Ridge’s tri-lemma. (6-8) I did not, that is, have to choose between licensing poaching, punishing poaching outside the ordinary legal system proportionally, or just punishing it outside the system draconically. I had at least one more option. I could simply have supposed that poaching was impossible. I could have supposed that because the assumption would preserve the applicability of the market theory I need. I chose not to suppose that because I prefer to keep my model as close to the familiar as possible and so, had to do something about poaching that did not beg the question I wanted my model to answer. Punishing poaching draconically outside the system of licensing did that. I may thereby have introduced some injustice into the system. But, since the system is constructed so that poaching is likely to be rare, I cannot see why Ridge thinks the resulting society would be radically unjust—or even why it would overall be less just than his or mine. For the ancients, Draco’s Athens exemplified injustice but severe justice. Here again Ridge owes us an argument.

Why do I prefer to keep the model as close to the familiar as possible? There are at least two reasons. The first is practical. Catching errors in reasoning is easier if the reasoning stays close to what is familiar. The second reason is rhetorical. I do not want readers to reject my model because it is “unrealistic” (though it is). The fewer hard-to-swallow assumptions I introduce, the harder it is for careless readers to reject the model as unrealistic. Neither of these reasons separately, or even the two together, are decisive. Construction, like design, is an art in which even equally good solutions may differ much. I worry only when equally good solutions yield importantly different results. Like previous critics, Ridge has yet to show that there are equally good models of unfair advantage yielding importantly different results. Indeed, like other critics, he has yet to show that he understands the method.

BOOK REVIEWS


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I.

At seventy-eight, Mrs. D. suffers from a variety of chronic conditions, including arthritis and high blood pressure. She also, like many people her age, tends to lose her balance and fall, resulting in trips to the emergency room and frequent, albeit short, hospitalizations. Otherwise, as her doctors keep telling her, she’s in good shape: strong in constitution, mentally alert, able with help to live alone. What Mrs. D. wants as she remarks to her doctor, is to “stop being a patient” and become “a person again.”

This distinction between being a patient and being a person is at the heart of two recent books dealing with end-of-life issues: David Kuhl’s just published What Dying People Want: Practical Wisdom for the End of Life, (Perseus Books, 2002) and Timothy Quill’s Caring for Patients at the End of Life: Facing an Uncertain Future Together (Oxford 2001). Beginning with the assumption that this distinction matters philosophically and clinically, Kuhl and Quill call for a program of humanistic medical care designed to recognize the person in the patient. This is a simple idea, but profound in its implications. Its adoption, as these texts make clear, would alter our understanding of what an effective doctor-patient relationship is. This in turn would require significant revamping of medical education and clinical practice in this country.

Although different in detail, the model of humane care and reformed clinical practice described in each of these books grows out of extensive clinical experience. Kuhl, a Canadian doctor, spent fifteen years taking care of patients with cancer and AIDS in Vancouver before undertaking the research project on which his present book is based. Quill, also an M.D. and Professor of Medicine, Psychiatry and Medical Humanities at the University of Rochester, is a well-known advocate for dying patients and their families. Indeed, in one of two important cases to reach the Supreme Court that argued for the right to have physician-assisted suicide, Quill served as a plaintiff (Quill v. Vacco, 1997). Despite differences in the medical systems in Canada and the United States, Drs. Kuhl and Quill concur that healthcare workers, policy makers, medical insurance companies and government agencies need to do a better job at recognizing the needs of patients facing the end of their lives.

II.

What Dying People Want is written as a guide for people who have a terminal illness or know someone who has. Aside from this primary audience, Kuhl directs his book at anyone who wants to understand the inner experience of living with (or dying from) a terminal illness. It is this latter ambition that makes his book of interest to philosophers, particularly those interested in understanding the meaning of illness or what
awareness of death’s immanence means to the living. Kuhl provides excellent practical guidelines for breaking bad news, asking medical questions, planning and carrying out decision-making meetings (with or without the medical team), managing pain and so on.

Quill’s *Caring for Patients at the End of Life* covers much of the same ground, although targeting healthcare professionals more directly. Thus Quill includes chapters comparing various options for relieving intractable suffering, dealing with patient requests to “die faster” and the legal and policy issues of physician-assisted suicide. He also devotes a chapter to examining the doctrine of double-effect, its religious and philosophical origins and its shortcomings as a practical clinical guide [165]. Readers trained in philosophy will appreciate Quill’s sensitivity to this and other philosophical principles underlying distinctions between voluntary cessation of eating and drinking, physician-assisted suicide, and voluntary active euthanasia.

Like other books of this genre, both books rely on patient testimony (the stories of those Kuhl calls his ‘co-researchers’). In addition, however, Kuhl draws liberally from ancient mythology and literary sources such as the poetry of Emily Dickinson, and T.S. Eliot, and Tolstoy’s *The Death of Ivan Ilyich*. These fictional and non-fictional narratives resonate throughout the text, merging seamlessly with discussion of practical matters, and bringing depth to Kuhl’s reflections on the various ways of being human. Perhaps because of this, Kuhl is in many ways the more interesting writer of the two, even in some ways the more philosophical. Let me thus begin by focusing on the trajectory of his argument.

Kuhl begins by reflecting on what it is to be a doctor. He characterizes his work and that of doctors in general as that of a detective: identifying disease, finding the causes of pain and working to prescribe effective medication or treatment. Trained as a physician, he describes himself as someone who rarely asked about the impact of terminal illness on the patient, on his or her life, hopes and dreams, relationships with others, and belief system. In other words, he was trained to treat persons as patients, and patients as diseases or “terminal conditions.” Just as an aside, I follow the lead of both authors here in focusing primarily on doctors rather than other healthcare providers, the nurses, nurse practitioners, social workers, psychologists and others who make up medical teams. The reason for this is simple. As Quill puts it, one focuses on doctors because they are “paradoxically the most powerful yet least reliable members of the health care team.” Nurses are frequently the pivotal figures, spending more time at the bedside and often demonstrating the kinds of commitments doctors need to learn [9].

This theme of the need to (re)educate the physician appears throughout Kuhl’s own narrative. He relates how his experience caring for one particular cancer patient, Alice, a rare case whose pain didn’t respond to any of the strategies usually effective for her condition, awakened him to the fact that dying is “hard work,” a challenge “we would rather avoid” [xvii]. Alice taught Kuhl that he had little knowledge or understanding of what his patients really felt, of what it was like to learn one has a terminal illness. This awareness led Kuhl to ask the following question: What is the lived experience of knowing you have a terminal illness? What is it like to be told you are dying? To get up every morning “knowing that the disease within you will likely cause your death” [xx]? Thinking that he might more effectively address the medical needs of such patients if he understood the psychological and spiritual dimensions of their suffering, he enrolled in an undergraduate course in counseling psychology aimed at developing communication skills, especially skills in listening. Kuhl describes his resulting performance in less than glowing terms. As his professor constantly reminded him, he was very good at asking questions (being a detective); bad at listening. But it was listening his patients needed. Kuhl thus undertook to learn from patients what this experience meant to them, how it fit into their sense of themselves and altered the shape of their lives.

Once he learned how to listen, what did Kuhl learn? Let me briefly mention three key lessons. First, and this is the primary message of the book: people who are dying are still living. This simple fact is easily overlooked. Grasping it has a profound impact on how one treats the terminally ill. Dying people suffer from diseases or “life-threatening conditions.” But as the stories in Kuhl’s book so eloquently demonstrate, they also have hopes and fears, friends and family, jobs and projects, entrenched habits, likes and dislikes, desires to travel or write, see their adult children marry or their grandchildren grow up. Dying people have old loves, unfinished business, hurts, memories and well, you get the idea.

The thrust of Kuhl’s argument is that we need to change our understanding of what an effective doctor/patient relationship is. We need, he maintains, to learn “to see a person experiencing an illness, rather than a patient in some stage of a disease process.” This is a radical change in perspective, one that regards the patient as someone with a life that has been interrupted, temporarily, or in some cases permanently, by the intervention of disease or disability. Patients in other words are persons, worthy of respect in Kant’s terms, deserving of our empathy and understanding. One of the noteworthy things about this change in perspective is that patients become more interesting; their values and experiences reward curiosity and may provide sources of meaning for physicians and care-givers.

A corollary to this first point is this. If, as current opinion holds, the experience of pain has an emotional and psychological component, then we cannot alleviate pain and suffering by focusing on pain’s physical component alone. As Kuhl’s patients attest, physical pain is not separate from other sources of suffering, from the fear or dread that comes with knowledge that one is facing one’s death, that time is short, that issues remain unresolved or even in some cases irresolvable. While physicians can not “fix” these deeply human problems, part of the challenge is to stay with problems that have no medical solution, assessing pain from the perspective of the whole person [94].

The second lesson of Kuhl’s book concerns time. In his words, “time is now.” Patients and their families naturally tend to focus on a cure, waiting for something other than what they have now. Kuhl terms this the Magic Cure Problem [137]. But how much time a patient—or indeed any of us—has is unpredictable. The time to remember, to talk about what individuals or families mean to one other, have given to each other, will leave behind, as Kuhl insists over and over, is now [28]. This theme Quill sounds as well, stressing the doctor’s role in encouraging patients and their families not to wait—to say good-bye, heal old wounds, put their practical and emotional affairs in order.

The third lesson of Kuhl’s book and the last I will survey here is the need for compassionate communication. This is a point particularly worth stressing in the context of delivering palliative care, for sensitivity and good communicative skills become especially crucial when faced with the obligation of conveying bad or discouraging news. Again, Kuhl and Quill speak with one voice, noting sympathetically that medical education rarely trains physicians in how to tell patients they...
are dying. Nor does it offer physicians resources for handling the strong emotions that delivering such news may elicit. As a physician-colleague of this reviewer points out, doctors rarely ask *Which of us* should tell this patient the bad news? *Who among us is best suited* to tell this patient she is dying? (Only on ER do doctors manage, despite a never-ending series of interruptions and competing crises, to find just the right words). In real life, who breaks the news, and how, generally gets decided in ad hoc fashion.

The unfortunate results—the horror stories—are legion. So, for example, one of Kuhl's co-researchers, a patient named Marjorie, relates the story of how she learned she had cancer. Lying in bed, still coming out of anesthesia after a biopsy, she looks up to find her doctor standing outside her hospital room door. “We were wrong,” he announces, “it’s metastatic carcinoma.” “What?” the patients asks groggily. “What does that mean?” “It means you have cancer,” he replies. But “don’t worry. I’ll make an appointment for you at the cancer clinic.” Then without coming into the room or uttering another word, he disappears[45].

Both Kuhl and Quill regard such lapses—almost comic in their horror—as unforgivable. They are nevertheless understandable, a result of (inadequate) medical training. The remedy is better training, better communicative skills and more self-knowledge. Like Kuhl, Quill devotes an entire chapter to the topic of conveying bad news, including sensitive, practical guidelines for a range of circumstances likely to face patients and their families. Kuhl suggests allowing patients who are dying to communicate bad news to their families themselves. Both recommend asking patients if they would prefer to have their physician—so far only a “de facto” role, but potentially a new patient role in some stage of a disease process—to communicate directly with their families in this “intensely personal way” or find the time and space to engage with patients living with the knowledge of their terminal illness. In real life, who breaks the news, and how, generally gets decided in ad hoc fashion.

The need for compassionate communication and the difficulties of asking physicians and other healthcare workers to engage with patients living with the knowledge of their impending death leads me to mention what I take to be the most valuable feature of Quill’s book. As evident from the discussion so far, Quill, like Kuhl, maintains that doctors and other medical professionals have obligations that extend beyond treating their patients’ as patients, i.e., as mere instances of “metastatic carcinoma.” He goes further, however, usefuly formalizing that obligation into two general principles. The first is to treat patients and their families with the caring and concern that you would want for yourself or your loved ones. The standard embodied here—an obvious version of the Golden Rule—is a tough one, as Quill admits [22]. It demands “genuinely caring about the outcome,” using the resources of medical and palliative care in “an intensely personal and individualized way.” The physician must engage her patient not only with sympathy but also with “empathetic imagination,” a requirement which “allows for much more emotional and existential proximity” than existing standards of care demand or allow[22-23].

Quill’s second principle he calls the Principle of Non-Abandonment. What does a principle of non-abandonment require? Basically, a commitment by the clinician to enter into a “continuous caring partnership,” one that doesn’t end when cure becomes unlikely or impossible. Non-abandonment asks the physician to engage in a partnership, an agreement “to face the unknown together with his or her patient and family” [29]. The aim is to communicate about complex end-of-life issues in a way that “allows patients and families to make the most of the end of their lives” [122]. Accepting this commitment may mean playing a continuing role in final illness, even death. This is a role contemporary medicine—operating one might say from a Principle of Non-Commitment—normally leaves to hospice workers and family care-takers. The Principle of Non-Abandonment, then, together with the prescription to treat every patient as one would wish to be treated oneself, sets a very high professional and moral standard.

III

*What of the difficulties* physicians face in meeting this standard? How are they meant to engage patients and their families in this “intensely personal way” or find the time and inner resources to engage the whole person they are treating? Quill makes no bones about—indeed, is particularly good in acknowledging—the obstacles to developing the communicative skills, self-awareness and simple humanity called for by the broader model of healing outlined here. Much of medical training, as Quill and Kuhl both recognize, is directed at suppressing reactions such as sadness and anger. Ultimately, the changes in physician-patient relationship they advocate require a corresponding change in perspective toward the physician herself, as healer and medical professional. That, in turn, requires a radical alteration in the kind of training typical of North American medical schools. The acquisition of self-knowledge, capacity to reflect, and willingness to engage the existential and personal dimensions of dying (and living) take time. So do the long-term, open-ended physician-patient relationships many physicians regard as indispensable not only to good end-of-life care, but to medical care across the board. The problems Quill and Kuhl address, it is worth emphasizing, do not arise only with the terminally ill; they are systemic.

Eventually, guidelines for improving patient-physician relationships may be more easily articulated than implemented. Consider the dimension we have focused on already: time. Probably nothing is in such short supply in a fixed four-year medical curriculum or in highly specialized residencies and internships. Training in how to deliver bad news, ethical decision-making or good communication, like courses in literature or the medical humanities, compete head on with the necessity to cover more and more scientific information and train for a range of new specialties. These skills do not lend themselves to the occasional visiting lecturer or short web-based courses (frequent strategies for dealing with growing pressures for ethics training in medicine and biological science). It will surprise no one familiar with American medical schools to learn that much of what constitutes humanistic medical education gets short shrift. Nor can a healthcare system training to fit more and more patients into a billing hour, while trying to meet the needs of the under and uninsured and an expanding elderly population, reasonably be expected to nurture one-on-one physician-patient partnerships or individualized decision making.

What then are we to make of the calls for transformed model of healthcare implicit here? To my mind, Quill and Kuhl deserve considerable credit for illuminating the difference between treating someone as *a person experiencing an illness* and as a *patient in some stage of a disease process*. Their individual and collective argument for the importance this difference makes in medical care, particularly, but not exclusively, as life draws to a close, strikes this reviewer as indisputable. It is also inspirational, doing the service of providing guidance for healthcare workers laboring in a system that militates against compassionate care. If the authors reviewed here disappoint, it is perhaps only in failing to recognize how very deep and entrenched are the barriers to the kind of medical care we would all hope to have for ourselves and our loved ones—barriers of training, medical habit, outlook, hospital procedure and economic reality.
That said, Caring for Patients at the End of Life should, as its cover blurb insists, “be required reading in every medical school and for every doctor nationwide.” I would add only that both books deserve a place as well on the shelves of philosophers and bioethicists interested in end-of-life issues or anyone hoping to understand the deep existential connection between dying and living.


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Though opinions on abortion fall along an exceedingly wide spectrum, nearly everyone has formed some opinion regarding the subject. Peter Korn’s book, Lovejoy: A Year in the Life of an Abortion Clinic, highlights the debate and also explores the rationale and leadership fueling both sides of the argument. This narrative, written from the viewpoint of abortion clinic administrators, is not philosophic, nor is it intended to be. Rather, this unique perspective provides the reader with a rare opportunity to experience not only the emotional side of abortion but also to view the procedure as a business. The book explores a myriad of issues surrounding the abortion debate and serves as a wonderful jumping off point for deeper discussion.

Peter Korn spent 1995 inside the Lovejoy Surgicenter in Portland, Oregon. As a journalist working in one of the country’s busiest abortion clinics, he was given intimate access to the people and events most closely involved in the abortion controversy. Lovejoy’s focus therefore reflects three central themes, namely, the pressure to have an abortion, the pressure to have an abortion, and healthcare allocation justice.

The decision to have an abortion is intensely personal and often extremely difficult. Although some women may ultimately decide an abortion is the best thing for them, many still harbor distinct reservations ranging from fear of ridicule should friends and family discover their decision to feelings of guilt and helplessness. At Lovejoy, like many other abortions clinics across the country, would-be patients are harassed, sometimes violently, by anti-abortionists who gather outside the facility. Signs urging “STOP THE MURDER” and shouts of “SINNER” and “BABY KILLER” are nothing out of the ordinary. Korn focuses on *Advocates for Life*, a national organization that has been particularly active at Lovejoy. In addition to harassing women, the group has even gone so far as to target individual physicians and staff members, distributing flyers containing personal information about them across the city. As one representative put it, “They [the staff] are no different from the receptionist at Auschwitz. What’s the difference?” (84). Such behavior illustrates the sometimes overwhelming pressure to carry a pregnancy to term.

In contrast, there can also be a great deal of pressure, usually from friends or family members, to have an abortion. Korn illustrates this point with a particularly memorable case. Jessica, a 16-year-old in her first trimester, arrived with her parents for an abortion. Though she gave several seemingly well thought out reasons for wanting the procedure, she also casually stated that she did not believe in abortion. Her statement was cause for concern and the staff at Lovejoy quickly realized that “there [were] two strong wills in conflict and they [belonged] to Jessica and her father. Mother [was] just a bystander” (215). When the counselor approached her father and informed him that he could not force his daughter to sign the consent form, he became enraged.

“He eyes [were] those of a diamond cutter about to strike his blow. His lips [were] pressed so tightly together that they almost disappeared. “She’s under eighteen,” he [said] in a clipped voice. “She’s my child. She will sign that consent form.”” (215).

Although it was Jessica’s choice to make, her father was attempting to force her into doing what he thought was best.

There are also many women, who, instead of being pressured by their parents, are coerced by husbands or boyfriends who do not want a baby. Beverly had been married to her husband for ten years and they had agreed long ago that they did not want children. She had come to Lovejoy seeking an abortion. Tim, one of the resident counselors, talked to her before they scheduled the procedure.

She was straightforward about wanting the abortion. But a tremor in her voice told another story. What Beverly had described, when Tim thought about the words and the voice together, was an ultimatum from her husband—terminate the pregnancy or divorce (91).

Beverly almost had her abortion. At the last minute she decided that it was not right for her. She and her husband eventually divorced, but she was overjoyed with the presence of a child in her life. Staff members at the Lovejoy clinic are caught in this constant struggle: they wish to provide women with the healthcare that they need and want but it is also imperative for the patient to be certain about her decision. The patient should be the one who is actually making the choice and not simply acting on behalf of someone else’s desires.

The allocation of resources is also a central issue throughout the book. While all women in the United States are guaranteed the same rights, many, due to place of residence, insurance coverage or simple lack of means, are denied care. Korn recounts several cases that illustrate this point.

After discovering she was pregnant, a 27-year-old woman elected to have an abortion. When an employee at Lovejoy called to verify the woman’s insurance, she learned that the company would pay 80% of all billable expenses. Unfortunately, the policy also had a $250 yearly deductible and only $66 of the deductible had already been paid. The employee quickly realized that if she billed the insurance provider the woman would pay $290 whereas if she were to pay out-of-pocket it would cost her only $230.

The woman reacted to this helpful information with disappointment. She had medical insurance, and yet she was being told it would cost her less to pay cash. And she did not have the cash with her that day (122).

This woman scheduled another appointment later that week. Many women, however, do not have the financial resources to pay for an abortion, much less regular insurance coverage.

Several months later, a 17-year-old who was ten weeks pregnant, came in for an abortion. She was, however, absolutely terrified of the pain associated with the procedure and did not think she could go through with it unless she was given general anesthesia. The woman was insured under ODS, one of Oregon’s largest HMOs. ODS will not cover a general anesthetic for an abortion until at least the 16th week of a pregnancy. The state health plan regulations would not allow the woman to pay the difference out of pocket. The woman...
discussed waiting to have the procedure so that her insurance would cover the anesthesia but she decided that the risks associated with late-term abortion were not worth taking. Carye, a counselor at Lovejoy, believed she had found a loophole:

“If the woman were to drive across the border to Washington and immediately establish residency with her sister, Carye explained, she would qualify for a Washington state-assisted abortion within twenty-four hours, and there she could get the general anesthetic” (302).

Weeks later Carye would learn that the woman had taken her advice and had gotten the procedure that she wanted. The ODS policy disturbed Carye deeply. Allene, a colleague told her not to worry too much. Eventually ODS would realize that their policy was actually costing them more money and they would change it. “To ODS . . . this is simply business” (302).

The book does an excellent job of framing the issues involved in the abortion debate. Korn does not display his bias and affords equal treatment to both pro-life and pro-choice. Social stigmas as well as healthcare allocation are explored in clear and understandable dialogue.

There is no specific discussion of ethical questions in this book. There is no direct debate concerning when life begins or whether abortion is morally acceptable. Yet the book provides a good sounding board to facilitate further discussion concerning the beginning of life, social stigma surrounding abortion, access to healthcare and allocation of resources. Therefore, Lovejoy may be of use not only to those interested in the modern abortion debate but also to educators and students in the fields of reproductive ethics or legislative and public policy.