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HOWARD BRODY
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ANNOUNCEMENTS
FROM THE EDITORS

After serving as editor and co-editor of this Newsletter for more than seventeen years, I am resigning from the position and leaving the Newsletter in the able hands of Mary Rorty and Mark Sheldon. In this role, and as an ex officio member of the APA Committee on Philosophy and Medicine, I have been committed to promoting bioethics as a legitimate and important area of philosophy. I have also tried to make the Newsletter serve as a tool for communicating announcements from the Committee and other groups as well as timely and interesting contributions of philosophers who share our interests. Over the years the Newsletter has offered readers a rich collection of submitted papers, poetry, stories, and book reviews, as well as proceedings from recent programs sponsored by the Committee. I have learned a great deal from serving in this role and enjoyed the friendship and camaraderie of my co-editors, the Committee chairs and members, and the generous contributors to the Newsletter. I trust that Mary and Mark will continue to serve our readers in this tradition and enjoy similarly rewarding relationships.

This issue of the Newsletter continues to deliver the timely and interesting work that readers have come to expect. Again, we have papers on timely and controversial issues, and a story for your entertainment.

Kenneth Kipnis has sent us his paper, “Forced Abandonment and Euthanasia: A Question from Katrina.” In light of the Orleans Parish grand jury’s recent refusal to indict Dr. Anna Pou for the murder of four patients, this is an especially timely piece. Kipnis’s paper reviews the ethics of “battlefield euthanasia” and the norms that should govern healthcare professionals in considering euthanasia in the clinical setting under disaster conditions. He also presents compelling arguments for allowing doctors to choose euthanasia over forced abandonment of their dying patients in extreme situations.

We also present two papers from presenters at the Committee-sponsored Pacific Division session on “Genetic Testing of Children for Adult Onset Conditions.” In her paper, “Using the Best Interests Standard to Decide Whether to Test Children for Untreatable, Late-Onset Genetic Diseases,” Loretta M. Kopelman invokes “the Best Interests Standard” to support the current professional consensus against testing children for severe, untreatable, late-onset genetic diseases. On a related topic, Professor Steinbock discusses the ethics of prenatal genetic testing for adult-onset conditions in her piece, “Prenatal Testing for Adult-Onset Conditions: Cui Bono?” She explains that prenatal genetic testing is often used to decide whether to abort the fetus, and she considers the justifications and lack thereof for this practice.

The session at the Central Division meeting focused on Howard Brody’s new book, Hooked: Ethics, the Medical Profession, and the Pharmaceutical Industry. Included in the Newsletter is Lance Stell’s expanded reaction to Brody’s presentation, and comments by Brody in reaction to Stell. Brody’s book is a very thorough analysis of what he (and many others) perceives to be a very problematic relationship between medicine and pharma. The situation, in Brody’s view, requires deliberate disentanglement on the part of the medical profession from the influence of pharma. Stell’s response, “Industry’s Relationship with the Medical Profession: Impure and Unholy?” involves acceptance of the issue in a broader context, historic and economic, and ultimately suggests a different kind of engagement on the part of the medical profession. In “Conflicts of Interest in Medicine: Avoidable or Unavoidable,” Brody sees Stell’s response as indicative of a certain kind of rationalization that requires further attention.

Also included in this issue is an essay by Timothy F. Murphy. Observing this year’s medical school graduation, Murphy started to think about the ceremonial use of oaths. In “Oaths and Ethics in Medical School,” he sets out his thoughts on this issue.

A story by Felicia Nimue Ackerman, “What Would You Like To Know?” concludes our issue. It describes the first meeting of a woman and her biological mother and offers a challenging context for considering the claim that adopted children have a right to information about their genetic parents.

In order to continue offering our readers exciting issues jam-packed with timely and informative pieces that introduce provocative philosophical discussions, please continue to send us your work. We also remind you to think of this Newsletter as a place for your announcements, letters, papers, case analyses, poetry, and stories. Please feel free to volunteer a book review. Your contributions and queries should be sent to Mary or Mark at the addresses below. Please include your phone and fax numbers and email address.

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**FROM THE CHAIR**

John Lizza  
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As I begin my tenure as the new chair of the Committee on Philosophy and Medicine, I would like to welcome Fritz Allhoff (Western Michigan University), Loretta Kopelman (East Carolina University), and Kevin McDonnell (St. Mary’s College), who also join the committee as of July 1, 2007. The continuing members are Robert Baker (Union College), Kenneth Richmond (Massachusetts College of Pharmacy and Health Sciences), Mary Rorty (Stanford), Rosamond Rhodes (Mt. Sinai School of Medicine), and Mark Sheldon (Northwestern). Mary Rorty will join Rosamond Rhodes and Mark Sheldon as a co-editor of the *Newsletter on Philosophy and Medicine*. I would also like to thank David DeGrazia, Lee Brown, Ben Rich, and Gary Seay for their dedication and service on the Committee over the last three years. The former chair, David DeGrazia, was very gracious and helpful in bringing me up to speed on the workings of the Committee. However, I am sure it will be a learning process for me as we move forward.

One of the main functions of the Committee is to sponsor sessions on philosophy and medicine at the three Divisional meetings of The American Philosophical Association. This year Robert Baker has arranged and will chair a session on “The Philosophical Foundations of Bioethics” at the Eastern Division meeting on December 27-30, 2007, in Baltimore, MD. Speakers include Hilde Lindemann and Larry McCullough. The Committee also plans to sponsor sessions on “Persons, Human Organisms, and Bioethics” at the Pacific Division meeting on March 19-22, 2008, in Pasadena, CA, and “Physicians at War” at the Central Division meeting on April 17-20, 2008, in Chicago, IL.

For a second year the Committee is collaborating with the American Society for Bioethics and Humanities (ASBH) to co-sponsor a session at that organization’s annual meeting, held this year in Washington, D.C., October 18-21. That session, on “Genetic Testing of Minors for Adult-Onset Disorders,” will feature papers by Ray Frey, Loretta Kopelman, and Bonnie Steinbock. Gary Seay chaired a similar Committee-sponsored session at the 2007 Pacific Division meeting. Also on the ASBH program is Robert Baker’s submitted workshop, “Rationing Antivirals, Vaccines, and Critical Care;” which is a follow-up to his 2006 Eastern Division Committee-sponsored session, “Ethics During Epidemic: Bioterrorism and Natural Disasters,” and will include Dan Brock, David Perlman, Sean Philpott, and Alan Wertheimer.

The *Newsletter on Philosophy and Medicine* has been an excellent source for cutting-edge work in the field and will continue to be published biannually. Although articles for the *Newsletter* are often solicited from speakers at our APA sessions, the *Newsletter* welcomes contributions in the form of papers, book reviews, case analyses, letters, poetry, stories, and announcements. Please send these to Mary Rorty or Mark Sheldon at the addresses indicated in their column.

I am excited about serving on this committee. Philosophical discussion in metaphysics and moral theory is sometimes highly abstract and far removed from practical concerns. On the other hand, bioethical discussion sometimes gives superficial treatment to the underlying issues in ontology and moral theory. Both are critical errors. Theory unchecked by experience is not a worthy guide, and practical deliberations lacking theoretical support lead to naïve relativism. Progress in bioethics and the philosophy of medicine requires a depth of consideration of theoretical and practical perspectives. Some of the most interesting work in philosophy is being done by those who have not lost sight of the interdependence of the theoretical and practical. I hope that the Committee on Philosophy and Medicine will do what it can to encourage this approach. It bodes well for the field.

**ARTICLES**

*Forced Abandonment and Euthanasia: A Question from Katrina*  
Kenneth Kipnis  
*University of Hawaii–Manoa*


**Introduction**

I do not know what happened on the seventh floor of Memorial Medical Center (MMC) during the darkest hours of the New Orleans catastrophe.¹ We do know that, in addition to staff, patients, and family members, hundreds of others had sought shelter in the hospital as Hurricane Katrina approached Louisiana on Sunday, August 28, 2005. By Monday afternoon the storm had passed but the levee walls along the city’s canals had begun to fail. A foul mixture of waters from the city’s sewer system and Lake Pontchartrain was coursing through the streets, eventually reaching the low-lying area where the hospital stood, inundating the lower floors of its buildings and submerging the cars in the hospital’s parking lot. From the outside, MMC had become an island. On the inside, the electricity and plumbing were failing. The staff would have no lighting, no elevators, no toilets, no running water, no overhead pagers, no refrigeration, no air conditioning, no telephones, no ventilation, and no powered medical devices. The flood had crippled the hospital’s capacity to provide standard medical care for its patients and, with perhaps 2,000 patients and refugees crowded together, Memorial Medical Center may have become a health hazard. Notwithstanding, the staff continued to care for patients, moving those they could to the roof of a nearby parking garage, where they might be evacuated by helicopters, or to the second floor, where they might board water craft.²

As the days passed, many of those in the hospital were able to leave. But many hundreds remained, including the sickest patients who could not be moved, and the staff who were staying on to care for them until help arrived. There had been assurances of a timely rescue. But early Thursday morning—three days after the hurricane—it was announced that those still in the hospital would be on their own (Deichman 2006, 110). There would be no rescue by federal, state, or local government agencies. Dr. Richard Deichmann, the chief of medicine, described the effect.

It was a phenomenal blow to hear that nobody was coming to get us. The worst thing for us was always waiting for someone to come and get us and then never showing up. There was this feeling of betrayal all the time. That freezes your ability to do things. And that is what happened Wednesday and Thursday. (Meitrodt 2006)
Some clinicians may have concluded, perhaps reasonably, that both they and their patients had been abandoned.

After days of enervating heat, darkness, and sickening stench, some clinicians are said to have ended the lives of some patients before leaving the hospital themselves. No living patients were left behind. Alleging that there had been homicides, Louisiana's attorney general subsequently ordered the arrest of a doctor and two nurses.

It is unclear, at this writing, how many indictments there will be. It is too early to make a confident judgment about what the conditions were at MMC between its isolation in Katrina's floodwaters and the final evacuation by Tenet, the corporation that owned the hospital and that sent helicopters for the last survivors. Nor is it now possible to say who did what during the crisis and what they believed and intended at the time. Journalists have given us a preliminary account, the courts may follow with further evidence, and historians will eventually have the last word. But we may never know the full story.

Despite the obscurity of the actions and circumstances, Katrina has posed a new question that complicates our thinking about caring for patients at the end of life. Can the conditions in a collapsing healthcare delivery system ever excuse euthanasia? The focus here is on the ethical norms that should govern healthcare professionals working in extremis. There is a need for responsible standards that, in fairness, should be honored by practitioners and respected both by the law and by society. What might those standards be?

In the pages that follow, I will, in Section I, review some of the current thinking about the causation of death in the clinical setting, looking at some familiar standards from law and ethics. I will then consider the permissibility of euthanasia, focusing initially on what I will call the argument from "intractable suffering": perhaps the strongest and most common justification. I will also survey objections to that argument.

With that as background, I will go on to look at disaster medicine and a different reason for withholding and withdrawing life support. When, following mass casualties, medical resources are in short supply, it then becomes justifiable to withhold them from seriously injured patients, allowing them to die even though, on an ordinary day, clinicians would act aggressively to save them. In this context, I will consider an issue that has received comparatively little attention in mainstream bioethics: battlefield euthanasia. Circumstances that may be unheard of in civilian medical care are tragically more familiar in military medicine. I will show that conditions arising on the battlefield can mirror conditions that could have arisen during Katrina. Building on that discussion, I will develop and defend a professional standard for assessing the conduct of healthcare professionals who are, in this way, in extremis. If not a wholly new line of thought, the narrow defense of euthanasia that is offered here is at least one that has largely gone unnoticed in the bioethics literature. The argument from "forced abandonment" (as I shall call it) sidesteps some objections to the argument from intractable suffering.

So there will be no misunderstanding, the pages that follow are not intended as a defense of what healthcare professionals did in Louisiana. As has been emphasized, we do not know what that was. Current accounts of the events in question are neither comprehensive nor consistent with each other and, indeed, it would not be a surprise to discover that some elements of my narrative are incorrect. But the argument of this paper does not turn on the accuracy of its account of the Katrina catastrophe. This inquiry is a more abstract one. Are there conditions which, had they been present in New Orleans (or anywhere else), would have excused ending the lives of patients, conditions under which both law and professional ethics should withhold condemnation? The answer offered here is yes. Where it is impossible to evacuate patients and dangerous and medically futile to remain with them, clinicians may have to choose between abandonment and euthanasia. There may be no third option. I will argue that physicians who choose euthanasia under these conditions should be excused from ethical and legal responsibility for misconduct. It would be wrong to blame them for what they have done.

The distinction between justifying and excusing conditions is central to what follows. When an act is justified, it is not a wrong at all: "I didn't file a tax return because the law says I am not supposed to. Not filing a return was the right thing to do." However, when a wrongful act is excusable, the agent should not be blamed or punished for it: "I didn't file a tax return because I was gravely ill at the time. While I should have filed, it would be wrong to fault me for having failed to do so." Section II of this essay explores a common justification for one type of euthanasia. In contrast, Section III defends the excusability of another type.

I. Euthanasia and the Medical Causation of Death

"Euthanasia": The Greek roots of the term "euthanasia" denote "good death." Though it is common to think of death as unequivocally bad—it is, after all, our most severe punishment—it is easy to distinguish between dying processes that are mercifully tolerable and others that are agonizing beyond endurance. During the events that have become known as 9/11, scores of people who were trapped in the World Trade Center leaped from windows to escape the heat and smoke, some holding hands with others as they fell. Knowing their lives had come to an end, it is likely they were choosing deaths that were better than the ones they would suffer if they remained inside. Though it was tragic that so many died in this way, it does not appear to have been publicly argued that it was wrong for them to have ended their lives as they did.

Euthanasia requires a second person's involvement. Sometimes called "mercy killings," these acts are done by one person for the benefit of another. Again, the everyday inclination is to think that, except for self-defense and a few other cases where killing is justified or excused, it is a grave wrong to cause the foreseeable death of another human being, to harm another in that comprehensive way. But one can imagine oneself struggling through the heat and smoke to reach a window high in the World Trade Center. A co-worker who uses a wheelchair is also there, but unable to get past the debris and into the air outside. She asks for your assistance.

Euthanasia, as an ethical problem, has traditionally engendered debate on whether and, if so, when, killing another person can be justified or excused on the grounds that the person killed is benefitted rather than harmed. Except in some European countries, euthanasia is a crime. Those who end the lives of the intractably suffering, even when they are following urgent requests, can expect to be charged with homicide. Should the law be changed to permit some beneficent killings?

Clearing the Ground: In examining euthanasia, three issues characteristically muddy the waters. First, "euthanasia" was the euphemism the Nazis used to sanitize their early extermination of those they deemed defective. The program quickly evolved to kill millions: Jews, Romani, homosexuals, communists, and so on. Treated as vermin, those who were involuntarily and secretly gassed in the concentration camps were not killed beneficently. Indeed "involuntary" euthanasia—"beneficently" killing another against his or her will—seems a contradiction in terms. While some fear that loosening the law of homicide will send us down the slippery slope to holocaust, such prognostications must be examined with care.
The second issue concerns what some still call “passive euthanasia”: the discontinuation of life-prolonging measures, often the removal of a ventilator (a mechanical breathing device). When a patient or an authorized proxy withdraws consent to treatment, then the doctor, no longer at liberty to continue, can lawfully withdraw life support, causing death. It is sometimes urged that these patients die from their underlying diseases rather than from the doctor’s action. But if death is a foreseeable consequence, then the clinical removal of a ventilator kills a patient (Brock 1993) just as surely as the removal of a regulator kills a deeply submerged scuba diver. The law of homicide already includes this special exception for doctors, and much of the ethical and legal discussion of death and dying turns on the patient’s legal and ethical power to refuse treatment, often through an advance directive and/or a legally authorized representative. While suffering can sometimes be averted by withdrawing life-support, this strategy is often unavailable and, moreover, the deaths caused by abating treatment may not be as tolerable as those that are induced. Nonetheless, it is nearly everywhere unlawful to administer medications for that purpose. Should this be changed?

Life-supporting treatment can also be withdrawn on the grounds that it no longer constitutes a benefit for the patient or, while it may be beneficial in some ways (prolonging life for a few additional days for example), the treatment is disproportionately harmful in other ways (painful or costly, for example). Doctors may be permitted to withdraw life support, causing death, on the grounds that continuing treatment would either be futile or harmful on balance: i.e., not “medically indicated.” Here as well death is caused by the withdrawal of treatment.

The third issue has to do with physician-assisted dying, now legalized in Oregon. Here a doctor provides the means to end life: commonly a prescription with special instructions. Note that the doctor does not take the final life-ending step. While the reasons given for physician assistance are somewhat similar to the arguments for euthanasia (considered just below in Section II), I shall not explore them here.

I will now examine the active causation of death when it is done for the benefit of the one killed. Should the law of homicide be amended to permit some beneficent killings? I will consider two types of case where the defense of euthanasia is perhaps the strongest. The more familiar one arises in connection with intractable suffering. The argument from intractable suffering, together with some objections, will be explored in Section II just below. The second argument, in Section III, arises in connection with forced abandonment. It is, if perhaps not a novel argument, at least one that is less familiar. It is proposed that this second argument is sound and that, legally and ethically, such acts of euthanasia ought to be excused.

II. The Argument from Intractable Suffering

The Standard Argument: Suffering commonly affects patients with progressive illness—metastatic cancer, multiple sclerosis, Huntington’s disease, etc. As Hippocrates put it, they are or soon will be “overmastered” by disease. While much of the euthanasia literature fixates on pain, the sufferings brought on by severe illness come in many flavors: dizziness, diarrhea, disfigurement, itching, insomnia, incontinence, exhaustion, strains upon relationships, shortness of breath, anxiety, cognitive impairment and dementia, debt, depression, disabilities of all kinds, dependency, loss of control, nausea, offensive odors, and the losses of dignity that can accompany these. These conditions are familiar to those who provide hospice care. Sometimes—but not always—symptoms can be managed while preserving positive elements that give value and richness to a waning life: talking with loved ones, listening to music, enjoying a sunset. But residual abilities too can succumb, even as a patient retains sensitivities that can make life intolerable.

One strategy is “terminal sedation.” Doctors can render a patient unconscious while withholding nutrition and hydration: death ensues in a matter of days. But not every patient would prefer such “care” to a timely passing. There is a broadly understood difference between having a life and being alive in the biological sense. It is the former—the life one has—that is often paramount for a patient. As with those trapped on 9/11, that life can come to an end before death occurs.

When a human life deteriorates to the point where one reasonably desires to end it, the argument for the permissibility of euthanasia can turn on autonomy: the ethical and legal power, within civic constraints, to chart the course of one’s own life, especially in areas where the stakes that others have in the choice are not as great as one’s own. The root political idea is that, provided there are no sound and proportional countervailing reasons, adults should enjoy the freedom to make their own decisions. The presumption ought properly to be in favor of liberty: here the liberty of informed, suffering, competent individuals to choose the manner and time of their death. In the face of intractable suffering and an expressed and settled preference for death, there are strong arguments (1) that voluntary euthanasia should be permitted in these cases and (2) that it is cruel to prohibit or condemn charitable assistance to those who are relevantly similar to the 9/11 co-worker in her wheelchair. Those who act out of courageous compassion in these cases are surely not the criminals we have in mind when we build prisons. Accordingly public policy should regulate, but not prohibit, voluntary euthanasia.

The Objections: Objections to the argument from intractable suffering focus on the proviso that there be “no sound and proportional countervailing reasons.” Here it is useful to distinguish between “yellow light” objections, urging caution, and “red light” objections, admonishing one to stop. While the former express concerns about the possibility of adverse consequences, the latter hold that euthanasia is impermissible on its face.

Many are the yellow-light objections. There is the alleged slippery slope down which we can slide to holocaust. Further, compassionate homicide might erode the professional commitments of physicians as well as our trust in doctors. (That might be a reason for barring the involvement of physicians.) There are the fears that patients will be depressed or pressured at the time of decision, that they may have been misdiagnosed, that haste in ending patients’ lives can prevent possible recoveries, that relatives and healthcare providers will conspire to end the lives of the ill, and that protective measures will be unequal to the task of preventing carelessness and misconduct. These objections can be definitively assessed only when we have determined (1) what protective measures we are talking about and (2) how these have worked in practice. Here we can usefully study the Oregon record, as it comes available, and the experience of the Dutch, the Belgians, and the Swiss. Unlike the Nazis, we can require our protocols to be implemented in the light of day. And even if some adverse consequences should occur following legalization, these would have to be measured carefully against the adverse consequences of prohibition.

Prematurity is a concern that permeates many of the yellow-light objections: worries that life-ending decisions will be unnecessarily rushed. If only there were enough time to confirm the diagnosis, to labor with patients about their decisions, to try out other strategies for alleviating discomfort or for stopping the progress of the disease, to await new treatments that might suddenly become available, to rule out depression or undue pressures on the part of friends and relatives....
In a disaster, there may not be enough to treat all patients who now seem too ready to let go of their lives might decide to hold on instead. Physicians have weighty duties to prevent the deaths of their patients or, failing that, to see them through the burdens of the dying process. When the death of another is a foreseen consequence, one wants to be sure there are no better options. Perhaps no one can ever be sure enough. There is here a venerable ideal of a certain type of therapeutic partnership between the vulnerable patient and the steadfast clinician. Even if a dying person is pleading for the relief that only death can promise, a clinician who kills a patient arguably betrays his or her commitment to that alliance.

Many of the red-light objections emerge from within discrete religious traditions. These sectarian counter-arguments often proceed from a premise that human life is, in some way, sacred, not to be discarded or taken; that euthanasia is, at bottom, a mortal sin. But in a pluralist society, the considerations that settle public issues ought to be ones that can, at least in principle, persuade any reasonable person: not just those who have embraced some preferred sectarian view. So if, for example, the closely related idea of human dignity can be given a secular interpretation—one that is both broadly persuasive and sufficiently weighty—and if the favored understanding of that idea mandates the continuation of medical care while precluding euthanasia, then it may be reasonable to keep the law of homicide as it is (Sulmasy 1994). Such arguments would have to be examined in detail (Dworkin 1993, 68-101 and 179-217).

No position is taken here on whether the argument from intractable suffering is sound or whether any of the listed objections constitute effective refutations. I now proceed to the second argument.

III. The Argument from Forced Abandonment

Disaster Triage: In a disaster, there may not be enough to go around. The number of patients who present at a hospital can significantly exceed its carrying capacity and, moreover, it may not be possible to transfer them to other regional medical centers. Plane crashes, explosions, epidemics, and the release of toxic gas: all of these (and others) can overwhelm the resources of a community’s hospitals.

Hospitals everywhere practice specialized procedures for these events. Disaster triage is the distinctive sorting method used in patient intake. Clinicians must narrow their attentions to patients who will probably live if treated but probably die if untreated. Using colored tags and rapid assessment techniques, they will set aside patients without life-threatening injuries (the “walking wounded”) and those who will likely die despite treatment. Patients in this last group—sometimes termed “expectant” and identified with black tags—are not abandoned. They receive ongoing comfort care (pain medications) and medical reassessments, especially if they unexpectedly survive the period of scarcity. On an ordinary day, the patients who are set aside to die would usually be treated aggressively, and many might survive. What would be a serious wound in a hospital with an un tapped surge capacity can become a fatal injury in a hospital coping with disaster.

These queuing procedures are intended to save the maximum number of lives. Because there is not enough to go around, it is imperative to avoid waste. Resources are wasted when they are expended on patients who are (1) likely to die even if they receive treatment (the black-tagged, most severely injured) or (2) likely to live even if treatment is withheld (the walking wounded, the least severely injured). But resources will be efficiently used if clinicians prioritize those who will live if treated but die if untreated, the group in the middle. And, within that subset, those who are both closest to death and most easily treated will receive medical attention first.

Notice that the reason for withholding life-prolonging treatment from black-tagged patients has nothing to do with intractable suffering nor with any decision these patients have made about having had enough. There is a dramatic shift in these situations from an individualized doctor-patient relationship to something more like a public health perspective, with attention refocused on the group rather than on the individuals making it up. Compassion and individualized commitment, so much the pride of everyday clinical practice, can cost lives during a disaster. A skilled emergency physician will complete a physical assessment in no more than 90 seconds. The colored tag is attached and it is on to the next patient. The goal is to have saved, at the end of the day, the maximum number of lives.

Catastrophe and Battlefield Euthanasia: In a medical disaster, the resources of a healthcare setting are overwhelmed. Triage helps to solve the problem. In contrast, a medical catastrophe occurs when a healthcare delivery system collapses (Kipnis 2003, 95-107). The hospital (or any setting where medical care has been provided) has somehow become hazardous to the point where all must relocate to safety. Though this may or may not have occurred at Memorial Medical Center, there are scenarios where this condition would be met. Here are three. (1) An earthquake and ongoing aftershocks have caused structural damage and are threatening to topple occupied sections of a now burning hospital. (2) Biological, chemical, or radiological agents have contaminated the buildings even while the clinical staff are unprepared to protect themselves. And (3) a deadly epidemic is fueling riots by angry mobs who believe that essential supplies are being hoarded inside. In all three cases, clinicians and patients are present in the hospital and, for different reasons, it is not safe for them to remain.

The argument from forced abandonment arises against the background of a medical catastrophe: the collapse of a healthcare delivery system. It becomes applicable when, in addition, it is impossible to evacuate black-tagged patients and impossible to remain with them. While rare, such conditions are more familiar in battlefield medicine. In his World War II personal narrative, The Road Past Mandalay, John Masters recounts one such episode (Masters 1979, 277-78). Commanding a British unit in Burma, he and 2,000 of his men are being forced to retreat by a fresher and better equipped Japanese force. A doctor has summoned him.

The stretchers lay in the path itself, and in each stretcher lay a soldier of 111 Brigade. The first man was quite naked and a shell had removed the entire contents of his stomach. Between his chest and pelvis there was a bloody hollow, behind it his spine. Another had no legs and no hips, his trunk ending just below the waist. A third had no left arm, shoulder or breast, all torn away in one piece.... Nineteen men lay there. A few conscious. At least, their eyes moved, but without light in them.

The doctor said, “I’ve got another thirty on ahead, who can be saved, if we can carry them.... These men have no chance.... None can last another two hours, at the outside.”....

I said aloud, “Very well. I don’t want them to see any Japanese.” ...Shells and bombs burst on the slope above and bullets clattered and whined overhead.

“Do you think I want to do it?” the doctor cried in helpless anger. ""We can’t spare any more morphia."
“Give it to those whose eyes are open,” I said. “Get the stretcher bearers on at once. Five minutes.”

He nodded and I went back up to the ridge, for the last time. One by one, carbine shots exploded curtly behind me. I put my hands to my ears but nothing could shut out the sound.

There are several features that are worth noticing in this description.

1. There is, in the background, a medical disaster. The nineteen men who can no longer be saved have, in effect, been black-tagged but not abandoned. They are receiving narcotics and, with difficulty, are being evacuated. The medical objective is to save as many lives as possible and to ensure that even the most severely injured receive care and attention that is appropriate under the circumstances.

2. The moving British unit is attempting to carry out an organized retreat from an attacking Japanese force. Their lives depend on the execution of this difficult maneuver. Whatever semblance of a clinic that existed before the retreat began, nothing is left of it now. A medical catastrophe has occurred.

3. It appears to be impossible to evacuate the black-tagged patients without risking the lives of thirty less severely wounded soldiers. One supposes that further casualties would be expected if the retreat were interrupted.

4. It is not possible for the doctor to remain behind with the black-tagged patients. Were he to do this, it would be a culpable abandonment of the other wounded soldiers in the unit. He would likely be captured or killed by the advancing Japanese and he has weighty duties not to let either of these happen.

5. It appears to be unacceptable to abandon the black-tagged patients to capture by the Japanese. Perhaps it is believed that they will be mistreated; or that they will not be provided with appropriate medical attention during their remaining hours; or that, grievously wounded and left alone to die, they will endure deaths that human beings should be spared, if possible, by those caring for them. The officer may also appreciate what he would be required to do with Japanese wounded were the situation reversed.

6. Though neither the doctor nor the officer says so, it is evident that the issue is whether to euthanize the gravely injured soldiers before moving on. It is striking that the two men are not deliberating. Their common purpose seems rather to confirm the inevitability of a profoundly unwelcome choice.

The Question from Katrina: I can now address the question with which we began: Can the conditions in a collapsing healthcare delivery system ever excuse euthanasia? As on the battlefield, healthcare professionals and their patients, during massive civilian disasters like Katrina, can also be compelled to evacuate. Should it prove impossible to relocate the black-tagged patients, healthcare professionals will have only three choices: (1) they can remain with their patients, (2) they can leave them behind, or (3) they can euthanize them before leaving themselves (Swann 1987).

The first option, remaining with the black-tagged patients, tests the commitments of physicians, nurses, and others. While the obligations that clinicians have to their patients are weighty, it would be hard to defend the proposition that they are absolute: to be honored regardless of the costs to the caregivers and to others with competing claims. To be sure, the continuing presence of healthcare professionals may extend somewhat the lives of dying patients, may make the dying process more endurable, and may express a community’s commitment to respect the dignity of those in the greatest need. But whatever the sources and the weight of the duty to remain with patients, it is an open question what burdens healthcare providers must shoulder in order to fulfill this professional obligation, and what expectations others (clinician’s families, other patients) must forfeit. A catastrophic collapse of a healthcare system can require doctors and nurses to work without proper equipment in uncontrolled environments; without adequate food, water, or sleep; and amidst hazards that threaten their own lives and health. What they can accomplish by remaining may be precious little and far less than what they might do elsewhere. At some point they may have done everything required of them.

There appear to be two distinct justifications for setting a limit to the obligation to remain with patients where leaving them would constitute abandonment. In the first place are unreasonable personal burdens that healthcare professionals and their families would have to take on were they to remain. Family members and others may also suffer significant derivative loss. In the second place are competing professional obligations. As with the doctor in the Burma narrative, other patients may have weightier claims than the black-tagged patients. In a disaster, allocation rightly shifts resources to where they can do the most good. Accordingly, any decision to remain with victims who are beyond saving may violate weightier obligations to attend to salvageable patients in urgent need of vital care. For these reasons, I will assume in what follows that the prohibition on abandoning patients cannot be absolute.

One other consideration is worth mentioning. Consider the risks routinely taken by fire fighters, soldiers, and police officers. Notice that the community helps them do their jobs in reasonable safety. Fire fighters receive breathing equipment and protective clothing. The burden of remaining at one’s station despite hazards does not fall solely on their shoulders. Society must support essential services if it is to expect men and women to act heroically when the need arises. Now whatever the social obligation of fire fighters to enter burning buildings, it is arguably diminished when a community fails to provide protective equipment and other forms of support. Likewise, if a community expects healthcare professionals to remain steadfast during a catastrophe, it must be prepared to support them through the darkest hours, so they can keep at their work while protecting themselves. But when healthcare professionals are abandoned by the communities they serve, the duty to brave hazards may be attenuated.

So if, as I have argued, there is a line delimiting where there is no duty to remain, and if it is reasonable to judge that it has been crossed, healthcare professionals could conclude that they were at liberty to leave. But having chosen to leave, clinicians would then face a second dilemma: either abandon the black-tagged patients to die unmedicated and unattended, or euthanize them before leaving themselves. There is no third option.

Two of the weightiest medical norms are here in collision: the prohibition against abandoning patients and the prohibition against killing them. Where it is impossible to evacuate patients and dangerous and medically futile to remain with them, one of these two norms must give way.

In the professions of medicine and nursing, there is a broad consensus on the twin issues of non-abandonment and euthanasia. While euthanasia has been heavily contested in the professional literatures, that is less so of non-abandonment.
Loyalty and fidelity to patients and clients are commonly invoked as core professional values. Patients and clinicians stand in a fiduciary relationship. At the center is trust on the part of the patient and a reciprocal commitment to be worthy of that trust on the part of the clinician. Accordingly, it is a serious matter for a doctor to “fire” a patient: for non-payment of bills or for imposing unnecessary risks on staff and other patients. Physicians are well advised to give notice in writing, and with ample time for the patient to obtain the services of another caregiver. Likewise nurses know that they may not leave their units if there aren’t enough staff to care for the patients. While leaving a gravely ill patient alone, to die unattended and unmedicated, would be a paradigmatic violation of professional ethics—an egregious betrayal of loyalty—the pertinent principles were not conceived in the light of medical catastrophe.

Along with abandonment, euthanasia is also commonly prohibited by authoritative professional standards.

Facing the Dilemma: To fix ideas, let us restrict our focus to cases that arise only under the following three conditions.

1. The care setting has become hazardous to the point where clinicians are no longer under a duty to remain.
2. The patients who are being attended in the care setting are not expected to survive with the treatments that are available there. Nor is it expected that supplemental clinical resources will become available in time to improve their prognosis.
3. It is not possible to evacuate these patients.

There are at least three considerations that support excusing euthanasia under these specific circumstances.

1. Clinicians who abandon the care setting early, leaving others to take up the common burden, are able to sidestep the problem. Only the clinicians who stay on to the last will have to choose which of the two medical norms they will betray. To charge these men and women with criminal or professional misconduct would be (1) to discourage or punish the very heroism they earlier displayed by remaining at their posts despite the hazards, and (2) to encourage early desertion as a way of avoiding censure. Taken together, these pragmatic considerations amount to a powerful justification for withholding condemnation.

2. Earlier, in Section II, I reviewed certain “yellow-light” objections based on prematurity. I noted that steadfast clinicians might refrain from ending the lives of intrinsically suffering patients out of a worry that such an irrevocable step would be premature—other strategies might still be tried. But forced abandonment puts a full stop to such reflection. Once the patient is unattended, no further care can be on offer. When the only other option is to abandon the patient (no care at all), it may be that the best treatment would be one that beneficently and painlessly ends life. The euthanizing of black-tagged patients under conditions 1-3 above may represent “appropriate care under the circumstances”: the “least-worst” option. On this argument, forced abandonment would justify euthanasia rather than merely excuse it. Not only would it be a reasonable choice: it would be the right choice.

3. But even if it could not be shown that euthanasia is the preferred option, faced with the forced choice, it remains that neither option is plainly the wrong one. The ethics literature does not authoritatively prioritize the prohibitions on abandonment and euthanasia when circumstances dictate that one of the two must give way. The two norms seem always to be considered independently, perhaps because it is not imagined that they can conflict. Clinicians who are forced to choose between the two are therefore not in violation of professional ethics, considered as a whole. So if it cannot be maintained that a clinician made the wrong choice under the circumstances, there is no basis for condemnation. Notwithstanding the violation of a weighty norm, the offense, if there is one, should be excused. The circumstances forced a choice between two weighty norms, one of which had to be violated. In the absence of an accepted priority rule, neither choice should be condemned, and either choice should be excused.

Were one to apply this standard to the events at MMC, here are the questions that would have to be addressed.

1. Did the conditions that followed Katrina require the evacuation of the hospital?
   A positive answer to this question might establish that the clinical staff was no longer required to remain in the hospital.
2. Were the remaining patients likely to die despite the best effort that might be made with the staffing and resources then available in the hospital? Was it reasonable to believe that supplemental clinical resources would not arrive in time to improve their prognoses?
   A positive answer to these questions would establish that the patients were not expected to survive.
3. Was it reasonable to believe that rescue efforts to evacuate the remaining patients would not arrive in time to improve their prognoses?
   A positive answer to this question would establish that the remaining patients were not expected to be evacuated.

Where all three conditions are satisfied, clinicians must choose between abandoning their patients or euthanizing them before leaving themselves. Paradoxically, it is precisely because each of the two options stands as an egregious violation of an important healthcare norm, and because there is no third option, that neither violation can be rightly condemned. We can only have compassion for those who had to face the forced choice.\(^6\)

If my analysis of the issue is correct and if, in the end, it turns out to be applicable to the events at Memorial Medical Center, then, as a matter of professional ethics and law, what clinicians did or did not do during the darkest hours of the New Orleans catastrophe might not be consequential. To be sure, patients suffered and certainly some died. And we can imagine a small number of clinicians, tired, overworked, despondent about the lack of support, having to make one of the most painful and vexing moral decisions human life can force upon anyone. We can imagine clinicians reasonably concluding that their hospital has become hazardous, that their patients cannot be evacuated nor are they expected to survive, and that no one is coming to help. We can imagine clinicians telling any patients who were still alert enough to understand:

Because of the disaster, we can neither keep you alive for very long nor can we move you to a safer location. This hospital has become dangerous and help is not on the way. The staff must evacuate. We can leave you as you are, hoping for the best but realistically expecting
something quite bad. Or we can provide you with drugs that will put you into a deep sleep from which you will never awaken. You can make the choice to die soon, with us still here with you, rather than after we have gone. We have no other option to offer. Please help us to make this decision.

While the argument from forced abandonment may have a broadly understood application on the battlefield, its requisite conditions are exceedingly rare in civilian settings. If the conditions were satisfied at MMC, that event might be one of only a handful where a civilian healthcare institution collapsed catastrophically. It should not be a worry that the decision to excuse euthanasia in these extremely rare circumstances will lead inexorably to the Nazi gas chambers.

The problem of euthanasia arises in externis. In one case, the life of a suffering person approaches a ruinous and horrific end. In a second, rarer, and less studied case, a collapsing healthcare system is unable to minister to the most grievously afflicted. It can be distressing to ponder what it might be like when such important matters go so dreadfully awry, and difficult to discern professional responsibilities when they do.

But these tragedies do befall us, challenging our capacities to craft decent and just social practices, and to act rightly out of charity, compassion, and respect.

Endnotes

I am grateful to Leanne Logan, Rosamond Rhodes, Michael Gross, Edmund G. Howe, and Thomas P. Gonsoulin for suggestions that have improved this essay. Most of all, I am indebted to Peggy Battin for her generous comradeship and counsel as this project unfolded. Some of these materials were drawn from an earlier article on “Euthanasia” that I prepared for The Encyclopedia of Social Problems (Sage, forthcoming).

1. The seventh floor of MMC had been leased by LifeCare Hospital. A separate hospital within a hospital, LifeCare patients were among the most gravely ill in the building (Deichmann 2006, 64-65).

2. My sketch of these well-reported events is drawn from hundreds of sources, the most important of which were reports in the New Orleans Times-Picayune and the New York Times. Jeffrey Meitrodt’s five-part series in the Times-Picayune—“For Dear Life: How hope turned to despair at Memorial Medical Center”—offers an excellent overview. (Meitrodt 2006). MMC’s chief of medicine has written a first-person narrative of his experience during the episode (Deichman 2006).

3. If it is permissible, under the circumstances, to do some thing one oneself (leaping to one’s death from a World Trade Center window), one must ask why it would not, by implication, be equally permissible to lend assistance to another who reliably and reasonably desires to do that same thing, but is physically unable to do so? While I believe this issue is worth pursuing, I will pass over it here.

4. Among the many proponents of this highly influential idea are John Stuart Mill (Mill 1985), John Rawls (Rawls 1989), and Joel Feinberg (Feinberg 1987).

5. The issues here are well explored in John Rawls’ Political Liberalism (Rawls 1993, 35-40, and 133-72).

6. It would be still be appropriate to condemn others who, in various ways, allowed or caused conditions to deteriorate to a point where only those two unwelcome options remained.

References


Oaths and Ethics in Medical School

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During medical school graduation this year, our dean asked the students to stand in front of family, friends, and faculty and recite the Oath of Hippocrates. The “brand name” of the Hippocratic Oath persists despite the fact that virtually no one has taken that oath in the last 2,500 years. Even in its own time, it was scarcely known, yet the students stood and recited a text as asked. In fact, they were professing not the Hippocratic Oath but the much better Declaration of Geneva. The Hippocratic Oath carries significant moral cachet but has, in fact, limited value in contemporary medicine.

For example, in its original version the Hippocratic Oath invokes Apollo, Hygieia, Panacea, and other deities as its guarantors, but the temples of these long-forsaken deities are entirely empty. Across the centuries, some commentators have tried to preserve the Oath by editing out elements that did not resonate with the times. For example, after antiseptic techniques paved the way to cut safely into human bodies, the Oath’s admonition against surgery appeared senseless. No one seriously believes anymore—if they ever did—that physicians-in-training should financially support their teachers who fall on hard times. Contemporary proponents of abortion and physician-assisted death must also reject the Oath’s prohibitions of those practices. A redacted Hippocratic Oath accommodating current day sensibilities would scarcely resemble the original.

For reasons like these, medical schools in the United States bypass the Hippocratic Oath in favor of other oaths, usually the World Medical Association’s (W.M.A.) Declaration of Geneva. Written in the aftermath of World War II and especially in reaction to the horrors of Nazi and Imperial Japanese biomedical atrocities, this 1948 Declaration sets forth an unflinching standard of professional responsibility. Physicians swearing the Declaration pledge, among other things, not to let race, religion, nationality, party politics, and social standing compromise their medical duties.

Even though an international array of physicians helped forge these professional promises after unparalleled lapses in
medical ethics, the Declaration has needed improvement. In fact, the W.M.A. has introduced changes to the text five times since its original formulation, most recently in 2006, when it added sexual orientation to the list of considerations that should not interfere with a physician’s duty toward patients. Even though this change expands an already-long list of professional duties, the inclusion of sexual orientation in this statement of professional aspirations is an important ethical advance.

When same-sex couples routinely appear in newspaper wedding and civil union announcements and a number of jurisdictions have adopted non-discrimination statutes, things may appear rosy enough for gay, lesbian, and bisexual people in the United States. Yet around the world, sexual minorities do not enjoy uncompromised social standing, and the implications of that second-class status are menacing. The president of Zimbabwe, for example, has tried to ban rallies of gay people and uses epithets against gay people whenever it suits his political purpose. Physicians and other healthcare professionals can hardly pursue the unique healthcare needs of patients who must remain hidden in the name of their self-protection. Even in the United States, gay and lesbians sometimes shy away from health care, worried that they may encounter misunderstanding and disapproval. Robust non-discrimination standards in medical ethics can do their part to mitigate these effects wherever they occur.

By contrast, sexual orientation comes into play in the Hippocratic Oath in a markedly different way: physicians pledge not to have sex with patients or members of their household, male or female for reasons of professional decorum—not to do so, their bisexual interests notwithstanding. But look where we are: discussing the standards of professional conduct as they play out in the Declaration of Geneva and the Hippocratic Oath. Graduation ceremonies simply do not offer opportunities for important discussion like this, and neither are they very good at imparting ethics lessons capable of lasting a lifetime. When not bogged down by musty ritual and pretentious speeches, graduations do better as rituals of well wishes and fond farewells. Unfortunately, some medical students encounter the oath whose recitation admits them—morally speaking—into the medical profession only at this very last educational moment. This same problem can occur at the onset of medical education too because many schools now integrate oaths into “white coat” ceremonies that inaugurate students into medical education. When put on the spot to recite an oath, students can certainly pick and choose what words they want to say aloud and thereby preserve some degree of choice in the commitments they make. They can even make mental reservations about what they are saying aloud—demurrals under their moral breath so to speak—but picking through a medical oath like a salad bar leaves much to be desired.

If medical schools use an oath once, they should use it twice: first as a text for discussion and only then as a public profession. Asking graduating medical students to swear an oath not to have sex with patients or members of their household, male or female for reasons of professional decorum—not to do so, their bisexual interests notwithstanding. But look where we are: discussing the standards of professional conduct as they play out in the Declaration of Geneva and the Hippocratic Oath. Graduation ceremonies simply do not offer opportunities for important discussion like this, and neither are they very good at imparting ethics lessons capable of lasting a lifetime. When not bogged down by musty ritual and pretentious speeches, graduations do better as rituals of well wishes and fond farewells. Unfortunately, some medical students encounter the oath whose recitation admits them—morally speaking—into the medical profession only at this very last educational moment. This same problem can occur at the onset of medical education too because many schools now integrate oaths into “white coat” ceremonies that inaugurate students into medical education. When put on the spot to recite an oath, students can certainly pick and choose what words they want to say aloud and thereby preserve some degree of choice in the commitments they make. They can even make mental reservations about what they are saying aloud—demurrals under their moral breath so to speak—but picking through a medical oath like a salad bar leaves much to be desired.

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II. The Professional Consensus

An assumption underlying the professional consensus is that predictive genetic testing of children should be undertaken when it is in their best interest, but not otherwise, even if parents request it. Testing may be best for them because useful means of prevention or treatment exist, such as medications, dietary interventions, or surveillance for complications. For example, it would be important to test children for the adult-onset disease polycystic kidney disease because if the test is positive it is crucial to monitor and control their blood pressure.

In contrast, testing should generally not be done on healthy children for late-onset conditions when no useful means of treatment or prevention interventions exist. Exceptions might be made for some clear and compelling reasons, such as parents mistakenly viewing their child’s behavior as symptomatic of Huntington’s disease (Fryer 2000). Absent good reasons, it is more beneficial to children to wait and let them decide if they want testing when they are competent to do so.

Around the world, many organizations adopt this consensus and its reliance on the Best Interests Standard. For example, the authors of “Guidelines for Genetic Testing” by the Japan Society of Human Genetics explicitly identify the “best interest of the subject” as the basis for their policy:

If a surrogate representative makes the decision, because the subject is deemed to be unable to exercise autonomous decision-making, a decision for genetic testing must be made that protects the best interests of the subject. Therefore, the testing of children for adult-onset genetic disease that have no effective treatment or means of prevention should be avoided. (Stress added. Matsuda et al. 2000, Recommendation 8)

The American Medical Association’s Council on Ethical and Judicial Affairs (CEJA) also recommends against testing unless it can be justified as being useful to the child, something CEJA regards as difficult to demonstrate where no treatments or prevention strategies exist (CEJA 2007). The American Academy of Pediatrics’ Committee on Bioethics (AAP 2005) and the Canadian Paediatric Society (2003) also ground their support for the professional consensus on what is best for the child. The Working party of the Clinical Genetics Society in the U.K. also agrees that predictive testing of children must not be done unless it is useful to them.

Further evidence of the widespread support for the professional consensus may be found in a comprehensive review of ethical and clinical position papers and guidelines from 1991-2005. P. Borry and colleagues (2006) undertook an analysis of 31 organizations and reported:

The main justification for presymptomatic and predictive genetic testing was direct benefit to the minor through either medical intervention or preventive measures. If there was no urgent medical reason, all guidelines recommended postponing testing until the child could consent to testing as a competent adolescent or as an adult. (Borry et al. 2006, 374)

In addition, there is evidence that few laboratories are willing to test children for un treatable, severe late-onset genetic diseases (Wertz and Reilly 1997). Most minors tested are carefully screened adolescents who are able to participate responsibly in decisions about testing (Duncan et al. 2005).

Critics who reject the professional consensus generally agree with defenders that policy should reflect what is best for children (Cohen 1998; Rhodes 2006; Pelias 2006). They argue, however, that testing young children is often useful and affirm parental authority to decide what is best for their own children. They point out that parents often have to balance the interests of one person with those of other family members. There can be, of course, an important difference between the best interests of an individual child and the best interests of the family when it comes to many matters, including predictive genetic testing.

Agreement among critics and defenders about the relevance of seeking what is best for a minor offers an opportunity to evaluate their incompatible positions from the perspective of the Best Interests Standard. In doing so, the discussion will focus on predictive testing for two late-onset, neurologically and psychologically devastating diseases, Huntington’s disease and early-onset Alzheimer’s disease. Predictive testing for Huntington’s disease is accurate and children of affected individuals have a 50 percent chance of getting the disease. Early-onset Alzheimer’s disease also may be predicted with considerable accuracy. Analysis of the Best Interests Standard is given in the next section and applied to this debate about predictive genetic testing for children in those that follow.

III. The Best Interests Standard

The Best Interests Standard is a widely-recognized guidance principle for decision makers to use in making choices for children and other persons who lack capacity to make decisions. For example, the United Nations writes:

Article 3: In all actions concerning children, whether undertaken by public or private social welfare institutions, courts of law, administrative authorities or legislative bodies, the best interests of the child shall be a primary consideration.

Recently, the Maryland Appellate Court wrote, “We have long stressed that the ‘best interests of the child’ is the overriding concern of this Court in matters relating to children...” (Grimes 2001, 852-3).

Many important policies also recommend using the Best Interests Standard in making decisions for others including the Institute of Medicine in setting research policy for children (2004) and The President’s Council in selecting care for the non-autonomous elderly (2005).

The Best Interests Standard is an “umbrella concept” because it unites under one principle different meanings and uses about how to make good decisions for those lacking decision-making capacity. It is sometimes employed to express goals about what is ideal and sometimes to make practical judgments about what is reasonable given the circumstances.

In saying, “it is in the best interest of every child to have good health care,” it is being used to express an ideal or goal. This usage is different from applying it to make practical decisions, where it may be impossible to provide what is ideal. It might be best for a child to have a kidney transplant, but may be reasonable and necessary to use dialysis if no kidney is available for transplant. While practical decisions using the Best Interests Standard should be informed by appropriate goals, their purpose is to find good and reasonable options, which are often less than perfect.

The Best Interests Standard was introduced into medical, moral, research, legal, and other discourse to gain some protection of the interests of persons lacking decision-making capacity independent of the wishes of their guardians, not to get them “the best” by ignoring everyone else’s interests. In its practical uses, it does not require that everyone have “the best” since this would be incoherent or self-defeating.
In medicine, clinicians may decide it would be ideal to test all children for every treatable genetic disease, but if tests are expensive and resources scarce, they may justifiably decide to test only those at higher risk of getting the disease. Nor does this standard require that everyone else’s interest, needs, duties, or allocation plans be ignored. Rather, when we look at how this standard is used to make practical decisions, it calls for a good and reasonable choice to be selected from available options.

When the Best Interests Standard is understood in terms of how it is used, it is no more vague or likely to be abused than other guidance principles. It is more than someone’s intuitions about how to rank benefits and hazards for others. Rather, this standard sits in a web of moral, legal, medical, or social factors about duties to people who cannot make decisions for themselves, including policies about abuse and neglect, custody determinations, children’s rights, parental obligations, professional duties, practice guidelines, legal precedents, and acceptable thresholds of care.

The Best Interests Standard is neither an entirely objective nor an entirely subjective principle, but has features of both. Judgments about what decisions are best for others have “subjective” features in the sense that they are, in part, shaped by the decision-makers’ values, views, and perceptions about what is best. Some parents believe it is best for them to ignore the prevalence of late-onset disorders in their family while others prefer to discuss the matter with young family members.

The Best Interests Standard also has “objective” features in the sense that judgments about what is best for others should be shaped by sound scientific, logical, and medical analyses, predictions, and judgments as well as well-considered policies about what constitutes acceptable care, abuse, and neglect. A father may sincerely believe it is best to use prayer alone to treat his child’s cystic fibrosis but his judgment about what is best should be challenged. He can lose custody temporarily or permanently and the courts will decide what option is best (Kraus 1986; Kopelman 1997). Obviously there is a gap between what parental decisions are barely “good enough” from a legal perspective and what is optimal or recommended by professional groups.

The Best Interests Standard when used as a practical guide for decision makers should, I have argued elsewhere, be analyzed in terms of three necessary and jointly sufficient features (Kopelman 2005; 2007; 2008). This analysis is intended to reflect its practical uses, including how it is used in many professional, moral, or legal circumstances.

1. First, decision makers should use the best available information to assess the incompetent or incapacitated person’s immediate and long-term interests and set as their prima facie duty that option (or from among those options) that maximizes the person’s overall or long-term benefits and minimizes burdens.

2. Second, decision makers should make choices for the incompetent or incapacitated person that must at least meet a minimum threshold of acceptable care; what is at least good enough is usually judged in relation to what reasonable and informed persons of good will would regard to be acceptable, were they in the person’s circumstances.

3. Third, decision makers should make choices compatible with moral and legal duties to incompetent or incapacitated individuals (those unable to make decisions for themselves).

IV. Using the Best Interests Standard

In the next sections, I will apply these three features of the Best Interests Standard to the controversy over predictive testing for children and argue this offers a powerful way to settle disputes about what is best for those unable to make decisions for themselves.

How to Rank Burdens and Benefits

The first necessary condition of the Best Interests Standard (see above) concerns assessing potential benefits and risks on behalf of incompetent or incapacitated persons. We generally agree about what things are good, better, or best in life; it is good for children to have proper medical care and an open future with greater rather than fewer opportunities; we agree that it is best to live a long life free of pain and suffering and full of pleasure and accomplishments; we agree it is good to learn to do what is socially beneficial and to help our families.

For example, because it is clearly beneficial, parents and clinicians would be negligent not to test a child showing symptoms of a genetic disease. In other cases, reasonable and informed people of good will may disagree about how to maximize benefits and minimize burdens because they differ about the relevant values to use, the salient information, or how to rank potential benefits and risks (including their nature, probability, and magnitude).

In the case of the debate over the professional consensus, defenders and critics cite similar potential benefits and risks, but disagree about how to rank them. Potential benefits of finding a faulty gene(s) include that persons will have more information to make informed choices about life plans including reproduction, marriage, career, financial management, medical treatment, and end-of-life options. Greater information and openness within families may help children adjust to the diagnosis early in life (Fryer 2000; Rhodes 2006).

They also agree about the likely benefits of a test showing the presence of the faulty gene(s). This result would likely be a great comfort to many, relieve their anxiety in waiting for early signs, let people plan their lives differently, and avoid clinical monitoring or irrational identification (pre-selection) of a family member as faded to have the illness.

There are potential risks even of testing negatively, however, about which they agree. Family members may reject or resent the child who is spared the faulty gene(s) or have a false assurance that she is entirely healthy. The person is also at risk for having “survivor guilt” (Meiser and Dunn 2000).

Finally, they agree risks exist if a positive result for a late-onset genetic disease is found, which include: parents may feel guilt, reject the child, confirm irrational beliefs about who will have the illness (pre-selection), or see him as more vulnerable than he really is. Risks to the child of finding the faulty gene(s) include low self-esteem, stigmatization, anxiety, or depression. Critics and defenders are also concerned about whether parental attitudes to the child will change. In addition both are aware of the social, economic, and personal hazards to the child once information about a positive result exists, including discrimination in employment or insurance. Table 1 summarizes many of the potential benefits and risks to testing.

The controversy among defenders and critics about the professional consensus seems mired in competing intuitions about how best to rank these potential benefits and risks of predictive testing for children. Defenders argue that the potential benefits of such testing are speculative, while the risks are substantial. Critics argue defenders minimize benefits and cite hazards for which there is little evidence. In the remainder of this section, I consider arguments about how to rank these agreed upon potential benefits and risks, arguing they offer...
Table 1. Possible psychological benefits and dangers from childhood testing (Fryer 2000, p. 284)\(^6\)

<table>
<thead>
<tr>
<th>Result</th>
<th>Possible Danger</th>
<th>Possible Benefits</th>
</tr>
</thead>
<tbody>
<tr>
<td>Faulty gene absent</td>
<td>Rejection by family affected</td>
<td>Avoid clinical monitoring</td>
</tr>
<tr>
<td></td>
<td>False reassurance about health status</td>
<td>Emotional relief</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Ability to plan life</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Avoids effects of later disclosure</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Avoids “preselection” [irrational views about who is destined to have the disease]</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Relieves anxiety about possible early signs of this disorder</td>
</tr>
<tr>
<td>Faulty gene present</td>
<td>Impair child’s self esteem</td>
<td>Child has time to adjust—avoids emotional problems of later disclosure</td>
</tr>
<tr>
<td></td>
<td>Impair child’s long-term adjustments</td>
<td>Enables parents to prepare child psychologically for the future, e.g., education, career, housing, etc.</td>
</tr>
<tr>
<td></td>
<td>Impair relationship with parents (post-test changes in parental attitudes)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Stigmatization/overprotection</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Discrimination in education, employment, insurance, mortgage</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Impair relationships with future partners</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Removes autonomy to decline testing</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Confirms any “preselection” [irrational views about who is destined to have the disease]</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Could generate anxiety about early symptoms</td>
<td></td>
</tr>
</tbody>
</table>

support for the ranking given by defenders of the professional consensus.

1. Honesty and Openness

A dispute exists over how best to promote frankness and forthrightness. Some critics of the professional consensus use an argument from analogy to conclude testing children for untreatable late-onset diseases of children and informing them of results would promote these values.\(^8\) A substantial body of evidence exists that properly informed children cope better with information about their serious illnesses and even impending death than those who are not informed. The failure to be candid about what is known by others isolates them from important support that discussions might bring. Thus, the argument goes, if children who are informed of their serious diseases or impending death do better than those who are not told, then children at risk of serious genetic diseases later in life would probably do better as well.

There are, however, problems with this argument from analogy since several important differences among these groups exist. First, the groups differ because one group is sick and the other healthy. When children face death, disabilities, or serious illness, they know something is wrong and suffer more because they sense they are not being told something important (Bluebond-Langner 1978). In contrast, the other group is healthy and without genetic testing, no one has the results; so the conditions for the isolating and destructive effects of secrecy are not present.

Second, the professional consensus cannot be faulted for proposing a lack of candor because it encourages age-appropriate and open discussions among all family members, including children, about genetic diseases.\(^9\) Parents can reinforce the idea that being at risk for a disease does not define the whole of someone’s life. This gives minors under 18 years of age opportunities to think in general ways about the illness in their family, future plans, possible discrimination, reproductive options, career choices, economic risks of testing, etc.; they can decide for themselves if they want testing at 18 years of age.

Evidence about the benefits of informing children of their serious illnesses, disabilities, or impending death, then, does not seem to support the judgment that similar benefits would accrue to healthy children tested for serious, adult-onset diseases for which there are no interventions. Thus this attack on the professional consensus’ ranking potential benefits and risks fails.

2. Clinical Judgment

The professional consensus against testing children for severe, untreatable, late-onset diseases such as Huntington’s and Alzheimer’s relies to some degree on clinical judgment. Because so little testing of children for these diseases has been done, the professional consensus is not based on studies comparing outcomes for children who are tested and informed and those who are not. Rather, it is based on clinicians’ experiences with people who have these maladies and their abilities to identify conflict of interest, bias, and other factors that may distort people’s reasoning when requesting this testing for their children.\(^10\)

Some parents of minors who want testing, however, might agree the clinicians know more about most cases but claim to better understand the special features of their own case. Other critics respond that clinicians are mistaken and that testing for children should be encouraged (Rhodes 2006).

In response clinicians may point out that the economic basis for professions is the “selling” of competent and unbiased information by members who are committed to acting in people’s best interests. Professionals belong to societies that have special privileges and duties to ensure members are competent and act as they should. Clinicians “sell” the public (patients) their informed and good judgments and recommendations (get surgery, use steroids, etc.) and services. In contrast, “let the buyer beware” serves as the typical approach one should expect in non-professional, “market” driven situations. Clinicians, geneticists, genetic counselors, and their professional organizations have an economic interest in “selling” their services, so their recommendations against their use are unbiased.

Moreover, other evidence exists that the professional consensus for children is evenhanded because it is consistent with recommendations for adults. The Huntington’s Disease Society of American (1996) recommends against testing for anyone who cannot decide for himself, unless there are special reasons to do so, such as the person is showing symptoms. The American Geriatric Society (AGS) writes:

At the present time, the role of genetic testing for the prevention, diagnosis, and treatment of late-onset disorders is uncertain. Until further information is available to clearly define the benefits of genetic testing for condition such as Alzheimer’s disease, physicians should not routinely order genetic tests for late-onset disorders mentioned above. (AGS 2001, 225).
Thus the professional consensus’ ranking of potential benefits and risks for children seems evenhanded and consistent with recommendations for adults. There is, however, another consideration regarding the benefits of preserving an open future for children.

3. Open Future

Defenders and critics disagree about whether testing and informing children of the results promotes the child’s open future. Joel Feinberg (1980) and Dena Davis (1997) argue that parents should not close off possibilities for their child, such as having them sterilized or denying them life-saving blood transfusions. According to the professional consensus when parents test their child for adult-onset diseases such as Huntington’s disease or Alzheimer’s disease, they unjustifiably limit the child’s options. Delay does not cause medical harm to children and by preserving their open future, we let them decide for themselves if they want predictive testing at a later time.

Critics may respond that predictive testing could enhance children’s open future if they shape their choices in light of their special risks. Many decisions can be put off until the person can consent, such as reproductive decisions, but some cannot and learning of adult risk early in life may help them make rational decisions. A girl might decide to become a gymnast because skills peak early and this would not interfere with an adult-onset disease; a boy might decide to take the longed-for adventure earlier in life rather than later. Sufficient information for such plans, however, might be available if parents openly discussed the genetic diseases in their family. Yet Rosamond Rhodes contends that “…pediatricians should encourage parents to pursue genetic testing of children at a young age” (Rhodes 2006, 609). “Putting off testing until the child reaches adolescence can also be expected to have a negative impact on the child. The delay amplifies the dread…” (Rhodes 2006, 614). She argues that advocates of what I call the professional consensus minimize the harms of living with uncertainty and the benefits of allowing families to plan for family members’ predicted future disabilities. Cynthia Cohen (1998) argues that defenders have overestimated the risks or underestimated the potential benefits of testing.

This attack on the professional consensus is undercut by two considerations, or so I will argue. First, most adults do not want testing when it is offered and second, serious concerns exist about discrimination once testing produces information about positive results for diseases like Parkinson’s and early-onset Alzheimer’s disease.

First, studies consistently show that only 10-20 percent of at-risk adults want testing for late-onset diseases when asked (Meiser et al. 2000; Lerman et al. 1996; Chapman 1992). In a comprehensive survey of the psychological impact of genetic testing on adults for Huntington’s disease, Meiser and Dunn (2000) report:

About 10-20% of people at risk request testing when approached by registries or testing centres. Most of the evidence suggests that non-carriers and carriers differ significantly in terms of short term, but not long term, general psychological distress. Adjustment to results was found to depend more on psychological adjustment before testing than the testing itself. … There is evidence that people who choose to be tested are psychologically selected for favorable responses to testing. (Meiser et al. 2000, 574)

Arguing by analogy this suggests that given the opportunity, 80-90 percent of children at risk for genetic diseases when they become competent adults would rather not be tested. This supports the professional consensus that testing for untreated adult-onset diseases such as Alzheimer’s and Huntington’s diseases should be postponed until people are old enough to decide if they want it.

Critic Rosamond Rhodes acknowledges “only 10-15% of at-risk adults opt for Huntington’s disease genetic testing” (Rhodes 2006, 615); but she attributes this to unreasonable fears which lead to uninformed choices about their education, finances, and reproductive choices. Testing would be reassuring to many, she argues, since in some cases between 50-75 percent of those who are at risk will hear good news. Rhodes concludes that adults should decide to be tested and pediatricians should encourage testing.

Yet if so many adults want the liberty to decline it seems reasonable to preserve this freedom for children, who, as adults, may also decide not to be tested. Moreover, the decision not to be tested does not seem irrational. Informed and reasonable people of good will may decide they do not want testing because they do not envision the results changing how they want to plan their lives; or they may fear the information would distress them and dominate their lives and so would rather live with uncertainty; or they may dread bad news more then they would be relieved by good news.

Recommendations that everyone should be tested, moreover, may not take into account personal differences. Meiser and Dunn (2000) report people who are by nature socially extroverted with good ego strength are more likely to request testing than those with tendencies to be depressive.

People who reported being at risk of suicide or anticipated feeling depressed should the results be positive were significantly less likely to want the test, compared to those not anticipating suicidal or depressive feelings. …Interestingly, people who declined were more likely to have learned about their being at risk for Huntington’s disease during adolescence rather than adulthood.” (Meiser and Dunn 2000, 575)

Surprisingly, they also report that those finding out they were non-carriers sometime had trouble coping with the information.

Second, people may rationally decline genetic testing when it is offered because they fear a positive result will expose them to discrimination, especially in the workplace or in seeking insurance (Annas 2001). If they are not tested, the information does not exist and people cannot discriminate against them. George Annas argues that fear of discrimination prompts commentators to seek specific legislative protections focusing on protection from genetic discrimination.

Concern is high enough about the problem that President George W. Bush called for specific protection against discrimination by insurance companies. Annas supports this idea but cites the difficulty of gaining such protections (such as defining a genetic test). Patricia Roche and George Annas (2006) document the struggles states are having trying to offer protection of genetic information. Nancy King (2007) argues that while there is uncertainty about the degree to which discrimination exists for those undergoing predictive genetic testing, “it may be time to say no to the genetic testing explosion—at least until we know what is hype and what is not” (King 2007, 114).

Concerns about discrimination once information is available support the professional consensus. If testing of children for late-onset, serious, untreatable disease such as Alzheimer’s or Huntington’s disease could expose them to such risks of discrimination, and if there is no medical benefit to testing earlier, it seems better to wait and let them decide for themselves.
To summarize, it seems more likely that children’s open future is enhanced by waiting until children are old enough to decide for themselves if they want predictive testing for diseases such as Alzheimer’s or Huntington’s. First, most adults do not want testing when asked. If most people do not want such testing, then you take away people’s liberty to decide whether to test if you test them as children. Second, it also lets them decide how to evaluate the possibility of facing discrimination once the information exists.

4. New Findings and Policies

Even if it is reasonable to defend the professional consensus and its recommended ranking of potential benefits and risks, and I believe it is, there are obvious qualifications that need to be made. New information may quickly change recommendations about the potential benefits and risks of testing. As the field of genetics advances, it is likely that earlier monitoring or interventions will be found useful, undercutting policies discouraging certain testing (Green et al. 2003; Fulda et al. 2006). This would of course have implications for which conditions are regarded as untreatable, severe, or late-onset genetic diseases. There might also be policy changes such that attitudes to testing change; for example, people may gain confidence once good protections from discrimination exist.

This is no defense of “genetic exceptionalism” (the view that genetic tests and their results are fundamentally different from other tests). I agree with Green and Botkin (2003) that the dangers of pediatric predictive testing are not because genetic tests are unique, but because such precautions are needed for children whenever the results of studies may cause family discord, psychological distress, stigmatization, or discrimination.

To conclude, the professional consensus about how to rank potential benefits and risks of predictive testing of children for untreatable, severe, late-onset diseases such as Huntington’s disease or Alzheimer’s disease seems justified. Even though it does not rest upon large and persuasive studies it is supported by clinical judgment, concerns about discrimination, analogies to adult choices, and desires to preserve of an open future for children to decide for themselves.

An Acceptable Threshold for What?

The second necessary condition of the Best Interests Standard (see above) acknowledges that reasonable persons of good will sometimes make different choices, but sets limits. A father who ignores sound medical advice and decides it is best to treat his son’s sickle cell disease with herbal tea should be challenged since this behavior would almost certainly constitute medical neglect. As noted, when parental decisions about what they think is best endanger their children, the courts can intervene to take custody temporarily or permanently and decide what is best (Kraus 1986; Kopelman 1997). Endangerment is judged in terms of what is sound, logical medical and scientific views, arguments, and conclusions. Clinicians, judges, and others help set standards about when wards are neglected, abused, or otherwise endangered in their guardians’ care (Kraus 1986).

Parents have legal authority to decide what is best for their children and they do not lose authority if they provide care that is minimally acceptable. A choice is often judged “good enough” in relation to what reasonable and informed persons of good will would regard to be acceptable were they in the person’s circumstances. Obvious differences can exist among an ideal choice, a reasonable decision, and what is minimally acceptable. For example, a judge should allow what is acceptable and not require what is ideal in deciding whether a morbidly obese child should be taken out of a loving but indulgent home. Yet the Best Interests Standard should not be regarded as the “good enough” standard since choices should be better than merely acceptable.

Even if one strongly disagrees with parents about the wisdom of testing their children for Huntington’s disease or Alzheimer’s disease, it is implausible that testing meets the legal threshold of endangering them the way denying them life-saving treatment would. As critic Mary Kay Pelias points out, “…both society and the law operate from the presumption that parents act in the best interests of their children. These arguments are readily extended to support the right of parents to seek genetic testing for their own children, including testing for adult-onset diseases” (Pelias 2006, 607).

Thus, even if the evidence about how to balance potential benefits and risks (the first necessary condition of the Best Interests Standard) supports the professional consensus from a medical or moral perspective, this is not necessarily the case from other vantages. Taken from a legal perspective about competent parenting, parents’ choice for predictive testing of children for adult-onset disorders does not seem to meet the threshold of endangerment that is used to remove parental authority to decide what is best for their children. This does not mean their choice is best from a professional perspective.

Moreover, this does not mean parents can get testing whenever they wish since they must find professionals willing to do the testing. Deciding whether to do predictive testing for children is a joint decision between clinicians and parents, and clinicians should refuse to participate in something they regard to be wrong. Parents who want to test their children and not tell them the results have been criticized on all sides for the possible tensions and bias resulting from such secrecy (Rhodes 2006). Even if this approach of testing and not informing the minor of the results is imprudent from a moral and medical standpoint, it would almost certainly not meet the legal threshold of endangering a child.

Which Rights and Duties?

The third necessary condition of the Best Interests Standard (see above) requires decision makers to make choices for those who cannot make them for themselves that are compatible with more general duties to them. The Best Interests Standard is part of a larger picture about how to treat people and these more general values can offer important practical guidance, like a lighthouse guiding a ship.

For example, suppose parents think it would be best to enroll their seven-year-old child in a genetic study to gather information to learn about genetic diseases in their community. The parents know that the study will use medical and school records and is not intended to benefit her. For five hundred dollars, they agree to enroll their child in a study where their child’s blood samples are left indefinitely with the investigators who are at liberty to do whatever tests they wish.

Even if an institutional review board approves this study, one might still argue based on other articulated moral, social, or legal duties to children, that such a study should not be done. It offers no direct benefit to the child and might place her at significant psychosocial risks of harm (psychological, economic, emotional, psychosocial, or other risks relating to confidentiality, loss of self-esteem, stigmatization, or workplace or insurance discrimination). Moreover, parents’ agreement to enroll their child might be influenced improperly by the large amount of money they receive. (This example illustrates other possible breaches of duties such as those of the oversight committee members or investigators.)

Some controversies exist in this debate about how to understand children’s rights. For example, some defenders of the professional consensus argue against predictive testing.
on the grounds it fails to protect the children’s “rights” to autonomy, confidentiality, and not to know they have a genetic disease (Working group, British Society, 1994). This argument is an easy target for critics who point out that children lack autonomy and autonomy rights and that parents have legal authority to act on their behalf, including how to protect their privacy and confidentiality (Pelias 2006; Rhodes 2006). This criticism, however, is not decisive. As noted, essentially the same point can be made without appealing to the child’s so-called “autonomy” or “rights of autonomy,” but stated in terms of the benefits of enhancing children’s open future.

Older minors have some autonomy rights (to get certain medical treatments, marry, join the military, and so on) and reasonable and informed persons of good will may disagree about how much authority to give to their choices as they approach the age of majority. Duncan and Delayccki (2006) propose rectifying the dearth of outcome data about predictive testing for children by testing, informing, and studying results for older minors who request predictive testing for late-onset diseases. They argue there would be greater willingness to test older adolescents who seek such testing because they can participate in the decision.

V. Conclusion

A new analysis of the Best Interests Standard is employed to evaluate the controversy over what I call “the professional consensus” (the view that it is generally not in children’s best interest to be tested for untreated, severe late-onset genetic diseases such as Huntington’s disease and Alzheimer’s disease). When used as a practical guidance principle, the Best Interests Standard may be analyzed into three necessary and jointly sufficient conditions. Once these features are distinguished it becomes a powerful tool for settling disputes about how to make good decisions for those unable to make them for themselves, including whether to support the professional consensus.

The first component guides decision makers to assess potential benefits and risks and act to maximize the persons’ interests and minimize the burdens. Critics and defenders cite the same potential benefits and risks of predictive testing for diseases such as Alzheimer’s and Huntington’s, but rank them differently.

I have supported the ranking of potential benefits and risks found in the professional consensus (generally delay predictive genetic testing for adult-onset conditions such as Huntington’s and Alzheimer’s diseases) as being in children’s best interest; it preserves an open future for children by allowing them to decide for themselves if they want testing, allows them to assess the hazards of discrimination once positive results exist, acknowledges that few adults want such testing when it is offered, and squares with clinical judgments about testing for adults.

The second component of the Best Interests Standard guides decision makers to make choices for people who cannot decide for themselves such that at least meet a minimum threshold of acceptable care. But acceptable for what? An acceptable threshold in one circumstance may not be in others. For example, a gap exists between what is minimally acceptable and a real choice, so where what is minimally acceptable for others must meet standards of care, evidence, and good judgment. For example, once the Best Interests Standard was introduced parents who were at liberty to select unproven over proven and life-saving therapies for themselves could no longer select them for their children because it constituted medical neglect.

Using this new analysis of the Best Interests Standard, I have supported the professional consensus against testing children for untreated, severe late-onset conditions such as Huntington’s disease or Alzheimer’s disease unless it can be justified as being useful to the child, something that is difficult to demonstrate when no preventive or treatment strategies exist. I have also argued that parents have the legal authority to authorize such testing for their child, if they can find clinicians willing to do the test. This discussion could be affected by the proliferation of prenatal predictive genetic tests and over the counter products since the market could make an end-run around the professional consensus.

References


Grimes v. Kennedy Krieger Institute, Inc. 782 A. 2d 807, 366 Md. 29 (Court of Appeals of Maryland, 2001).


for the children in pediatric studies since that would have the effect of stopping research unless a case could be made that it is best for each child; the courts and regulatory bodies allow non-therapeutic or “no benefit” studies that have a low risk. For a further discussion of this see Kopelman 2002.

4. The Best Interests Standard in its practical uses is tied to what a reasonable person would decide is best in similar situations. For example, the President’s Council offers an analysis of the legal use of Best Interests Standard: “Best interest: a legal standard of caregiving for incompetent patients, defined by the courts in terms of what a ‘reasonable person’ would decide in the same situation. A consideration of best interests generally attempts to weigh the burdens and benefits of treatment to the patient in his present condition, when no clear preferences of the patient can be determined” (President’s Council 2005, 231). Authors Halameister and Hannaford agree, writing that in judicial opinions the “…‘best interest’ incorporates what a reasonable person in the patient’s position would want” (Haefmeister et al., 19n). They point out that for medical decisions the courts frequently consider an incompetent person’s diagnosis and prognosis and other objective medical criteria, the person’s prognosis for suffering or enjoyment, and the likelihood that the person will have a tolerable quality of life.

5. This is discussed in detail in LM Kopelman 1997, 2005, and 2007. As noted, it seems compatible with legal definitions of the Best Interests Standard in terms of a reasonable person standard. For example, see the President’s Council (2005, p. 231) and Halameister and Hannaford (2000, 19n).

6. There is more of a consensus that we agree about these points than why.

7. Three alleged benefits of testing where the faulty gene(s) is present were omitted from Fryer’s table because he acknowledges that they are controversial or doubtful. They are “16 years may not be a good age to be tested” “?Beneficence” and “?Lessen society discrimination.” See Fryer 2000, 284.

8. See Fryer (2000) and Rhodes (2006). Karen Kovach also gave a version of this argument in her paper at The American Philosophical Association’s meeting in San Francisco on April 6, 2007. She argued that the parents and children should decide about testing along with the clinician. While I agree and do not find this general stance to be controversial, few clinicians will do the testing and that is how the problem arises. The issue is whether their resistance is justifiable.

9. This view is widespread and has been for many years. See, for example, the policy statements from the Working group of the British Society of Human Genetics, 1994, the AAP, 2005, and the CPS, 2003.

10. I have not found arguments about the disinterestedness of clinical judgment in the literature as such but they seem implied.

11. There has been little judicial attention to this issue of testing for untreatable, severe late-onset genetic diseases perhaps because the two extremes (test everyone, test no one) are so implausible.

12. A correlative problem was discussed by the President’s Commission in its discussion of making decisions for incompetent elderly persons with dementia. A majority of the commissioners recommended setting aside the once-competent person’s advance directive if decision makers decided it was now not in their best interest. A minority of the commissions sharply disagreed.

13. The Best Interests Standard is a relatively recent legal doctrine replacing the view that children are property of their parents. Other countries may give children fewer rights, not give the Best Interests Standard the same meaning, or interpret it differently. There seem to be some international differences about the professional consensus. Fryer (2000) finds geneticists in Canada, Northern Europe, and the U.S. would generally not agree to test while those in other parts of Europe, Asia, and Latin American would. Arguably the difference concerns how parental duties and authority are envisioned.

— Philosophy and Medicine —

Prenatal Testing for Adult-Onset Conditions: Cui Bono?

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There is a widespread consensus in the medical and bioethical communities that minors should not be tested for untreatable adult-onset genetic diseases. The Committee on Bioethics of the American Academy of Pediatrics recommends that persons under eighteen years of age be tested only if testing offers immediate medical benefits to the child: “Unless there is anticipated benefit to the child, pediatricians should decline requests from parents or guardians to obtain predispositional genetic testing until the child has the capacity to make the choice.” (American Academy of Pediatrics 2001, 1454). In a similar view, the New York State Task Force on Life and the Law suggested that children generally should not undergo genetic testing for late-onset disorders in the absence of a medical benefit. Recently, critics have challenged this consensus, affirming the right of parents to decide what is best for their child and their family.1 The question of how to determine a child’s best interests is richly complex.2 However, that is not the topic of this paper. Rather, I am interested in how we should think about benefit when it is not existing children who are involved, but embryos and fetuses, as in the case of prenatal testing for adult-onset conditions. Who benefits from such testing? To answer this question, we must ask, What is the purpose of prenatal testing? Is it to enable couples to make informed reproductive decisions, in particular about whether to continue the pregnancy or have an abortion? If so, then the benefit is that of the prospective parents. Or is the purpose to reduce the prevalence of certain diseases in society? If so, then it is society that is presumed to benefit from prenatal testing. Or can prenatal testing be done “for the sake of the child”? Does the child itself benefit from prenatal screening for adult-onset conditions?

Let us begin by looking at prenatal testing or screening2 for early-onset genetic diseases. Such testing has become common, even routine, in the United States. Pregnant women over the age of thirty-five are routinely tested for Down syndrome. Nor are the tests confined to older women, whose risk of having a child with Down syndrome is significantly higher than the risk faced by younger women. In fact, recently the American College of Obstetricians and Gynecologists (ACOG) recommended that all pregnant women, regardless of age, be offered prenatal testing for Down syndrome, because 80 percent of babies with Down syndrome are born to women under the age of thirty-five, for the simple reason that younger women are the ones who have the most babies.

In most cases, the result of such testing will be reassurance. The risk of having a child with a serious disorder is about 2 percent in the general population. It’s a little higher in the population using assisted reproduction, about 5 percent. But even here, 95 percent of couples or women will get good news. There’s no guarantee, of course, that the baby will be healthy. Not every genetic disease can be detected and not all defects are genetic. Moreover, there is always the risk of a false negative. Nevertheless, most prospective parents are reassured by prenatal genetic tests. Because of this, Sherman Elias and George Annas argued thirty years ago that prenatal testing
actually results in the births of more children, not fewer. This is because many couples use prenatal diagnosis for reassurance that their fetus is not affected with a particular disorder: “without the ability of this reassurance, a significant number of couples would decide against pregnancy, and many women would choose abortion upon becoming pregnant” (Elias and Annas 1986, 83).

However, it is far from clear that the net result of prenatal testing is a greater number of babies being born, because it is unlikely that most couples would not have risked pregnancy if prenatal testing were not available. It seems more likely that avoidance of pregnancy, in the absence of testing, would be restricted to couples who know that they are at risk for having a child with a devastating and lethal disease, like Tay-Sachs or Lesch-Nyhan. However, most couples are not like this. Most couples who are offered or who seek prenatal testing would have gotten pregnant anyway. Undoubtedly many more cases of Down syndrome will be detected as the number of women being tested increases. Judging from past experience, most of those pregnancies will be terminated (about 85-90 percent). Thus, the number of pregnancies that are terminated is almost certain to be much greater than the number of pregnancies that would not have been attempted, but for prenatal testing. This explains why critics of prenatal testing do not view it as enabling births that would otherwise not have occurred but, rather, as a “search and destroy” mission. One of those critics is the columnist George Will, the father of Jon who has Down syndrome. In a recent column on ACOG’s recommendation, Will notes that there is no therapy for Down syndrome, thus, “...diagnosing Down syndrome can have only the purpose of enabling—and, in a clinically neutral way, of encouraging—parents to choose to reject people like Jon as unworthy of life” (Will 2007).

Now, one might think that the debate here is between those who generally oppose abortion (of whom Will is one), and those who do not. The abortion debate turns largely, though not entirely, on the moral status of the fetus—an issue I am not going to address here. However, at least some disability advocates do not base their opposition to prenatal testing on a general opposition to abortion. Adrienne Asch (1999) supports abortion (or a woman’s right to choose abortion) when the woman, for whatever reason, does not want to become a mother. She opposes abortion when the woman wants to become a mother, but does not want to be a mother to a child with certain characteristics, e.g., a disabling condition. This is sometimes called the “any/particular” distinction because it distinguishes between an abortion of any child, and an abortion only of a particular child, or particular type of child. Asch believes that the desire to abort a wanted child, when it is discovered that the child likely will have a disability, stems either from ignorance about what it would be like to raise such a child, or discriminatory attitudes toward people with disabilities, or both. From the perspective of the “disability critique,” prenatal testing is rarely, if ever, in the interests of the future child.

There is one exception, and that is when prenatal testing is done not in order to terminate the pregnancy but, rather, to learn about any special needs due to the disability. For example, if spina bifida is discovered in utero, the doctors will probably want to do a cesarean section, since the travails of normal labor might further damage the child’s spine. A woman who would not consider aborting a fetus with spina bifida might, for this reason, want prenatal testing in order to have the safest type of delivery. In addition, some conditions can be treated surgically immediately after birth or even in utero. Prenatal testing might also help the parents be better prepared to care for and raise a child with special needs.

Could this rationale for prenatal testing have implications for adult-onset conditions? Obviously adult-onset conditions would not affect planning for the birth or medical care or education during childhood. However, it is possible that there are preventive measures that could be adopted during childhood to lessen the risk of developing an adult-onset disease. Perhaps a child at high risk for developing heart disease or diabetes as an adult might be able to reduce that risk with dietary modifications from childhood on, just as children born with phenylketonuria (PKU) can avoid mental retardation with a severely limited diet. In such cases, prenatal genetic testing might have a benefit for the future child.

However, this justification for prenatal testing is dubious for two reasons. First, for most people and most adult-onset diseases, genetic testing is not predictive. (This differentiates increased genetic risk for heart disease from PKU, where severe mental retardation is virtually certain to occur unless the child is put on the special diet.) In diseases like heart disease and diabetes, the environment plays a large role in whether the individual develops the disease, even in the presence of genetic risk factors. For most adult-onset diseases, even if there are childhood interventions that could be taken, a prenatal genetic test will not reveal if the interventions are necessary or desirable. It should be remembered that interventions to prevent disease may themselves have adverse effects. (Sadly, this is also true for PKU, where a false positive could mean that a child was placed on a severely restrictive diet needlessly. Sometimes this has even resulted in brain damage to the developing infant brain, resulting ironically in mental retardation.)

There are some adult-onset diseases where a small percentage of people inherit particular mutations that cause a strong predisposition to the disease in virtually any environment, making the tests highly (if not absolutely) predictive. For example, a very small percentage of women who get breast or ovarian cancer (about 1 percent) have the BRCA1 or BRCA2 gene variant. This means that they are born with a strong genetic predisposition to the disease. Women who have the BRCA1 or BRCA2 gene variant have up to an 85 percent risk of developing breast cancer by age seventy, as compared to a 12 percent risk over a ninety-year life span for women who do not have these mutations. Women who have the BRCA1 or BRCA2 gene variants could be identified prenatally. (Myriad has refused to license BRCA1 tests for prenatal screening, but in theory, such tests could be done.) The question is, What would be the point of prenatal testing for breast cancer? Certainly not to institute preventive measures in childhood. The only preventive measure is frequent screening in adulthood, or having the breasts and ovaries prophylactically removed. One need not do a prenatal test, or testing in childhood, to do this sort of prevention. The only reason for prenatal screening for breast cancer is to avoid the birth of a girl who is likely to have breast cancer at some point in her life. I will return shortly to the question of whether abortion can be seen as in the best interest of the future child.

Another example of an adult-onset disease is schizophrenia, which usually develops between late adolescence and the mid-thirties. This too is a disease with a significant genetic component, and one that follows the same pattern as breast and ovarian cancer. That is, most people who develop schizophrenia do not have one of the gene variations that have been found to correlate with the disease. For this reason, population screening for schizophrenia makes no more sense than population screening for breast cancer. It would not pick up the vast majority of those who will go on to develop the disease. Where there is a family history of schizophrenia, however, there might be a reason to perform prenatal testing for the particular genetic
variant associated with the disease. Could such testing be done “for the sake of the child”? Perhaps. It is possible that a child likely to become schizophrenic needs to be handled differently from other children, even in infancy, right from day one, and that such interventions could ameliorate, if not prevent altogether, the onset of the disease. This is not entirely far-fetched. Infants with autism, another disease which probably has a genetic component, need to be treated differently from other babies. They need less stimulation, for example. So it is possible that even prior to the onset of symptoms, children at high genetic risk of developing schizophrenia could benefit from special rearing techniques. Alternatively, there is the risk of labeling and stigmatizing the child as mentally ill, which could turn out to be a self-fulfilling prophecy.

If a genetic test had very strong predictive value, that is, if the test could reveal with near certainty that the individual would develop the disease, that might be a reason for wanting the test prenatally. An example is Huntington’s disease (HD), an autosomal dominant adult-onset disease with virtually 100 percent penetrance. HD is a fatal and degenerative brain disorder. Symptoms usually appear between the ages of thirty and fifty; there is no cure and no treatment. It is possible to determine if a fetus carries the gene for HD by amniocentesis or chorionic villus sampling. If the prospective parents would terminate the pregnancy if the fetus was affected, they most likely would want the test. If they would not abort, there is no reason to have the test. Thus the rationale for prenatal testing for HD depends on the willingness to abort. This has been born out by a study in Canada (Adam et al. 1993), where prenatal genetic testing for HD has been available since 1986. Early survey data suggested that 32 to 65 percent of those couples with one partner at risk of developing HD would want prenatal testing. However, during the study, researchers found that only fourteen couples (30 percent) initially requested prenatal testing, and of those fourteen, seven withdrew. (Admittedly, this is not a large sample.) “The most frequently cited reason for declining prenatal testing was the hope that a cure would be found in time for their children” (Adam et al. 1993, 549). This suggests that even where a test is strongly predictive of a dreadful disease, a significant number of people would decline the test because they retain the hope that advances in medicine will prevent their child from getting the disease.

What if there was no hope of avoiding the disease? Might we in such a case view abortion as being chosen (perhaps required) for the sake of the child? This idea is sometimes expressed when people say things like, “It would be unfair to the child to be born in such a condition. If you knew your child would have condition X, how could you do that to a child?” The condition might be a medical condition, but could also be a social condition, such as being born to an older father, who was unlikely to live to the child’s adulthood, being born in extreme poverty, etc. This issue has been the subject of a substantial literature. Some have taken the position that birth can never be a harm to the individual, that life is always worth living, whatever the magnitude of the disability or the amount of suffering. This seems far too strong. It is not difficult to imagine a life so brief and so filled with unrelievable suffering and so absent of the things that make life worth living that life itself is not a benefit but a harm. A less extreme view holds that life is a benefit except where the individual himself or herself, or a proxy acting on his or her behalf, would prefer nonexistence. This is known as the wrongful life standard, after legal cases in which it was alleged that an infant plaintiff was harmed by being born, and owed damages by the negligent physician responsible for the child’s birth, even though the physician did nothing either to cause the harmful condition or to prevent its occurrence. The only way to have avoided the child’s being born in such a condition would have been to avoid the child’s birth altogether.

The wrongful life condition can explain how the child has been harmed and wronged. If the child’s life is so terrible that the child himself or herself would prefer nonexistence, then the child would be better off unborn. Being brought into existence under such conditions both harms and wrongs the child. The difficulty with this standard is that it is hardly ever met. Most disabilities, even very severe ones, do not impose terrible suffering. Indeed, some of the most devastating conditions, such as anencephaly, impose no suffering, as it seems likely that the child experiences nothing, and therefore is not in pain. In addition, many people who have serious disabilities report having lives well worth living. They do not wish that they were dead or that they had never been born. It becomes, then, a real challenge to explain how children can be said ever to have been harmed or wronged by birth with a serious disability, or to explain the basis of the alleged obligation to prevent their births. It may be that, in many cases, the correct explanation for the obligation to avoid procreation stems from impersonal, rather than person-affecting, reasons.

If it is difficult to explain the obligation not to have a child with a seriously disabling condition, the difficulty is compounded in the case of adult-onset diseases. Consider one of the worst, HD. Before the test for HD was developed, individuals could know of their risk only if either of their parents had HD. If they had inherited the gene, every child they had would have a 50 percent chance of inheriting the disease as well. But this could not be known until they became symptomatic, usually not until their late forties or fifties—long after reproductive age for most people. In 1978, Laura Purdy argued that someone who knew that he or she was at risk for HD had a moral obligation not to reproduce. Had Arlo Guthrie taken her advice, he would not have had his three children. As it turned out, he had not inherited the HD gene from his father, Woody Guthrie. His gamble paid off. Today, with predictive genetic testing available, there need be no gamble. Anyone at risk can be tested for the HD gene prior to reproducing. If the test is negative, the individual need not worry about passing on the disease. But what if the test is positive? Is it clear that there is a moral obligation not to reproduce? Arlo Guthrie allegedly felt that even if he passed on the gene, it would not be wrong of him to have children. He felt that he had had a good life, and did not wish that he had not been born. Therefore, he would not feel guilty providing his children with forty or fifty years of disease-free life, even if they developed HD. Moreover, as we saw earlier, some of those at risk for HD do not wish to avoid reproduction because they hope that a cure will be found in the children’s life times. The same argument applies more strongly to breast cancer, which has less penetrance and where prophylactic measures are possible.

What about schizophrenia? On the one hand, it is likely to occur much earlier, reducing the amount of “good time” before the onset of disease. On the other hand, people do manage to live with schizophrenia, and many are able to control their symptoms with medication. Given that genetic tests cannot reveal how severe the disease will be, it is difficult to maintain that there is an obligation to undergo prenatal testing where there is a family history of the disease, or that reproduction must be avoided “for the sake of the child.” Whether parents might justifiably wish to avoid having a child at high risk for schizophrenia is a separate question.

Conclusion

Prenatal genetic testing is usually desired on grounds of reproductive autonomy. I think that individuals who want to avoid the birth of a child with a severe disability are morally entitled to do so by having an abortion, though I have not
attempted to defend that claim here (see Steinbock 2000). At the same time, it is much more difficult to justify prenatal testing and selective abortion as being for the sake of the child who otherwise would have been born because in almost all cases the child, once born, will have a life worth living. This is so even in the case of severe disability at birth, and much more so in the case of adult-onset disorders.

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Endnotes

1. See, for example, Rhodes R (2006).

2. See, for example, Kopelman LM (2007) and Steinbock B (2005).

3. The distinction usually made between testing and screening is that testing is offered to an individual based on individual risk factors. Thus, a couple at risk of passing on a rare genetic condition might be offered prenatal testing for that disease. By contrast, screening is done on an entire population to reduce the prevalence of a disease, e.g., the screening of all pregnant women for HIV. However, the line between testing and screening is not always clear. Prenatal testing for Down syndrome can be seen as genetic testing when it is offered to women on the basis of a risk factor (advanced age). But equally it can be seen as a kind of de facto screening program because it is so widely and routinely offered. Moreover, the effect, if not the purpose, of such screening is to reduce the prevalence of the disease, since pregnancy is terminated approximately 90 percent of the time when Down syndrome is detected in the fetus.

4. The information about breast cancer, testing for BRCA1, and Myriad’s policy on prenatal genetic testing for BRCA1 comes from Lee Silver.

5. Huntington’s Disease Society of America. www.hdsa/hdtest.htm#testing


7. I discuss such cases in Steinbock 1986.

8. I defend this possibility in Steinbock (forthcoming).

Industry’s Relationship with the Medical Profession: Impure and Unholy?

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In purity and holiness I will guard my life and my art.1 Physicians hold themselves out as fiduciaries of their patients’ health interests. This implies their willingness to shoulder a duty of loyalty and a duty of care heightened by the advanced education, training, and skill possessed by the profession’s practitioners. Adherence to the duty of loyalty is essential for sustaining patients’ trust and confidence. It requires that physicians will use their best, independent judgment when giving medical or surgical advice and will act in their patients’ best (health) interests.

Twenty-five hundred years ago, Plato stated the basic idea of fiduciary duty succinctly. In doing so, he explicitly recognized the conflict of interest that results from practicing two arts while professing only one: the unprofessed “art of payment” promotes the physician’s interest in health. This implies their willingness to shoulder a duty of loyalty and a duty of care heightened by the advanced education, training, and skill possessed by the profession’s practitioners. Adherence to the duty of loyalty is essential for sustaining patients’ trust and confidence. It requires that physicians will use their best, independent judgment when giving medical or surgical advice and will act in their patients’ best (health) interests.

Rather than prohibit dual agency where the physician acts on his own behalf as well as the patients’, the fiduciary principle orders those interests: “no physician, in so far as he is a physician, considers his own good in what he prescribes, but the good of the patient; for the true physician...is not a mere money maker.”2

Despite that the physician’s interest and the patient’s often converge (one may do well by doing good) they are imperfectly aligned. And, for psychological and epistemological reasons, there must be uncertainty, especially at the margin, for both the patient and the physician, about when the physician’s

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voice is medicine talking or the art of payment. No one’s insight is so fine as allow a certain diagnosis in all cases. Nor is it worthwhile to try. Still, when a wallet-biopsy (“May we see your insurance card for our records?”) always precedes “the doctor will see you now,” we get a reminder that first things first means “No Margin, No Mission” not “primum non nocere.” It may be worthwhile to spend the thought and time to determine whether one’s priorities have become deranged. But maybe not.

By now, we all know the drill about incentives. Still, when physicians repeatedly complain that declining reimbursement from Medicare/Medicaid will eventually hurt their patients, they acknowledge that government reimbursement policy intensifies the conflict between their interest in patient care and maintaining a tolerable bottom line to the point where the ordering required by the fiduciary principle will invert.

The prevalence of defensive medicine shows how the behavior of another profession’s practitioners (personal injury lawyers) intensifies the conflict of interest between physicians’ patient-focused care decisions and decisions intentionally made to reduce their own litigation anxiety. Ninety-one percent of physicians say their medical colleagues order needless studies and treatments for this reason. Seventy-nine percent admit to doing it themselves. Diagnosing others’ problematic conduct at a higher rate in others than in one’s own case should prompt a smile, if not a chuckle. Less amusing: 93 percent of faculty and resident physicians say that they would (and not merely “should”) disclose a hypothetically described major medical error (= resulting in death/disability). Five percent say that they had disclosed an actual major error. 3

The Hippocratic Oath highlights the hazard of mixing non-medical interests with one’s practice of “the art” when it makes the physician swear, on pain of divine retribution, that he will keep himself and his art “pure and holy.” In other words, the physician vows not to allow extraneous interests to distort his art or threaten his independent medical judgment—purity of heart is to will one thing—the good of the patient.

Purity of heart is not in the cards for human physicians. But Plato knew that too, [because] “no one takes on the troubles of strangers, to straighten them out, but everyone expects pay for that.” 4 The problem is that no payment system aligns incentives so as to prevent the physician from subordinating the patient’s status as ill-person to the patient’s payer-status.

“Pay” and “pay-offs” may be denominated in many forms besides money. Status and professional recognition are motivators, so is social prestige, and wielding power—to help one’s friends and hurt one’s enemies. Plato pointed out that even “avoidance of a penalty” may function as “pay,” most especially for practitioners of the ruling arts (among which he classified medicine). Money and status may lose their incentive effects for the truly eminent. All that’s left to motivate them to take on an especially burdensome role or a very complicated case is they will thereby forestall the lesser able, not to mention quacks/frauds, from serving instead.

The complexity of human motivation aside, Brody tends to reduce everything to the monetary nexus. Industry’s resources exceed that of the NIH so by implication, it has the ability to hire the best brains in the business.” Thus when discussing the Kefauver amendments, requiring any drug introduced between 1938 and 1962 to be effective or else removed from the market, Brody expresses initial surprise that some industry-sponsored researchers are jealous of their autonomy. A salary increment may not induce their surrendering it. They also dislike having to account to anybody, let alone accept research direction and deadlines from anybody. Businessmen are not necessarily the best judge of research talent. They must rely on surrogate measures. The names everyone knows may have ceased being productive years ago. Their reputations may have been established by others’ work. Spotting research promise, like picking the next Derby-winner from race-bred three-year-old race-horses—very tricky. Not being research scientists themselves, they will be torn between “wasteful blank check” and “a dollar saved is a dollar earned.” Their ignorance puts them at increased risk of over-investing or under-investing in talent as well as over-investing/under-investing in support. What heuristic should guide them? Buy the biggest name who’ll sign up? Or “all Ph.D. researchers are pretty much equal.” Mistakes are possible either way. It’s the extraordinary company that bets right consistently. Brody doesn’t look at excellence in drug companies—only “industry” over all.

How to achieve an acceptable degree of physician adherence to fiduciary duty is a chronic, but ultimately unsolvable problem, a management problem whose daunting complexity is a function of all the things physicians may care about, all the relationships they have, including being on good terms with oneself, which includes the ethical project of keeping oneself and one’s art holy and pure.5 Overdoing the moral purity project is self-indulgent and ultimately self-defeating. “No compromise” may be horrifying rather than praiseworthy. Robespierre “the incorruptible” was no moral hero.

A physician’s susceptibility to incentives of whatever kind varies with age, wealth, upbringing, career-stage (partner? professor? tenured?), experience and reputation, acquired tastes and bad habits. Financial incentives are always in the mix, but how many afternoons of golf are “too many”? To what lengths may one go encouraging/cajoling/nagging one’s research subjects to preserve the integrity of a study when subject drop-outs threaten data significance? What if several of your previous studies had been vitiated in this manner? What if one subscribes to more golf magazines than professional journals?

The most egregious instances of physicians’ betrayal of the art’s principles and patient trust have been in their securing exclusive, legally protected privileges for themselves and, in their becoming willing accomplices to systematic, state-sponsored human rights violations—Nazi doctors, the Public Health Services’ decades-long study of “the natural history of syphilis” among African-American men at Tuskegee, U.S. government’s human radiation experiments, eugenic social-hygiene sterilization, participation in prisoner abuse, willingness to assist police in forcibly recovering swallowed evidence that “shocked the conscience” of the U.S. Supreme Court, etc. Drug company pens, pills, and pizza played no role in recruiting doctors’ complicity in these outrages. Of all the things about American medicine begging for reform, it’s far from obvious that cleaning and pressing the medical profession’s character should start with its pharmaceutical industry relations.

Medicine’s Most Problematic Relationship? 

Howard Brody6 argues that medicine has allowed itself to become fatally compromised by the pharmaceutical industry’s influences. With well-told stories and study summaries as premises, Brody argues that the industry has too much influence on:

• the funding, design, and conduct of biomedical research and clinical trials,
• the dissemination of biased information,
• determining which drugs and devices are selected for development in clinical trials,
• the regulatory approval process for marketing of drugs and devices,
• the content of clinical practice guidelines,
• physician prescribing behavior,
• the financial viability of professional journals and meetings,
• medical education (especially graduate medical education and continuing medical education),
• patient welfare.

Brody claims that the industry uses demonically successful compliance strategies (especially “gifting” physicians with seemingly trivial items as pens, pads, mugs, pizza) that trigger a hard-wired, subconscious mechanism so powerful that ordinarily compliance-resistant physicians, who are otherwise noteworthy for clinical inertia, wind up writing prescriptions for industry-promoted products—against their better judgment and contrary to their patient’s best interests.

Moreover, he argues that physicians, like dependency-denying drug-addicts, seem to lack insight. They deny that industry’s influence systematically subordinates and de-professionalizes them when their prescribing behavior says otherwise. In Brody’s telling, the medical profession has become drug-company dependent—HOOKED! As a remedy, Brody rejects a “management strategy” because it is premised on the view that there is nothing fundamentally wrong with the relationship. Instead, he favors an across-the-board divestment—Drug Reps Off Campus, No Free Lunch, Zero Tolerance for financial entanglements with industry.

Industry Spends More Than $5 Billion Each Year Marketing to Physicians. Why?

Americans are eager to take drugs—to cure their diseases, to treat their illnesses, to relieve their distresses, and to enhance their lives. The pharmaceutical industry provides an unprecedented array of effective medicines to meet consumer demand. So it is very easy to understand why industry would focus its marketing strategies on patients—to sell sickness, and to invent new diseases in relentless pursuit of expanding markets.

Several additional facts are necessary to explain why industry invests so much in its relationship with physicians and why marketing to physicians far outstrips direct-to-consumer advertising.

• Medical practice statutes secure to the medical profession a legal monopoly over the practice of medicine. The free market did not confer this monopoly.

• The prescription system secures to licensed physicians monopoly control over access to drugs and devices that have not been specifically designated by the FDA for over-the-counter (OTC) sale. The free market did not confer this monopoly.

• With but few exceptions, physicians may prescribe FDA-approved products for whatever “indications” they deem appropriate, irrespective the FDA’s “approved-indications.” The free market did not confer this privilege.

• Medicine opposed the creation of the modern FDA (in 1938) until it had won clear statutory assurance that the Agency’s authority over the marketing of the pharmaceutical industry’s products should not extend to regulating the practice of medicine.

• Anything classified as a drug or medical device requires a prescription from a licensed physician (unless the FDA has approved its marketing for over-the-counter sale). Industry may seek physicians’ expert advice in product development, but it cares even more about what they write on their prescription pads. The free market did not create the FDA—it is not merely the state version of Underwriters Laboratories.

• When “indications-approved” for marketing by the FDA, a drug or device’s patent protection (usually twenty years) is more than half gone and is counting down. We have Thomas Jefferson to thank for the patent system, not the free market.

• The drug or device maker’s property interest in patent-protected marketing time is very valuable. It has an interest in maximizing its value.

• Physicians have no incentive to care about a product’s patent clock.

The Current Extent of Medicine’s Relationship with Industry

Physicians’ relationships with industry are indeed extensive. But a recent study finds that interactions vary by type and by specialty and to some extent by gender, with males more likely to receive payments than females. It asked physicians whether, in the past year, they had received food or beverages in the workplace; free drug samples; honoraria for consulting; payment for service on scientific advisory boards or board of directors; payment in excess of costs for enrolling patients in industry-sponsored trials; costs of travel, time, meals, lodging, or other personal expenses for attending meetings; gifts as a result of prescribing practices; free tickets to cultural or sporting events; free or subsidized admission to meetings or conferences for which continuing medical education (CME) credits were awarded.

The study’s authors found that 94 percent of physician-respondents reported some type of industry relationship within the last year. Eighty-three percent reported getting food in the workplace. Seventy-eight percent reported getting drug samples. Thirty-five percent got reimbursement for attending professional meetings or continuing medical education. Eighteen percent got paid for consulting, 16 percent for giving lectures, 9 percent for serving on advisory boards, 3 percent for enrolling patients as research subjects in clinical trials. Seven percent reported getting free tickets to cultural or sporting events. [The latter violates PHRMA's 2002 Code of Ethics as well as the AMA Ethical Principles.] Respondents were not polled on whether they had received free golf balls, tennis balls, luggage, etc. Nor were respondents who acknowledged being paid for consultations or advisory board service asked how much they were paid. Anecdotes reported in the press indicate that such payments can be very sizable—running as high as several hundreds of thousands of dollars annually in some cases.

Family medicine doctors met more frequently with industry reps than physicians in other specialties and were more likely to get drug samples or reimbursements than pediatricians and anesthesiologists. Hospital or clinic-based physicians met with reps less frequently than doctors in solo or group practice. Cardiologists were more than twice as likely to get paid for consulting or giving lectures than pediatricians, anesthesiologists, or surgeons.

From an economic point of view one would predict that industry would focus its marketing on physicians who it perceived as influencing the prescribing behavior of other physicians. The survey’s results were consistent with that prediction. Overall, all specialties except anesthesiology seem to meet more frequently with industry reps than they did only seven years ago.
Off-Label Prescribing

By law, both the FDA and the country’s 750,000 licensed physicians have legal authority to expand the market for the drug industry’s products. An application for expanded, FDA-approved “indications” for a product’s package insert is time-consuming, costly, sometimes political, and may fail. The more stringent the Agency’s review process becomes, the more attractive for industry to turn to doctors for market expansion—off-label use.

Physicians’ off-label prescribing privilege functions, in effect if not by design, as an institutional safety valve for too-stringent regulatory behavior. It also invites the medical community to use its enormous store of clinical knowledge, which vastly exceeds regulatory appreciation. Perhaps only 20 percent of medical/surgical practice is grounded in the principles of evidence-based medicine.

But off-label use makes more difficult systematic post-approval evaluation of prescription drugs and devices. Physicians’ privilege to prescribe off-label strengthens the incentive for industry illegally to promote off-label uses as legal avenues for market expansion become more costly. It also creates a gaming incentive for industry to apply for FDA approval on narrower grounds than it has evidence for because the broader the application, the larger, more complex, and more costly the clinical trials must be. Retrospective studies and physicians’ off-label privileges may expand the market. Openly discussing what everyone knows about the background institutional facts in the context of the development of any drug or device puts those involved at risk for conspiring to violate federal law. An evidence-based absolutist might claim that such gaming would be profoundly wrong. A wiser institutionalist says, “ambition must be made to counter ambition.”

Their legally protected off-label prescribing privilege (plus their First Amendment freedom) puts physicians at liberty to discuss with each other their experience (+/-) with off-label product use. But if industry picks up the chatter, promotes and transmits it, substantial liability results. Industry’s commercial speech in product promotion is subject to FDA regulation and penalties. But never mind, industry can take advantage of physicians’ tendency to credit each others’ clinical experiences by paying an honorarium to physicians for lecturing about off-label uses. Social psychologists know that when we are uncertain about what should be done, we look to others for guidance, and as a heuristic, it’s not a bad rough-and-ready assumption that when we don’t know, others do. Doctors tend to credit medical opinions much more highly that non-medical opinions, despite that pharmacologists, epidemiologists, or other Ph.D. specialists might be more reliable in particular instances.

For purposes of informed consent, should physicians disclose to their patients when the drugs or devices prescribed are not FDA “indications-approved”? When hospitals order and bill for drugs and devices that will be used off-label on in-patients—should the consent to treatment of procedure disclose “not FDA-approved”?

Brody criticizes industry’s off-label product promotion in violation of law’s letter or spirit. He tends to equate FDA-approved uses to a drug’s appropriate uses. Yet, Brody nowhere even considers the pros/cons of legally abolishing doctors’ privilege to prescribe off-label. Nor is any justification offered for its continuation.

If off-label prescribing/use were illegal and if pharmacists were prohibited from dispensing any drug for other than FDA-approved indications, as attested on the script by the prescribing physician (with license-loss penalty for fraud), the corrupting incentive for industry to push the envelope on off-label promotion would virtually disappear.

How might medicine respond if legislation were introduced to make off-label prescribing illegal, in the name of “evidence-based medicine”? Almost certainly, organized medicine would expend substantial political and financial resources to crush it. It would point out that the vast bulk of prescribing is “off-label.” Patients would be harmed by prohibiting it, and so on. But the privilege to prescribe off-label is also perceived by the medical profession as very valuable to doctors. The pharmaceutical industry’s incentive to court holders of this privilege follows as the night, the day.

Industry’s product marketing should be about truth-in-advertising, we think. But there is a gray area—label warnings may encourage off-label use. For example, drugs to treat erectile dysfunction (ED) are among the most widely promoted in direct-to-consumer (DTC) advertising. These drugs are not FDA-approved for enhancement of erectile function. Street rumors say they work that way. On the list of risks that must be DTC-disclosed is priapism ("an erection lasting longer than 4 hours").

The Case of Dr. Olivieri

In the introduction, Brody warns the reader that his book will have the appearance of “industry bashing.” Indeed it does. At least one story that should have been painted in shades of gray is instead painted as virtually black and white.

In recounting the case of Dr. Nancy Olivieri and the scientific and academic-freedom controversies that rocked Canadian, American, and European medicine, Brody portrays the physician-heroine, who perhaps naively assigned ownership of her data to her commercial sponsor, but who fearlessly blew the whistle on the Canadian drug giant Apotex when it tried to suppress her attempts to warn the medical world that the oral iron chelator she had been studying caused hepatic fibrosis in some of her Thalassemia Major patients. Instead of helping spread the alarm, the profit-hungry company shut down her studies and threatened her with lawsuits to prevent her publishing her data. When things got hot, her university shamefully failed to defend her right to publish.

According to Brody, the story starts in 1993 when Dr. Olivieri, already a prominent hematologist, got interested in studying a promising new drug called deferasiprone, or L1.

In fact, Olivieri first learned about L1 in December 1987 while attending a meeting of hematologists in San Antonio, Texas. The drug’s early developer had found it non-toxic in cell cultures, safe and effective as an iron chelator when used in rabbits, and similar to standard therapy in rats. The drug was unpatented and already in the public domain. Dr. Olivieri was impressed and determined to develop the drug in her Thalassemia patients on a compassionate use basis because they had no good alternative.

However, in the summer of 1989, Dr. Olivieri got evidence that L1 was potentially toxic to humans because an article in Lancet had reported its toxicity in mice. The journal knew that there were human trials involving the L1 going on around the world, so it consulted with hematologists and in the fall of 1989 recommended that all human trials involving the drug should stop.

Dr. Olivieri did not include this information in her annual research report to her hospital ethics board. On the basis of the information she provided, in 1990, the Board determined that her project was “ethically acceptable.” And when preparing a research grant application to Canada’s Medical Research Council, she detailed the problematic aspects of desferal, the standard chemotherapy drug for Thalassemia, which many patients couldn’t or wouldn’t tolerate, but omitted mentioning the Lancet editorial that found L1 “too toxic” for use in humans.
All this occurred before Dr. Olivieri approached Apotex, signing a contract with the company in April 1993.

Because of the incredibly demanding obligations Dr. Olivieri had assumed in patient care, in resident teaching plus her stunningly productive and influential research/publication record (she could fairly lay claim to the status of a legendary “triple-threat” doctor), she fell behind in making timely research reports to Apotex about her projects as she had promised to do. Without success, Apotex had been nagging Dr. Olivieri for data to enable company scientists to audit her work.

So when Olivieri, in 1997, communicated her concerns, but not alarm, about L1’s possibly causing hepatic fibrosis in some patients, Apotex, already short on patience because of her delayed research reports, challenged her assessment of the evidence. Apotex demanded Dr. Olivieri’s liver-biopsy slides for a consulting pathologist’s review. She provided them. He disagreed with her conclusions.

A key scientific issue is joined precisely here: Did Dr. Olivieri’s slides show that some of her patients had developed hepatic fibrosis? If so, was L1 the likely cause? The scientific issue should be kept distinct from the issue of academic freedom and the ethical duty to warn. This is not easy because some commentators have gone so far as to say that the scientific question, whether Dr. Olivieri was right or not, is totally irrelevant.

Brody suggests that Apotex’s consulting pathologist disagreed with Dr. Olivieri’s interpretation of her slides because he was biased, if not pre-ordained, to reach company-favorable conclusions. But that’s not quite the way it was. The pathologist who reviewed the slides concluded that the slides could not be used to decide about hepatic fibrosis one way or the other because they had been made in such a way as not to allow one to discern whether one was examining fibrotic-appearing cells from the liver’s capsule or (possibly) fibrotic hepatocytes.

Assessing liver tissue for evidence of fibrosis is complicated by the fact that normal cells from the liver’s capsule are fibrotic-appearing. Pathologists have a special tissue protocol to ensure that the tissue is collected and slides made in a manner that rules out mistaking normal liver capsule tissue from fibrotic hepatocytes. A consulting pathologist might be quite blunt in criticizing slides not made according to a specialist’s standards. And a non-pathologist might be quite defensive, counter-attacking the motives of the pathologist and his sponsor to explain the disagreement.

The stage was set for an explosion. A background history of simmering mutual low-grade annoyances and minor communication problems between Apotex and Dr. Olivieri gradually grew hotter. When Dr. Olivieri reported her suspicion that L1 was causing patient harm, but that she wanted to fix the protocol, the company aggressively moved to challenge the scientific basis for her judgment. What resulted was a total rupture of trust and good will. She proposed modifying the protocol, the company aggressively moved to challenge her assessment of the research protocol. The company shut down her studies, her access to the drug, and prohibited her from publishing any company-owned data. She may have perceived that shutting down her studies amounted to stealing her work, cutting her off from further developing a drug she proposed to study further.

Brody tells the story of a well-respected community physician industry recruited supposedly as a consultant for a day. He was asked to provide written evaluations of the company’s reps’ performance in detailing a product. One after another, a rep would present his/her drug-pitch to the doctor and the doctor would fill out an evaluation. Unbeknownst to him, the company had no interest in the doctor’s opinions as a consultant. Their prescribing data, no doubt enabled by purchasing his “doctor number” from the AMA, showed that the physician was a low prescriber of the company’s drug. However, his busy practice suggested that his potential as a prescriber was very high. His “honorarium” for a day of consulting was in fact payment for enduring successive details in the belief that such extended exposure to marketing would turn him around on the company’s drug. The drug reps were laughing behind his back.

Two points should be made about this story. The doctor was subjected to a disrespectful variant of “deception research” of a kind regularly studied in college-level social psychology classes. But the doctor’s honorarium, his “consultation,” was not a “gift.” It was payment for his time and attention (but not for his opinion about drug reps’ performance).

I’d suggest that “pens,” “pizza,” and “mugs” are token payments, not gifts (that allegedly trigger the reciprocation mechanism). The token payment (in the form of a pen or pad) is given in reciprocation and out of recognition for what the drug rep has taken or asks for from the physician—some of his/her time and attention.

Dr. Robert Goodman, an internist at Columbia University, maintains a “cold turkey” website that not only documents the extent of industry influence on physicians, but more than half-seriously appeals to addictionism when he recommends that physicians take his adapted version of the CAGE screening questionnaire for alcoholism as step one in their road to no free lunch.

• Have you ever prescribed Lipitor?
• Do you get Annoyed at people who fuss about drug company sponsored lunches and free gifts?
• Is there a medication iGo on the pen you’re using right now?
• Do you drink your morning Eye-opener out of a Lipitor coffee mug?

If you answered “yes” to 2 or more of the above, you may have acquired drug company dependency.

The key proposition in Brody’s argument for total divestment is the claim that “at none of the levels [of medicine’s engagement with industry] is a financial-exchange relationship essential to medical or social ends.” And this claim assumes that financial conflicts of interest pose a greater hazard to medical integrity than non-conflicts of interest.

Conflict of Interest

“Conflict of interest” describes a condition or situation, not an act or omission. The incentives of a principal and the person empowered to act on the principal’s behalf, her agent, are never perfectly aligned.11 If so, no agent is absolutely trustworthy. The principal has reason to trust the agent in proportion to her trustworthiness. And there are risks both ways. Too little precaution, over-trusting, is foolhardy. Too much precaution, under-trusting, unreasonably sacrifices agency benefits.

Reliance on the physician’s sense of integrity and self-discipline for adherence economizes on monitoring and enforcement costs but at the risk of the physician’s biased, subjective, self-indulgent tendency to cut himself plenty of slack. Peer review corrects for first-person bias but at increased monitoring/disciplining costs and cronism risks. Having physicians swear oaths that invite divine oversight and punishment for non-adherence is potentially very effective, but only if God reliably monitors, rewards, and punishes per the invocation. Secular external sources of discipline by markets (especially by patients and their sponsors), personal injury liability at law or by state regulation are further necessary expedients, but their monitoring of physician adherence is very
imperfect, their disciplinary measures haphazard, and each may compete with and put at risk effective professional discipline and self-discipline.

The potential sources of information on medical conditions and drugs/devices to treatments is vast and expanding. Banning advertising in regulated settings will not result in its disappearance, but instead will redistribute it to less-regulated/unregulated settings. Didn’t the Noble Experiment and the War on (people who use) Drugs teach us that?

The proper response to industry bias and manipulative marketing is light and heat—thought education, expose the compliance tricks, and demand higher quality information. This requires constructive engagement, not prohibition, challenging drug reps in a graduate medical educational setting when their supportive studies are poor. On-campus bans that can be enforced will only invite off-campus involvement that cannot be prevented. Residents should be taught what techniques have been used and likely will be used on them (just as Consumer Reports warns subscribers about the techniques of car salesmen/women). It teaches residents how to spot spin and misrepresentation and alerts them to the psychological strategies that all compliance professionals know, and it stands some chance of improving the quality of information the industry supplies to physicians.

Endnotes

4. Plato, op. cit.
7. Phillips LS, et al. "Clinical Inertia." Ann Intern Med 135 (2001): 825-34. "Strong evidence now indicates that therapy for hypertension, dyslipidemia, and diabetes can prevent or delay complications. The goals for management are well defined, effective therapies are widely available, and practice guidelines for each of these diseases have been disseminated extensively. Despite these advances, health care providers often do not initiate or intensify therapy appropriately during visits of patients with these problems. We define such behavior as clinical inertia—recognition of a problem, but failure to act."

Conflicts of Interest in Medicine: Avoidable or Unavoidable?

Howard Brody, M.D., Ph.D.
University of Texas Medical Branch–Galveston

I have spent the last thirty-five years of my life engaged in the ethics of medicine and health care. Approximately the last five years were spent on a detailed study of the ethical issues in the relationship between medicine and the pharmaceutical industry.¹ For some time I sensed that this latter ethical issue was quite different from most of the issues that I had previously studied, but could not articulate the precise reason.

Finally concluded that I was simply not used to the degree of rationalization that seemed to pervade almost all the discussion of pharmaceutical issues, especially among physicians. When, for example, people who believe in the sanctity of life decry the removal of feeding tubes from terminally demented elderly patients, they generally state very frankly the nature of their reasoning. They don’t try to convince you that what you thought was a feeding tube is actually an aquarium pump. Yet defenders of the pharmaceutical industry will look at you with a straight face and try to persuade you that what seems to the average onlooker to be a sales pitch is really a form of education.²

Stell’s commentary on my book unfortunately illustrates one way in which this rationalization process works. Now that it has become commonplace to identify and to decry conflicts of interest in medicine, especially at academic medical centers,³ we have begun to hear a particular rationalization in reply—conflicts of interest are really ubiquitous in medicine, and pervade every aspect of practice, so it would be naïve to imagine that we could somehow eliminate them.¹ Moreover, the cost of the intrusive system of regulations needed to weed out these conflicts would be much greater than the damage done by the conflicts themselves.⁵

So let us track the examples of conflicts of interest that Stell mentions. First, he discusses the basic conflict between being well-paid and doing what is best for the patient. He then addresses the conflict between leisure activity (golf) versus spending more time working on behalf of one’s patients. He moves to the conflict between a careful respect for informed consent and voluntary choice among research subjects versus one’s felt need to recruit enough subjects to make the data scientifically valid.

Finally, at the end of his paper, Stell addresses financial conflicts of interest due to relations with industry: “This [Brody’s] claim assumes that financial conflicts of interest pose a greater hazard to medical integrity than non-conflicts [I assume he means non-financial conflicts] of interest. This claim is unsubstantiated by data.”

Without meaning to, I would imagine, Stell has given us a reprise of the common rationalization—conflict of interest is all over the landscape, so get over it. But he has added to it a twist that misunderstands the argument I am making—that somehow I am trying to distinguish between financial and non-financial conflicts. Rather, my point is to distinguish between avoidable and unavoidable conflicts.

I agree with Stell both that the payment versus service conflict is an extremely serious one, and also that it is practically
unavoidable—as Plato astutely pointed out, if we don’t pay physicians, we will find no one willing to care for us in times of illness. I assume that virtually all physicians want some time to themselves as well as lives devoted to patient service. And I am happy to admit that the scientific pressures of study design and conduct often conflict in subtle ways with a robust desire to protect the rights of research subjects.

What I will not agree to is that physicians must talk to and take gifts and meals from drug detail representatives, or else they will be ignorant about new medications. Or that academic investigators must accept from industry not only grants to do the research project, but also consulting fees, speakers’ bureau fees, and stock options. Or that physicians cannot afford to pay registration for their own continuing medical education, but must have such costs heavily subsidized by the industry. Or that medical professional societies must accept as much as a third of their revenues from the pharmaceutical companies and cannot possibly (like the APA) survive on member dues.

When conflicts of interest, however serious, are also unavoidable, then we must seek strategies to manage them as best as we can. The argument that I make in my book is that when a conflict of interest is both serious and avoidable, as are the majority of the worst financial entanglements that afflict medicine and the pharmaceutical industry, professional integrity and public trust require not management but avoidance. In the present environment, the claim that “we cannot eliminate conflicts of interest with the drug industry, so we must manage them” becomes yet one more layer of rationalization obscuring our ethical duties.

Stell makes two other comments about my book that deserve brief replies.

Stell is curious as to why I am not in favor of outlawing physicians’ off-label prescribing of medications, as that would eliminate the companies’ incentive to surreptitiously market off-label uses. I do not fully explain my views on off-label use in the book mainly because I agree with Stell. It is a handy safety valve against over-regulation, and a number of off-label uses of drugs are appropriate. Indeed the one drug example I talk about the most, the seizure medicine gabapentin (Neurontin), has in my view a completely acceptable off-label use for chronic neuropathic pain. The off-label marketing that landed the manufacturer in trouble was promoting the drug for a wide variety of mental health uses where there is no good evidence of efficacy. The off-label uses that I criticize in the book are all examples, where in my view, there is no good evidence to defend that method of prescribing.

Stell devotes a goodly portion of his commentary to rehashing the Nancy Olivieri case. He mentions the one footnote in my book in which I offer apologies for coming so late upon Shuchman’s book, which offers an account quite contrary to that of Stell. He mentions the one footnote that Stell fails to cite,6 knowing that there would be a need regularly to update the information that the book contains, I undertook to write a blog to supplement the book’s contents, and one of my early entries expanded my discussion of the Olivieri case and Shuchman’s treatment of it.7 I suggested in that posting that while the account that I gave in my book was based on a thoroughly researched and apparently authoritative investigative report by the Canadian Association of University Teachers (which Stell fails to cite),6 the Shuchman book nonetheless raises questions about its accuracy. I was therefore unhappy that one prominent Canadian authority on the case, who attacked the Shuchman book as obviously incorrect and biased, I will stand by my final conclusion in the blog posting, that the battle lines in that case are so sharply drawn that it is unlikely that we will ever know the full truth.

Endnotes


What Would You Like To Know?

Felicia Nimue Ackerman
Brown University


The woman answering the doorbell looked nothing like Marie, who had a narrow, pale face and hair the brown of coconut shells. This woman was sturdy and definite, with broad, ruddy cheeks and black hair showing just traces of gray although she looked about fifty—another reason she wouldn’t be the right person. Too bad, Marie thought; the woman seemed remarkably approachable as she stood in the doorway, saying cheerfully, “Yes?” and when Marie hesitated, “Well, what good cause are you? Cancer and diabetes were here last week and I gave to both, but I told the Jehovah’s Witnesses to take their pamphlets and shove them. They’re probably praying for me right now—No, Cassandra.” She scooped up the tortoiseshell cat that had come through the door to rub against Marie’s legs. “She loves everyone, I guess it’s a virtue in a cat. Well, what are you, the Heart Association?” Her glance went beyond Marie, to the sky, and she smiled.

Marie said, “I—you’re not Rosalind Thetford, are you? I was given this address, but it’s pretty old.” Twenty-three years old, in fact, but it was all Marie had, since the telephone operator had said the only R. Thetford was unlisted.

“I’m not Roz Thetford? That’s news to me. Who are you and what can I do for you?” The woman stuck her thumbs through belt loops of her red pants—her fingers were ringless, Marie noticed—and regarded Marie with a kind of good-natured challenge.

This is it, Marie thought, looking away and forcing her mind to fill up with details. The house was painted white. The yard had daffodils and tulips. There was a silver Honda Accord in the driveway, with the bumper sticker “I’d Rather Be Eating Chocolate.” Marie was allergic to chocolate. She was allergic to cats, and she looked nothing like this woman with the right name and right address. “My name is Marie Hallowell,” Marie said. Her lips felt thick and unfamiliar.
as if someone else’s mouth had been stuck into her face. “I was born in Williams Hospital on October 9, 1963. My mother’s name was Rosalind Thetford, and she gave me up for—”

“Wow,” said the woman. “That’s me, all right. This is amazing. Come on in!”

Marie gaped. The woman turned, leading Marie into a living room with many windows. There was a gray velvet sofa and a pair of armchairs to match, a mostly-blue Oriental rug and a marble fireplace. The room looked airy and suggested prosperity. Marie was glad, because even if this woman was too old to have been the pregnant teenager of Marie’s imagination, she hardly could have had it easy when she’d had to give Marie up, and Marie always liked to think the last would someday be first. And the first would be last. It was her favorite thing about teaching junior-high-school students. Their pecking order was so clear, but, you could always tell yourself, so temporary.

“Sit down anywhere,” said Roz Thetford, settling into an armchair. Marie sat down on the edge of the sofa. Roz propped her chin on a fist and stared at Marie brightly. “Well,” Roz said, “tell me all about yourself. Or ask me questions. I guess that’s part of what you’re here for. What would you like to know?”

Marie shivered a little and pulled her blazer around her. She was wearing what she had worn to job interviews, a tailored blue corduroy dress and a camel-colored blazer. The combination was supposed to be serious and stylish, her best meeting-people outfit. But sitting in the room with this woman in red pants and a black corduroy dress and a camel-colored blazer. The combination was so clear, but, you could always tell yourself, so temporary.

“Twenty-three? That was six years before you were born. And why is it that you once read an article on weather forecasters, or sometimes the only one. I had magical powers.”

“If she says one more thing about the weather, I’m going to scream, Marie thought, although she knew she had asked for it, and anyway, she never screamed. Maybe Roz did. She seemed more the type. She’s nervous, Marie tried to tell herself; that’s why she’s rattling on this way. But Roz didn’t seem nervous. She seemed bouncy and friendly, as if Marie were a neighbor who had dropped in for the afternoon. What’s the matter with you? Marie wanted to scream. “You’re my mother,” she said, “and I don’t know you.”

“No, I guess that wouldn’t be the main thing on your mind right now,” she said. “What else can I tell you?”

Tell me about yourself. How you... no, tell me more about your work,” Marie finished, feeling ridiculous but recalling a principle from a counseling course: Begin by letting people talk about what is easiest for them.

“What?” Roz looked startled but pleased. “Well, I can get so sentimental about my work I would make Tiny Tim squirm. Marie felt silly to have come dressed as if she were trying to get a teaching job. And how was she supposed to answer the question, What would you like to know? She felt disoriented. She could hardly say, I’d like to know how you’ve longed for me; why aren’t you sobbing and falling all over me right now? Marie’s arms tingled as if waiting to be embraced. She thought of her fantasy mother, with the narrow, pale face, faded from years of waiting. “I’d like to know about my family,” Marie said, stiffening as the cat walked with sure steps into her lap.

Roz nodded. “You don’t like cats?”

“I can’t help it,” Marie said. “I’m a bit allergic. It’s okay as long as a cat isn’t actually on me.”

Roz got up and walked over to the sofa. As she took the cat from Marie’s lap, the back of her hand brushing against Marie’s—maybe the first time my mother ever touched me, Marie thought—but it was over almost before it began, and Roz was rubbing the cat’s head. “I’ll be right back,” she said and left the room, reappearing in a few moments, catless and holding a plate of coconut macaroons, which she set down beside Marie after taking two for herself.

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bank loans—you have to look as if you don’t need them or you’ll be rejected.”

“That is absolutely right.” Marie sat up straighter. “I wonder why.”

“Well, people want to think you want them, not just anyone. Also, they’re afraid of being overwhelmed—not if they really love someone, but how often does that happen?”

“Not very, I guess.” Marie gazed at Roz thinking, Once she was alone and pregnant, and now she’s fifty-two, and she still has romantic ideals like a teenager—or like me.

“Well, that was me at twenty-three,” Roz said with a little flutter of her hand. “Tell me about yourself. The agency people said you were going to a couple that had been on their waiting list for over a year.”

“The people I went to were good to me in their way,” Marie said, adding some details about where she had grown up. “My father, I mean my adoptive father, is a minister, so I had to go to church a lot.” She looked at the wall facing her. There was a blue-and-green abstract painting and two framed photographs of tornadoes that looked like thick gray funnels coming down from the sky. “I didn’t like church,” she said slowly, “except for a few ideas no one really paid attention to. Like...well, I teach junior high. The best part is that even though the kids are so unequal, there’s nothing final about it. You can always tell yourself that when they grow up, the last shall be first,” Marie finished in a sudden rush, a bit short of breath.

“That’s a nice thought,” said Roz. “Not too realistic, maybe, but you might as well imagine what you want.”

“Exactly,” said Marie, wondering what it would have been like to have been brought up by this woman who understood about fantasies and unfairness, instead of by religious people who thought you shouldn’t covet what wasn’t yours. “The thing is,” Marie was breathing deeply, pacing herself, “I have a sister, Christine. She was adopted too, three years younger, smarter and prettier, and she always liked church. Now she’s a sister. Christine. She was adopted too, three years younger, smarter and prettier, and she always liked church. Now she’s even planning to go to divinity school. I always felt they loved her more than me. I never told anyone this before.

“Maybe they did love her more,” said Roz. “It sounds as if she was more their type of person. I mean, how can you contract in advance to love people equally, regardless of what they’re like?”

“I wanted to be loved the most of all,” Marie said.

“Doesn’t everyone?”

“I don’t know.” Marie glanced out the window. The sky was still mostly blue, but the clouds were shifting—not the wrong way for Roz, she hoped. Marie opened her mouth, closed it, then opened it again. “Are you willing to...tell me about my father?” she said.

“Of course,” said Roz, and Marie was surprised to see her expression soften. “I’ve never known anyone else like him, so...” Roz smiled as a trapezoid of sunlight fell across her lap. “You know, women nowadays aren’t supposed to want to be taken care of. But it’s what I’ve always wanted—and wanted to give in return. I’ve always wanted, ...” Her voice was so soft and languid she sounded like a different person.

“But—” Marie said.

“I’ll tell you a story about him,” Roz said, bouncing forward in her chair as her voice regained its sparkle. “A month before he was coming up for tenure, two years before you were born, he had to go to a history department party. It was a dark and stormy night, just like in the parodies, only I’d convinced the office to forecast that the storm would bypass the city, so I wasn’t feeling too great. But Bob hated those parties and I knew he’d want me as company, so I put on my best red dress with matching shoes and a smile and went along.” She wrapped a lock of hair around her finger. “The chairman’s wife was a psychiatrist. She never would have twitted a surgeon about an unsuccessful operation, but of course as soon as we got there, she said, ‘I don’t know about you, Roz, but this isn’t exactly my idea of a partly cloudy with temperatures moderating into the fifties.’ Roz leaned back in her armchair, and Marie realized this must be Roz’s favorite story. How many times had it been relived over the past quarter century?

“Well, I managed a sickly little giggle that sounded like a cross between a sneeze and a dying cat,” Roz continued dreamily. “But Bob wasn’t having any. He said, ‘Think of it this way; no one’s ever gotten locked up in a mental hospital because of a wrong prediction by a meteorologist.’ He said that to his chairman’s psychiatrist wife with the chairman standing right there.”

“And what happened?” said Marie.

“Oh, he got tenure. The chairman’s wife even told me later she was impressed that he said what he did. She wasn’t a bad person, just a little unimaginative, and when I got to know her better, I ended up liking her about as much as I could like anyone who rented out compassion by the hour.”

But, Marie reminded herself, Roz had ended up alone, deserted by the lover whose memory she had cherished for decades; the party story shone in her life as if it had happened yesterday. Marie didn’t realize she was crying until she felt the wetness and heard Roz say, “Marie? What’s the matter?”

“You loved him, and he abandoned you...and you still love him,” Marie said thickly. “Why don’t you hate him? I would.”

“Abandoned me?” said Roz. “What do you mean?”

“Why, when you had me.” Marie wiped her eyes with the back of her hand. “You said he’s a history professor; he’s still alive....”

“Oh, dear,” said Roz. “I just assumed that whoever gave you my name told you.”

“Told me what? They only gave me your name and address.”

“Your father and I are married,” said Roz. “We were married three years before you were born.” She glanced at her hands. “I take off my rings when I’m doing stuff around the house, but I thought you knew.”

Marie heard the words, but her mind at first registered “three years after.” She was about to say, So by then the adoption was final and you couldn’t get me back? Then she realized what Roz had said. “Three years...before?” said Marie. “But why...why didn’t you... why did you give me up?”

“Because,” said Roz as matter-of-factly as someone else talking about the weather, “we didn’t want kids. We both wanted to be loved most of all, and that is what we got, you see.”

Marie’s mind skidded up against this idea and jolted to a stop. “You... I... You... How could you?”

“Look,” Roz looked at her, then looked away. “Please.” Roz’s left eyelid twitched. “Being parents would have ruined our life together.” Her voice rose. “It would have ruined it, can’t you see? You went to a couple that really wanted... I mean... Look, I could have made up a pretty story for you, but that kind of lie never—”

And then the telephone rang and Roz got up and disappeared into the next room. “Bob, you’ll never guess who’s here,” Marie heard hear say flatly. But even as Roz spoke, Marie was rising, leaving quickly, quietly; she felt as if she were gliding. Gliding into the brilliant blue afternoon that she hoped would soon turn into what Roz had not forecast, on toward
ANNOUNCEMENTS

Call for Submissions: An Ethical Competition
The Method in Bioethics Research
Prof. John Harris

"'Tis madness, but there's method in't." But is there? There are many different ways of doing bioethics. It is a point of pride and of truth that bioethics is a multidisciplinary and sometimes an interdisciplinary activity. All of the constituent disciplines doubtless have their methods, but in the case of theoretical bioethics, thought of by philosophers or by those with a philosophical turn of mind as philosophical bioethics, there is a problem. What do we answer when asked what is our methodology? Or what methods will we use to address and answer the questions we asked or those which are asked of us?

This may seem an idle question; those who are philosophically trained know what they are doing; but how to describe it? Increasingly, theoretical bioethicists seek funding to support their research. Funding bodies have the annoying habit of wanting to know the methodology or methodologies that will be used in carrying out the proposed research.

Empirical researchers have a ready set of answers to this question but it seems not a little lame, not to say disingenuous, when philosophers, when asked about their methods, are tempted to reply, "reading, writing, and thinking." It may not be possible to provide a definitive answer to this question, but what is sought is a persuasive and, it is hoped, plausible answer.

The editors of the leading journals in bioethics have resolved to try to find the answer, or perhaps a set of answers, to this question. Accordingly, we are launching a competition to find an answer to the ultimate question of bioethics: What is or are the methods of theoretical bioethics?

The best five answers to this question will be published in each of the journals listed above. Entrants to this competition must imagine they have been asked on a grant application to state the methodology or methodologies to be used, in not more than 500 words.

You may have applied for funding to answer any of the theoretical questions of bioethics, for example: Is abortion unethical? How would one decide whether euthanasia is justifiable? Is Human Embryonic Stem Cell Research justifiable? What are the ethical issues in producing animal/human hybrids or chimeras? Is research on animals or on nonhuman primates permissible and under what circumstances? Devise an ethical framework for human subject research. Is fully informed consent the gold standard of human subject research and what does it mean to have fully informed consent? On what basis could one decide if human enhancement should be pursued or designer children created? This is not intended to be an exhaustive list; you can imagine your own research topic or provide a general methodology for all and any research topics.

Your 500-word answer on the methods of theoretical bioethics should be received no later than February 1, 2008. Mark your entry "METHODS IN BIOETHICS COMPETITION" and submit to: methodinbioethics@yahoo.co.uk

The competition will be judged by all the editors of these journals and the best five answers will be published in all of the journals simultaneously, thereby, for the one and only time, breaking the absolute prohibition on multiple submissions to journals.

Conference
On September 17-18, 2007, Public Responsibility in Medicine and Research (PRIM&R) will host IRB Administrator 101. This program is tailored specifically to the educational needs of Institutional Review Board (IRB)/Human Research Protections Program (HRPP) members, administrators, and staff. This course will identify the key components of HRPPs, examine the primary responsibilities of administrators, and review the strategies and policies for developing and/or strengthening your institution's research protection. The Sheraton Baltimore North Hotel in Towson, Maryland. [www.primr.org](http://www.primr.org). Mariellen Diemand, indemand@primr.org or by phone at 617-423-4112, ext. 210.

First Annual Hospital Ethics Committee Swap Shop
A gathering of hospital ethics committee members and clinical ethics consultants from the Northeast to swap interesting, surprising, and vexing cases and to discuss topics of interest to everyone involved with clinical ethics consultation.

September 28, 2007, 10:00 am to 4:30 pm
Old Chapel, Union College Campus, Schenectady, New York
[bioethics@union.edu](mailto:bioethics@union.edu)
Hosted by The Union Graduate College–Mount Sinai School of Medicine Bioethics Program

Program
Professionalism at Academic Medical Centers: Challenges and Opportunities. This one and a half day program will address important opportunities and challenges in promoting, teaching, learning, and assessing professionalism at academic medical centers. October 4-5, 2007, Leighton Auditorium, Second Floor, the Siebens Medical Education Building, Mayo Clinic, 100 Second Avenue Southwest, Rochester, Minnesota. [www.mayo.edu/cme/oct2007.html](http://www.mayo.edu/cme/oct2007.html) Mayo School of CME, Plummer 2-60, 200 First Street SW, Rochester, MN 55905, tel. 1-800-323-2688, fax 507-284-0532, [www.mayo.edu/cme](http://www.mayo.edu/cme).

ASBH Annual Meeting
October 18-21, 2007
Renaissance Washington, D.C. Hotel
Washington, D.C.
[http://www.asbh.org/meetings/annual/index.html](http://www.asbh.org/meetings/annual/index.html)

Conference
Conference
The 22nd International Conference of the European Society for Philosophy of Medicine and Health Care, presented with the Centre for Ethics, University of Tartu. The theme will be “European Bioethics in a Global Context,” and the conference will be held August 20-23, 2007, in Tartu, Estonia. Bert Gordijn, Ph.D., Secretary of the ESPMH, Department of Ethics, Philosophy, and History of Medicine, Radboud University Nijmegen Medical Centre, PO Box 9010, 6500 HB Nijmegen, The Netherlands, e-mail: b.gordijn@efg.umcn.nl.