denying through the doctrine of double effect a terminally ill patient's request to be given a lethal injection or to have ordinary life-sustaining measures stopped so she could die.

Cases for Evaluation (Ch.3)

CASE 1

Faith-Healing Parents Arrested for Death of Second Child

A religious couple already on probation for choosing prayer over medicine in the death of their toddler son may be facing similar charges in the death of their newest child. "They lost their 8-month-old son, Brandon, last week after he suffered from diarrhea and breathing problems for at least a week, and stopped eating. Four years ago, another son died from bacterial pneumonia."

That boy, a two-year-old named Kent, died after the Schaibles refused to take him to the doctor when he became sick, relying instead on faith and prayer. The couple were convicted of involuntary manslaughter and sentenced to 10 years on probation.

In the latest tragedy, they told police that they prayed for God to heal Brandon instead of taking him to a doctor when he fell ill. Officials said that an autopsy will be performed on the child, and depending on those results the parents may be charged with a crime.

The couple attend, and have taught at, Philadelphia's First Century Gospel Church, which cites Biblical scripture favoring prayer and faith over modern medicine. Other religions, including Followers of Christ Church, Christian Scientists, and Scientology, have doctrines that prohibit or discourage modern medicine and therapeutic interventions.

This is not the first time that parents have gone on trial for child abuse or neglect for refusing their children medical attention. Though freedom of religion is guaranteed by the First Amendment to the U.S. Constitution, the practice of that religion does not give followers license to break the law—especially when the result is injury or death to a child.*

Do you agree with the court's sentence of ten years of probation? Should the sentence have been harsher? Why or why not? Do you think that parents should have the right to reject medical treatment for their children on the basis of religious beliefs? What moral principle would support your judgment? Should religious liberty be construed to allow parents to do anything *with their children as long as the actions are based on religious considerations? If not, what sorts of actions should and should not be allowed?*

*Discovery.com, 24 April 2013.

CASE 2

State Paternalism and Pregnant Women

(AP)—Public hospitals cannot test pregnant women for drugs and turn the results over to police without consent, the Supreme Court said Wednesday in a ruling that buttressed the Constitution's protection against unreasonable searches [*Ferguson v. City of Charleston*].

Some women who tested positive for drugs at a South Carolina public hospital were arrested from their beds shortly after giving birth.

The justices ruled 6-3 that such testing without patients' consent violates the Constitution even though the goal was to prevent women from harming their fetuses by using crack cocaine.

"It's a very, very important decision in protecting the right to privacy of all Americans," said Priscilla Smith, lawyer for the Center for Reproductive Law and Policy, who represented the South Carolina women. "It reaffirms that pregnant women have that same right to a confidential relationship with their doctors."

Justice John Paul Stevens wrote for the court that while the ultimate goal of the hospital's testing program may have been to get women into drug treatment, "the immediate objective of the searches was to generate evidence for law enforcement purposes in order to reach that goal."

When hospitals gather evidence "for the specific purpose of incriminating those patients, they have a special obligation to make sure that the patients are fully informed about their constitutional rights," Stevens said.

South Carolina Attorney General Charles Condon, who as a local prosecutor in Charleston began the testing program, issued a statement saying the program can continue if police get a search warrant or the patient's consent. "There is no right of a mother to jeopardize the health and safety of an unborn child through her own drug abuse," Condon wrote.

Condon developed the policy along with officials at the Medical University of South Carolina, a Charleston hospital that treats indigent patients. The women were arrested under the state's child-endangerment law, but their lawyers contended the policy was counterproductive and would deter women from seeking prenatal care. . . .

The decision reversed a federal appeals court ruling that said the South Carolina hospital's drug-testing policy was a valid effort to reduce crack cocaine use by pregnant women.

The hospital began the drug testing in 1989 during the crack cocaine epidemic. If a woman's urine test indicated cocaine use, she was arrested for distributing the drug to a minor. In 1990 the hospital gave drug-using maternity patients a choice between arrest or enrolling for drug treatment.

Ten women sued the hospital in 1993, saying the policy violated the Constitution. The hospital dropped the policy the following year, but by then police had arrested 30 women.*

Do you agree with the Supreme Court's decision? Why or why not? Should the state force pregnant women to behave in certain ways while carrying a fetus? If pregnant women can be legally punished for "fetal abuse," how should it be defined? Is a pregnant woman guilty of fetal abuse if she refuses to eat properly? Drinks any amount of alcohol? Forgoes prenatal care? Whose interests should be given greater weight—the woman's or the fetus'?

*Associated Press, "Court: Consent Needed to Drug-Test Pregnant Women," CNN.com., 21 March 2001.

CASE 3
Medical Futility

(*Washington Post*)—A 17-month-old deaf, blind and terminally ill child on life support is the latest focus in an emotional fight against a Texas law that allows hospitals to withdraw care when a patient's ongoing treatment is declared "medically futile."

Since Dec. 28, baby Emilio Gonzales has spent his days in a pediatric intensive care unit, mostly asleep from the powerful drugs he is administered, and breathing with the help of a respirator. Children's Hospital here declared his case hopeless last month and gave his mother 10 days, as legally required, to find another facility to take the baby. That deadline, extended once already, was due to expire Wednesday, at which time the hospital was to shut off Emilio's respirator. Without the machine, Emilio would die within minutes or hours, hospital officials have said.

But the child's mother, Catarina Gonzales, 23, and lawyers representing a coalition of state and national disability rights advocates and groups that favor prolonging life persuaded a Travis County judge Tuesday to force the hospital to maintain Emilio's care while the search for a facility to accept him continues. The group's attempt last week to persuade a federal judge to intervene in the case failed.

County Probate Judge Guy Herman appointed a guardian ad litem, or attorney, to represent Emilio's interests and issued a temporary restraining order prohibiting Children's Hospital from removing life-sustaining care from the child. He set an April 19 hearing on the mother's and lawyers' request for a temporary injunction against the hospital.

"I believe there is a hospital that is going to accept my son," said Gonzales following the brief hearing. "I just want to spend time with my son. . . . I want to let him die naturally without someone coming up and saying we're going to cut off on a certain day."

Michael Regier, senior vice president for legal affairs of the Seton Family of Hospitals, which includes Children's Hospital, said the child's condition continues to deteriorate although he has not met the criteria to be declared brain dead. He said the

hospital has contacted 31 facilities "without any single indication of interest in taking the transfer."

Gonzales and her lawyers are seeking a transfer for the child, diagnosed with a terminal neurometabolic disorder called Leigh's disease, to a hospital that will perform a tracheotomy and insert a feeding tube so that he can live out his life in the facility or at home with his mother. But Children's Hospital doctors have declared that continuing treatment is potentially painful and is prolonging the child's suffering.

Emilio's case has drawn interest and support nationwide, including from the siblings of Terri Schiavo, the Florida woman who was in a persistent vegetative state and who died in 2005 after doctors, acting on a court order, removed her life-sustaining feeding tube.

Texas's six-year-old "futile-care" law is one of two in the country that allow a hospital's ethics committee to declare the care of a terminally ill patient to be of no benefit and to discontinue care within a certain time frame. The patient's family or guardian must be informed in advance of the ethics committee meeting and must be allowed to participate. The family must also be given 10 days to find a medical facility willing to accept their terminal relative. After that period, the hospital may withdraw life support. Virginia gives a family 14 days to transfer a patient once a futile-care decision is made.*

Do you agree with the hospital's reasons for wanting to withdraw care? Do you agree with the child's parents? Explain. Do you believe that life should be preserved at all costs (the sanctity of life view)? Why or why not? Do you believe that quality of life is more important than the preservation of life in cases like this? If so, how would you justify that view?

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*Sylvia Moreno, "Case Puts Futile-Treatment Law Under a Microscope," *Washington Post*, 11 April 2007.

FURTHER READING

Tom L. Beauchamp and James F. Childress, *Principles of Biomedical Ethics*, 5th ed. (New York: Oxford University Press, 2001), 176–94, 283–336.

Dax Cowart and Robert Burt, "Confronting Death: Who Chooses, Who Controls? A Dialogue Between Dax Cowart and Robert Burt," *Hastings Center Report* 28.1 (1998): 14–17.

Harriet Hall, "Paternalism Revisited," *Science-Based Medicine*, December 16, 2008, https://www.sciencebasedmedicine.org/paternalism-revisited/ (20 October 2015).

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Ravi Parikh, "When Paternalism Doesn't Work for Patients," *Huffington Post*, May 29, 2015, http://www.huffingtonpost.com/ravi-parikh/doctor-patient-relationship_b_7447236.html (20 October 2015).

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Gregory E. Pence, *The Elements of Bioethics* (New York: McGraw-Hill, 2007).

Robert M. Veatch, "The Dying Cancer Patient," in *Case Studies in Medical Ethics* (Cambridge, MA: Harvard University Press, 1977), 141–47.

NOTES

1. This summary of positions takes its inspiration from Tom L. Beauchamp and James F. Childress, *Principles of Biomedical Ethics*, 5th ed. (New York: Oxford University Press, 2001), 182–87.
2. Linda Greenhouse, "Supreme Court Roundup: Christian Scientists Rebuffed in Ruling by Supreme Court," *New York Times*, 23 January 1996.
3. *Prince v. Commonwealth of Massachusetts*, 321 U.S. 1958 (1944).
4. Steven H. Miles, "Informed Consent for 'Non-Beneficial' Medical Treatment," *The New England Journal of Medicine* 325.7 (15 August 1991): 512–15; "Brain Damaged Woman at Center of Lawsuit over Life-Support Dies," *New York Times* (6 July 1991), 8.
5. John Stuart Mill, *On Liberty* (1859; rpt. Gateway ed., Chicago: Henry Regnery, 1955), 17–18.
6. *Bouvia v. Superior Court*, 179 Cal. 3d 1127, 1135–43, 225 Cal. Rptr. 297 (Ct. App. 1986).
7. *Ibid.*

principle of autonomy, the idea that people should be allowed to exercise freely their rational capacity for self-determination.

Confidentiality concerns patients imparting information to health professionals who promise, implicitly or explicitly, not to disclose that information to others. Consequentialist arguments for confidentiality say that without it, physicians would be hard pressed to obtain information from patients that could help in treatment, and trust between physician and patient would break down. Moreover, disclosure of confidential medical information could expose patients to discrimination, disrupt their personal relationships, and subject them to shame or public ridicule. Nonconsequentialist arguments appeal to the principle of autonomy, contending that autonomous persons have a right to determine what may or may not be done to their bodies as well as to their private lives. They have a right to privacy, the authority of persons to control who may possess and use information about themselves.

A major issue is whether the obligation to respect confidentiality is absolute or prima facie. Some argue for absolute confidentiality, insisting that any breech of it undermines trust between physicians and patients and amounts to impermissible deception. But many believe that exceptions are sometimes justified when confidentiality must be weighed against other duties, such as the duty to prevent serious harm to the patient and others.

Cases for Evaluation (Ch. 4)

CASE 1

Disclosing Information about the Risk of Inherited Disease

Mrs. Durham was diagnosed with an invasive epithelial ovarian cancer and, in conjunction with conversations about her treatment, was offered genetic testing for the BRCA1 and BRCA2 mutations. It was revealed that she carried a harmful BRCA1 mutation that is known to increase the lifetime risk of breast and ovarian cancer significantly. Once the results came back, her oncologist brought up the option of a prophylactic mastectomy and advised her to inform her living relatives of the results of the test.

Mrs. Durham's primary care physician, Dr. Bartlett, expected she would do so, too. At her first appointment after the diagnosis, Dr. Bartlett asked Mrs. Durham how she was holding up and how her sister, Mrs. Weir—her only living family member and also one of Dr. Bartlett's patients—had taken the news.

"Oh. Well, I haven't told her."

"Are you going to?" asked Dr. Bartlett.

Mrs. Durham responded, "You know we haven't spoken in quite some time, and I can't imagine making this the topic of our first conversation."

"Yes, I know... but I think this is important information that may affect her health."

Mrs. Durham sighed. "We're estranged, for one thing, and for another, I want to keep my cancer private. I don't want people knowing I'm sick and pitying me."

Dr. Bartlett felt pulled in two directions—his obligation to respect Mrs. Durham's wishes and protect her privacy conflicted with his obligation to promote Mrs. Weir's health. BRCA1 mutations are not "reportable" illnesses like HIV and tuberculosis, so he was not compelled by law to break Mrs. Durham's confidentiality. Dr. Bartlett considered how he might be able to encourage Mrs. Durham's sister to be tested for the BRCA mutations while preserving Mrs. Durham's confidentiality.*

Does Mrs. Durham have a moral obligation to inform her sister of the results of the test? Why or why not? For Dr. Bartlett, what moral principles are in conflict? If Mrs. Durham refuses to inform her sister, should Dr. Bartlett tell her? What should Dr. Bartlett do if he can't subtly ask Mrs. Weir to be tested (that is, if he can't ask her without revealing the real reason for his request)?

AMA Journal of Ethics, vol. 17, no. 9 (September 2015), pp. 819–825.

CASE 2
HIV and a Researcher's Duty to Warn

John, a licensed psychologist, is Principal Investigator for the "Assist" Project. His project is designed to identify behavioral trends among HIV+ adults in the New York City area. Participants were recruited from HIV/AIDS support groups, HIV/AIDS advocacy and service organizations, and through publicity in local bars, clinics and media outlets. John uses several measures to identify patterns among these individuals. He looks at help-seeking behaviors, physical and emotional symptoms, nutrition and diet habits, sexual behavior and knowledge of HIV/AIDS.

John uses an individual interview format as the method for the study. Each participant is asked to sign an informed consent form, which guarantees that all information revealed during the interviews will be kept confidential. The consent form describes the study and informs participants of the risks involved, which John identifies as minimal. Each participant is paid $50 for each interview. Participants in the study are also provided free psychological counseling and medical care. Participants are interviewed three times over a two-year period.

In accordance with the research protocol, John asks a participant during one of the initial interviews about her current sexual practices. The participant tells John that she is having unprotected sex with her boyfriend. She states that her boyfriend does not know about her HIV status and that she has no plans to reveal her condition. Later during the interview she mentions the name of her boyfriend. John notes the information and continues with the interview.

Upon going back to his office, John becomes anxious about what he was told by the participant. He ponders what he should do. John thinks about his moral responsibility from a relational perspective, assessing the ethical problem from the standpoint of his responsibility to preserve the scientific integrity of the project, the participants' confidentiality and the boyfriend's welfare.*

What moral principles seem to be in conflict in this scenario? How would you resolve the conflict? Suppose John's only options are either to maintain confidentiality or to violate it by revealing the subject's HIV status to her boyfriend (the subject refuses to notify him voluntarily). What should John do, and on what grounds could either action be justified? Suppose that state law prohibits researchers from revealing a subject's HIV status. Would this fact change your judgment? Should *any such legal fact change your judgment?*

*Brian Schrag, ed. (Association for Practical and Professional Ethics), "Graduate Research Ethics: Cases and Commentaries—Volume 3, 1999," Online Ethics Center for Engineering, 27 March 2006, www.onlineethics.org/CMS/research/rescases/gradres/gradresv3.aspx. (14 November 2007).

CASE 3
Emergency Department Dilemma

A 25-year-old young man is dropped off by a friend at the emergency department (ED) and states that he was in a motor vehicle accident 30 min before arriving. He says that his car was extensively damaged but that he was able to get out of the car and walk around at the scene. There was no loss of consciousness. He states that the police were at the scene investigating. He does not volunteer whether the police questioned him personally or why the police let him leave. Except for bumps and bruises, he is not significantly injured enough to justify a radiograph or computed tomography scan of his head. However, I detect the odor of ethanol on his breath, and so I order a blood ethanol to evaluate his capacity further. It is my opinion that if he is legally impaired, then he cannot leave the ED unless someone picks him up and assumes responsibility for him. He does not refuse the test and his blood ethanol level is 0.17 mg/dl, indicating that he is legally impaired.

Emergency physicians know that people who think they might be legally impaired have a strong incentive to leave the scene of accidents to avoid detection by investigating police. This patient's story about being involved in a multicar crash severe enough to cause significant property damage, and then the investigating police allowing him to leave the scene without checking him for potential ethanol intoxication does not ring true.*

Should the physician maintain doctor-patient confidentiality? Should he tell the police that his impaired patient probably broke the law and may have hurt others? What moral principles are relevant to deciding what to do? How much weight would you give to them? Should regard for public safety and the law ever outweigh doctor-patient confidentiality? Explain.

Cases for Evaluation

CASE 1 (Ch. 5)

Informed Consent or Not?

A 64-year-old woman with multiple sclerosis (MS) is hospitalized. The team feels she may need to be placed on a feeding tube soon to assure adequate nourishment. They ask the patient about this in the morning and she agrees. However, in the evening (before the tube has been placed), the patient becomes disoriented and seems confused about her decision to have the feeding tube placed. She tells the team she doesn't want it in. They revisit the question in the morning, when the patient is again lucid. Unable to recall her state of mind from the previous evening, the patient again agrees to the procedure.*

Explain your answers: Has the woman given her informed consent? Should she be judged competent? Should her final agreement to the procedure be sufficient to establish informed consent, or should her earlier waffling and confusion also be taken into account?

*"Informed Consent," *Ethics in Medicine* (University of Washington School of Medicine), http://depts.washington.edu/bioethx/topics/consent.html (17 November 2007).

CASE 2

Informed Consent and Organ Transplants

(AP)—A woman in her 30s who is one of the four organ transplant patients [who became] infected with HIV and hepatitis [because of the transplant] was not told that the infected donor was high risk, and had previously rejected another donor "because of his lifestyle," her attorney said.

Attorney Thomas Demetrio filed a petition Thursday in Cook County Circuit Court on behalf of the woman, asking officials to keep a hospital and an organ procurement center from destroying or altering any records involving the donation.

"She's really a mess right now," Demetrio said of the Chicago-area woman. "She's still in shock."

The patient, identified in court documents as Jane Doe, received a kidney transplant at the University of Chicago Medical Center on Jan. 9, Demetrio said.

Gift of Hope Organ & Tissue Donor Network in Elmhurst and the University of Chicago both knew the kidney donor was high-risk and did not inform the patient, Demetrio said.

University of Chicago spokesman John Easton responded in an e-mail: "We believe we follow guidelines, and of course with the patient's consent we will provide necessary records and documents, as is consistent with our open process."

Gift of Hope did not immediately respond to requests for comment.

The woman had been told the donor was a healthy young man, her attorney said. But on Tuesday, hospital officials disclosed to the woman that he was actually high-risk, a 38-year-old gay man, Demetrio said. CDC guidelines say that gay men who are sexually active should not be used as organ donors unless the patient is in imminent danger of death.

The woman was told she had HIV and hepatitis on Nov. 1, he said.

"The (organ) procurement group knew, the hospital knew, but the most important person did not know," he said. "The people that dedicate their lives to these transplant surgeries, they're just great people, but they need to bring the patient into the mix and let them make an informed decision."

U.S. Centers for Disease Control and Prevention guidelines were violated twice, the attorney said. One violation was not informing the woman about the donor's status and then not testing her afterward for HIV until just recently, after HIV and hepatitis were found during tests on another patient who was being evaluated for a second transplant. . . .

She's been started on an HIV drug regimen "and unfortunately one of the side effects is it's not good for the kidneys," Demetrio said. She's not hospitalized.

Dr. Dan Berger, medical director of a large HIV-AIDS clinic in Chicago, said U.S. doctors have had several years of experience treating HIV-infected patients who went on to get transplant organs. Such patients need an HIV specialist and a transplant

specialist to monitor their medications, which include anti-rejection drugs for the transplant and antiretrovirals for HIV, he said.

The four patients infected by the high-risk donor's organs have extra medical concerns, Berger said.

"When a patient first becomes infected with HIV there's a huge spike in viral load and (at the same time) severe immune compromise," he said. "The fact that they also are on immune-suppressive medications (after transplant) may put them at extreme risk for opportunistic infection."*

If Jane Doe had not become infected with HIV and hepatitis after her transplant, would the failure of the donor network and the university to fully inform her about the donor have been morally wrong? If so, why? Would her consenting to the transplant have been permissible if she had known that the donor was high risk? Should a patient have the right to consent to and undergo risky treatments? Explain.

*The Associated Press, "Atty: Woman Wasn't Told Donor Was a Risk," 16 November 2007.

CASE 3
Adolescent Informed Consent

In mid-summer, a 14-year-old youth was brought to the pediatric emergency department by his mother for evaluation for altered mental status. The mother returned from work to find her son acting strangely. She had last seen him the previous evening, and there were no problems or complaints at that time. Earlier in the week the child had sustained several mosquito bites. The child was now at times lethargic and at other times agitated. There were two episodes of vomiting. There was no history of fever trauma, medications, or known ingestions. The medical history was negative. The social history was significant for a high-achieving honor student who came from a very financially successful household. Physical examination revealed a drowsy and disoriented athletic male. The vital signs were temperature of 37.8° Celsius, heart rate of 107 beats per minute, respiratory rate of 20 per minute, and blood pressure of 123/87 mm Hg. The general physical examination was unremarkable. The neurologic examination revealed a disoriented teenager with ataxia, brisk reflexes throughout, reactive pupils, and intact cranial nerves II through XII. A bedside glucose test and pulse oximetry were both normal. Given the ongoing epidemic of West Nile virus at the time of presentation, the mother was convinced that the child had contracted the insect-borne disease because of the combination of mosquito bites and altered mental status. The mother was absolutely insistent that a spinal tap (lumbar puncture) be performed immediately, to evaluate for the possibility of West Nile virus.

The patient's pediatrician was also concerned and requested a full and thorough evaluation. An intravenous line was started and routine blood evaluations were ordered. The patient seemed at times to be more lucid, but at other times was again disoriented. When interviewed alone, he denied having West Nile virus, but he agreed to tell the physician why he believed this to be the case, but only if his parents were not told. The physician explained that all information given by the patient would be kept in strict confidence. Because of the assurance of confidentiality, the patient disclosed that he had bought a large amount of dextromethorphan on the Internet and had taken it with his friends after school.

Dextromethorphan ingestion, even in large quantities, generally does not require anything but supportive care. The mother, not knowing about the ingestion of this drug, continued to be insistent that further tests be performed, including a spinal tap.*

Who, if anyone, in this scenario should be allowed to give informed consent to treatment (or no treatment)? Why? Should the physician regard the 14-year-old as a mature minor? What actions should the physician take if she regarded him as a mature minor? What actions would the physician likely take if she decided to set aside the issue of informed consent and act only in the patient's best interests?

*Reza Keshavarz, "Adolescents, Informed Consent and Confidentiality: A Case Study," *The Mount Sinai Journal of Medicine* 72.4 (4 July 2005), 232–35.

~~entitled to the same level of care that subjects in developed countries get.~~

Cases for Evaluation (Ch. 6)

CASE 1

Giving Placebos to Children

(*New York Times*)—Researchers give a 6-year-old girl who suffers from asthma attacks a promising new drug in addition to her old medicine, then withdraw it to see how she will do without it. A depressed teenager enrolls in a study for an antidepressant, but does not know if he will get a sugar pill or the real thing. The parents of an epileptic youngster enroll her in a test of a new drug that has worked well in adults. But no one knows whether she will get the new medication, or the one that has worked only moderately well for her in the past.

These quandaries, all based on actual experiences, are likely to be faced by an increasing number of parents, children, and medical researchers around the country as the federal government steps up its efforts to test drugs on children.

Over the last three years, largely because of financial incentives that Congress has given pharmaceutical companies, pediatric studies of new drugs have boomed. In December, the Food and Drug Administration will begin mandating that such tests be done on certain drugs, and the agency wants to make sure researchers protect child participants.

"What level of discomfort or risk should a child in a study be exposed to?" asked Dr. Steven Hirschfeld, a medical officer at the F.D.A.'s Center for Drug Research and Evaluation. "If a child gets an asthma attack and starts to wheeze, are people willing to tolerate that to get complete information about a potentially helpful drug for children?"

Today, an F.D.A. advisory panel met in Bethesda, Md., to begin discussions aimed at setting the first guidelines for researchers on the controversial use of placebos in drug trials for children. Placebos are sugar pills, injections, or other treatments that resemble the drug that is being tested without having any of the same effects.

Dr. Hirschfeld said that the particular vulnerability of children often makes placebo controls necessary. "Children are not only very susceptible to their own expectations," he said in an interview. "They are very susceptible to their parents' expectations."

But a panelist, Dr. Charles Weijer, a bioethicist and an assistant professor of medicine at Dalhousie University in Halifax, Nova Scotia, said it was wrong to submit children to risks while providing them no immediate benefit.

"An investigator's chief concern ought to be the health and well-being of her patients," Dr. Weijer said at the hearing. . . .

The panel of 27 researchers that met today included several researchers from Europe who are working on international standards for clinical trials in children.

"What you people decide will affect directly not only children in the U.S., but children in Europe and the world at large," said Francis Crawley, chairman of a group working to set standards in Europe.

Dianne Murphy, the associate director for pediatrics at the F.D.A.'s Center for Drug Evaluation and Research, said that use of placebos can reduce the number of children needed in a study and can ensure the most conclusive outcome. "If you need a placebo trial to get an answer, and you don't do it, then you've wasted that child's blood, time and possible chance, in a trial that won't give them an answer," she said. . . .

But experts disagree on the ethics of withholding effective treatment from children when studying nonfatal conditions such as allergies or skin rashes. And there is no consensus for how to treat children with other serious ailments, such as depression, where the best treatment is unknown.*

Is giving children placebos in clinical trials ever morally permissible? If so, under what conditions should placebos be used? What if in a clinical trial some children suffer asthma attacks because effective treatment is withheld from them—is that acceptable? What if no effective treatments for some childhood diseases could be developed without

using children in placebo-controlled trials. Would that fact outweigh any objections to such trials? Give reasons for your answers.

*Alexis Jetter, "Efforts to Test Drugs on Children Hasten Drive for Research Guidelines," *New York Times*, 12 September 2000, http://www.nytimes.com/2000/09/12/science/12ETHI.html (6 March 2008).

CASE 2
Research and Medicine Collide in Haiti

(*New York Times*)—The impoverished patients who step from the dirt sidewalk into the modern AIDS research clinic run by Cornell Medical College in Port-au-Prince, Haiti, are offered a seemingly simple arrangement.

"We would like to test your blood because you live in an area where AIDS may be common," the English version of the clinic's consent form reads. "We will provide you with medicine if you fall sick and cannot afford such care."

But the transaction is not as straightforward as it sounds. Many Haitians who visit the clinic are at once patients and subjects of United States-financed medical research, and circumstances that are bad for their health are sometimes best for research results.

That conflict is especially true in Cornell's most tantalizing research in Haiti, a study of sex partners, only one of whom is infected with the AIDS virus. Researchers, seeking clues to developing a vaccine, study the blood of both partners, particularly the uninfected ones who continue to be exposed to the virus through unprotected sex. They are trying to find out whether some people have natural protections against infection with the AIDS virus that could be replicated in a vaccine.

The Haitians are ideal research subjects, largely because they are not receiving the kind of care now standard in the world's developed countries. Condom use is low in Haiti, for cultural and other reasons. Antiretroviral drugs that are successful at suppressing the virus are unavailable except to the very wealthy, and are not included in Cornell's promise to provide medicine.

Nearly 20 years after Cornell opened the clinic, it provides some of the best AIDS treatment available in a country devastated by the epidemic, fighting the myriad illnesses that result from AIDS. But that is a lower standard of care than patients receive routinely at American institutions, including the hospital affiliated with Cornell in New York City.

If the research were done in the United States, experts agree, the physicians would be obligated to prescribe the anti-retrovirals and deliver the most effective possible counseling against unprotected sex.

The ethical questions posed by Cornell's work among Haiti's poor are at the heart of a global debate about AIDS research that is roiling international health organizations from Geneva to Thailand, challenging ethics formulations established decades ago.

"It's really like a Faustian bargain," said Marc Fleisher, a member of the committee at Cornell that reviews research on humans. "It's like, since we're making this a better place, we're going to exploit it in a way we could never get away with in the United States," said Mr. Fleisher, the outside member on a board made up mostly of university employees who are doctors.

Cornell doctors defended the couples study as vitally important and stressed that its subjects receive the same counseling about the dangers of AIDS and the same care as other patients at the Haitian clinic.

United States standards for research on humans were strongly influenced by outrage over the Tuskegee syphilis study earlier this century, which misled impoverished black subjects for years while tracking their disease, and withheld treatment even after penicillin was discovered.

Today's subjects are not to be pressured to participate in research, according to Federal regulations. They are to be fully informed about the research's purposes and risks. They must receive the best available therapy for their illnesses and be told about any findings relevant to their health.

In theory, the same rules apply to federally financed studies overseas. But an examination of

15 years of records related to the Haiti couples research shows that it has received scant scrutiny from Government officials in Washington.

And the Government's rules barely address the moral ambiguities of AIDS research in indigent countries. . . .

Dr. Warren D. Johnson, the chief of international medicine and infectious diseases at Cornell, called the couples study "a very high priority," though he said it had been temporarily suspended while the university concentrated on other research in Haiti. "This is the critical group in the world—couples—that's where the war is to be fought," he said.

At least 97 couples have been enrolled in the blood study since 1991, records show, but Dr. Johnson said only 30 couples are still being followed. The study will be expanded to new couples early next year, he said, and coordinated with AIDS vaccine trials, which are expected to start in Haiti this fall using similar couples as subjects.

Cornell's clinic in Haiti offers strong inducements to subjects. It is the only center in the country providing free screening and treatment for H.I.V., venereal disease, and tuberculosis, a common complication of AIDS. The thousands who flock to it are too poor to buy food, let alone the simple medicines and vitamins that serve as "a powerful incentive for study participation," in the words of one Cornell grant report.

The head of the clinic, Dr. Jean William Pape, is a Haiti native and Cornell professor who has studied AIDS in Haiti for two decades. Dr. Pape, who trained at Cornell, defended the treatment of research subjects in the couples study, saying they benefited from the same counseling and free condoms available to everyone who visits the clinic.

Dr. Pape said that offering the life-saving drugs to the handful of research subjects would be an unethical lure to participate. Treating all H.I.V.-infected citizens, he said, would cost 10 times Haiti's health budget.

If the research on couples succeeds, he said, it could help lead to a vaccine against AIDS. "You have to take into account people who mean well for their country and not impose on them things that you feel are good for Western ideas," he said. . . .

The Haitians were valuable for another reason. Unlike AIDS patients in the United States and Europe, they were not receiving the anti-retroviral drugs that proved effective in halting the disease's progress.

The lack of those drugs "may allow identification of novel findings not easily studied in the U.S.A.," Dr. John L. Ho, a Cornell immunologist, wrote in an application for Federal funds. In 1995, the Federal Government awarded Cornell an extra $60,000 to expand this part of the Haitian couples study. . . .

Ethical standards for Federally financed studies require that patients be told why researchers want to study them. But the written consent form approved at Cornell and read aloud in Creole to each potential subject does not mention that the study focuses on couples in which one sexual partner has tested positive for H.I.V.

The form tells subjects their blood is being tested because "you live in an area where AIDS may be common." It promises all patients that H.I.V. test results will be kept confidential. . . .

After reviewing clinic materials, Marie Saint Cyr, a native of Haiti who now directs an AIDS program for women in Harlem, said there was a "clear conflict of interest" between the desire to collect information from research subjects and the obligation to effectively warn patients at risk.

"If you know somebody is positive and is having sex with a partner who is negative, you have a life and death situation in front of you," she said. "You have to do individualized counseling to really tap into what those people value in life, to confront them with the reality of H.I.V. and AIDS. This in no way addresses those serious things."*

Is the Cornell research ethical? Should subjects in the study get the same AIDS treatment available to people in the United States? Should the researchers provide stronger warnings to subjects about the dangers of not using condoms? Is the informed consent process morally acceptable? Explain your answers.

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*Nina Bernstein, "Strings Attached: For Subjects in Haiti Study, Free AIDS Care Has a Price," *New York Times*, 6 June 1999, http://www.nytimes.com/pages/health (6 March 2008).

CASE 3

To Stop or Not to Stop a Clinical Trial

(*New York Times*)—Recently, scientists made the startling decision to halt a large multinational clinical trial that was testing a new drug regimen for breast cancer. The five-year trial was stopped after just two and a half years when results showed that the study drug cut the yearly rate of breast cancer recurrence by nearly half.

The decision has already provoked controversy: breast cancer recurrence is not necessarily the same as death, the critics say, so it is not clear whether the new drug actually saves lives.

The National Breast Cancer Coalition, a patient advocacy group, argued that researchers should have continued the study to see if the new drug prolonged lives.

The issue gets to the core of biomedical research. What is ideal for researchers may not always be ideal for subjects or for the demands of public health.

In this study, the researchers were looking to see if letrozole, which blocks estrogen synthesis, was more effective than a placebo in preventing the recurrence of breast cancer in women who had already taken the estrogen-blocking drug tamoxifen.

Because the advantage of letrozole on disease-free survival was apparent early on, the researchers had to halt the study.

Dr. James N. Ingle of the Mayo Clinic and a principal investigator in the study said he was surprised by the criticism over ending the study. "Preventing disease recurrence is a valid endpoint," he said. "If you sit down with patients, they will tell you that they don't want their cancer to come back. That's their first concern.

"In fact, I can't think of a study of breast cancer where actual survival is the primary endpoint. Disease-free survival is a well-accepted outcome with strong precedence in cancer research."

But to some researchers, the study stopped short of answering important questions. Does letrozole promote actual survival? What are its long-term adverse effects? How long should women continue to take it?

The results, for example, suggest a slight increase in osteoporosis in women taking letrozole compared with a placebo. So, other side effects may emerge over time.

The pursuit of perfect data may be the researcher's dream, but the perspective of a woman with breast cancer is vastly different. If you were privy to the interim analysis, you would most likely choose the new drug over the placebo.

Imagine the outcry if investigators had withheld the early evidence of the drug's benefit and finished the study, hoping for better data. Millions of women with breast cancer could then have correctly claimed they were denied a new treatment.

"A woman with breast cancer who wakes up the next morning without a recurrence of her disease is a survivor," said Dr. Paul Goss of Princess Margaret Hospital and lead author of the study. "What most people and even doctors don't understand about the course of breast cancer is that it is a chronic relapsing disease over many years."

Proving that letrozole saves lives will require a study lasting many years, Dr. Goss said. "We've done the first step, which is to show that letrozole works in preventing breast cancer recurrence," he said. "The next step is to do an extended trial to find out the optimal duration of treatment and long-term side effects."

When people enroll in research studies they sign informed consent agreements explaining the potential risks and benefits. In this case, the form promised subjects that they would be told if new information about their disease was discovered in the study. This virtually mandated early disclosure.

And although subjects are explicitly told in a consent form that they themselves may receive no direct benefit, many continue to hope for it. At the very least, they reasonably expect to be kept from all foreseeable harm.

But avoiding harm is not the same thing as getting benefit. In fact, in many clinical trials subjects are randomly assigned to take the drug or a placebo.

This has prompted some researchers to question whether the use of placebos is even ethical because some very sick people will essentially get no active treatment and may get worse.

What about using placebos in studies of serious illnesses like depression? Treatments for it are known to be effective, though imperfect. There is

little doubt that the most powerful way to show a drug's efficacy and safety is to assign patients at random to the drug or a placebo. But depressed patients who get a placebo may not improve; they may get worse and even become suicidal.

Sure, scientists could compare an experimental drug with a proven standard drug, but this would require a much larger sample and would expose more people to risks of the new drug. That's because research results differ more widely between the use of placebos and active drugs, than between two active treatments.*

Were the researchers right to halt the breast cancer study early? Suppose by extending the trial the scientists could gain valuable knowledge that would help save many women's lives in the future. Would halting the trial early then be wrong? Suppose extending the trial would save lives in the future but also result in the deaths of some women in the study. Would the extension then be permissible? Was the use of placebos ethical? Explain your answers.

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6. Eugene Passamani, "Clinical Trials: Are They Ethical?," *New England Journal of Medicine* 324.22 (1991), 1589–91.

Many in favor of human cloning appeal to reproductive liberty and to cloning's possible benefits, such as enabling infertile couples to have a child that is genetically related to them. Critics charge that cloning is unnatural, that it violates the right of the resulting clone to a unique identity or future, and that it will result in the demeaning artificial manufacture of children as products.

Cases for Evaluation (Ch. 8)

CASE 1

The Fate of Frozen Embryos

Abstract

BACKGROUND. The moral status of the human embryo is particularly controversial in the United States, where one debate has centered on embryos created in excess at in vitro fertilization (IVF) clinics. Little has been known about the disposal of these embryos.

METHODS. We mailed anonymous, self-administered questionnaires to directors of 341 American IVF clinics.

RESULTS. 217 of 341 clinics (64 percent) responded. Nearly all (97 percent) were willing to create and cryopreserve extra embryos. Fewer, but still a majority (59 percent), were explicitly willing to avoid creating extras. When embryos did remain in excess, clinics offered various options: continual cryopreservation for a charge (96 percent) or for no charge (4 percent), donation for reproductive use by other couples (76 percent), disposal prior to (60 percent) or following (54 percent) cryopreservation, and donation for research (60 percent) or embryologist training (19 percent). Qualifications varied widely among those personnel responsible for securing couples' consent for disposal and for conducting disposal itself. Some clinics performed a religious or quasi-religious disposal ceremony. Some clinics required a couple's participation in disposal; some allowed but did not require it; some others discouraged or disallowed it.

CONCLUSIONS. The disposal of human embryos created in excess at American IVF clinics varies in ways suggesting both moral sensitivity and ethical divergence.*

One study estimates that as many as 400,000 embryos remain frozen in fertility clinics in the United States; this survey tried to document what happens to them. If you were faced with trying to decide what to do with frozen embryos, which of the options described here would you choose? Why? Do you believe that parents should have a say in what happens to their embryos? Do you think embryos have a right to exist regardless of the parents' wishes? Explain. Given that a frozen embryo is minute (comprising only two to four cells), do you think it merits a disposal ceremony? Why or why not?

*Andrea D. Gurmankin, Dominic Sisti, and Arthur L. Caplan, "Embryo Disposal Practices in IVF Clinics in the United States," *Politics and Life Sciences* 22.2 (August 2004), 3–8.

CASE 2

Surrogate Versus Father

(MSNBC)—Despite a court ruling against them, a Florida couple vows to continue their legal battle to gain custody of a child born by the woman they hired as a surrogate, but who then decided to keep the baby.

The issue, Tom and Gwyn Lamitina say, is not about Florida surrogacy law, which clearly gives the woman the right to the child. They are fighting for Tom Lamitina's rights as the father of the child.

"We filed an appeal," Scott Alan Salomon, the attorney for the couple, told TODAY co-host Meredith Vieira when all three appeared on the program Tuesday. "The trial judge overstepped his bounds. He had no right whatsoever to terminate parental rights in a paternity action."

Gwyn Lamitina, 46, said the couple wants custody of the child they think is rightfully theirs.

"We would ultimately like to have primary custody," she said. "If the judge deems that [the surrogate] has visitation, we would be up for that."

The child, Emma Grace, was born five months ago to Stephanie Eckard, whom the Lamitinas had met through an online site on which women who want to be surrogates advertise their availability.

Eckard, 30, is a teacher and a single mother of two other children of her own. According to Salomon, she had delivered three surrogate children for other couples before meeting the Lamitinas. Eckard lives in Jacksonville, in the northeast corner of the state, while the Lamitinas live in the Central Florida town of Oviedo. Eckard has declined all requests to be interviewed.

But a month after Eckard became pregnant, she and the Lamitinas had a confrontation over Eckard's smoking. Eckard broke off contact and decided to keep the child as her own. The Lamitinas had paid her $1,500 to carry the child.

The Lamitinas have never seen the girl. "I haven't known anything about her," Gwyn Lamitina told Vieira. "I had to find out she was born through the press."

Because Emma Grace was conceived with Eckard's egg and not Gwyn Lamitina's, Florida law gives Eckard the absolute right to decide to keep the child up until 48 hours after the birth. The trial court upheld that law on Oct. 11.

For that reason, Florida surrogacy lawyer Charlotte Danciu told NBC News in a recorded interview, "Couples should never let a surrogate use her own egg." . . .

As Danciu said, the law in Florida is very clear: A surrogate pregnancy with the surrogate's own egg is treated as an adoption and the birth mother can decide to keep the child, even if there is a signed contract. Tom Lamitina is the father of the child, but the law treats him as a sperm donor with no parental rights.

"That is absolutely incorrect," said Salomon. "A sperm donor is one that signs a contract that says 'I am waiving my parental rights.' Tom voluntarily paid money to give a woman his sperm. He is not a sperm donor. He was doing this with the sole intent to become a father. That's the biggest joke of this whole case."

He said the Lamitinas' case is rightly a paternity case in which Tom Lamitina is seeking custody of his own daughter.

"Half of this child's DNA is Tom's," Salomon said. "The judge unilaterally said, 'We don't care about that. You have no rights.'"

Vieira asked if there is a legal precedent for that claim, to which Salomon replied, "There will be one now."*

Should the father have any rights to the child in this case? Is Florida law correct in giving the surrogate the right to decide to keep the child up until 48 hours after the birth, even if she had signed a surrogacy contract? In determining the custody of a child, should who gestates it carry more weight than genetic links to it (that is, where the egg and sperm come from)? Should genetic or gestational links carry more weight than the ability to properly care for the child? Explain your answers.

*Mike Celizic, "Couple Vows to Fight Surrogate Who Kept Baby," *MSNBC.com*, 23 October 2007, http://www.msnbc.msn.com/id/21435600/ (29 November 2007).

CASE 3

Cloning to Bring Back a Child

(MSNBC)—Katherine Gordon of Great Falls, Mont., whose 17-year-old daughter, Emily, was killed by a drunk driver five years ago, says she became obsessed with bringing a part of her daughter back in some way. Spurred on by the news of [the birth of the cloned sheep Dolly], she had her daughter's cells frozen and stored for possible future cloning. "I started to spend all day researching on the Internet and contacting biologists," she recalls. "I really went off the deep end."

Now she's resigned herself to the fact that the technology probably won't be available in time to help her bear Emily's clone, as she's now 42. But she says that if it were possible in the next couple of years, she would do it.

"I know it wouldn't be Emily—it would be her twin sister," she says. "Emily was perfect—she was beautiful and smart, too, and most of that is genetic. Her predisposition was real kind. Even if the clone had some of her negative qualities that would be

fine, too. I don't know what the new person would be like, but she would have a good start in life." . . .

Dr. William Hurlbut, a bioethicist at Stanford University and member of President Bush's Council on Bioethics, urges parents to look at cloning from the perspective of the child. "I don't think anyone should have to live their life in the footsteps of someone else," he says. "The baby may be held up in comparison with some idealized image of the lost child. It seems morbid and insensitive to the love of the child."

But Gregory Pence, a pro-cloning bioethicist at the University of Alabama, Birmingham, and author of "Who's Afraid of Human Cloning?" defends that choice. "People have replacement children all the time. It's as good a reason as any to have a child sexually. Why are people creating children anyway? To create a sense of family, someone to take care of them when they're older. There are many self-centered reasons people have kids, parents just normally don't have to [spell] out these reasons."*

If Katharine Gordon could give birth to a clone of her deceased daughter, should she? Is grief over the loss of a child a morally legitimate reason for wanting to clone him or her? Is there a morally relevant difference between sexually producing a child to replace a lost one and producing a child through cloning for the same reason? Explain your answers.

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*Julia Sommerfeld, "Coveting a Clone," MSNBC.com, undated, 2006, http://www.msnbc.msn.com/id/3076918/ (29 November 2007).

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Embryonic stem cells can be derived from blastocysts, aborted fetuses, research cloning, and—apparently—genetically engineered somatic cells. The core issue regarding them is whether it is morally permissible to destroy them in a search for cures. Those who assign personhood status to embryos say no. Those who reject that view may grant embryos no special status at all, or they may say that embryos are not persons but are still worthy of some respect. In either case, embryonic stem-cell research is thought to be permissible.

Cases for Evaluation (Ch. 9)

CASE 1
Selecting Babies

(*TimesOnline*)—A British couple have won the right to test embryos for a gene that leads to high cholesterol levels and an increased risk of heart attacks, *The Times* has learnt.

The decision by the fertility watchdog will reopen controversy over the ethics of designer babies, as it allows doctors to screen embryos for a condition that is treatable with drugs and can be influenced by lifestyle as well as genes.

While the procedure is designed to detect a rare version of a disease called familial hypercholesterolaemia (FH), which often kills children before puberty, it will also identify a milder form that can be controlled by drugs and diet.

Critics argue that the test will allow couples to destroy embryos that would have had a good chance of becoming children with fulfilling and reasonably healthy lives.

The test will also create an unprecedented moral dilemma for some couples, as it could show that they have produced no embryos completely unaffected by the disease. This would force them to decide whether to implant embryos that they know have a genetic risk of premature heart disease and death, or to throw them away and deny them a chance of life.

Britain's first licence to test embryos for FH will be awarded next week to Paul Serhal, of University College Hospital in London, by the Human Fertilisation and Embryology Authority (HFEA).

Its decision breaks new ground because it permits Mr. Serhal to screen out not only the severe form of the condition but also the milder type, which is usually treatable.

Embryo screening has previously been approved only for disorders in which a gene invariably causes a serious disease, or for conditions such as breast cancer in which mutations carry an 80 per cent lifetime risk.

FH occurs in two forms. The more common version, heterozygous FH, affects 1 in 500 people. It is caused by a single mutated gene, which raises cholesterol and thus the risk of hardened arteries, heart disease, and stroke. It can usually be managed with statin drugs and diet.

One in 250,000 people inherits two defective copies of the gene and develops homozygous FH, which is much more serious. Sufferers show severely elevated cholesterol from the age of 5, and can suffer angina by 6 or 7. Many die in childhood, and most have suffered at least one heart attack by the end of their twenties.

Mr. Serhal's patients, who are in their thirties, both have the milder heterozygous FH. They discovered their status only when they had a daughter, now 5, with the homozygous form, and they also have an unaffected son.

They said yesterday that they were delighted. "We had no idea that we both carried a gene for high cholesterol until the double gene was expressed in our first child. We are very lucky that our child has responded so well to the very high-dose drug regime. We have been led to understand that other children with the same double gene may not be so lucky." . . .

Mr. Serhal said: "This obnoxious disease can cause cardiovascular accidents at a very young age. Ideally, we will find embryos with no FH genes, but it is possible we will not and it will be up to the patients to choose. Some people would think twice about using embryos that they know have a risky gene, and others would say you shouldn't screen out a condition that can be managed so people can live with it. It will be an awkward choice."*

Is it wrong for parents to screen out embryos with disorders that are treatable? What about embryos that will

probably—not certainly—develop a serious disease? Or those that will develop a fatal disease only in middle age? Is it morally permissible to cause to exist persons who are severely disabled and likely to suffer horribly throughout their lives? Give reasons for your answer.

*Mark Henderson, "Designer Baby Fear over Heart Gene Test," TimesOnline, 15 December 2007, http://www.timesonline.co.uk/tol/news/uk/science/article3054249.ece? (15 January 2008).

CASE 2
Causing Deaf Children

(*New Scientist*)—A few years ago, a lesbian couple in the U.S. sparked controversy when they chose a deaf sperm donor to ensure their children, like them, would be deaf. Now it appears that some would-be parents are resorting to pre-implantation genetic diagnosis (PGD) to achieve the same thing, by selecting and implanting embryos that will develop into deaf children.

This comes from a survey by the Genetics and Public Policy Center in Washington DC on how PGD is being used in the U.S.

Deep inside the report is this paragraph: "Some prospective parents have sought PGD to select an embryo for the presence of a particular disease or disability, such as deafness, in order that the child would share that characteristic with the parents. Three per cent of IVF-PGD clinics report having provided PGD to couples who seek to use PGD in this manner."

It is not clear how many, if any, children have been born after embryo selection for a disability, or which disabilities have been selected for. I asked Susannah Baruch, the lead author of the GPPC report, who told me that the team does not have any more details.

So let's do the sums: Since the survey included 137 IVF-PGD clinics, 3% means 4 couples at least, more if you assume some of the 200 clinics who did not respond to the survey have also provided this service. And since the success rate of IVF is roughly 30%, even if each couple made only one attempt at least one child must have been born with a designer disability, most likely deafness, with the help of PGD.*

Is it right to deliberately cause a child to be deaf and thereby limit her opportunities in life? If so, why? If not, why not? Should medical authorities or the government restrict the use of IVF and PGD to selecting only healthy embryos? If both prospective parents have inherited deafness, there is a high probability that their child will be deaf. So their failing *to use IVF/PGD to select healthy embryos would almost guarantee a deaf baby. Is such a failure morally wrong? If so, is deliberately selecting impaired embryos equally wrong? Explain.*

*Michael Le Page, "Designer Deafness," *New Scientist*, 29 September 2006.

CASE 3
Cosmetic Embryo Selection

(*London Telegraph*)—Embryos are to be screened for a cosmetic defect for the first time in a British clinic.

Doctors have been given permission to create a baby free from a genetic disorder which would have caused the child to have a severe squint.

The Bridge Centre family clinic, in London, has been licensed to treat a businessman and his wife to create the baby. Both the businessman and his father suffer from the condition, which causes the eyes only to look downwards or sideways.

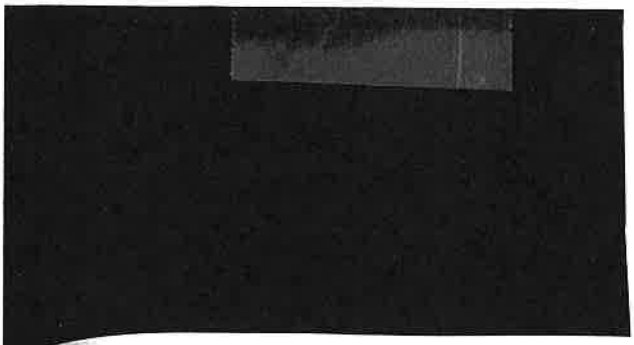
Critics have said that the permission is another step on the road to creating only perfect-looking babies in the laboratory.

The licence was granted by the Human Fertilisation and Embryology Authority (HFEA) to Prof. Gedis Grudzinskas, who believes the landmark ruling marks a shift away from granting licences only for life-threatening conditions.

He said: "We will increasingly see the use of embryo screening for severe cosmetic conditions."

He added that he would seek to screen for any genetic factor at all that would cause a family severe distress.

When asked if he would screen embryos for factors like hair colour, he said: "If there is a cosmetic aspect to an individual case I would assess it on its merits. [Hair colour] can be a cause of bullying which



can lead to suicide. With the agreement of the HFEA, I would do it. If a parent suffered from asthma, and it was possible to detect the genetic factor for this, I would do it. It all depends on the family's distress."

He argued that a baby born with the squint condition, congenital fibrosis of the extramacular muscles, would have to undergo several potentially dangerous operations from a young age. . . .

If successful, the screening could be the first case in the world where doctors have been able to select embryos without the condition. . . .

Until last year screening was restricted to life-threatening conditions such as cystic fibrosis or fatal blood disorders.*

Should prospective parents be permitted to screen their embryos for cosmetic reasons? Is there a moral difference between embryo selection against severe disabilities and embryo selection against cosmetic imperfections that cause the child to suffer psychological distress or social discrimination? Is embryo selection for cosmetic reasons a form of discrimination or disrespect for people with disabilities or imperfections? Explain your answers.

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*Roland Hancock, "Clinic to Weed Out Embryos with a Squint," Telegraph.co.uk, 5 July 2007, http://www.telegraph.co.uk/news/main.jhtml?xml=/news/2007/05/07/nbaby07.xml (15 January 2008).

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Adrienne [illegible]

issue in these cases is what criteria should be used to decide which patients get transplants and who should make the decisions.

Cases for Evaluation (Ch. 11)

CASE 1

Black Market in Organ Transplants

(*San Francisco Chronicle*)—Tears well up in P. Guna's eyes as he stares at a long scar running down his side. A year ago, he attempted to stave off mounting debt by swapping one of his healthy kidneys for quick cash.

"Humans don't need two kidneys, I was made to believe," he said. "I can sell my extra kidney and become rich, I thought."

At the time, an organ trader promised Guna, 38, a motorized-rickshaw driver with a fourth-grade education, $2,500 for the kidney, of which he eventually received only half. Since then, he has experienced excruciating pain in his hip that has kept him from working full time and pushed him deeper in debt.

In recent years, many Indian cities—like Chennai in southern India—have become hubs of a murky business in kidney transplants, despite a 1994 nationwide ban on human organ sales (the Transplant of Human Organ Act states only relatives of patients can donate kidneys).

An influx of patients, mainly foreigners, seeking the transplants has made the illicit market a lucrative business. Some analysts say the business thrives for the same reasons that have made India a top destination for medical tourism: low cost and qualified doctors. In fact, medical tourism is expected to reach $2.2 billion by 2012, according to government estimates.

Not surprisingly, an organized group of organ traders in cahoots with unscrupulous doctors is constantly on the prowl for donors like Guna.

In Gurgaon, a posh New Delhi suburb, police last month busted an illegal organ racket, which included doctors, nurses, pathology clinics, and

hospitals. In the past 14 years, the participants allegedly removed kidneys from about 500 day laborers, the majority of them abducted or conned, before selling the organs to wealthy clients.

Police say the doctor believed to be the mastermind behind the operation, Amit Kumar, searched for donors by cruising in luxury cars outfitted with medical testing machines, and kept sophisticated surgical equipment in a residential apartment. In his office, police found letters and e-mail messages from 48 people from nine countries inquiring about transplants.

On Thursday, police arrested Kumar in Chitwan, a Nepalese jungle resort. Local news reports said he was identified by a hotel employee who recognized him from Indian television broadcasts seen in Nepal. "I have not duped anybody," Kumar later told reporters in Kathmandu, according to the Associated Press.

Nepalese authorities say they won't extradite Kumar until they finish an investigation on whether he violated currency laws by not declaring $230,000 in cash and a check for $24,000 that he was carrying when arrested. He is scheduled to appear in a Nepalese court Sunday.

In another high-profile arrest, a renowned Chennai surgeon, Palani Ravichandran, was arrested in October in Mumbai for involvement in a kidney racket. He admitted to arranging organ transplants for wealthy foreigners—mainly from Persian Gulf states and Malaysia, whom he charged up to $25,000. Mumbai police say Ravichandran had performed between 40 and 100 illegal transplants since 2002.

Police say kidney donors can earn between $1,250 and $2,500, while recipients pay as much as $25,000, according to ActionAid India, an anti-poverty organization that has worked with kidney trade victims in the southern state of Tamil Nadu.

The same procedure can cost as much as $70,000 in China and $85,000 in the United States.

"These middlemen act more like cut-and-grab men whose only interest is to hack out the organ," said Annie Thomas, a field co-coordinator for ActionAid in Chennai, formerly known as Madras. "This is a reprehensible abuse of the poor, and this practice needs to be curbed."

Thomas says many middlemen typically masquerade the donors as relatives to circumvent the law while many foreigners in need of a kidney arrive on tourist visas rather than the required medical visas; some resort to false documents.*

Is it morally permissible to sell your own organs? Is it morally permissible to buy organs from consenting adult donors? Should organ selling be illegal in all cases? Are the Indian organ donors described in this article being exploited? How? Give reasons for your answers.

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*Anuj Chopra, "Organ-Transplant Black Market Thrives in India," *SFGate*, 9 February 2008, http://www.sfgate.com (11 April 2008).

CASE 2

Expensive Health Care for a Killer

(*Statesman Journal*)—Oregon taxpayers are shelling out more than $120,000 a year to provide life-saving dialysis for a condemned killer.

Horacio Alberto Reyes-Camarena was sent to death row six years ago for stabbing to death an 18-year-old girl and dumping her body near the Oregon Coast.

At the Two Rivers Correctional Institution in Eastern Oregon, Reyes-Camarena, 47, gets hooked up to a dialysis machine for four hours three times a week to remove toxins from his blood.

Without dialysis, he would die because his kidneys are failing.

Each dialysis session costs $775.80 for treatment and medication, according to Corrections Department figures. At that rate, his dialysis costs $121,025 a year.

As the state keeps Reyes-Camarena alive, thousands of older, poor, sick and disabled Oregonians are trying to survive without medications and care that vanished amid state budget cuts.

Some Oregon hospitals are considering closing dialysis units because of Medicaid-related reductions.

Reyes-Camarena said he wants to sever his ties to the dialysis machine. The convicted killer wants

to be the first Oregon inmate to receive a taxpayer-financed organ transplant.

"It's much better for me, and them, too," Reyes-Camarena said, referring to his desire for a kidney transplant, a procedure sought by nearly 57,000 Americans.

The prisoner cited medical reports indicating that transplant costs prove to be cheaper than dialysis in the long run.

Even so, transplant surgery is costly: $80,000 to $120,000. It also requires $500 to $1,200 a month in lifelong drugs to keep the recipient from rejecting the new organ.

Studies have found that the death rate for dialysis patients is about 23 percent a year. A successful transplant reduces that risk to about 3 percent a year.

But the number of transplants is severely limited by a national scarcity of available organs. As of this month, 56,895 Americans, including 192 Oregonians, were waiting for kidney transplants, according to the Virginia-based United Network for Organ Sharing, which maintains the nation's waiting list for organs.

Because the waiting list is long and there aren't enough organs to go around, some people die before a transplant becomes available.

Overall, 86,157 Americans are waiting for organ transplants—mostly kidneys, livers, pancreases and lungs. Officials estimate that about 700 will die this year while waiting.

Lifesaving care for Reyes-Camarena raises questions about the bounds of medical treatment for prisoners.*

Is society obligated to prolong the life of felons like Reyes-Camarena? As thousands of dollars are spent each year by the state to provide him with health care, many lawful citizens cannot afford critical care and die as a result. Is this arrangement just? Do prisoners have a right to health care? Does anyone have a right to health care? Explain your answers.

*Alan Gustafson, "Death Row Inmate Seeks Organ Transplant," *Statesman Journal*, 28 April 2003, http://news.statesmanjournal.com/article.cfm?i=59756 (11 April 2008).

CASE 3

Should We Have Universal Health Care?

(*TCU360*)—Since the dawn of the twentieth century, a debate over health care has raged in America.

The debate centers around the argument over whether the federal government is obligated to ensure that its citizens have health care, thus preventing them from economic headaches associated with rising costs of basic medical care.

Historian and sociologist Paul Starr wrote in his book, *Remedy and Reaction: The Peculiar American Struggle over Health Care Reform*, that efforts to "provide all Americans access to medical care and protect them from economic ruin" have long been a "liberal inspiration."

Beginning in the early decades of the twentieth century, reform from the Progressive Era gave Americans antitrust laws, labor legislation, the Federal Reserve and workers' compensation, but reforming health care proved to be more challenging.

Reform has come slowly. After the New Deal, Social Security was passed to give seniors a fiscal safety net in their later years. Along with Social Security came the GI Bill and the minimum wage.

For decades liberals sought a system of universal health care that would protect all Americans from the pain of illness and burdensome medical bills.

With the establishment of Medicare and Medicaid, progressives hoped they had broken through—not so.

Starr wrote that "if Americans came to know one thing about the history of battles over health insurance, it was that a government program to make health care a right of citizenship had always been defeated."

Early ideas for government-led health insurance programs came from Europe.

British national health care and German sickness funds were unpopular and never gained traction in America. Workers compensation shows similarities to German sickness funds, but the idea of national health care similar to Britain was, to the chagrin of progressives, politely frowned upon in the States.

In 1912, progressives within the Republican Party established the Progressive Party that included in its platform support for social health insurance.

Canada boasts a single payer system with striking similarities to the United States' Medicare system. Progressives had hoped that the Medicare system would serve as a precursor to a more wide-reaching program to establish a system for all Americans, offering insurance akin to the coverage offered to seniors by Medicare....

In reality, none of the proposals in the United States even closely resembles true government health care like Britain's universal health care system.

Reality shows that Democrats largely played on Republican turf.

Coupling reform with deficit reduction, championing the originally Republican idea of the individual mandate and dropping advocacy for a government-run "public option" meant that Democrats sought compromise on the bill.

They sought agreement on one of the most divisive issues in America's history. Agreement may have been sought, but discord was found.

Perhaps the fact that the debate requires Americans to draw upon deep-seated ethical principles precludes agreement.

Or perhaps the problem is deeper.

Perhaps Americans are truly divided over the role government should play in people's lives.*

Should the United States establish a system of universal health care? Why or why not? What moral principle seems to underpin opposition to such a system? What moral principle seems to favor it? What would be the negative effects of having universal health care? What would be the positive effects?

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*Alex Apple, "Universal Health Care Debate a Controversial Topic for the United States," *TCU360* (Texas Christian University), 22 November 2012, https://www.tcu360.com/ (21 January 2016).

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