CHAPTER

13

Issues in Bioethics

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In January 1996 my brother-in-law, Brian, was injured in a catastrophic industrial accident that left him with second- and third-degree burns over 95 percent of his body, as well as strong indications that his throat and lungs had been seriously burned.

Brian's accident occurred literally in sight of a major hospital with a regional burn unit, and he was brought to the hospital within minutes. Following the accident, Brian remained in a strange limbo between life and death—unconscious although not comatose, and kept alive by aggressive medical treatment and an ever-increasing assortment of drugs and machines. Burned everywhere except his genitals and the soles of his feet, bandaged from head to toe with only his face showing, and swollen grotesquely, Brian's appearance was literally nightmarish; no one who saw him slept well afterward. Each day brought minor crises, and each week brought a major crisis that made death seem imminent—as indeed it was, for Brian died three and a half weeks after the accident.

The severity of Brian's injuries immediately made me wonder whether it might be best to treat only his pain and let him die a natural death. Brian had never written a living will (a document specifying the circumstances in which he would no longer want medical treatment), but he had told his wife, Lisa, that he would not want to live if his quality of life was ever compromised substantially. Questions about whether treatment made sense became increasingly salient to the family as the days passed; his lungs, stomach, and kidneys failed; and bacterial, viral, and fungal infections assaulted his body.

Because Brian remained unconscious throughout his hospital stay, legally Lisa was authorized to make treatment decisions for him. The doctors acknowledged that the final decisions were up to Lisa and that they could not ethically or legally proceed without her informed consent. In practice, however, they kept decision-making authority to themselves by defining certain decisions as purely technical matters not requiring Lisa's consent, shaping her treatment decisions by providing information selectively, ignoring her decisions when they disagreed with them, cutting off her questions when they found them uncomfortable, and telling her that withholding treatment was unethical and hence out of the question. Although some nurses indicated quietly to Lisa that her concerns were valid, the hospital's pastoral counselors and social workers urged Lisa to trust the doctors' judgment.

In the end, Brian's condition began deteriorating so rapidly and completely that the doctors had no further treatments to try. Around the same time, a new resident who took Lisa's concerns seriously joined the staff. A long conversation with him helped Lisa both to understand the doctors' perspective and to express her own view. When this resident recommended that she consent to withdrawing the drug that kept Brian's heart beating, Lisa agreed. Brian died that night (Weitz, 1999).

For centuries, doctors have formally recognized that health care should be based on ethical principles. The Hippocratic Oath, for example, written in about 400 BC, instructed doctors to take only actions that would benefit their patients and to forswear euthanasia, seducing patients, and divulging patients' secrets. As Brian and Lisa's story suggests, however, in practice, health care still can fall short of meeting ethical principles. In this chapter, we explore the history of **bioethics**, the study of all ethical issues involved in the biological sciences and health care, and analyze how bioethics has—and has not—affected American health care and medical research.

To some students and faculty, it might seem odd to include a chapter on bioethics in a sociology textbook. Yet the issues raised by bioethics are sociological ones, for many revolve around the impact of power differences among social groups (most importantly, between physicians and patients). Even when exploring the same issues, however, bioethicists and sociologists use different lenses. Robert Zussman, a sociologist who has studied bioethics extensively, succinctly summarizes the difference:

> Medical ethics may be thought of as the normative study of high principles for the purpose of guiding clinical decisions. In contrast, the sociology of medical ethics may be thought of as the empirical study of clinical decisions for the purpose of understanding the social structure of medicine. Clearly then, medical ethicists and sociologists of medical ethics travel much of the same terrain, but they do so traveling in different directions (1997:174).

A HISTORY OF BIOETHICS

Since its beginning in 1848, the **American Medical Association (AMA)** has required its members to subscribe to its code of ethics. The code, however, speaks more of medical etiquette—proper relations among doctors—than of medical ethics or, more broadly, bioethics. Indeed, throughout the nineteenth century and well into the twentieth century, doctors' ideas regarding bioethics remained ill-defined, and their commitment to bioethics remained weak. Although doctors undoubtedly would have identified relieving human suffering as their primary goal, both in their research and in clinical practice, doctors sometimes behaved in ways that would horrify modern doctors and bioethicists. For example, Dr. J. Marion Sims, considered the father of modern obstetrics, achieved fame during the 1840s for developing a surgical procedure to correct vesicovaginal fistulae, tears in the wall between a woman's vagina and bladder usually caused by overaggressive medical intervention during childbirth (Barker-Benfield, 1976). Women who suffered these fistulae could not control the leakage of urine and often had to withdraw from social life altogether because of odor and the resulting social shame. To develop a surgical cure, Sims

bought black women slaves who had fistulae and then operated on them as many as 30 times each, in an era before antibiotics and antisepsis and with only addictive drugs for anesthetics. When Sims announced his new surgical technique, the medical world and the public greeted him with acclaim. No one questioned his ethics.

A century later, Nazi doctors working in German concentration camps also used socially disvalued populations for equally barbaric—and even less justifiable—experiments. The world's response to these experiments would mark the beginnings of modern bioethics.

The Nazi Doctors and the Nuremberg Code

In 1933, the German people voted the Nazi party and Adolf Hitler into power. At that time, Germany's medical schools and researchers were respected worldwide, and its health care system was considered one of the world's best (Redlich, 1978).

Shortly after coming to power, the Nazi government passed the Law for the Prevention of Congenitally Ill Progeny (Lifton, 1986). This law required the sterilization of anyone considered likely to give birth to children with diseases that doctors considered genetic, including mental retardation, schizophrenia, manic depression, epilepsy, blindness, deafness, or alcoholism. Under this law, government-employed doctors sterilized between 200,000 and 300,000 persons. Two years later, in 1935, the government passed the Law to Protect Genetic Health, prohibiting the marriage of persons with certain diseases.

Both these laws reflected a belief in **eugenics**, the theory that the population should be "improved" through selective breeding and birth control. The eugenics movement has had many followers throughout the Western world. By 1920, 25 U.S. states had passed laws allowing the sterilization of those believed (usually incorrectly) to carry genes for mental retardation or criminality. Several states also passed laws forbidding the marriage of persons with illnesses considered genetic (Lifton, 1986).

As the power of the Nazis grew in Germany and as public response to their actions both within and outside Germany proved mild, the Nazis adopted ever bolder eugenic actions (Lifton, 1986; Redlich, 1978). Beginning in 1939, the Nazis began systematically killing patients in state mental hospitals. Doctors played a central role in this program, selecting patients for death and supervising their poisoning with lethal drugs or carbon monoxide gas. Doctors and nurses also watched silently while many more patients starved to death. In total, between 80,000 and 100,000 adults and 5,000 children died (Lifton, 1986). Doctors played similar roles in Nazi concentration camps where millions of Jews, Gypsies, and others died (Lifton, 1986; Redlich, 1978). In addition, doctors working in these concentration camps (including university professors and highly respected senior medical researchers) performed hundreds of unethical experiments on prisoners—such as studying how quickly individuals would die when exposed to freezing cold and seeing whether injecting dye into prisoners' eyes would change their eye color. Doctors also used prisoners to gain surgical experience by, for example, removing healthy ovaries or kidneys or creating wounds on which to practice surgical treatments.

Box 13.1 Principles of the Nuremberg Code

1. The voluntary consent of the human subject is absolutely essential....
2. The experiment should be such as to yield fruitful results for the good of society, unprocurable by other methods or means of study, and not random and unnecessary in nature.
3. The experiment should be so designed and based on the results of animal experimentation and a knowledge of the natural history of the disease or other problem under study that the anticipated results will justify the performance of the experiment.
4. The experiment should be so conducted as to avoid all unnecessary physical and mental suffering and injury.
5. No experiment should be conducted where there is an *a priori* reason to believe that death or disabling injury will occur....
6. The degree of risk to be taken should never exceed that determined by the humanitarian importance of the problem to be solved by the experiment.
7. Proper preparations should be made and adequate facilities provided to protect the experimental subject against even remote possibilities of injury, disability, or death.
8. The experiment should be conducted only by scientifically qualified persons. The highest degree of skill and care should be required through all stages of the experiment of those who conduct or engage in the experiment.
9. During the course of the experiment, the human subject should be at liberty to bring the experiment to an end....
10. The scientist in charge must be prepared to terminate the experiment at any stage if he has probable cause to believe ... that a continuation of the experiment is likely to result in injury, disability, or death to the experimental subject.

SOURCE: *Trials of War Criminals before the Nuremberg Military Tribunals under Control Council Law No. 10* (1949).

After the Nazi defeat, the Allied victors prosecuted 23 of these doctors for committing "medical crimes against humanity," eventually sentencing seven to death and nine to prison (Lifton, 1986). These decisions constituted the basis for what is now known as the **Nuremberg Code**, a set of internationally recognized principles regarding the ethics of human experimentation (See Box 13.1). The code requires researchers to have a medically justifiable purpose; do all they can to protect their subjects from harm; and ensure that their subjects give **informed consent**, that is, voluntarily agree to participate in the research with a full understanding of the potential risks and benefits.

The 1960s: The Rise of Bioethics

Because the trials received relatively little publicity in the United States and because Americans typically viewed Nazi doctors as *Nazis* rather than as doctors, few drew connections between Nazi practices and American medical practices (Rothman, 1991). As a result, discussion of bioethics remained largely dormant in the years following the Nuremberg Trials. During the 1960s, however, ethical

questions regarding medical care and research in the United States became topics of popular discussion.

One reason for this was the rise of new technologies, such as life support systems for comatose persons. Of particular importance was the development of kidney dialysis, a technology that could keep alive persons whose kidneys had failed (Fox and Swazey, 1974). Demand for dialysis far outstripped supply, forcing selection committees made up of doctors and, in some cases, lay people to decide who would receive this life-saving treatment and who would die. Forced to choose from among the many who, on medical grounds, were equally likely to benefit from the treatment, these committees frequently based their choices on social criteria such as gender, age, apparent emotional stability, social class, and marital status. When news of these committees' work reached the public, the resulting outcry led to new federal regulations designed to allocate kidney dialysis more fairly.

Although the dialysis issue sparked public concern about medical *practice*, medical *research* still remained outside the bounds of public discussion. In 1966, however, one article changed this. Writing in the *New England Journal of Medicine*, respected medical professor Henry Beecher (1966) described 22 research studies, published in top journals in the recent past, that had used ethically questionable methods. In one study, for example, soldiers sick with streptococcal infections received experimental treatments instead of penicillin, causing 25 soldiers to develop rheumatic fever. In another, doctors inserted catheters into the bladders of healthy newborns and X-rayed them, without parental consent, to study how bladders worked.

To determine the frequency of such studies, Beecher looked at 100 consecutive research studies published in a prestigious medical journal. In 12 of the 100 studies, researchers had not told subjects of the risks involved in the experiments or had not even told the subjects that they were in an experiment. Yet no journal reviewer, editor, or reader had questioned the ethics of these studies.

Beecher's article sent ripples of concern not only through the medical world but also through the general public as news of the article spread through the mass media. This public concern translated into pressure on Congress and on the U.S. Public Health Service (PHS), at the time the nation's major funder of medical research. To demonstrate to Congress that they could handle the problem themselves and to keep public concern from turning into budget cuts, the PHS in 1966 published guidelines for protecting human subjects in medical research (Rothman, 1991).

The responses to Beecher's article and the dialysis issue demonstrate the increased role that the mass media and the general public had begun to play in health care decision making. Meanwhile, the growth of the civil rights and women's rights movements stimulated discussion both about patients' rights generally and about birth control and abortion specifically. Taken together, these changes led observers to proclaim the birth of a bioethics movement (Fox, 1974; Rothman, 1991).

The 1970s: Willowbrook, Tuskegee, and the Right to Die

The Willowbrook Hepatitis Study During the 1970s, three cases further stimulated popular, legal, and medical interest in bioethics. The first of these, the Willowbrook hepatitis experiments, reached public attention in 1971. Willowbrook State School, run by the state of New York, was an institution for

mentally retarded children. Conditions in Willowbrook were horrendous, with children routinely left naked, hungry, and lying in urine and excrement. As a result, hepatitis, a highly contagious, debilitating, and sometimes deadly disease, ran rampant among the children and, to a lesser extent, the hospital staff.

In 1956, to document the natural history of hepatitis and to test vaccinations and treatments, two pediatrics professors from New York University School of Medicine began purposely infecting children with the disease. In addition, to test the effectiveness of different dosages of gamma globulin, which the researchers knew offered some protection against hepatitis, they injected some children with gamma globulin but left others unvaccinated for comparison. The children's parents had consented to this research but had received only vague descriptions of its nature and potential risks.

The researchers offered several justifications for their work. First, they argued, the benefits of the research outweighed any potential risks. Second, they had infected the children only with a relatively mild strain of the virus and therefore had decreased the odds that the children would become infected with the far less common but considerably more dangerous strain that also existed in the school. Third, the children who participated in the experiments lived in better conditions than did the others in the institution and therefore were protected against the many other infections common there. Fourth, the researchers argued that the children would probably become infected with hepatitis anyway, given the abysmal conditions in the institution. Finally, the researchers believed they should not be held accountable because the parents had given permission. Using these arguments, the researchers had obtained approval for their experiments from the state of New York, the Willowbrook State School, and New York University. Over a 15-year period, they published a series of articles based on their research without any reviewers, editors, or readers raising ethical objections.

In 1970, however, Methodist theologian Paul Ramsey (1970) exposed the ethical flaws of these experiments in his influential book, *The Patient as Person*. Shortly thereafter, in the spring of 1971, an exchange of letters and editorials debating the ethics of these experiments appeared in the prestigious British medical journal, *The Lancet*. Ramsey and others wrote in *The Lancet* that parents had not given truly *voluntary* consent because they could get their children admitted to Willowbrook only by allowing them to participate in the hepatitis experiments. In addition, parents had not given truly *informed* consent because researchers had not told them that gamma globulin could provide long-term immunity to hepatitis. Writers to *The Lancet* also questioned why the researchers experimented on children, who could not give informed consent, rather than on hospital staff. Finally, these writers questioned why the researchers—who, after all, were pediatricians—had chosen to take advantage of this "opportunity" to study hepatitis rather than trying to wipe out the epidemic. This debate exploded in the New York media and, in the ensuing public outcry, the research ground to a halt.

The Tuskegee Syphilis Study A year later, in 1972, the Tuskegee Syphilis Study made headlines (Jones, 1993). Begun by the federal PHS in 1932, the study, which was still under way, was intended to document the natural progression of untreated syphilis in African American men. At the time the study began,

medical scientists understood the devastating consequences of untreated syphilis in whites (including, in its later stages, neurological damage and heart disease). But reflecting the racist logic of the times, the scientists suspected its progression took a different and milder form in African Americans.

For this study, researchers identified 399 desperately poor and mostly illiterate African American men, all with untreated late-stage syphilis, who lived in the Tuskegee, Alabama, area. The men were neither told they had syphilis nor offered treatment. Instead, researchers informed them that they had "bad blood" (a local term for a wide variety of ailments) and offered them free health care, transportation to medical clinics, free meals on examination days, and payment of burial expenses—enormous inducements given the men's extreme poverty—if the men would participate in the study.

At the time the study began, treating syphilis was difficult, lengthy, and costly. The development of penicillin in the early 1940s, however, gave doctors a simple and effective treatment. Yet throughout the course of the study, researchers not only did not offer penicillin to their subjects but also kept them from receiving it elsewhere. During World War II, researchers worked with local draft boards to prevent their subjects from getting drafted into the military, where the subjects might have received treatment. When federally funded venereal disease treatment clinics opened locally, researchers enlisted the support of clinic doctors to keep research subjects from receiving treatment. Similarly, they enlisted the cooperation of Tuskegee's all-white medical society to ensure that no local doctor gave penicillin to their subjects for any other reason.

The Tuskegee Syphilis Study, which treated African American men as less-than-human guinea pigs, was not the work of a few isolated crackpots. Rather, it was run by a respected federal agency with the cooperation of state and county medical associations and even of doctors and nurses from the local Tuskegee Institute, a world-renowned college for African Americans. Over the years, more than a dozen articles based on the study appeared in top medical journals without anyone ever questioning the study's ethics. Yet the study patently flouted the Nuremberg Code and, after 1966, the PHS's own research ethics guidelines. Nevertheless, the study did not end until 1972 after a newspaper exposé resulted in public outrage. By that time, at least 28 and possibly as many as 100 research subjects had died of syphilis, and an unknown number had succumbed to syphilis-related heart problems (Jones, 1993).

The Right to Die Several years later, in 1975, public attention focused on Karen Quinlan, whose case raised issues not of medical experimentation but of medical treatment. At the age of 21, after ingesting a combination of drugs at a party, Quinlan fell into a coma. Initially, her parents encouraged her doctors to do everything possible to keep her alive and restore her health. Once her parents learned that she had suffered extensive brain damage and would never regain any mental or physical functioning, however, they asked that she be removed from life support and allowed to die. When the doctors refused, the parents took their fight to the courts. After almost a year of legal battles, Quinlan's parents won the right to remove her from the mechanical respirator that had kept her alive.

The Quinlan case gained enormous public attention and sympathy for the right to die and highlighted the problems involved in having too much, rather than too little, access to medical care and technology. In addition, the Quinlan case signaled both the entry of lawyers and the legal system into health care decision making and the problems with using the courts to decide such intensely personal issues (Bosk, 2010).

More recently, the case of Terri Schiavo raised a similar set of issues (Annas, 2005). For unclear reasons, in 1990, Schiavo fell into a "persistent vegetative state" in which, according to her doctors, she could not feel, communicate, or think, and from which her doctors believed she had no chance of recovering. After Schiavo had been in this condition for eight years, her husband requested that her doctors remove the feeding tube that kept her alive.

By law, Schiavo's husband, who believed she would never have wanted to be maintained in such a condition, had the legal right to make this decision on her behalf. Her doctors supported his decision, citing medical ethics that oppose continuing futile medical interventions. Nevertheless, Schiavo's parents brought suit against her husband and doctors, arguing that she was in fact conscious and capable of recovery and that, at any rate, any life was worth continuing. After 15 years of litigation, including the unprecedented involvement of U.S. President George W. Bush and Congress, the federal court (supporting the decision of several lower courts) ordered Schiavo's feeding tube removed. An autopsy performed after her death confirmed that half of her brain had been destroyed many years earlier, leaving her with no possibility of thought, emotion, or recovery.

In retrospect, the most striking aspect of the Schiavo case is that it generated so much controversy even though it raised no new medical, ethical, or legal issues. Instead, the Schiavo controversy highlights the new willingness of politicians to enter private medical decision making, the increasingly contentious atmosphere surrounding right-to-life and **right-to-die** debates, and the spread of political divisions stemming from the abortion controversy to other areas of medicine and the law.

The 1980s and 1990s: Reproductive Technology, Enhancements, and Priorities

During the last decades of the twentieth century, questions about the benefits of medical technology increased substantially. At the same time, questions increasingly were raised about inequities in access to even the most basic health care. All of these questions continue to simmer in bioethical debates.

Reproductive Technology One area that has sparked considerable debate since the late 1970s is **reproductive technology**, or medical developments that allow doctors to control the process of human conception and fetal development. Reproductive technology first came to the public's attention in 1978 with the birth of Louise Brown, the world's first "test-tube baby." Louise's

mother was unable to conceive a baby because her fallopian tubes, through which eggs must descend to reach sperm and be fertilized, were blocked. Using a technique known as *in vitro fertilization*, her doctors removed an egg from her body, fertilized it with her husband's sperm in a test tube, and then implanted it in her uterus to develop. Nine months later, Louise Brown was born.

Louise Brown's birth raised questions about how far doctors should go in interfering in the normal human processes of reproduction. Subsequent cases raised even trickier questions. For example, courts have had to decide whether fetuses should be placed for adoption when the biological parents have died and whether custody of fetuses after divorce should go to the parent who wants the fetuses implanted or the one who wants them destroyed. More recently, doctors and others have debated whether couples should be allowed to hire women to carry their fetuses to term for them and whether postmenopausal women should be allowed to have a baby using another woman's egg.

More broadly, these cases have raised basic questions regarding the morality of intervening so directly in the process of human reproduction, including whether individuals are harmed or helped by having access to such technologies. Those who favor the new reproductive technologies argue that the technologies give couples greater control over their destinies. Those who oppose the new technologies, on the other hand, argue that these technologies seduce couples into spending enormous amounts of time and money in a usually futile effort to have children who share on or of? their genes rather than finding other ways (such as adoption) to create meaningful lives for themselves. Opponents also question whether these technologies encourage the idea that children are purchasable commodities and the idea that, for the right price, prospective parents can guarantee they will get "perfect" children (Rothman, 1986).

More recently, increasing use of *in vitro* fertilization and related technologies has contributed to a rise in women carrying multiple fetuses and, consequently, to an increase in premature births. About 12% of U.S. babies are now born prematurely (Martin, Osterman, and Sutton, 2010; Saul, 2009).

When a woman learns she is carrying multiple fetuses, she (and her partner, if she has one) must decide either to abort some of the fetuses or to risk having twins, triplets ... or octuplets. Regardless of their previous feelings on abortion, deciding to abort is very difficult for anyone who has struggled to have a child.

If the woman continues with multiple fetuses, the entire family, at some level, is at risk. The woman may be confined to bed for months to avoid miscarrying, placing her under significant physical, psychological, and financial stress if she can no longer work. Childbirth, too, is especially dangerous for both mothers and babies during multiple births. Moreover, because more than 50% of twins and more than 85% of triplets are born prematurely, many need ferociously expensive intensive care, die within the first year, or suffer permanent mental or physical defects, often resulting in long-lasting emotional strains, financial strains, or time burdens on the family (Saul, 2009).

Enhancing Human Traits The past 30 years also have witnessed growing concern about the ethics of medical interventions designed to enhance human traits. No clear definition of such enhancements exist, but the term is used to refer to techniques used to improve human traits beyond a level generally considered normal rather than to treat conditions considered deviant or defective. This is a necessarily subjective definition because individual judgments regarding what is normal vary greatly. Nevertheless, we would probably all acknowledge a qualitative difference between providing cosmetic surgery to a person with a severely burned face versus providing it to a professional model who desires more prominent cheekbones. Similarly, there is a qualitative difference between using psychotropic drugs to avoid schizophrenic hallucinations versus using them to improve one's exam grades—a process psychiatrist Peter Kramer (1993) refers to as "cosmetic psychopharmacology."

Ethical questions regarding enhancements have increased as their use has increased (Whitehouse et al., 1997). Is it ethically justifiable for individuals to improve their offspring through genetic preselection or fetal surgery, and if so, will those who do not use these technologies become a "genetic underclass?" Should health insurance cover drugs such as Viagra, which helps men achieve erections and can improve quality of life perhaps beyond the norm for a given age? Should health insurance cover cosmetic (as opposed to reconstructive) surgery, and should doctors promote surgeries (such as liposuction) whose benefits are purely cosmetic and whose potential risks include death? Should psychotropic drugs be prescribed to individuals who do not have diagnosable mental illnesses but who want to be more sociable, alert, or assertive? And is it ethical to provide potentially harmful medical care to enhance some individuals while others still lack basic medical care? Finally, some have questioned whether enhancements provide unethical advantages. If Olympic athletes are forbidden from taking drugs to improve their performance, why are waitresses allowed to get breast implants to generate more tips and businesspeople allowed to take Ritalin to improve their concentration? Conversely, is it ethical to restrain the options of those who would provide or purchase such services?

Setting Priorities For many years, policy analysts, researchers, and ethicists have raised questions about inequities in access to health care. However, whereas earlier debates on funding health care focused on deciding which *individuals* should get specific scarce resources such as kidney dialysis, beginning in the late 1980s, debates focused on setting priorities to help decide which *procedures* should be funded. This debate came to the fore in 1989 with passage of legislation establishing the Oregon Health Plan (OHP), which promised to provide free care to all Oregonians who were too poor to purchase insurance but not poor enough to get **Medicaid** (Saha, Coffman, and Smits, 2010). To do so, OHP would first list all possible health care services in order of priority based on effectiveness and costs as well as public priorities and values. It would then prospectively contract with **managed care organizations (MCOs)** to purchase services for OHP members, beginning at the top of its priority list and working its way down until it reached its budget limit. Thus, based on the budget

available in any given year, lower priority services might be eliminated, but no individuals would be dropped from the program. Unfortunately, this plan fell apart in 2003 after OHP's budget was cut so sharply that it had to drop many people from the plan. Nevertheless, the priority list remains in place for those who still remain on the plan.

The OHP legislation marked the first time that a governmental body in the United States explicitly rationed health care—deciding in advance that some procedures simply cost too much to provide to some populations. The explicit use of rationing resulted in an outcry across the country, both from those who considered it discrimination against persons with disabilities and those who believed it was unethical to ration care only for the poor. As a result, it took the state almost five years to win federal approval to pilot the program, and ethical questions continue to plague the system. More recently, Arizona officials were met with national outrage when they announced in 2010 that state's health plan for the poor would no longer pay for certain organ transplants that typically increase life spans only slightly.

Yet rationing always has existed in the United States (Callahan, 1998). This rationing, however, is implicit rather than explicit: People do not get health care if they can't afford it, not because someone decides certain services shouldn't be offered. In the absence of some system for prioritizing services and making care accessible, health care dollars routinely are spent on services that offer little benefit or that offer great benefit only to a few, while many others go without basic services. The Oregon system at least attempted to rationalize rationing, deciding, for example, that it made more sense to fund vaccinations for thousands of children than heart transplants for a handful.

The New Millennium: Stem Cell Research

These days, clinicians, researchers, patients, and their families remain haunted by the ethical questions of earlier generations, such as whether there is a right to die and who should decide which medical services ethically can be offered. New technologies have added to the urgency of these and other questions.

One issue that has gained special attention in the past decade is the use of stem cells and the associated technique of cloning (Dunn, 2002). Stem cells are naturally occurring human cells that have the ability to grow into numerous types of cells. Although no successful treatments have yet been developed from stem cells, researchers hope someday to use them to replace defective cells in individuals with diseases such as diabetes and Parkinson's disease.

There are two ways to grow stem cells. First, scientists can grow stem cells in the laboratory after harvesting them from adults or from fetal blood left in a woman's blood system after giving birth. No ethical issues have been raised about this use of stem cells, which now accounts for about half of all research in this area (Kolata, 2004b). Second, scientists can grow stem cells from embryos. To do so, researchers fertilize human eggs with sperm in a laboratory to turn them into embryos. They then leave the embryos for a week or so until each has grown

into a few hundred cells and then extract their stem cells (thus destroying the embryos). Alternatively, researchers can replace the nucleus from an unfertilized human egg with a cell nucleus taken from a donor's skin or muscle, artificially stimulate this egg (instead of fertilizing it) so it develops into an embryo, and then extract its stem cells. This second process is a form of cloning because the embryo will be genetically identical to the donor.

To many opponents of stem cell research, the destruction of human embryos to harvest stem cells is the same as killing humans. Other critics argue that producing human cells to treat other humans is too close to selling human beings and human body parts. This is particularly worrisome because heavy political opposition to stem cell research has shifted much of this research to the for-profit sector, where it escapes most regulation. Others object specifically to the use of cloning to produce stem cells on the grounds that it is only a matter of time before some doctors begin using cloned embryos to create cloned babies. They wonder whether in the future babies will be "farmed" and "harvested" to match parents' images of the perfect baby.

Supporters of human stem cell research argue that its potential benefits outweigh its potential problems (Dunn, 2002). Most of the support for this research has come from persons who hope stem cells will provide a cure to the diseases that affect them or their loved ones. Supporters also argue that destroying an artificially created embryo that has no potential to grow into a human being unless it is somehow implanted in a woman's uterus is not morally equivalent to destroying a human being. Finally, with regard to cloning, supporters argue that many women who want babies already have donor eggs implanted in their uteruses and that few would choose to use cloned eggs because the chances of success are so low. (So far, no researcher has been able to keep a cloned egg alive for more than a few days, much less for a nine-month pregnancy.) For all of these reasons, supporters of stem cell research argue that instead of trying to eliminate this research, we should adopt regulations to ensure that it is conducted ethically.

INSTITUTIONALIZING BIOETHICS

Concern about bioethics has led to the development of formal mechanisms to ensure that health care and health research will be conducted ethically. In this section, we look at four of those mechanisms: hospital ethics committees, institutional review boards, professional ethics committees, and community advisory boards.

Hospital Ethics Committees

The origins of hospital ethics committees can be traced to the 1950s. Similar to the Seattle Kidney Center, many other hospitals used committees to select patients for kidney dialysis. Similarly, hospitals routinely used committees to

decide which women merited abortions on medical grounds. At the time, the legal status of abortion was unclear, and the moral status of abortion was just starting to become a public issue (Luker, 1984).

Other hospital ethics committees arose in the aftermath of the 1982 "Baby Doe" case, in which parents of a newborn who was mentally retarded and had a defective digestive system decided that they did not want the defect corrected by surgery. The doctors complied with their decision, and the baby died six days later. When news of the case broke, a public furor arose. These days, most large hospitals have ethics committees or consultants available to review any cases considered ethically problematic.

Institutional Review Boards

Although universities and hospitals began establishing committees to review research ethics in the 1960s, such committees did not become common until the 1970s. In the aftermath of the Tuskegee scandal, Congress in 1974 created the National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research. The Commission's reports laid the groundwork for current guidelines regarding research ethics. That same year, the National Research Act mandated the development of **institutional review boards (IRBs)** charged with reviewing all federally funded research projects involving human subjects. Such boards now exist at all universities and other research institutions.

In recent years, though, pharmaceutical research has increasingly shifted from federally funded projects in hospitals and universities to for-profit projects funded by pharmaceutical companies and conducted by research organizations, individual doctors, or the pharmaceutical companies themselves. To oversee this research, for-profit, *commercial* IRBs have emerged, either run by or under contract with pharmaceutical companies or other research organizations (Lemmens and Freedman, 2000).

The conflict of interest involved in such IRBs is obvious. When employees of a pharmaceutical company review their company's research, they know that their company's success depends on getting that research approved. Similarly, those who work for commercial IRBs know that they are unlikely to get future contracts from pharmaceutical companies unless they approve those companies' research proposals.

Professional Ethics Committees

Many professional organizations now also have ethics committees that establish guidelines for professional practice. The American Fertility Society, for example, has published a statement of principles regarding the moral status of human embryos created in laboratories, and the ethics committee of the American College of Obstetrics and Gynecology has published guidelines regarding the ethics of selectively aborting fetuses when a woman who has used fertility drugs becomes pregnant with multiple fetuses.

Community Advisory Boards

The most recent development in this area is the emergence of community advisory boards (CABs). The purpose of CABs is to bring individuals from the community together with health care providers to make difficult bioethical decisions regarding both research and treatment (Quinn, 2004). For example, CABs may be asked to represent patients in treatment decisions when the patients are unconscious or incompetent and family members are unavailable.

The use of CABs to evaluate research designs is linked to the rise of genetic research. Typically, we think of genetic testing as an individual decision: Should someone whose mother died of breast cancer or whose sister has Down syndrome get a genetic test to ascertain her own risk of having or passing on these diseases? But genetic testing also has implications for communities. Genetic tests can stigmatize an entire community (when, for example, African Americans were first identified as having higher risks of sickle cell anemia), can challenge ideas about who *belongs* to a community (when genetic differences are found within a population), and can challenge a community's ideas about its origins (when, for example, Native American legends regarding tribal origins in the Americas clash with genetic findings suggesting Asian origins). For these reasons, researchers have begun involving communities in discussions of research priorities, research design, and the dissemination of research findings. This leaves open, however, the very large question of who constitutes and who should represent a community.

THE IMPACT OF BIOETHICS

The growth of the bioethics movement and the institutionalizing of bioethics in U.S. hospitals and universities have made ethical issues more visible than ever before. Articles on bioethics, virtually nonexistent before the 1960s, now appear routinely in medical journals, while in both the clinical and research worlds, ethics committees have proliferated.

These developments have led some observers to conclude that the bioethics movement has fundamentally altered the nature of medical work. According to historian David Rothman:

> By the mid-1970s, both the style and the substance of medical decision-making had changed. The authority that an individual physician had once exercised covertly was now subject to debate and review by colleagues and laypeople. Let the physician design a research protocol to deliver an experimental treatment, and in the room, by federal mandate, was an institutional review board composed of other physicians, lawyers, and community representatives to make certain that the potential benefits to the subject patient outweighed the risks. Let the physician attempt to allocate a scarce resource, like a donor heart, and in the room were federal and state legislators and administrators to help set standards

> of equity and justice. Let the physician decide to withdraw or terminate life sustaining treatment from an incompetent patient, and in the room were state judges to rule, in advance, on the legality of these actions. (1991:2)

Other observers, however, contend that the impact of the bioethics movement has been more muted (Annas, 1991). These critics argue that hospital, research, community, and professional ethics committees, like the earlier hospital abortion committees, exist primarily to offer legal protection and social support to researchers and clinicians, not to protect patients or research subjects. Furthermore, they argue, although clinicians have become more concerned with *documenting* their allegiance to ethics guidelines, they have not become any more concerned with *following* those guidelines. The following sections evaluate the impact of bioethics on health care research, medical education, and clinical practice.

The Impact on Research

According to ethicist George Annas, the bioethics movement, as institutionalized in research ethics boards and committees, has affected medical research only slightly. In his words, the

> primary mission [of research ethics committees] is to protect the institution by providing an alternative forum to litigation or unwanted publicity.... [For this reason] its membership is almost exclusively made up of researchers (not potential subjects) from the particular institution. These committees have changed the face of research in the U.S. by requiring investigators to justify their research on humans to a peer review group prior to recruiting subjects. But this does not mean that they have made research universally more "ethical." In at least a few spectacular instances, these committees have provided ethical and legal cover that enabled experiments to be performed that otherwise would not have been because of their potentially devastating impact on human subjects. (1991:19)

As an example, Annas cites the case of "Baby Fae" (not her real name), who died in 1984 soon after doctors replaced her defective heart with a baboon's heart. Although all available evidence indicated that cross-species transplants could not succeed, the doctors who performed the surgery had received approval from their hospital's IRB. A subsequent review found that Baby Fae's parents had not given truly informed consent because the doctors had not suggested seeking a human transplant, had disparaged available surgical treatments, and had unreasonably encouraged the parents to believe that a baboon transplant could succeed.

Lack of resources and conflicts of interest also limit the effectiveness of IRBs. IRB members are unpaid volunteers who typically must review between

300 and 2,000 proposed experiments yearly and who, in many cases, have vested interests in approving research proposals so their institutions can obtain research funding (Hilts, 1999). Meanwhile, final responsibility for overseeing IRBs falls to the federal Office of Protection from Research Risks, which is far too understaffed to thoroughly review human subjects research.

Nevertheless, and despite the limitations of IRBs and research ethics committees, the rise of bioethics has curbed the most egregious abuses of human subjects. According to David Rothman:

> The experiments that Henry Beecher described could not now occur; even the most ambitious or confident investigator would not today put forward such protocols. Indeed, the transformation in research practices is most dramatic in the area that was once most problematic: research on incompetent and institutionalized subjects. The young, the elderly, the mentally disabled, and the incarcerated are not fair game for the investigator. Researchers no longer get to choose the martyrs for mankind (1991:251).

In fact, the balance has shifted to such an extent that we now sometimes read news stories not of researchers pressuring individuals to become research subjects but, rather, of desperately ill individuals pressuring researchers to accept them as research subjects for experimental treatments. At the same time, the shift toward for-profit drug testing (described in *Contemporary Issues: "Guinea Pigging"*) has raised new concerns not only about the safety of research subjects but also about the credibility of the research enterprise itself.

The Impact on Medical Education

One obvious result of the bioethics movement has been the incorporation of ethics training into medical education, with courses on ethics now common at U.S. medical schools. As critics have noted, however, those courses too often are divorced from real life, aimed at teaching students ethical principles and legal norms through classroom lectures rather than at teaching students how to negotiate the everyday ethical dilemmas they will face. Moreover, such courses often assume that students who are already undergoing socialization to medical culture still can identify ethically problematic aspects of that culture (Hafferty and Franks, 1994). Finally, ethics courses cannot compensate for the ways in which ethics are discounted in the "hidden curriculum" of medical practice and culture. For example, a structure that expects students both to provide care for patients *and* to learn techniques on patients without the patients' knowledge inherently teaches students to view patients at least partly as objects rather than as subjects. From this perspective, only through "the integration of ethical principles into the everyday work of both science and medicine" can we expect new doctors to adopt more ethical approaches to care (Hafferty and Franks, 1994:868).

CONTEMPORARY ISSUES

"Guinea Pigging"

The term *guinea pigging* first entered the mainstream American vocabulary in January 2008, when an article by that name was published in *New Yorker Magazine* (Elliott, 2008). *Guinea pigging* refers to healthy individuals (overwhelmingly poor, sometimes students) who participate in clinical drug trials for pay.

In the past, most participants in drug trials were either medical students and personnel who at least intellectually understood the risks they faced or persons struggling with illnesses who might benefit from the drugs they tested. Over the past ten years, however, as drug testing and development have exploded and have largely shifted from nonprofit to for-profit operations, the need to quickly find large numbers of research subjects has led to the widespread use of healthy subjects for pay in early trials of drugs. (If the drugs prove safe with healthy subjects, they are then tested for efficacy on ill subjects.)

These human guinea pigs can earn up to several thousand dollars for participating in research studies that can last weeks or months. The risks they face, though, can be high. The obvious dangers come from the drugs themselves. In March 2006, for example, six volunteers who participated in tests of a potential treatment for immune disorders were almost killed, and apparently all are now permanently disabled (Elliott, 2008). In addition, testing sometimes involves invasive and potentially dangerous procedures such as biopsies or endoscopies. Moreover, most clinical trials do not cover medical costs—let alone compensation for pain or lost wages—when volunteers are injured or become ill as a result of the experiments. Participating in drug trials can also be extremely unpleasant, requiring subjects to wear rectal probes, experience food or sleep deprivation, live for weeks in hospital-like environs, or the like.

In addition to the risks faced by volunteers, the public is also placed at risk when drugs are tested in these circumstances. When subjects participate because they need money, they may feel no qualms about ignoring research protocols, such as sneaking food or alcohol when they are supposed to fast or abstain. Similarly, when researchers are employed by for-profit corporations, they may be inclined to interpret results optimistically or to recruit homeless alcoholics who need money rather than spending the time needed to recruit a more representative sample.

The Impact on Clinical Practice

Relatively few studies have looked at the impact of the bioethics movement on clinical practices. One series of studies looked at the impact of New York's 1987 law establishing formal policies for writing "do not resuscitate" orders (orders forbidding health care workers from intervening if the lungs or heart of a terminally ill patient stops functioning). These studies found that after the law's passage, doctors significantly altered how they *documented* their actions but not how they *acted* (Zussman, 1992:162). Similarly, studies have found that hospitals sharply limit access of patients, family, and nonmedical staff to ethics consultations. As a result, consultations primarily function to provide additional institutional support to doctors confronted by families or patients they consider disruptive, such as those who challenge doctors' decisions regarding how aggressively to treat a patient (Kelly et al., 1997; Orr and Moon, 1993). These findings

have led researchers to conclude that the true purpose of ethics consultations is to reinforce doctors' power.

The most extensive study of the impact of bioethics on clinical practice appears in *Intensive Care: Medical Ethics and the Medical Profession* (1992) by sociologist Robert Zussman. Zussman spent more than two years observing and interviewing in the intensive care units of two hospitals. His research suggests both the impact and the limitations of the bioethics movement.

Although cases such as Karen Quinlan's and Baby Doe's might suggest that doctors often want to use aggressive treatment despite the objections of patients and families, Zussman found that on intensive care wards, the reverse is usually the case. Knowing that most of their patients will die, doctors on these wards often hesitate before beginning aggressive treatment, which might only escalate costs, increase their work as well as their patients' suffering, and prolong the dying process. Patients and their relatives, however, often face a sudden and unexpected medical crisis. Unable to believe the situation hopeless, they demand that health care workers "do everything." In these situations, the doctors Zussman studied expressed allegiance to the principle that families have the right to make decisions regarding treatment. In practice, however, doctors found ways to assert their discretion, if no longer the authority they had in years past.

Doctors asserted their discretion in several ways. First, doctors made decisions without asking the family on the assumption that the family would agree with their decisions. Second, doctors sometimes ignored a family's stated decisions, arguing that it was cruel to force a family to make life-or-death decisions that they might later regret. Third, doctors might respect a family's wishes but only after first shaping those wishes through providing information selectively. This information included defining the patient as terminally ill or not—a highly significant designation because ethical guidelines permit health care workers to withhold or terminate treatment only for terminally ill patients. Fourth, when doctors failed to shape a family's wishes, the doctors could discount those wishes on the grounds that the family was too emotionally distraught to decide rationally.

Finally, and perhaps most important, doctors continued to assert their discretion by defining the decision to withhold treatment as merely a technical problem and thus defining family members' wishes as irrelevant. For example, doctors might acknowledge families' general wishes regarding how aggressively treatment should proceed but then define each specific intervention as a technical decision best left to doctors.

Summing up his findings, Zussman writes:

> The picture I have drawn corresponds neither to an image of unbridled professional discretion nor to one of patients' rights triumphant. As many observers of contemporary medicine have argued, the discretion of physicians in clinical decisions (like the discretion of professionals in other fields) depends on their ability to make successful claims to the exclusive command of technical knowledge. Yet, while ... physicians ... make such claims, they do not always succeed either in convincing

> themselves that they are legitimate or in converting them to influence over patients and their families, for the claims of physicians are met by the counterclaims of patients and, more important, families.... The institutionalization of patients' rights, in law and in hospital policy ... empower[s] families when they do insist on doing everything. In such a situation, physicians may continue to exercise considerable influence and enjoy considerable discretion. By no means have they been reduced to the role of technicians and nothing more. But at the same time, they must, at the very least, take the wishes of patients and families into account (1992:159–160).

IMPLICATIONS

As we have seen, bioethics and sociology have much in common. At a very basic, if typically unacknowledged, level, bioethics, like sociology, is about power. The abuses of the Nazi doctors, for example, not only illuminate the horrors possible when ethical principles are ignored but also illustrate both how social groups can obtain power over others and how individuals can be harmed or even killed when this happens. Conversely, sociology, in similarly unacknowledged ways, is at a basic level an ethical enterprise. Hidden assumptions about what society *should* be like and how society *should* be changed often underlie abstract, technical sociological discussions. Such assumptions often draw on philosophies regarding justice, autonomy, human worth, and other basic ethical issues. Yet in the same way that bioethicists often ignore the sociological implications of their work, sociologists often ignore the ethical implications of the questions they ask, the research they conduct, and the findings their research generates.

It seems, then, that bioethicists and sociologists can provide each other with broader perspectives that can only enrich our understanding of both fields—encouraging bioethicists to see not only individual cases but also broader social and political issues and encouraging sociologists to see the world and their work in it as an ethical as well as a political and intellectual enterprise. These are issues that all of us should keep in mind as we seek our place in the world.

SUMMARY

1. Bioethics is the study of ethical issues in biological sciences and health care. Many of the issues bioethicists ponder revolve, whether explicitly or not, around the use and impact of power—a central concern of sociologists.
2. Although U.S. doctors have been required to subscribe to a Code of Ethics since 1848, in the past, many doctors conducted research and practiced medicine in ways that would horrify modern bioethicists. One example was Dr. J. Marion Sims' use of African American slaves as surgical guinea pigs.

3. After the Nazi defeat, Allied countries prosecuted 23 doctors as part of the broader war crimes trials popularly known as the Nuremberg Trials. These trials resulted in the development of the Nuremberg Code, a set of internationally recognized principles regarding the ethics of human experimentation.
4. Interest in bioethics in the United States grew substantially during the 1960s, sparked by popular and medical articles on kidney dialysis selection committees and on unethical medical research practices.
5. Key bioethics cases during the 1970s included the Willowbrook hepatitis experiments, the Tuskegee syphilis experiments, and the Karen Quinlan "right to die" case. (More recently, the Terri Schiavo case illuminated the new willingness of politicians to enter private medical decision making, the increasingly contentious atmosphere surrounding "right to life" and "right to die" debates, and the spread of political divisions born primarily in fights over abortion to other areas of medicine and the law.)
6. Bioethical issues that rose to prominence during the 1980s and 1990s included reproductive technology, setting priorities for and rationing medical procedures, and the enhancement of human traits (through, for example, cosmetic surgery or memory-enhancing drugs). In the twenty-first century, these issues remain, along with new ones such as the use of stem cells and the associated technique of cloning.
7. In recent years, various institutional mechanisms have developed to ensure that bioethical principles will be followed in health care and health research, including hospital, research, community, and professional ethics committees. An important new development is the use of for-profit research ethics committees.
8. The growth of the bioethics movement and the institutionalizing of bioethics in U.S. hospitals and universities have made ethical issues more visible than ever before. These changes have increased concern among doctors about bioethics, but it is not clear whether they have truly increased doctors' commitment to acting ethically.

REVIEW QUESTIONS

1. What is the Nuremberg Code, and how and why did it come into existence?
2. What factors led to the emergence of the bioethics movement in the late 1960s?
3. Why do researchers now consider the Tuskegee Syphilis Study and the Willowbrook hepatitis experiments to have been unethical?
4. What are the ethical problems involved in the new reproductive technology? In enhancements? In stem cell research?
5. What impact has bioethics had on health care and on health research?

CRITICAL THINKING QUESTIONS

1. How can U.S. health care be made more ethical?
2. What role does doctors' professional dominance play in creating ethical problems in medical care? What role does bioethics, as institutionalized in the American health care system, play in limiting doctors' professional dominance?
3. What notable similarities and differences do you see between the behavior of the medical community in the Tuskegee syphilis experiments and in the Nazi genocide?
4. You now hold a position of power in our health care system. (You choose what position.) What three changes could you realistically attempt to make so that health care would be provided more ethically? Justify your decisions.