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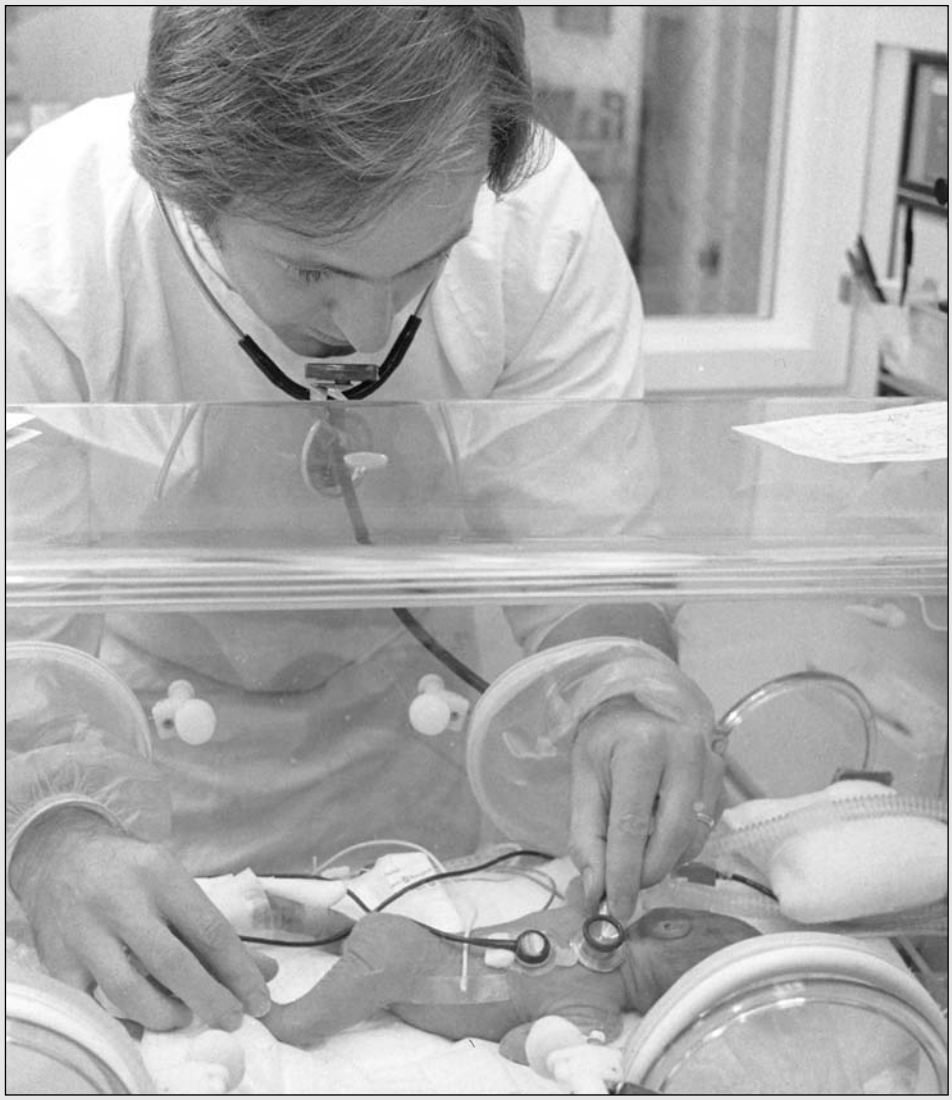
CHAPTER 13



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Issues in Bioethics

In January 1998 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 and with strong indications that he had suffered a severe inhalation injury.

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 afterwards. 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, 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

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themselves by, among other things, defining certain decisions as purely technical matters not requiring Lisa's consent, shaping her treatment decisions through selectively providing information, ignoring her decisions when they disagreed with her opinions, 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 joined the staff who took Lisa's concerns seriously. A long conversation with him greatly helped Lisa, both by allowing her to express her feelings and by helping her understand the doctors' perspective. When this resident recommended to Lisa that she give permission to withdraw the drug that kept Brian's heart beating, Lisa accepted his recommendation. 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 B.C., instructed doctors to take only actions that would benefit their patients and to foreswear euthanasia, seducing patients, or 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 issues, for many of the issues bioethicists ponder revolve around the impact of power differences between social groups (most importantly, between physicians and patients). Even when exploring the same issues, however, bioethicists and sociologists do so through 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)

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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 to medical etiquette—proper relations between doctors—than to 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 minimal. 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 vesico-vaginal 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 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 thirty 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 research ethics.

Almost 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 Nazis, under Adolf Hitler's leadership, into power. At that time, Germany's medical schools and researchers were known and respected worldwide and its system of health care was considered one of the best and most comprehensive (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.

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The eugenics movement had many followers throughout the Western world. By 1920, twenty-five U.S. states had passed laws allowing sterilization of those believed (usually incorrectly) to carry genes for mental retardation or criminality. Several states also passed laws forbidding interracial marriage and marriage by 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). Shortly after, the Nazi government began systematically killing Jews, Gypsies, and others whom they considered racially inferior. By the end of World War II, the Nazis had murdered between 5 million and 10 million people in their concentration camps.

At least 350 doctors played major roles in this genocidal policy (Lifton, 1986; Redlich, 1978). As prisoners entered the concentration camps, medical officers of the Nazi SS corps decided which to kill immediately and which to use for forced labor. When shooting those marked for death proved too expensive, doctors developed more efficient means of mass murder using carbon monoxide gassing. Medical corpsmen, supervised by doctors, conducted the murders. Those whom doctors selected for forced labor, meanwhile, usually died in a matter of weeks from starvation, overwork, or the epidemic diseases that ravaged the camps. In addition, doctors working in the 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 once 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.

Following the Nazi defeat, the Allied victors prosecuted 23 of these doctors for committing "medical crimes against humanity," eventually sentencing 7 to death and 9 to prison (Lifton, 1986). The decisions in these cases contained 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 within their power 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.

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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 subjects 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. During the course of the experiment, 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: http://www.hhs.gov/ohrp/references/nurcode.htm

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 (D. Rothman, 1991). As a result, discussion of bioethics remained largely dormant in the years following the Nuremberg Trials. During the 1960s, however, as health care costs rose exponentially, ethical questions regarding access to health care became topics of popular discussion.

New technologies, too, such as the development of organ transplants and of life support systems for comatose persons, raised issues not only of equity and access but also of how to balance the benefits of new technologies against their dangers. From these issues would emerge a heightened interest in bioethics.

These issues first came to a head with the development of kidney dialysis, a technology that could keep alive persons whose kidneys had failed

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(R. Fox and Swazey, 1974). Demand for dialysis far outstripped supply, forcing selection committees made up of doctors and, in some cases, laypeople 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 sex, 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 twenty-two 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 twenty-five soldiers to develop rheumatic fever. In another, doctors working without parental consent catheterized and X-rayed the bladders of healthy newborns to see 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 them 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, in turn, pressure on the U.S. Public Health Service (PHS), the major funder of medical research. To demonstrate to Congress that they could deal with the problem on their own and to keep public concern from turning into budget cuts, the PHS in 1966 published guidelines for protecting human subjects in medical research (D. 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. The patients' rights movement would also draw energy from the publication in 1969 of Dr. Elizabeth Kübler-Ross's book *On Death and Dying,* which called attention to the dehumanizing aspects of modern medical treatment of the dying.

The concept of patients' rights also found fertile ground during the 1960s because of the changing relationship between doctors and patients (D. Rothman, 1991). Before World War II, Americans typically received their health care at home or in a nearby office from general practitioners

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they had known for years. Doctors and their clients lived in the same neighborhoods and often shared the same ethnic and social class background. By the 1960s, however, as medical practice shifted from general to specialty care, from home and office to hospital, and from talking and direct physical interventions to impersonal technological interventions, the ties binding doctors and clients had weakened. In these circumstances, trust between doctors and clients diminished, and public demands for control over medical work grew. Similarly, medical research shifted from small-scale, rare events in which doctors typically conducted experiments first on themselves and then on their families and neighbors to large-scale business enterprises with only weak links between doctors and subjects.

By the late 1960s, writers could look at developments around the country and proclaim the birth of the bioethics movement (R. Fox, 1974; D. Rothman, 1991). Over the next few years, several important organizations devoted to bioethics were founded, including the Hastings Center for Bioethics, the Society for Health and Human Values, and the Center for Bioethics at Georgetown University, and bioethics secured at least a small place in medical education.

The 1970s: Willowbrook, Tuskegee, and Karen Quinlan

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 professors of pediatrics 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

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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 felt 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 the 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 over the Willowbrook studies was taken up by 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 Public Health Service (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 course of syphilis in whites (which, in its later stages, can cause 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 term used locally to cover a wide variety of health ailments. The researchers then told the men that if they participated in this study of bad blood, they would receive free and regular (if infrequent) health care, transportation to medical clinics, free meals on examination

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days, and payment of burial expenses—enormous inducements given the men's extreme poverty.

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 the all-white County 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, the PHS, with additional funding from the widely respected Milbank Fund. The study received significant cooperation from the state and county medical associations and even from doctors and nurses affiliated with 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. Not until 1972 did the study end, following a newspaper exposé and the resulting public outcry. 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). In addition, the study indirectly caused untold additional deaths by convincing many in the African American community to distrust public health workers. That legacy has lasted to the present day, contributing to suspicions among African Americans that the federal government created **HIV** to control population growth in their community (Jones, 1993; Thomas and Quinn, 1991).

The Right to Die

Several years later, in 1975, public attention would focus 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 make all efforts to keep her alive and return her to health. Once her parents learned that she had suffered extensive brain damage and would never regain any mental or physical functioning, 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 was keeping her alive.

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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 the entry of lawyers and the legal system into health care decision making.

More recently, the case of Terri Schiavo raised a similar set of issues (Annas, 2005). For unknown reasons, in 1990 Schiavo fell into a "persistent vegetative state" in which, according to her doctors, she could neither feel, communicate, nor 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 this decision, because medical norms 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 President Bush and the U.S. Congress, the federal court (supporting the decision of several lower courts) ordered Schiavo's feeding tube removed. An autopsy performed after her death a few days later confirmed that half of her brain had been destroyed, leaving her with no possibility of thought, emotion, or recovery.

In retrospect, the most striking aspect of the Schiavo case is that it raised no new medical, ethical, or legal issues. The fact that it nonetheless generated so much 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 born primarily in fights over abortion to other areas of medicine and the law.

The 1980s and 1990s: Reproductive Technology, Enhancing Human Traits, and Setting 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 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

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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 following 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 biologically their own, rather than finding other ways to make 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 (B. Rothman, 1989).

Enhancing Human Traits

The past 25 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 generally believed to improve human traits beyond a level 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 episodes and using them to get extra energy and improve final 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

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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 for the sake of enhancing some individuals while others still lack basic services? 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? Questions such as these are increasingly common, as evidenced by the special supplement that the *Hastings Center Report,* an influential bioethics journal, published on this topic in January–February 1998.

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 had incomes below the federal poverty level (Leichter, 1997). To extend coverage to individuals not eligible for **Medicaid,** the OHP currently provides a somewhat limited package of services. To decide each year which services to offer, OHP first prioritizes all the potential health care services it might offer. It then prospectively contracts with **managed care organizations (MCOs)** to purchase services for its members, beginning at the top of its priority list and working its way down until it reaches its budget limit. Thus, if OHP runs out of funding, some services are cut, but no individuals are dropped from the program.

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.

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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 because 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 much larger groups go without basic services. The Oregon system at least rationalizes rationing, deciding, for example, that it makes more sense to fund vaccinations for thousands of children than kidney transplants for a handful.

Current Issues

In these early years of the twenty-first century, 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 last few years 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

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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. Most of the support for this research has come from persons who hope stem cells will provide a cure to the diseases that afflict 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 are already having 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 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. Like 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). Because psychiatric problems were considered justifiable medical grounds for abortion, wealthy women easily could find doctors who would testify to committees that abortion was psychiatrically needed. Poor women, on the other hand, typically could obtain abortions only if their lives were physically endangered. In reality, therefore, these committees made their decisions more on social than on medical grounds and primarily existed to protect doctors who performed abortions from legal or social sanction (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. After news of the case broke, the federal government

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implemented regulations forbidding hospitals that received federal funds from withholding medical or surgical treatment from disabled infants. The regulations also urged but did not require hospitals to establish infant care review committees to prospectively evaluate decisions regarding withholding treatment from disabled infants. Many hospitals continued to use these committees even after the Supreme Court threw out the regulations in 1986. These days, most large hospitals have ethics committees.

More recently, hospitals have come to recognize the inherent difficulties in making decisions expeditiously by committee and so have shifted from relying on ethics *committees* to relying more on ethics *consultants*—individuals trained in bioethics and hired specifically to consult with hospital personnel regarding ethical issues. Ethics committees, meanwhile, have shifted from focusing on individual cases to consulting, advising, and providing information regarding broad ethical concerns, such as how to implement requests not to resuscitate terminally ill patients and whether hospital staff have an obligation to provide care to those with **HIV disease** (Fost and Cranford, 1985).

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 addition, *commercial* IRBs also now exist (Lemmens and Freedman, 2000). The growth of commercial IRBs reflects the movement of much drug research away from universities and to pharmaceutical companies, for-profit research organizations that contract with pharmaceutical companies, and independent doctors who contract to do research for pharmaceutical companies. Some commercial IRBs are run directly by pharmaceutical companies. Others are independent, for-profit organizations that contract with pharmaceutical companies or for-profit research organizations.

The conflict of interest involved in such IRBs is obvious. When a pharmaceutical company's employees review their company's research, these employees cannot avoid knowing that their company's success depends on getting research approved. Similarly, those who work for independent IRBs know that they are unlikely to get future contracts from pharmaceutical and research organizations unless they approve the proposed research designs.

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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 the laboratory, 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 together individuals from the community with health care providers to make difficult bioethical decisions regarding both research and treatment (Quinn, 2004). For example, when patients are unconscious or incompetent, and family members are unavailable, a CAB may be given the responsibility of representing the patient in treatment decisions.

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 their own risks of having or passing on these diseases? But genetic testing also has implications for communities. Genetic tests can lead to the stigmatizing of an entire community, can challenge ideas about who *belongs* to a community (when genetic differences are found within a population), and can challenge community ideas of their origins (as, for example, when Native American stories regarding tribal origins clash with genetic findings). For these reasons, researchers have begun involving communities in discussions of research priorities, research design, and the dissemination of research findings.

One major question raised by the use of CABs regards how hospitals, researchers, and others should decide who constitutes a community, and who should represent a community. There is, unfortunately, no easy answer to this question.

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.

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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 (e.g., 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. Further, 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. Finally, sociologist Daniel F. Chambliss (1996) argues that bioethics' emphasis on helping individual health care providers make more ethical decisions simply does not apply to health care workers like nurses, who often understand clearly what they should do ethically but lack the power to do so. For example, nurses often have a much better understanding than doctors of how much a patient is suffering and thus more often believe treatment should be discontinued unless it will improve quality as well as length of life. Yet nurses rarely can act on that belief because they lack the necessary legal standing, economic independence, and social status.

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)

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> 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 has only three full-time employees. These conditions make thorough review of human subjects research impossible.

Finally, even when IRBs work as designed, their authorizing statutes restrict them from addressing the broader issues of whether the benefits potentially available through research outweigh the potential for harm to society and whether the money allotted for a given research project could produce more beneficial effects if spent elsewhere (P. Williams, 1984). Yet these are often the most important questions to ask.

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.

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The Impact on Medical Education

One obvious result of the bioethics movement has been the incorporation of ethics training into medical education, with courses now common at U.S. medical schools. As critics have noted, however, those courses are too often 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 face. To achieve this latter goal, the University of Pennsylvania Medical School includes in its ethics course sessions in which students discuss ethical dilemmas they have encountered during their clinical training, such as pressures placed on them to perform medical procedures on unwilling patients (Christakis and Feudtner, 1993). Discussing situations like these can help students devise strategies for responding more ethically in future.

Other observers, however, have noted that a course like this also has its limits, for it assumes that students who are already undergoing socialization to medical culture still can identify ethically problematic aspects of that culture (Hafferty and Franks, 1994, 1998). Moreover, this strategy does not challenge 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).

The Impact on Clinical Practice

At a fundamental level, the bioethics movement challenges doctors' clinical autonomy, for it "substitutes principles and general rules for the case-by-case analysis that has long characterized medical practice . . . and attempts to reformulate medical problems as moral, rather than technical, issues" (Zussman, 1992: 10–11).

According to Annas (1991), professional ethics committees emerged to counter this challenge. Annas argues that the true purpose of these committees is not to foster more ethical behavior but to protect professional autonomy by providing clinicians with legal protection against accusations of unethical behavior. For example, published guidelines from the Ethics Committee of the American Fertility Society refer to human embryos created in the laboratory merely as "pre-embryos," even though they do not differ biologically from other embryos, and leave it up to each clinic to establish policies for their use. Similarly, published guidelines from the American College of Obstetrician-Gynecologists on whether to selectively abort fetuses when several embryos become implanted simultaneously in a

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woman's uterus state only that doctors and patients should make their decisions jointly. Such guidelines seem designed more to provide legal cover to clinicians than to encourage more ethical practices (Annas, 1991).

Relatively few studies have looked at the impact of bioethics on actual 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 stop 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 given condition (S. 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, however—and more important, their families (for, in most cases, the patients are incapable of communicating)—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 would later cause them guilt or grief. Third, doctors might respect a family's wishes, but only after first shaping those wishes through selectively providing information. This information included defining

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the patient as terminally ill or not—a highly significant designation, for 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 or terminate treatment as a technical rather than an ethical problem. The following example from Zussman's research demonstrates this process:

> The Countryside ICU [Intensive Care Unit] staff was considering whether or not to write a Do Not Resuscitate order for Mr. Lake, a 73-year-old man who had been admitted to the unit with acute renal [kidney] failure, a gastrointestinal bleed, pneumonia, and sepsis [infection]. Ken [the medical director of the ICU] asked what they should do "if the family wanted a full court press." One of the residents started to say what he thought were the "interesting ethical issues." But Ken cut him off, arguing that the decision depended entirely on prognostics: "There are no ethical issues. . . . I'm not an ethicist. I'm a doctor." When the resident attempted to distinguish different circumstances preceding codes [decisions not to resuscitate], Ken broke in again: "A code is a code. It's a medical decision, not an ethical decision." (Zussman, 1992: 150; ellipses in original)

Once doctors succeeded in defining treatment decisions as purely technical issues, they could define the family's stated wishes as uneducated and irrelevant. Doctors could end discussion regarding treatment decisions by declaring it simply a technical fact that any treatment would be futile. Similarly, 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. Because most treatment decisions involve not dramatically pulling a plug but rather a series of small, minute-to-minute actions, leaving doctors in control of these "technical" matters gives doctors power far outweighing families' general statements regarding whether to pursue aggressive treatment.

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

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Box 13.2 ***Making a Difference: Choosing Your Career***

By this point in the semester, some of you undoubtedly are just grateful that it is almost over. But others may now find that you are fascinated by the topic and wondering how you can somehow make a difference in this field. For those who are interested, four broad career options exist: clinical practice, administration, research and teaching, and policy work.

Many students take a course on the sociology of health, illness, and health care because they intend to become a health care practitioner of some sort. Now that you have reached the end of this semester, you probably have a better idea than when you started of the costs and benefits of entering the different health care fields. Perhaps you now recognize that you are attracted to the professional autonomy as well as the art and science of medicine, or realize that you would be more comfortable in a health care field that offers a more holistic approach to care. Perhaps you have second thoughts about entering nursing given its struggles for professional autonomy, or find it more appealing now that you understand the intellectual challenges and financial rewards available to those who obtain masters-level training. No matter what health care occupation you might enter, you should now bring to your work a greater understanding of the underlying sources of health and illness, the culture of medicine, the experiences of persons who live with illness and of other health care consumers, and the impact of the larger health care delivery system on both consumers and providers. Working as a compassionate, ethical, and educated health care provider is an important way of making a better world, one patient at a time.

Other readers of this book may realize, when they think about their personalities, skills, and interests, that they are not really suited for the "hands-on" work of dealing directly with patients. For those who enjoy the

> 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)

Conclusion

In this chapter we have explored the history of the bioethics movement and its impact on health care research and practice. 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 show how social and occupational groups can obtain power over others as well as the potentially deadly consequences when this happens. Conversely, sociology, in similarly unacknowledged ways,

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nitty-gritty details of the business world, there are many opportunities to work in health care administration, in everything from small nonprofit agencies that provide assistance to the uninsured to major hospital chains. Your goal, as students of the sociology of health, illness, and health care, will be to find a position that allows you to help *others* deliver high-quality, equitable health care.

A third option is to enter a career in research or teaching. Such a career requires that you be primarily fascinated by the process of generating knowledge (research), evaluating research conducted by others, and figuring out how to communicate research findings to others, whether through publications or in the classroom. Research positions can be found at all levels of government (from county health departments to the federal Centers for Disease Control and Prevention), in colleges and universities, and in nonprofit organizations and "think tanks" like the Kaiser Family Foundation and the Commonwealth Fund. In some of these positions you would have the freedom to develop your own research and teaching agenda, while in others you would be assigned to a general field of study or specific research tasks. But in all cases you would have the satisfaction of generating and communicating important knowledge about health, illness, and health care.

Finally, those of you who are most interested in effecting change on a broader scale, and who have the requisite personalities and skills, should consider careers in law, government, or political advocacy. Perhaps a reader of this book will some day direct a nonprofit organization that advocates for the rights of persons with disabilities, argue a right-to-life or right-to-die case before the Supreme Court, or propose on the U.S. Senate floor a new law guaranteeing universal health coverage.

Whatever path you choose, you *can* make a difference.

is at a basic level an ethical enterprise. Underlying abstract, technical sociological discussions about the nature of society there often lurk hidden assumptions about what society *should* be like and how society should be changed. These 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 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; Box 13.2 provides some suggestions for readers who are interested in pursuing a career related to health and health care.

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Suggested Readings

Andrews, Lori B. 1999. *The Clone Age: Adventures in the New World of Reproductive Technology.* New York: Henry Holt. Andrews, a lawyer and professor respected for her work in reproductive technology, trenchantly analyzes the potential, and potential pitfalls, of the field.

Elliott, Carl. 2003. *Better Than Well: American Medicine Meets the American Dream.* New York: Norton. A thought-provoking account of the new drugs, technologies, and cultural pressures to enhance human traits, ranging from botox to speech therapy used to reduce regional accents.

Hastings Center Report. An eminently readable and always fascinating monthly journal on bioethics, published by the Hastings Center (see "Getting Involved").

Zussman, Robert. 1992. *Intensive Care: Medical Ethics and the Medical Profession.* Chicago: University of Chicago Press. An engrossing sociological analysis of the impact of modern bioethics.

Getting Involved

The Hastings Center. Rt. 9D, Garrison, NY 10524–5555. (845) 424-4040. www.thehastingscenter.org. A nonprofit organization, the center is committed to research, lobbying, and public education on bioethics. Publishes the excellent *Hastings Center Report.*

Review Questions

What is the Nuremberg Code, and how and why did it come into existence?

What factors led to the emergence of the bioethics movement in the late 1960s?

Why do researchers now consider the Tuskegee Syphilis Study and the Willowbrook experiments to have been unethical?

What are the ethical problems involved in the new reproductive technology? in enhancements? What impact has bioethics had on health care and on health research?

Internet Exercises

1. Using InfoTrac® College Edition, look for articles on cosmetic surgery from a variety of sources. (You can access InfoTrac College Edition at www.infotrac-college.com/wadsworth, if your professor ordered it when ordering this textbook.) Do these articles suggest that there are any ethical or social issues inherent in cosmetic surgery, such as whether it is morally right or wrong, or whether social forces rather than objective aesthetic concerns

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press individuals to have this surgery? If yes, what ethical or social issues do they identify? If no, how do you explain why they do not recognize any ethical or social issues?

2. The ELSI program is a part of the Human Genome Project (which is itself a part of the National Institutes of Health) designed to investigate the ethical, legal, and social implications (ELSI) of human genetics research. Find the ELSI website, and learn about the types of research that have been sponsored by this program.

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