10

Bioethical Issues in Health Care

LEARNING OUTCOMES

After completing this chapter, you should be able to:

1. Explain why nurses should be aware of bioethical issues.
2. Outline the history of family planning in the United States and discuss how various value systems and beliefs have affected it.
3. List some of the ethical and legal problems associated with artificial insemination, surrogate motherhood, and in vitro fertilization.
4. Discuss the problems associated with determining when death has occurred and outline ways in which it impacts decisions regarding health care.
5. Analyze the multiple factors in right-to-die issues, including assisted suicide and the difference between active and passive euthanasia.
6. Analyze the various points of view related to withholding and withdrawing treatment.
7. Discuss the ethics that establish the foundation for providing clients with informed consent and involving them in decisions regarding treatment.
8. Identify the major concerns associated with organ transplantation.
9. Discuss the purposes of the Human Genome Project and identify possible bioethical issues that could evolve from it.
10. Describe the arguments for and against gene therapy and identify related bioethical concerns.
11. Analyze the reasons that controversy surrounds stem cell research and outline the positive and negative outcomes that could result from that research.
12. Discuss the multiple concerns that affect decisions regarding the treatment of the mentally ill.
13. Outline concerns related to the rationing of health care.

KEY TERMS

Abortion (spontaneous, therapeutic, elective)
Advance directives
Age of consent
Amniocentesis
Artificial insemination
Assisted death
Behavior control
Bioethics
Chorionic villus sampling (CVS)
Durable power of attorney for health care
Emancipated minor
Eugenics
Euthanasia—negative and positive
Family planning
Futile treatment
Gene therapy
Genetic screening
Genome
Human Genome Project (HGP)
Informed consent
In vitro fertilization
Living will
Mature minor
Organ procurement
Organ transplantation
Patient Self-Determination Act (PSDA)
Property rights
Rationing of health care
Right-to-die
Right to refuse treatment
Sonogram
Stem cell
Sterilization
Surrogate mother
Withdrawing/withholding treatment
Wrongful birth
Xenotransplantation

Bioethics is the study of ethical issues that result from technologic and scientific advances, especially as they are used in biology and medicine. This area of study is also called biomedical ethics because of its association with medical practice. It is a subdiscipline within the larger discipline of ethics, which (as discussed in Chapter 9) is the philosophic study of morality, or what is right and what is wrong. Today more than ever, nurses and their patients need to keep pace with the technologic changes occurring in health care. The critical choices that must be made by patients, their families, and members of the health care team are the result of changes that were not a part of our decision-making in earlier times.

This chapter discusses some of the choices with which nurses and their clients must grapple. It should be read, studied, and discussed within the framework of the information concerning ethical decision-making that was provided earlier. The content of the chapter should provide a basis with which you can look at judicial rulings, legal mandates, and social standards, and how they can be used to assist in resolving concerns that face us in health care delivery. You have had some experience in looking at what is right or wrong regarding your personal professional practice. This chapter examines more specifically the issues that apply to the bioethics of patient care.

MAJOR AREAS WHERE BIOETHICS ARE APPLIED

The bioethical issues surrounding the delivery of health care grow in number each year, constantly changing and taking on new scope and proportions. Today, issues related to birth and death, which earlier were the major focus of debates, represent just the "tip of the iceberg." Of equal or greater concern are such matters as universal access to health care and insurance for all, rationing of

health care, cost containment and quality of care, where and how federal dollars should be spent with regard to the nation's health, and the obligation of others to assist the homeless. Our media thrive on issues created by recent biomedical research, such as concerns regarding the Human Genome Project, gene therapy, and stem cell research, with one area blurring into another.

Each year the percent of America's gross domestic product (GDP) spent on health care increases. Today it is estimated at 14%, making it a $1.4-trillion industry (Schroeder, 2002). Because of lifestyle changes and medical breakthroughs, more people live today to reach old age, thus placing a greater burden on an already stressed system. Life expectancy has increased a year or 2 in each recent decade. In the United States, the life expectancy for females born today is 79.5 years, and for males it is 74.1, compared with 47 years at the beginning of the 20th century. Diseases such as Alzheimer's and AIDS, for which cures are still being sought, have increased in prevalence. With globalization have come new threats to our well-being, such as that created by the Nile virus. New technologies have led to treatments that were not available 15 years ago. Rather than decreasing health care needs, the new technologies have resulted in increasing needs because these specialized services are available today. Many treatments require use of technologies so expensive that they are priced beyond what an individual or family can afford without help from third-party payers. Finding new and better ways to treat life-threatening conditions challenges medical researchers, and the treatments that become available often invite debate among bioethicists. For example, the use of xenografts (animal-organ transplants) has been suggested to meet the increasing demand for healthy organs to transplant, but many people question this practice and, to date, it is relatively undeveloped.

Some would indicate that the "birth of bioethics" occurred with the publication of a magazine article in *Life* titled "They Decide Who Lives, Who Dies" (November 9, 1962). This article told the story of a group of individuals in Seattle whose duty it was to select patients for the first hemodialysis program to treat chronic renal failure. Many more patients needed treatment than could be accommodated; those not selected would likely die. This event was followed several years later by an article about the ethics of medical research that provided impetus for examining these issues.

Centers for research in bioethics emerged, most notably the Institute of Society, Ethics, and the Life Sciences, located in Hastings-on-Hudson, New York (often called The Hastings Center), and the Kennedy Institute of Ethics, located at Georgetown University in Washington, DC. The Kennedy Institute of Ethics, founded in 1971 by Joseph and Rose Kennedy, is a teaching and research center that provides ethical perspectives on major policy issues. It boasts the largest university-based faculty in the world devoted to research and teaching biomedical ethics. Journals such as the *Hastings Center Report* and the *Journal of Medicine and Philosophy* have come into being, and an encyclopedia*, The Encyclopedia of Bioethics,* has been published. Web sites devoted to the topic of bioethics are so numerous that they cannot be listed in the confines of this textbook. Today, bioethicists are included in many important task forces and special committees.

Entire textbooks have been devoted to bioethical considerations. Initially, most of these were written for medical students, but now just as many are written for nursing students. Some nursing programs include a course in ethics and bioethics in the curriculum. This chapter can only introduce the topic and, we hope, broaden your perspective and deepen your interest. You are encouraged to read about and study these issues further as they affect your nursing practice.

As we mentioned earlier, most of the bioethical issues have evolved as a product of the technologic advances occurring in medical practice and research and were not a concern 15 years ago. Table 10-1 lists some of the significant medical milestones that have occurred

TABLE 10-1. SOME MEDICAL MILESTONES OF THE 1900S

WHEN	WHO	WHAT
1928	Alexander Fleming	This British bacteriologist noticed that one of his culture plates had grown a fungus and the colonies of staphylococci around the edge of the mold had been destroyed. Because this fungus was a member of the *Penicillium* group, he named it penicillin.
1938	Howard Florey & Ernst Chain	These two pathologists took up the work of Fleming and demonstrated the efficacy of penicillin in treating infection. In 1945, the three were jointly awarded the Nobel Prize for Physiology of Medicine.
1951	Forrest Bird	The first Bird breathing device was developed (Bird Mark 7) and breathing treatment machines were introduced. Inhalation (respiratory) therapy rapidly developed as a health profession (Pilbeam, 1998).
1953	James Watson & Francis Crick	These two geneticists deciphered DNA's double-helix structure. Researchers began to focus on the internal functioning of the cell and molecular biology developed as a specialty.
1954	Physicians in Boston	Transplanted the kidney from one twin to the other, thus moving kidney transplantation from the experimental stage it had occupied since 1902. Kidney transplantations have been the most successful of transplantations (Miller-Keane, 1992).
1955	Jonas Salk	Public health officials began immunizing children against polio with Dr. Salk's vaccine, which contained dead virus.
1957	Albert Sabin	A polio vaccine was developed, which was based on weakened live virus, that could be administered orally.
1967	Christiaan Barnard	This South African surgeon performed the first human-heart transplant.
1972	British engineers	The computed tomography (CT) scanner, which assembles thousands of x-ray images into a highly detailed picture of the brain, was developed in England. It was later expanded to provide scans of the entire body.
1978	English physicians	The process of in vitro fertilization was developed. Louise Brown became the first person to be conceived in a test tube, then implanted into the mother's uterus.
1979	World Health Organization	This group declared that smallpox had been eradicated 2 years after the last known case was identified. This occurred because of world-wide immunization against the disease.
1981	Physicians in San Francisco and New York	Doctors from these two cities reported the first cases of what would later become known as acquired immunodeficiency syndrome (AIDS). To date, no cure exists.
1982	The U.S. Food and Drug Administration	The first drug developed with recombinant-DNA was approved by this group. It was a form of human insulin; its availability saves thousands of lives.
1995	Duke University surgeons	Hearts from genetically altered pigs were transplanted into baboons, proving that cross-species transplantations can be done. Transmission of animal viruses to humans emerges as a serious concern.
1998	James Thomas and Scientists from University of Wisconsin—Madison	Culture embryonic stem cells (cells that are the parent cells of all body tissues) from donated human blastocysts, opening the door to potential repair or replacement of diseased tissues or organs (DHHS, 2001).

* Much of the material for this table was gathered from an article by Sherwin B. Nuland, *Time Special Issue,* Fall 1996.

since 1920, some of which we have come to take for granted (eg, antibiotics and DNA). You readily can see that in 1960 there was no quest for human organs or critical decisions regarding the life status of a possible donor. We were not able to fertilize ova outside the human body and transfer the fertilized eggs in a woman's uterus until 1978. Certain life-saving machines (eg, ventilators) and miracle drugs (eg, some of the chemotherapeutic agents used today) were not available to offer extension of life. Technologies such as magnetic resonance imaging (MRI), which gives us information about the structure of tissues and allows for early diagnosis and treatment, were not available. Positron Emission Tomography (PET) was to follow. As advances occur in medical practice, we must challenge ourselves to think through our own beliefs and feelings about these practices, especially as they relate to quality of life and patients' choices.

BIOETHICAL ISSUES RELATED TO THE BEGINNING OF LIFE

Many bioethical issues with which we wrestle are focused on the process by which conception occurs, the products of conception, and the beginning of life, including whether it should occur. Much of the early debate related to family planning and conception.

Family Planning

Family planning refers to the various methods used to control the size of one's family or to space births. Although we often think of it as synonymous with contraception, in reality it is much broader. For some it could include abortion, for others it might involve adoption. It can employ natural methods, pharmaceutical preparations, or barriers. The religious beliefs and personal values of individuals usually influence the methods and approaches used.

In 1798, in an essay titled, "On Population," Thomas Malthus, a minister in the Church of England, expressed deep concern about a population that was growing faster than were the resources to support it. To offset this problem, he advocated late marriage, no marriage, or sexual abstinence in marriage. No forms of contraception as we know them today were available, although women sometimes developed homemade devices in an effort to prevent pregnancy.

In 1873, the U. S. Congress passed the Comstock Act, prohibiting the sale, mailing, or importing of "obscene literature and articles for immoral acts." All contraceptives and any material teaching about sexuality or birth control were encompassed in this prohibition. Those who continued to import and distribute birth control literature or contraceptives were breaking the law. You may have read about Margaret Sanger (1883–1966), a nurse who championed for contraceptive practices in the early 1900s. Although charged and sentenced for disseminating information on birth control, she went on to establish the National Committee on Federal Legislation for Birth Control, the forerunner of the Planned Parenthood Federation. In 1938, in Sanger's landmark case, a federal judge dismissed this federal law as unconstitutional, thus ending the federal ban on contraceptives. Although some states were more liberal than others, and some changed sooner than others, the state that had prohibitions against contraceptives for the longest time was Connecticut.

It was not until 1965, in the case of Griswold and Buxton vs. the State of Connecticut, that the Supreme Court of the United States overrode the state law forbidding sale or teaching about

contraception and established the right of the individual to obtain medical contraceptive advice and counseling. (*http://womenshistory.about.com/library/ency/blwh_comstock.htm*).

Much of the controversy over birth control is related to the theologic teachings of some religious groups, who believe interference with procreative powers is wrong. The Roman Catholic Church has strongly advocated that the natural purpose of sexual activity is to create new life and nothing should try to interfere with that potential.

The members of the Church of Jesus Christ of Latter Day Saints (Mormons), although less adamant in their teachings, also discourage the use of artificial birth control under normal circumstances. Some conservative Protestant Christians and conservative Muslims also advocate allowing God to plan families and do not use birth control methods. Orthodox Judaism has specific rules about when sexual intercourse may or may not occur; these rules have the effect of supporting sexual activity when a woman is fertile. The Orthodox Jewish population is so small in proportion to other groups that the impact is not significant.

The opposite end of the spectrum is found in those who are strong advocates of zero population growth and encourage individuals to limit families to one or two children in all instances. Others are so concerned about population growth and the state of the world that they decide to have no children.

During your career as a nurse, you will care for patients who represent many differing viewpoints. When caring for individuals whose personal beliefs prohibit the use of artificial birth control, you must be knowledgeable about natural methods of family spacing, such as fertility awareness methods, that will meet the patient's needs. If your personal views regarding contraception differ, your values must be set aside as you focus on assisting the patient in selecting a method that is compatible with the patient's personal values and beliefs.

Among the methods of birth control available to those who have no religious sanction against their use, not all methods are acceptable to all people. For example, some find the intrauterine device unacceptable because they believe that interfering with a fertilized egg should be viewed as abortion (researchers are not entirely sure how the intrauterine device works, but some suggest that it prevents the fertilized egg from implanting in the wall of the uterus). Those who find abortion an acceptable method of coping with an unwanted pregnancy represent another set of values.

Central to all discussions of contraception is the issue of freedom of a woman to control her own body. This immediately raises a second question: who has that right? Is it the woman's right because it is her body? What if the partners disagree about family planning practices? Does one have more say than the other? What if one partner wants to have a family and the other does not?

EXAMPLE

Abortion

In Pennsylvania in August 2002, a temporary injunction blocked a young single woman from securing an abortion. The injunction was issued in response to a lawsuit filed by her boyfriend (from whom she was estranged), who wanted the pregnancy continued. Appeals were filed. A week later, a judge dismissed the injunction and was critical of the fact that the young woman had experienced emotional distress and possible risk because of the delay. She miscarried (aborted spontaneously) the afternoon of this ruling.

Problems of Consent and Family Planning

The ability to procreate precedes what is generally considered legal age; therefore, we find ourselves grappling with problems related to age of consent, its definition, and the role of the parents and the family. In legal terms, the **age of consent** is the age at which one is capable of giving deliberate and voluntary agreement. This implies physical and mental ability and the freedom to act and make decisions. The age of consent is established state by state and varies from age 14 in Hawaii and Pennsylvania to age 18 in fourteen other states. Most states have established age 16 as the age of consent (*totse.com*, 2002).

Until children reach the age of consent, parents are required to give consent for the care of their children. Implicit in this is the assumption that the parents have the best interests of the child at heart and that they are better qualified than the child to make decisions in the child's best interest. Generally speaking, the parents are responsible for the care (including medical costs) and education of the minor. However, today's trends cloud the issue as we struggle with "rights."

With regard to research, federal guidelines required that children with a mental age of 7 years or older be informed about proposed treatment or research and agree or concur with the decision made by the parent or guardian. This is referred to as *assent.*

Another example is the concept of the **emancipated minor**. As previously discussed, emancipated minors (an individual legally under the age of majority), who are financially independent, married, or in the military, may give consent for medical treatment, including all treatment for sexually transmitted diseases, contraception, and pregnancy-related concerns, regardless of their parent's or legal guardian's knowledge or agreement. Most states recognize some form of emancipation of minors.

Mature minors are "individuals in their mid- to late teens who are considered mature enough to comprehend a physician's recommendations and give **informed consent**" (Judson & Hicks, 1999). Under this definition, most states allow mature minors to seek treatment for sexually transmitted diseases, drug or alcohol abuse, contraception, and pregnancy care without the consent of a parent or guardian. The most liberal legislation applies to the treatment of sexually transmitted disease and is endorsed by most states. Minors of any age can consent to diagnosis and care for sexually transmitted diseases. For more discussion of age of consent and informed consent, see Chapter 8.

In some instances, this autonomy of the mature minor may bring health providers into a conflict between two laws. Although the mature minor may be able to consent to treatment for sexually transmitted disease, if the health provider believes this to have been contracted through sexual abuse of the minor, the provider is required to report that abuse. Most authorities direct that child abuse laws take precedence over privacy laws.

Certainly, there are times when physicians' ethical and moral convictions prevent them from complying with adolescents' requests for care. This occurs most commonly in response to requests for contraceptive pills and abortions. In such cases, physicians often discuss their beliefs with the adolescent, and frequently refer the patient to a medical colleague for assistance.

A major controversy exists around the role of the school in the sex education of high school students and the dispensing of contraceptives through high school health clinics. The advent of emergency contraception in the form of birth control pills taken in high dose for a limited time after intercourse has added another dimension to these ethical issues about birth

control and minors. In some states, emergency contraception is available directly from a pharmacy without a physician's prescription. The pharmacist, therefore, is drawn into the decision-making web.

Those who are concerned about the high incidence of teenage pregnancies and sexually transmitted diseases argue that the information must be disseminated, regardless of who does it. Others believe that this promotes erosion of the role of the family, and worry that the indiscriminate dispensing of contraceptives encourages promiscuity among teenagers. Concern about the spread of AIDS has done much to alter thinking, particularly regarding the dispensing of condoms.

Abortion

What has been said about contraception becomes an even greater issue when related to abortion. In medical terms, **abortion** is the termination of pregnancy before the viability of the fetus—that is, any time before the end of the 6th month of gestation. An abortion may occur spontaneously as a result of natural causes (**spontaneous abortion**). A pregnancy may be interrupted deliberately for medical reasons (**therapeutic abortion**), or for personal reasons (**elective abortion**). It is the last two classifications (especially the latter) that induce bioethical debate. Ethically, the entire debate revolves around the definition of human life and when the fetus should be considered a human being. There are two major schools of thought about the nature of the fetus: one supports the belief that new life occurs at the moment of conception; the other contends that human life does not exist until the fetus is sufficiently developed biologically to sustain itself outside the uterus.

The legal aspects of abortion were clarified on January 22, 1973, when the U. S. Supreme Court ruled in the case of Roe vs. Wade that any state laws that prohibited or restricted a woman's right to obtain an abortion during the first 3 months of pregnancy were unconstitutional. In this case, the Supreme Court recognized that, during the first trimester of pregnancy, a privacy right exists that allows an individual woman to make the final decision with regard to what happens to her own body (Roe vs. Wade, 1973). Certain time limitations as to when an abortion can be performed were determined to be necessary, because of the state's interest in protecting potential life. At the period of viability, the state's interest took precedence over the mother's desire for an abortion. Supreme Court Justice Blackmun, in writing an opinion that met with agreement from six other justices in Roe vs. Wade, decided that a woman's decision to terminate a pregnancy was encompassed by the right to privacy, up to a certain point in the development of the fetus (Blackmun, 1981). It was established that this lasted until the end of the first trimester. Thus, the courts ruled that the state could not prevent abortions during the first trimester, but could regulate abortions in the second and third trimesters of pregnancy, at which point the interests of the fetus took precedence over those of the mother. In 1992, the Court reaffirmed the basic principles of the 1973 decision.

Despite these rulings, the issue of abortion continues to surface, with new legislation and rulings being considered each year and the issue being debated each presidential election. In 1977, Congress barred the use of Medicaid funds for abortion, with the exception of those done for therapeutic reasons and in other specific circumstances. However, the legal positions do little to help us deal with bioethical concerns. Many people view termination of life at any

point after conception as murder. The Roman Catholic Church firmly upholds its traditional position on abortion. Many conservative Protestant Christian groups also are active in opposing abortion.

Some believe that although abortion is not desirable, under certain circumstances it would be justifiable—for example, in cases of rape or incest, or in instances where amniocentesis indicates that a fetus would be born retarded or genetically defective. Others think that early termination of a pregnancy might be acceptable, but that termination after the 4th month would not be appropriate.

Those who support abortion without restriction usually do so because they believe that women should have control over their own bodies, which is tied to issues of privacy. They further argue that the quality of life of an "unwanted" child, or a child born with a deformity or genetic defect, may be minimal. Interesting and challenging cases have emerged with respect to this concept. These are generally known as **wrongful birth** cases, and are based on the principle that it is wrong to give birth to children (such as those with birth defects or limitations that can be diagnosed or anticipated before birth) who will not have the same quality of life as other children.

As a nurse, these issues present some difficult questions you will need to answer. To what extent do you believe you can personally participate in the abortion procedure? Would the stage of pregnancy and type of procedure make a difference? As a nurse, you have the right to refuse, based on your own ethical beliefs, to be involved in abortion procedures or the care of patients seeking abortion. Employment in certain areas (eg, labor and delivery rooms), however, may rest on the nurse's willingness and ability to assist with abortions and to give conscientious care to the patient who has had an abortion. Some religiously affiliated hospitals have elected to close their labor and delivery services rather than perform abortions.

Although textbooks traditionally have defined the age of viability (the earliest age at which fetuses could survive if they were born at that time) as 20- to 24-weeks' gestation, technology has increased the ability to enable very-low-birth-weight and premature babies to survive. The age of viability is less clear than it once seemed. Attention has been focused on incidents in which an abortion was attempted toward the end of the 5th or 6th month of gestation, and the fetus was born showing signs of life. Is the doctor or nurse obligated to try to keep the infant alive? Is the doctor or nurse guilty of malpractice, or even murder, if he or she does anything to hasten the infant's death? Should this infant be considered a human being? Does the infant have "rights"? Does the mother have legal possession of and responsibility for the child if, in fact, she attempted to abort the fetus? This issue, like so many others, probably will be settled in a court of law while we continue to debate it ethically.

The abortion issue also is complicated by consent problems. Many states have recognized the special problems related to parental consent for teenagers and to health care involving pregnancy and have legislated special exceptions. Nurses practicing in areas that provide abortions to minors must be concerned about parental consent and counseling issues because of the wide variations in state statutes governing abortions (Killion & Dempski, 2000).

In the last few years, the abortion issue has been made more complex by research that would use the fetal tissue resulting from an abortion for stem cell research and therapeutic purposes. We will discuss stem cell research later in this chapter.

As a society, it seems likely that we will continue to debate the issue of abortion. Ultimately, the decision rests with the individual who must make the choice. Certainly the legal

entanglements become more complex with each court ruling, and will be limited only by our willingness to challenge other aspects of the question.

Critical Thinking Activity

Select one of the positions taken regarding abortion. Defend your position, providing a strong rationale for your thinking. Examine your thinking for biases. Why did you develop those biases? Discuss the topic of abortion with a classmate who holds a different position, remembering that all persons are entitled to their own viewpoints.

Prenatal Testing

The ability to identify birth defects and genetic disorders of the fetus has created a different dimension in the abortion debates. A major breakthrough in our ability to detect genetic abnormalities in the fetus occurred in the 1970s with the development of techniques to carry out amniocentesis. **Amniocentesis** is performed between 14 and 20 weeks after the woman's last menstrual period. Amniotic fluid is aspirated and analyzed. From these cells, many genetic problems of the fetus can be diagnosed prenatally, including such conditions as Down syndrome (which accounts for about one third of the cases of mental retardation in Western countries), hemophilia, Duchenne's muscular dystrophy, Tay-Sachs disease, and problems related to the brain and spinal column (eg, anencephaly and spina bifida).

The potential for Down syndrome, a condition occurring with higher frequency in mothers in their early 40s and older, is the most common reason for seeking amniocentesis. When amniocentesis reveals a genetic disease, a woman will often choose to have an abortion. Rothstein (1990, p. 39) reports that "termination rates for muscular dystrophy, cystic fibrosis, and alpha and beta thalassemia are nearly 100%; they are 60% for hemophilia; and 50% for sickle cell anemia." Some couples request amniocentesis if they are in an "at-risk" group, but state that they would not abort the fetus under any circumstances; instead, they believe that an additional 5 months will give them time to adjust to the presence of a serious condition before the baby is born. Usually doctors are reluctant to do an amniocentesis under these circumstances, because the risk of performing the procedure, although small, does not seem justified.

Chorionic villus sampling (CVS) involves securing a sample of chorionic villi from the developing placenta. A sample of the placenta is obtained either vaginally or percutaneously and then analyzed genetically. Like amniocentesis, these tests can predict birth defects and certain diseases. CVS can be performed earlier than an amniocentesis, usually in the 10th or 11th week of pregnancy.

Today almost all pregnant women have a **sonogram** (ultrasound). It is most likely used for fetal assessment at least once in a normal pregnancy, more often in those who have a risk factor. The sonogram can detect a number of abnormal conditions in addition to assuring that the pregnancy is progressing normally.

The advent of amniocentesis, CVS, and ultrasound heralded the development of yet another medical specialty: prenatal surgery. Although the specialty is still new, some corrective surgery is being performed on infants while they are in their intrauterine environment.

Some people are concerned about prenatal testing because of where it might lead. Is mass genetic screening a possibility? **Genetic screening** makes it possible to determine if persons are predisposed to certain diseases and whether a couple might have the possibility of giving birth to a genetically impaired child. Ethicists have expressed concern about the possibility of the government making diagnostic amniocentesis and abortion of all defective fetuses mandatory. Others argue against genetic screening, counseling, and amniocentesis because of the stress it places on a marriage, and because of the guilt placed on the partner carrying the defective gene (when that can be determined). They argue that there are some things we are better off not knowing. Genetic screening also may result in at least one of the partners (often the carrier) seeking voluntary sterilization to prevent pregnancies with less than favorable outcomes. Despite concerns, amniocentesis has become a fairly common test offered to mothers who are in an "at-risk" group.

As a nurse, you may care for clients with varying viewpoints regarding prenatal screening and abortion, and you will also have your own values to consider. Will your values conflict with those of your clients? Are you obligated to advocate for a client when the client's request is squarely in opposition to what you believe to be right? Should you try to sway a woman who is indecisive toward either decision?

Sterilization

For years, surgical operations resulting in permanent **sterilization** have been performed for therapeutic purposes, such as the removal of reproductive organs to halt the spread of cancer or other pathologic processes. Although problems may arise for the patient and family as a result of such surgeries, usually they are resolved without serious ethical debate, depending on the family's religious values, the patient's body concept, family plans, and personal values.

With increasing frequency, voluntary sterilization has been requested by individuals to terminate reproductive ability. Although sometimes reversible, patients are counseled that these surgical procedures, whether performed on men or women, should be considered permanent and irreversible. Many people see it as the prerogative of an individual; others find any type of sterilization in conflict with their religious and moral beliefs. Sterilization may pose few problems for those who are satisfied with the number of children they have had or who are adults who have determined that they do not want to have children. People may decide not to have children for a variety of reasons, including personal health status, familial genetic disorders, or simply not wishing to parent. Full and informed consent is required of the person being sterilized; however, health care providers often prefer to obtain assent from the spouse if the person is married to avoid subsequent emotional and family problems. Some people question whether a man or woman should be free to make such a decision without consulting the partner, but doing so is completely legal. A few states still have laws forbidding voluntary sterilization for contraceptive purposes, but these laws may not be enforced. In 1935, Oklahoma passed a law that was not struck down by the U. S. Supreme Court until 1942. It resulted in 13 states' establishing laws specifically permitting sterilization of repeat criminals (Lombardo, 2002).

Chemical sterilization, sometimes referred to as chemical castration, refers to providing drugs that decrease libido, sperm production, and sexual ability. This approach has been used in individuals with a history of repeated rape, who are often incarcerated during the time they are receiving chemical sterilization. In some instances, this has been recommended or even

requested by those individuals who were convicted of repeated sexual offenses, particularly those against children. Despite the criminal history, some challenge the ethics of this action.

Because sex crimes are related to power and aggression, and not just to sex drive, this remains a controversial issue.

Eugenics

Eugenics is a term that has had different meanings in different eras but is generally thought of as the study of methods to improve inherited human characteristics. The idea of improving the quality of the human race is at least as old as Plato, who wrote on the topic in his *Republic*. The philosophic beliefs of certain 18th-century thinkers about the notion of human perfectibility were central to the eugenics movement, which is thought to have started in the 19th century. Charles Darwin's cousin, Francis Galton, who created the term eugenics, based his work on Darwin's theory of evolution. When Mendel's law provided a framework for explaining the transmission and distribution of traits from one generation to another, the eugenics movement took hold. Organizations focusing on eugenics were created around the world.

The center of the eugenics movement in the United States was the Eugenics Record Office in Cold Spring Harbor, New York, and its leader was geneticist Charles Davenport. Until the early 1930s, the eugenics movement grew. Eugenicists presented a two-part policy. Positive eugenics encouraged increasing the desirable traits in the population by urging "worthy" parents. "Superior" couples were encouraged to have more children. Negative eugenics advocated the elimination of unwanted characteristics from the nation by discouraging "unworthy" parents.

Negative eugenics included a variety of approaches, such as marriage restriction, sterilization, and permanent custody of "defectives." Many eugenicists were actively involved in other issues of the day, including prohibition, birth control, and legislation that would outlaw miscegenation (ie, marriage between two persons of different races, especially between white and black people in the United States). Indiana enacted the first law permitting sterilization on eugenic grounds in 1907; Connecticut followed soon after. In 1914, Harry Laughlin, who worked at the Eugenics Record Office, published a Model Eugenical Sterilization Law that proposed sterilization of the "socially inadequate," a group that included "feebleminded, insane, criminalistic, epileptic, inebriate, diseased, blind, deaf, deformed and dependent" including "orphans, ne'er-do-wells, tramps, the homeless and paupers." By the time the law was published in 1914, 12 states had enacted sterilization laws; by 1937, 31 of the 48 states had compulsory laws. By 1924, approximately 3,000 people in America had been involuntarily sterilized (Lombardo, 2002). This number increased to more than 60,000. The Immigration Restriction Act of 1924 also was passed at this time, dramatically limiting the immigration of people from southern and eastern Europe on the grounds that they were "biologically inferior." The trend in recent times has been for states to modify, repeal, or ignore sterilization laws.

The eugenics movement also grew in Germany. In 1933, Hitler sanctioned the Hereditary Health Law, or the Eugenic Sterilization Law, thus ensuring that the "less worthy" members of the Third Reich did not pass on their genes. This action resulted in the sterilization of several hundred thousand people and helped lead to the death camps. By the late 1930s, eugenics in the United States began a tremendous decline. Americans became concerned about the concept of a "master race."

When the eugenic movement was rekindled in the 1960s, it had a different focus—one related to genetic counseling and genetic research. Today, a couple giving birth to a child with a congenital anomaly (or who realize that one of them is carrying a genetic trait that could cause a child to have a congenital anomaly) might voluntarily seek genetic counseling, and possibly opt for the sterilization of one of the partners. Again, this approach offends the religious and moral values of some, but generally it is viewed as the couple's prerogative.

Citing a presentation given by Roberts at a bioethics course held in Washington D.C. in June 2000, Burkhardt and Nathaniel (2002) observe that the early birth control movement in the United States became tied to eugenics. This is supported by Randall (2002), who further states that in 1939, the Birth Control Federation of America planned a "Negro Project" to limit reproduction by blacks, who were seen as a portion of the population least fit for parenthood. The first public birth control clinics were established in the South, where poor black women were being coercively sterilized through government welfare programs. This resulted in a lawsuit that prompted federal regulation requiring informed consent and a waiting period before sterilization.

In states that permit sterilization of a person who is not competent to give consent, questions can be raised about who may request sterilization, who may sign the consent, and who must fund the procedure. Some states allow a guardian to make such a decision, but other states specifically prohibit guardians from consenting to sterilization. As the result of a court decision, federal dollars may not be used for sterilization of a person who cannot give personal consent. However, the taxpayer contributes to the cost of institutionalizing people who are not capable of living independently in today's society, and caring for those with severe illnesses and disabilities.

The question must be raised regarding the ability of two individuals who are mentally retarded to care for children they may parent. Therefore, it is not only a personal concern, but also society's concern.

In Vitro Fertilization

In 1978 in England, much attention focused on the birth of the first child who was conceived in a test tube, a process we refer to as **in vitro fertilization** (IVF). Due to a blockage in the mother's fallopian tubes, conception in her tubes was impossible. The ovum was removed from the mother, united with the father's sperm in a laboratory setting, and then implanted in the mother's uterus, where it grew to term and was delivered by cesarean section. Today, IVF and similar procedures (Table 10-2) help many infertile couples.

Many herald this as one of medical science's great advances. For others, it raises many concerns. Several fertilized ova are usually returned to the uterus to assure that at least one will survive. If more than one implant successfully, it is possible for the mother to have multiple births. Multiple births seldom go full term, resulting in financial and emotional costs. When the number of implanted embryos is too great, consideration is given to aborting several of them to improve the chances of full development for the remaining ones; this creates additional ethical dilemmas for the family.

What should be done with fertilized ova that are not returned to the uterus? (There are an estimated 100,000 to 200,000 such embryos in the United States.) Should they be thrown

TABLE 10-2 TYPES OF ASSISTED REPRODUCTIVE TECHNIQUES

NAME	INITIALS	DESCRIPTION	FIRST USED WITH HUMANS
Artificial Insemination: Homologous	AIH	Husband's semen is collected and then deposited at the cervical os or in the wife's uterus by mechanical means.	United States, 1884
Artificial Insemination: Donor	AID	Donor's semen is collected and deposited at the cervical os or in the woman's uterus by mechanical means.	United States, 1884
In Vitro Fertilization	IVF	After heavily medicating the woman with hormones to trigger ovulation, eggs are harvested and fertilized with father's sperm in a laboratory. Several of the resulting embryos are implanted in the mother's uterus.	England, 1978
Gamete Intrafallopian Transfer	GIFT	Eggs and sperm are inserted directly into the woman's fallopian tubes using a laparoscope. Embryos travel to the uterus for implantation.	United States, 1984
Zygote Intrafallopian Transfer	ZIFT	Eggs and sperm are combined in the laboratory. The resulting zygotes are then inserted into the woman's fallopian tubes and travel to the uterus for implantation.	Belgium, 1989
Preimplantation Genetic Diagnosis	PGD	Egg and sperm are united in the laboratory and the embryo is allowed to develop to 4–8 cells. One or two cells are removed and examined for harmful genes. Defective embryos are discarded; healthy ones are implanted in the woman's uterus.	United States, 1991
Immature Egg Harvest	IEH	Similar to IVF, the eggs are harvested from the ovaries while still immature, are cultured in the laboratory, fertilized, and transferred into the woman's uterus.	South Korea, 1991
Intracytoplasmic Sperm Injection	ICSI	In a laboratory setting, a single sperm cell is injected into an egg and then both are implanted in the woman's uterus.	Belgium, 1992

away? Given to a donor? Used for research? Should tax dollars be used to fund this type of research? If frozen, how long should they remain frozen? What should be done with them at the end of that time? Is discarding the embryos the moral equivalent to having an abortion?

Some couples with embryos to spare have chosen to give the embryos to another infertile couple. The fertilized ovum is implanted into the uterus of the infertile female and often results in a full-term pregnancy. Recently, a $1-million federal program was funded to promote the practice. Although opponents of abortion rights may view this as a better alternative than stem-cell research, in which embryos are destroyed, the moral and legal implications comprise a gray area. Are these embryos people, property, or their own entities worthy of respect? Like other adoptions, should a home study and background check be completed on the family receiving the fertilized ova? Some believe embryo donation is different because most state laws presume that a woman who carries and gives birth to a child has earned the right to be a parent.

Other offshoots of in vitro fertilization allow people who are carrying a severe genetic disease to be assured that their children will not be affected by the condition or carry the defective gene. Fertilized ova are examined for possible disease before being implanted in the uterus; those that are diseased would not be implanted.

EXAMPLE

In Vitro Fertilization

A Louisiana couple decided, after the death of their 3-year-old daughter from Tay-Sachs disease, not to risk having more children. They learned that they both carried one copy of the Tay-Sachs gene, which would result in a 1-in-4 chance of conceiving a child with the disease. Shortly thereafter, the couple were notified that a procedure had been developed through IVF and high-tech genetic testing (known as preimplantation genetic diagnosis [PGD]) whereby technicians can remove one or two embryonic cells from those fertilized in vitro and test for the harmful gene. This allows only healthy embryos to be transferred back to the woman's uterus. This procedure resulted in the birth of a healthy child for this couple, and one who is not a carrier of Tay-Sachs disease.

As wonderful as this may seem, concerns exist regarding what some would call the misuse of IVF. In Italy, a 62-year-old woman became pregnant using donated eggs and IVF before implantation in her uterus. She gave birth by cesarean section in 1994. A 59-year-old woman in England delivered twins by this method. A record was set for what is thought to be the oldest woman to give birth to a healthy infant, when it was announced in April 1997 that a 63-year-old woman had given birth via cesarean section on November 7, 1996. The woman, married and previously childless, is said to have told doctors she was 50 and had medical records attesting to that age. (The medical center where the IVF occurred sets an age limit of 55 on accepting patients.) A donor egg and the husband's sperm were used for the IVF (Roan, 1997).

In some countries, legislation has been passed to prevent such situations. In January 1994, the French Senate opted to prohibit the use of reproductive options in certain cases (Capron, 1994). One can readily identify some of the difficulties in starting the mothering process at age 62 or 63, not the least of which would be living long enough to see the child reach adulthood. Quality-of-life issues also may be involved. If the mother is 62 when the child is born, she will be 67 or 68 when the child starts school and 75 when the child becomes a teenager.

Other concerns focus on the fear that PGD will be used to make "perfect babies" or for sex selection, even when there is not a medical reason (such as hemophilia, Tay-Sachs, or sickle-cell anemia) for such action. A case was reported in Chicago in which a 33-year-old married geneticist used PGD to selectively screen for an embryo that would be free of the gene responsible for early-onset Alzheimer's.

Artificial Insemination

Other discussions revolve around the topic of **artificial insemination**, which is the planting of sperm in the woman's body to facilitate conception. Although we tend to think of this as a fairly new procedure, the first time artificial insemination is said to have been used was in

Philadelphia in 1884. There are two different kinds of artificial insemination: homologous (Artificial Insemination Homologous—AIH), in which the husband's sperm is used, and heterologous (Artificial Insemination Donor—AID), in which a donor's sperm is used. Using the husband's sperm is by far the most common and creates the fewest problems legally, ethically, and morally. In some instances, the sperm from the husband and the sperm from a donor with similar physical characteristics are mixed together. As a result, if conception occurs, the couple could easily believe it was the husband's sperm that was accepted by the ovum.

Although some religious groups may have objections, few concerns arise when the husband's sperm is used. That is not true with donor sperm. If the woman is artificially inseminated with donor sperm without the knowledge and consent of her partner, the problems are multiplied. If conception occurs and the child is not biologically that of the husband, can one say that adultery has occurred? Others suggest that the husband should legally adopt the child. To some extent, this helps to clarify issues of inheritance, child support (if the couple should later divorce), and the legal status of the child.

Single Parents

Another ethical issue has emerged as our society has developed greater acceptance for single-parent families. More single women are trying to adopt children, and some see artificial insemination as a logical solution. In some instances, these women are also lesbians. One of the couple will seek artificial insemination with a donor sperm; the child then is raised as family in the lesbian relationship. Providing a parenting option to lesbians is totally unacceptable to many people. Aside from the emotion that the issue of a lesbian relationship may introduce, there is the argument against the artificial insemination of any unmarried woman on the basis that the traditional two-parent family composed of a man and woman is in the best interests of all children.

Recent years also have witnessed the adoption of children by gay couples. Such instances do not involve artificial insemination but, rather, a formal adoption process through the courts. Again, some of the same arguments are set forth against this process as for lesbian parenthood.

Surrogate Mothers

A **surrogate mother** is one who agrees to bear a child conceived through artificial insemination and to relinquish the baby at birth to others for rearing. This practice has occurred with increasing frequency and in a variety of relationships and presents unique problems. The following represents one such situation.

EXAMPLE

Surrogate Mothering Within a Family

A 47-year-old woman agreed to serve as gestational surrogate for her own daughter, whose uterus had been removed because of disease. The daughter's eggs were inseminated with her husband's sperm and the embryos were then implanted in the mother, who gave birth to triplets when she was 48. Thus, this woman became the gestational mother and the genetic grandmother to triplets.

As you see, these artificial means of reproduction have complicated even the language that we are accustomed to using. The term biologic is no longer adequate for making some critical conceptual distinctions. Macklin (1991, p. 6) states, "The techniques of egg retrieval, in vitro fertilization (IVF), and gamete intrafallopian transfer (GIFT), now make it possible for two different women to make a biological contribution to the creation of a new life." Macklin further believes that the woman who contributes her womb during gestation is also a biologic mother. We find terms such as genetic mother used to refer to the individual contributing the ovum, and gestational mother used to refer to the individual who provides the uterus in which the child develops. In some instances the surrogate mother is both.

Surrogate mothering within a family has caused fewer problems than have been seen when a stranger serves as the surrogate mother. Ethically, carrying a child for a family member out of love and concern and planning to remain in that child's life as part of the family reflect a commitment to a child and respect for the personhood of the child. The majority of serious conflicts have occurred in situations in which a woman has been paid to serve as a surrogate mother. A formal, contractual relationship is usually established. The couple who wish to have the child agree to pay all expenses associated with the pregnancy, and to pay the surrogate mother an agreed sum for her time and involvement. The contract must be carefully drawn up because it is illegal in all states to sell a child.

Many ethicists view parenting for pay as a gray ethical area that may fail to value the personhood of the child. This becomes apparent when things do not go as planned. What happens if the child is born with an anomaly, as occurred with a New York couple in 1982? How are these dilemmas to be solved? What is to happen to the child? Who bears the responsibility?

EXAMPLE

Surrogate Mothering and a Child With an Anomaly

A man paid a woman to be artificially inseminated with his sperm and to carry his child. When the child was born with microcephaly (an unusually small brain), the man rejected the infant, stating that he could not be the father. The surrogate mother and her husband also did not want to accept the responsibility for parenting the child.

Recently, problems associated with surrogate mothering have centered around the surrogate mother's unwillingness to give up the child after birth (Fig. 10-1).

EXAMPLE

Surrogate Mothering and Custody

"Baby M," as the court called her, was born to a surrogate mother after she was impregnated with the sperm of a man for whom she agreed to bear the child. This man's wife, a pediatrician, chose not to bear a child because she had multiple sclerosis. Although signed agreements existed, the surrogate mother broke the contract within days of the baby's birth and asked for custody of the child.

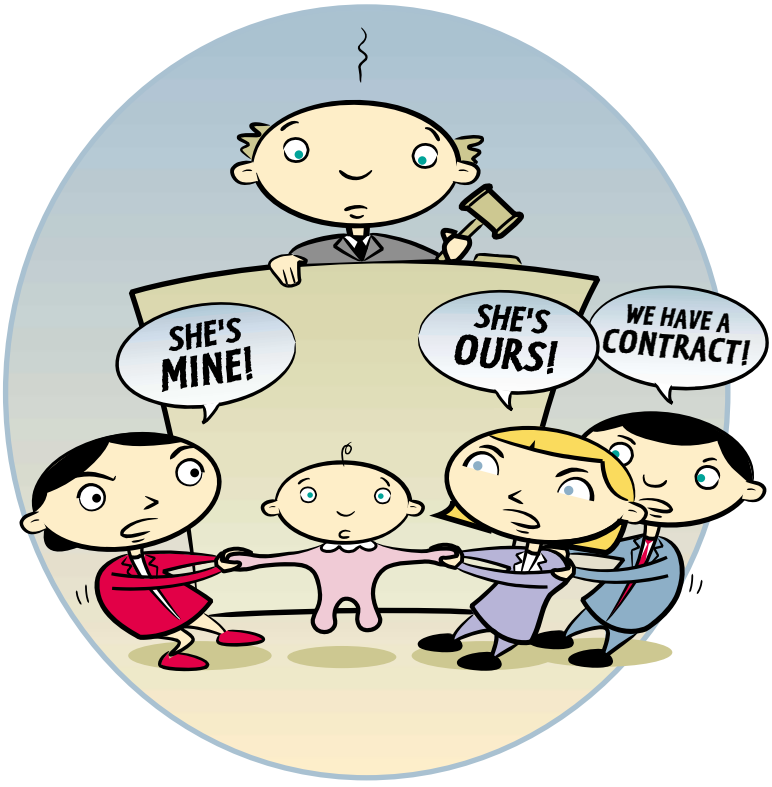

FIGURE 10-1 Complexities arise when surrogate mothers are unwilling to relinquish the infant after birth.

Critical Thinking Activity

What safeguards would you recommend regarding IVF, artificial insemination, and surrogate mothers to ensure respect for the human condition? Be specific about how you believe these safeguards would be effective. Reflect on your proposals. Are there any you would change? Discuss your proposals with a classmate.

Sperm Banks

Another aspect of the artificial insemination issue is that of sperm banks. Sperm banks have been established in different parts of the United States for various reasons. Men who want to have a vasectomy may contribute to a sperm bank "just in case" they change their minds in the future. Men who will be exposed to high levels of radiation in their work, or during treatment of disease, may wish to have sperm stored because radiation may cause mutation of the genes or result in sterility. This allows them to father children at a later date without concern about the effect on the sperm.

In most cases, the medical community establishes sperm banks so that sperm is available for artificial inseminations. In California, a sperm bank was started that contains only sperm of outstanding and brilliant men. The idea was to create children with this sperm who will be

genetically endowed with greater intelligence and creativity. Many find this unacceptable because it brings up the issue of creating a super race. Concerns also have been raised regarding the possible number of offspring in a single community who might be genetically related without knowing it.

Are there ethical implications for the man who becomes a sperm donor and is the biologic father of a child, but assumes no ethical responsibility for who receives that sperm or for the resulting child and, in fact, has no knowledge regarding the use of his sperm? Some ask how a man can ethically father offspring and have no responsibility for their well-being.

The Right to Genetic Information

All the issues of artificial insemination using donor sperm, surrogate mothering, single parenting, and sperm banks are further complicated by a recent trend toward providing individuals with information regarding their familial background, makeup, and history. You can readily anticipate the problems that would be created if donor sperm were used for insemination. In some instances, no record has been maintained regarding who donated the sperm.

As society emphasizes the importance of the role of fathers and the rights of children to know their family heritage, will anonymous sperm donation remain an option? How many individuals would be willing to donate sperm if it were to include a detailed background? What might be the ultimate legal involvement? On the other hand, what are the rights of the child to know what genetic factors he or she carries? Whose rights should take precedence? Oregon has passed legislation opening birth records for adults adopted as infants to learn their backgrounds, even though anonymity of the birth mother was guaranteed at the time of the adoption. Will tracking of sperm donors also become a concern in the future?

BIOETHICAL ISSUES CONCERNING DEATH

One of the most important areas of ethical debate revolves around the topic of death and dying. As mentioned earlier, the advent of life-saving procedures and mechanical devices has required redefinition of the term death, caused us to examine the meaning of "quality of life," and created debates about "death with dignity."

Also associated with the issue of death are several companion concerns that did not exist before the technologic advances that occurred in the past 15 years. Some of these concerns relate to euthanasia, the right to refuse treatment, and the right to die. Other concerns relate to organs retrieved from the dying, because of the scarcity of these medical resources. Generally, the demand for donated organs far exceeds the number of organs available to meet the needs. Superimposed on all these issues is that of informed consent.

Death Defined

Until recently, the most widely accepted definition of death was from Black's Law Dictionary, which defines death as the irreversible cessation of the vital functions of respiration, circulation, and pulsation. This traditional view of death served us well until the development of ventilators, pacemakers, and other advances in medical science that made it possible to sustain these

functions indefinitely. We also have learned that various parts of the body die at different times. The central nervous system is one of the most vulnerable areas, and brain cells can be irreversibly damaged if deprived of oxygen, while other parts of the body will continue to function.

Newer definitions of death have been built around the concept of human potential—meaning the potential of the human body to interact with the environment and with other people, to respond to stimuli, and to communicate. When these abilities are lacking, there is said to be no potential. Because this potential is directly related to brain function, the method most often used to assess capability is electroencephalography. Brain activity, with few exceptions, is said to be nonexistent when flat electroencephalographic (EEG) tracings are obtained over a given period, often 48 hours. At this point, the person may be considered dead, although machines may be supporting the vital functions of respiration and circulation. Many institutions now accept this definition of cerebral death and use it as a basis for turning off respirators and stopping other treatments. It is also used as a basis for determining death when there is a desire to recover organs from the patient.

Planning for End-of-Life Issues

Increasing emphasis is being placed on prior planning for end-of-life issues. Identifying futile treatments is one aspect of this process. Another important consideration relates to patient self-determination regarding these issues. Many hope that the use of such planning will decrease the ethical dilemmas in end-of-life situations.

FUTILE TREATMENTS

Futile treatments are those that "cannot, within a reasonable possibility, cure, ameliorate, improve or restore a quality of life that would be satisfactory to the patient" (Hudson, 1994b). For example, when an individual is dying of terminal cancer, treatment for a respiratory infection may be deemed futile because it will not alter the fact that the person is dying and will not restore a satisfactory quality of life. Identifying whether further treatment is futile may be extremely difficult. However, Schneiderman and Jecker (1993) suggest that if, in the last 100 cases of the same nature, there was no change in the outcome based on the treatment, it can be considered futile. Others take a position that treatment never can be declared futile. In their thinking, the future cannot be predicted accurately, and if there cannot be absolute certainty about the outcome, then futility cannot be clearly identified.

Other problems may arise when futility is declared. Does a patient have a right to treatment even if it has been identified as futile? What about cost considerations? Should insurance companies be required to pay for treatment that has been classified as futile? What about Medicare or Medicaid? Should there be differences in decisions based on age or quality of life?

Critical Thinking Activity

Do you think that factors such as ability to pay, treatment of children or younger adults versus the elderly, the cost of the treatment, and the percentage of time the treatment is effective should be issues considered when deciding whether treatment is futile? Provide a rationale for each answer. What are your biases?

ETHICAL ISSUES SURROUNDING ADVANCE DIRECTIVES AND LIVING WILLS

When end-of-life concerns arise, the patient is often unconscious or not able to participate in decision-making. This raises the question of obtaining consent. A patient may have left advance directives such as a living will or durable power of attorney for health care, indicating preferences and identifying a substitutionary decision-maker (see Chapter 8). If the patient has not done this, the law in each state specifies who may give consent when an individual is incapacitated. Would the ethical answer to this question be the same as the legal answer? Does everyone involved agree with the decision-maker? Are there others who should be involved? Even the existence of advance directives does not eliminate the ethical concerns surrounding some of these situations.

In an attempt to gain greater control over the area of dying, many people are now completing a variety of documents that have been titled advance directives. An **advance directive** is a legal document that indicates the wishes of an individual in regard to end-of-life issues.

In December 1991, the federal **Patient Self-Determination Act (PSDA)** went into effect. Passed by Congress in 1990, this legislation requires that all Medicare and Medicaid providers inform patients on admission of their right to refuse treatment. The intent of this legislation was to enhance an individual's control over medical treatment decisions by promoting the use of advance directives (see Chapter 8). The entire process has not been without its problems. The time of admission to a health care facility is often filled with anxiety, making it almost impossible to consider such matters. Most patients indicate that they prefer to discuss these matters with a doctor or nurse who is involved in their care, but in some settings, this task is delegated to an admissions clerk (Hudson, 1994a).

In 1995, the American Nurses Association (ANA) revised "A Position Statement on Nursing and the Patient Self-Determination Act," written in 1990. They believe that nurses should play a primary role in implementation of the Act, should facilitate informed decision-making for patients, and should occupy a critical role in education, research, patient care, and advocacy (ANA, 1995b).

A living will is a document that has been widely used as an advance directive (Fig. 10-2). In a **living will**, a person identifies what measures to include in care if he or she becomes terminally ill. The living will is often used to request that no extraordinary measures be implemented, although it can be used to indicate a preference that all possible actions should be taken. Although the living will is not necessarily considered legal consent, it does reveal the desires of the person receiving care. It may help families to make decisions more confidently.

Another approach being used with increasing frequency is the signing of a **durable power of attorney for health care.** In this type of an agreement, an individual (referred to as the "principal") may designate another person to have the power and authority to make health care decisions for the principal should the principal be unable to make those decisions. Durable power of attorney documents may simply name the decision-maker, or may contain detailed preferences of the individual. The durable power of attorney goes into effect after the principal is no longer capable of making decisions, but not until this point is reached. These forms can be purchased in most office supply stores and become valid if signed before a notary public. However, it is best to consult an attorney before entering into such an arrangement (Fig. 10-3).

TO MY FAMILY, MY PHYSICIAN, MY CLERGYMAN, MY LAWYER

If the time comes when I can no longer take part in decisions for my own future, let this statement stand as the testament of my wishes:

If there is no reasonable expectation of my recovery from physical or mental disability, I, _____ request that I be allowed to die and not be kept alive by artificial means or heroic measures. Death is as much a reality as birth, growth, maturity and old age—it is the one certainty. I do not fear death as much as I fear the indignity of deterioration, dependence and hopeless pain. I ask that medication be mercifully administered to me for terminal suffering even if it hastens the moment of death.

This request is made after careful consideration. Although this document is not legally binding, you who care for me will, I hope, feel morally bound to follow its mandate. I recognize that it places a heavy burden of responsibility upon you, and it is with the intention of sharing that responsibility and of mitigating any feelings of guilt that this statement is made.

Signed _____

Date _____

Witnessed by:

_____

_____

FIGURE 10-2 The living will.

Euthanasia

Euthanasia, meaning "good death," may be classified as either negative or positive. The word, as it is generally applied, refers to the act or method of causing death painlessly so as to end suffering.

NEGATIVE EUTHANASIA

Negative, or passive, euthanasia refers to a situation in which no extraordinary or heroic measures are undertaken to sustain life. The concept of negative euthanasia has resulted in what are called "no codes" (also designated as DNR—do not resuscitate) in hospital environments. In these situations, hospital personnel do not attempt to revive or bring back to life persons whose vital processes have ceased to function on their own.

It is difficult to describe what constitutes extraordinary measures, and to determine on whom they should or should not be used. Is it one thing to defibrillate a 39-year-old man who is admitted to an emergency department suffering from an acute heart attack, and quite another to defibrillate a 95-year-old man whose body is riddled with terminal cancer and whose heart has stopped? Often, people who are involved in giving medical and emergency care

develop an almost automatic response to life-saving procedures and have difficulty accepting dying as an inevitable part of the life process. It is difficult to know when it is permissible to omit certain life-supporting efforts, or which efforts should be omitted. If the 95-year-old man who is dying of terminal cancer were also to develop pneumonia, should his physician prescribe antibiotics? This brings us to the distinction between stopping a particular life-supporting treatment or machine, and withdrawing treatment or not starting a procedure in the first place—that is, withholding treatment.

[PLEASE NOTE: This is a standardized legal document that may not be appropriate for a person in your particular situation. You should consult your attorney before signing this or any legal document.]

DURABLE POWER OF ATTORNEY FOR HEALTH CARE DECISIONS

I, _____ as principal, domiciled and residing in the State of Washington, hereby enter into a Durable Power of Attorney to provide informed consent for health care decisions pursuant to the laws of the State of Washington.

1. **Designation.** I designate _____, if living, able and willing to serve, as my attorney-in-fact. If he or she is not living, able and willing to so serve, then I designate _____, if living, able and willing to serve, as my attorney-in-fact.

2. **Powers.** The attorney-in-fact, as fiduciary, shall have all powers to provide informed consent for health care decisions on principal's behalf.

3. **Effectiveness.** This power of attorney shall become effective upon the disability or incompetence of the principal. Disability shall include the inability to make health care decisions effectively for reasons such as mental illness, mental deficiency, physical illness or disability, advanced age, chronic use of drugs, chronic intoxication, confinement, detention by a foreign power or disappearance. Disability may be evidenced by a written statement of a qualified physician regularly attending me. Incompetence may be established by a finding of a Court having jurisdiction over me.

4. **Duration.** This power of attorney shall remain in effect to the extent permitted by RCW 11.94 notwithstanding any uncertainty as to whether the principal is dead or alive.

5. **Revocation.** This power of attorney may be revoked in writing by notice mailed or delivered to my attorney-in-fact, and by recording the written instrument of revocation in the office of recorder or auditor of the county of my residence.

FIGURE 10-3 Durable power of attroney.

6. **Termination.**

   a. By Appointment of Guardian. The appointment of a guardian of the person of the principal terminates this power of attorney. The appointment of a guardian of the property only does not terminate this power of attorney.
   b. By Death of Principal. The death of the principal shall be deemed to revoke this power of attorney upon proof of death being received by the attorney-in-fact.

7. **Reliance.** The designated and acting attorney-in-fact and all persons dealing with the attorney-in-fact shall be entitled to rely upon this power of attorney so long as neither the attorney-in-fact nor person with whom they were dealing at the time of any act taken pursuant to this power of attorney had received actual knowledge or actual notice of the revocation or termination of the power of attorney by death or otherwise, and any action so taken, unless otherwise invalid or unenforceable, shall be binding on the heirs, devisees, legatees, or personal representatives of the principal.

8. **Indemnity.** The estate of the principal shall hold harmless and indemnify the attorney-in-fact from all liability for acts done in good faith and not in fraud on behalf of the principal.

9. **Applicable Law.** The laws of the State of Washington shall govern this power of attorney.

10. **Execution.** This power of attorney is signed on this _____ day of _____, 200____, to become effective as provided in Paragraph 3.

Signature: _____
Print name: _____

STATE OF WASHINGTON)
) ss.
COUNTY OF KING)

I certify that I know or have satisfactory evidence that _____ is the person who appeared before me, and said person acknowledged that ____he signed this instrument and acknowledged it to be h____ free and voluntary act for the uses and purposes mentioned in the instrument.

FIGURE 10-3 *(continued)*

Some ethicists do not differentiate between withholding treatment in the first place and withdrawing treatment once it has been determined to be inappropriate or futile. They would see both as having the same position in terms of right and wrong. Those who support negative euthanasia support both withholding and stopping treatment. The general public often sees these as separate issues and may support withholding treatment, while not supporting the termination of treatment once it has begun. Increasingly, the legal system has supported withdrawing treatment that is determined to be futile. Even the Roman Catholic Church, which has a strong pro-life stance, has supported both the right not to institute heroic treatment and the right to withdraw it once it has begun.

POSITIVE EUTHANASIA

Positive, or active, euthanasia occurs in a situation in which the physician prescribes, supplies, or administers an agent that results in death. In the case (cited later in this chapter) in which parents choose to let a newborn with Down syndrome and an intestinal blockage die, positive euthanasia would have occurred if the doctors had hastened the infant's death with medication. There may well be more instances of positive euthanasia than we know about publicly.

On some occasions, a physician prescribes strong narcotics for a terminally ill patient and requests that the medication be given frequently enough to "keep the patient comfortable." Nurses often are reluctant to administer a medication that they realize has a potentially fatal effect when given in that dosage. In such cases, the ethical intent of the action is often considered. Medications given for the comfort of the dying patient may be ethically justifiable even if they hasten death to some extent. This is based on the ethical concept of double effect, in which the acceptable effect (such as pain relief) is the purpose of the medication and the secondary effect (such as depressing respiration) is not the intended effect. This is not legally considered positive euthanasia. When nursing staff have difficulty with this issue, a patient conference with an oncology specialist or with a nurse skilled in the area of death and dying can help the staff to clarify values and deal with individual feelings.

Right-to-Die Issues

Right-to-die issues are gaining much more attention than in previous years. Kass (1993, p. 37) identifies four reasons for such a right to be asserted:

1. Fear of prolongation of dying due to medical interventions; hence, a right to refuse treatment or hospitalization, even if death occurs as a result
2. Fear of living too long, without fatal illness to carry one off; hence, a right to assisted suicide
3. Fear of the degradations of senility and dependence; hence, a right to death with dignity
4. Fear of loss of control; hence, a right to choose the time and manner of one's death

A great deal of controversy has surrounded the issue of maintaining the lives of persons considered to be in a persistent vegetative state (PVS). Some of the issues that arise are the patient's rights, the family's wishes, and the cost to society. In most cases, the problems emerge when the life of a family member is being maintained through support measures that might be considered extraordinary.

In 1991, St. Francis-St. George Hospital in Cincinnati was sued in one of the first cases of its kind. The suit charged that the nurses should not have resuscitated an 82-year-old man

when he suffered a heart attack. In so doing they disregarded the "no code" status of the patient ("Hospital sued . . .," 1991).

WITHHOLDING TREATMENT

Withholding treatment could be considered negative euthanasia. A historic case occurred in 1963.

EXAMPLE

Withholding Treatment

A couple on the East Coast gave birth to a premature infant who was diagnosed as having Down syndrome, with the added complication of an intestinal blockage. The intestinal blockage could have been corrected by surgery with minimal risk; without surgery, the child could not be fed and would die. The Down syndrome, however, would have resulted in some degree of permanent mental retardation. The severity of the retardation could not be determined at birth, but would range from very low mentality to borderline subnormal intelligence. The parents, who had two normal children at home, believed that it would be unfair to those children to raise a child with Down syndrome and refused permission for the corrective operation on the intestinal blockage. Although it was an option, the hospital staff did not seek a court order to override the decision. The staff believed it was unlikely that a court would sustain an order to operate on the child against the parents' wishes, because the child had a known mental handicap and would be a burden to the parents financially and emotionally, and perhaps a burden to society. The child was put in a side room (an interesting action) and was allowed to die, a process that took 11 days. When confronted with the possibility of giving medication to hasten the infant's death, both doctors and nurses were convinced that it was clearly illegal (Gustafson, 1973).

The situation above stimulates both ethical and legal questions. Would the approach have been the same if the infant had not been mentally retarded? Would the staff have been guilty of murder if the infant had been given medication to hasten death? If a court decision to proceed with the surgery had been requested and granted, who would have been responsible for the costs incurred? What are the rights of the child? Who advocates for those rights if the child is unable to do so?

WITHDRAWING TREATMENT

In some instances, a family has sought to have extraordinary life-support measures discontinued, ie, **withdrawing treatment**. A landmark case is that of Karen Quinlan.

EXAMPLE

Withdrawing Treatment 1

Karen Quinlan was a young woman left in a vegetative state after suffering severe brain damage from chemical abuse that involved both drugs and alcohol. She was placed on a respirator, and her physicians believed that she would live only a short time if it were to be removed. Her parents requested that the respirator be discontinued, but because she continued to manifest a minor amount of brain activity, their request was refused. After previous petitions to the Supreme Court of New Jersey had been rejected, the courts ruled on March 31, 1976, that her parents could exercise her privacy right on her behalf, and the respirator was discontinued. Much to everyone's surprise, Karen continued to live after the respirator was stopped, although she never emerged from her comatose condition; she died in 1986.

This case represents a situation in which treatment was withdrawn even though the individual was not considered immediately terminal. Such cases represent hard decisions for all involved and evoke legal, moral, and ethical questions in almost all instances. A similar case that attracted much attention was that of Nancy Cruzan.

EXAMPLE

Withdrawing Treatment 2

In March 1988, Joe and Joyce Cruzan requested through the Jasper County, Missouri Probate Court that they be allowed to remove the gastrostomy tube that kept their daughter Nancy alive. Nancy had been in a persistent vegetative state since an automobile accident in 1983. Although the request was granted, Missouri's attorney general appealed the decision, asking for a clear precedent from a higher court. In June 1990, the U. S. Supreme Court effectively denied the request in asking for "clear and convincing" evidence of the patient's view. In reaching this point, a fine line was drawn between initially withholding medical treatment and later withdrawing it. In Missouri, once the family gives initial consent for treatment, they forfeit all power to undo that consent or to stop treatment. No other state has such a law (Colby, 1990). Treatment can be stopped in only two ways: if it can be demonstrated that it causes pain, or if the patient left behind clear and convincing evidence of his or her wishes prior to incompetency. The first was not an option because of Nancy Cruzan's persistent vegetative state. Therefore, her parents presented a state court with testimony from her physician and three friends that Nancy would not have wished to continue existing with irreversible brain damage. The Circuit Court judge ruled that this met the test and Nancy's feeding tube was removed on December 14, 1990. She died on December 26th.

Other cases have reached the headlines as individuals and families have striven to have more voice in determining issues related to the right to die. In all cases, much conflict exists in the arguments put forth by those supporting the right-to-die and right-to-life movements. In 1990, Congress took a major step regarding this issue by passing the PSDA. Increasingly, states have supported the right of appropriate substitutionary decision-makers to both refuse and withdraw medical treatment. Medical treatments include tube feeding, oxygen, medications, and intravenous fluids.

Of particular concern to nurses are their own feelings when a decision is reached to remove life-supporting measures, whether the measures are tube feedings or ventilators. Strong emotional attachments often form between the nurse and patient, even when the patient is in a vegetative state. Nurses who have worked to preserve the patient's dignity have great difficulty "letting go." In some instances, patients are transferred to other facilities to die in an environment where the nurses are not so emotionally involved with the patient.

POSITIONS ON WITHHOLDING AND WITHDRAWING TREATMENT

Several organizations and groups have issued guidelines for their members and others who would find them useful, with regard to the issue of withholding or withdrawing treatment. Key to all of these guidelines is whether the patient is legally competent (able to make decisions for herself or himself), or incompetent (in need of someone else to make those decisions). Table 10-3 outlines the date, organization and major tenets of some of those positions.

TABLE 10-3 POSITIONS ON WITHHOLDING AND WITHDRAWING TREATMENT

	ORGANIZATION	POSITION
1983	President's Commission Report—*Deciding to Forego Life-sustaining treatment*	Focused on the ethical, medical, and legal issues in treatment decisions. Distinguished between withholding (not starting) and withdrawing (stopping after it started) treatment without making a moral distinction between the two. Suggested that withholding may require more justification because the positive effects would not be known.
1986	American Medical Association—*Statement on Withholding or Withdrawing Life-prolonging Medical Treatment*	Stated that life-prolonging medical treatment and artificially or technologically maintained respiration, nutrition, and hydration, could be withheld from a patient in an irreversible coma even if death was not imminent (Fry, 1990).
1986	Office of Technology Assessment of the U.S. Congress—*Life-sustaining Technologies and the Elderly*	Issued the results of its study on the use of life-sustaining technologies on the elderly. Report noted that the most controversial of the technologies was that of nutritional support. Identified that the most troublesome aspect of nutritional support is whether it is intravenous feeding and hydration or a tube feeding (Fry, 1990).
1987	Hasting's Center—*Guidelines on the Termination of Life-sustaining Treatment*	Provided clear definitions of key terms and a general guideline for making decisions regarding treatment. Viewed nutrition and hydration as medical interventions, much as other life-sustaining measures. Placed emphasis on the patient's ability to make decisions and required case-by-case assessment (Fry, 1990).
1988	American Nurses Association—*Guidelines on Withdrawing or Withholding Food and Fluid*	Indicated that there were few instances under which it would be permissible for nurses to withdraw food or fluid from their patients. No distinction was made between withdrawing and withholding (ANA, 1988).
1995	American Nurses Association—*Position Statement on Foregoing Medically Provided Nutrition and Hydration*	Stated that the decision to withhold medically provided nutrition and hydration should be made by the patient or surrogate with the health care team. The nurse continues to provide expert and compassionate care to patients who are no longer receiving medically provided nutrition and hydration. Distinguished between medically provided nutrition and hydration and the provision of food and water (ANA, 1995a).

ASSISTED DEATH

Assisted death involves helping another end his or her life. The activities of a retired Michigan pathologist, Jack Kevorkian, who is alleged to have assisted patients in their suicide, have received much media attention in the past few years. Although eluding criminal charges for a number of years, in March 1999, Dr. Kevorkian was convicted of second-degree murder and the delivery of a controlled substance after CBS televised a video showing him administering lethal drugs. The first case in which he was charged but not convicted involved an Oregon woman with Alzheimer's disease.

In June 1997, the U. S. Supreme Court rendered a decision on physician-assisted suicide. This decision took the position that there was no constitutionally protected right to physician-assisted suicide on behalf of terminally ill patients. In October 1997, the residents

of Oregon legalized physician-assisted suicide, despite the Supreme Court decision. Legal debate regarding its continuance has been ongoing.

Statistics compiled by the Oregon Department of Human Services indicated that of the approximately 30,000 Oregonians who died in 2001, 21 used state law to get and take lethal medication. Most of these individuals were suffering from cancer and 76% were hospice patients; all had insurance. As in previous years, they tended to be better educated than average, beyond the traditional retirement age, 62% were female, and 95% were white. In 2001, 44 prescriptions for lethal doses of medication were written, an increase of 5 from 2000. Fourteen died of their underlying illnesses, and 11 were alive at the end of 2001. Some of the 21 who died during 2001 had received the prescription in 2000 ("Oregon suicides steady . . . ," 2002).

In April 2001, The Netherlands became the first nation to fully legalize euthanasia, a process that was 3 years in the making ("Netherlands is first nation . . . ," 2001). A year later in April 2002, Europe's leading human rights court threw out an appeal by a terminally ill and paralyzed British woman who wanted her husband to help end her life. Although suicide is legal in Britain, helping someone else commit suicide is a crime ("European court throws out . . . ," 2002).

The ANA has developed a position statement on assisted suicide in which they state that the nurse should not participate in assisted suicide. Such an act is viewed as a violation of the Code for Nurses (see Chapter 9). It is the position of the ANA that the challenge for nurses should not be in legalizing assisted suicide. Rather, the role of the nurse should be directed toward reversing the despair and pain experienced in the last stages of life, and in fulfilling the obligation to provide competent, comprehensive, and compassionate end-of-life care (ANA, 1994).

THE RIGHT TO REFUSE TREATMENT

The **right to refuse treatment** is an issue closely aligned with the right to die. However, it carries special implications that require separate consideration. Although we discussed some of the parameters of this issue in the previous section on the right to die, other aspects can create even bigger problems for the nurse. The moral, if not legal, precedent for refusing treatment occurred in 1971.

EXAMPLE

Refusing Treatment

Carmen Martinez was dying of hemolytic anemia, a disease that destroys the body's red blood cells. Her life could be maintained by transfusions, but her veins were such that a cut-down (a surgical opening made into the vein) was necessary to accomplish the transfusions. Finally, Martinez pleaded to have the cut-downs stopped and to be "tortured" no more. The physician, fearful of being charged with aiding in her suicide, asked for a court decision. The court ruled that Martinez was not competent to make such a decision and appointed her daughter as her guardian. When the daughter also asked that no more cut-downs be performed, the compassionate judge honored the daughter's request. He decided that although Martinez did not have the right to commit suicide, she did have the "right not to be tortured." She died the next day (Veatch, 1976).

People working in the health care professions often are confronted with such dilemmas. Cases such as one in which a patient refuses to have a leg amputated, even though not having the surgery undoubtedly will result in death, often will make the news. The right to refuse treatment can take on additional implications when the patient, by refusing one type of treatment,

is essentially demanding alternative medical management. Our support of the right to refuse treatment is based on a basic belief in and respect for the autonomy of the patient. When the refusal of medical intervention means that the individual is no longer a patient, it is known as a "negative right simpliciter" by bioethicists. In these cases, the patient's physician need only do nothing, as in cases in which the patient discharges himself or herself from the hospital.

When the patient refuses treatment but does not withdraw from the role of being the patient, the matter becomes more complex. An example would be the patient who refuses to have a gangrenous toe surgically removed and demands to have it treated otherwise. These are referred to as positive rights. In the case of a patient with a gangrenous toe, one form of treatment may be more accepted than another, but both may be successful. A case illustrating this right occurred in 1993 in Chicago and attracted national attention.

EXAMPLE

Refusing a Form of Treatment 1

A Pentecostal Christian mother refused to have a cesarean section when physicians recommended the procedure because her fetus was being deprived of oxygen and would die if delivered vaginally. The courts upheld the patient's right to refuse the surgery. She later gave birth to an apparently healthy boy.

When children are involved, it is even more newsworthy, and again points out that there is as yet no consensus about when minors should be allowed to refuse treatment.

EXAMPLE

Refusing a Form of Treatment 2

In November 1994, 16-year-old Billy Best made national news when he ran away from home to avoid another 5 months of chemotherapy and radiation. Suffering from Hodgkin's disease, the high school junior was experiencing nausea, aching, and fatigue, as well as hair loss, from the treatment. He stated, ". . . I could not stand going to the hospital every week. I feel like the medicine is killing me instead of helping me." (Dorning, 1994).

Often in such cases, the parents refuse to have the treatment started, many times because of religious beliefs. The courts usually become involved in reaching a decision. A case in Illinois in 1952 is typical.

EXAMPLE

Refusing a Form of Treatment 3

Eight-day-old Cheryl suffered from erythroblastosis fetalis (Rh incompatibility). Her parents, who were Jehovah's Witnesses, refused to authorize the administration of blood necessary to save her life. The judge in the case ruled that Cheryl was a neglected dependent and overrode the parent's refusal. In such instances, the child is usually made a temporary ward of the court and legal documents are attached to the record authorizing the needed treatment. Such court decisions usually have been based on the premise that the right to freedom of religion does not give parents the right to risk the lives of their children or to make martyrs of them (Veatch, 1976).

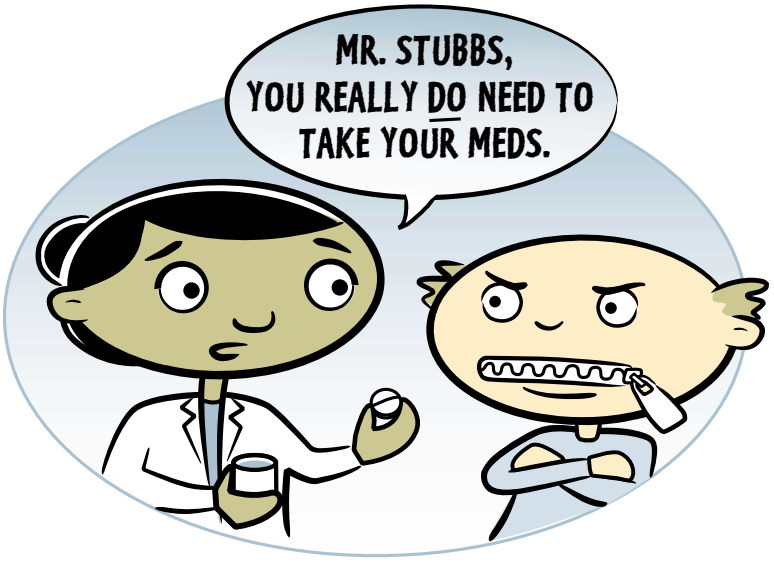

FIGURE 10-4 People working in the health care field are frequently confronted with the dilemma of patients who may wish to refuse treatment.

Sometimes, when time is not a factor, the court will recommend that treatment be delayed until the child is 15 or 16 years old and can make a decision as an older minor. Other judges will rule just the opposite, deciding that it is cruel to place the burden of the decision on this older minor.

Situations like those that have been cited are always difficult for the people involved. Because nurses have the most contact with patients, they must examine their own feelings and attitudes. Nurses must recognize that patients also have the right to attitudes and beliefs. If a nurse decides that his or her feelings are so strong that they might interfere with the ability to give compassionate care, it would be wise to ask to be assigned to other patients (Fig. 10-4).

BIOETHICAL CONCERNS RELATED TO SUSTAINING QUALITY OF LIFE

With the increase in technology, bioethical concerns have expanded significantly to include issues related to maintaining or sustaining the quality of life through such procedures as organ transplantation, xenotransplantation, and stem cell research. We cannot discuss all of these in detail but will provide an overview of the topics.

Organ Transplantation

Developments in the area of organ transplantation have created several issues deserving consideration. **Organ transplantation** is the process by which a tissue or organ is removed and replaced by a corresponding part. Transplants can be done using tissue from one's own body (eg, skin, bone, or cartilage); this is called an autograft. Transplantation using organs

from a donor's body is known as homograft or allograft; it might involve organs such as the kidney, liver, pancreas, heart, cornea, or skin of another individual. Some organs (eg, the heart) must be transplanted immediately or they will die. Others, such as the kidney or skin, can be stored for short periods. According to the United Network for Organ Sharing (UNOS), there are more than 80,000 individuals waiting for an organ transplant; 16 Americans die each day while waiting for an organ to become available ("Critical data . . . ," 2002).

Initially, the replacement for a diseased organ was obtained from a donor who had died. More recently, organs have been received from living donors. In 2001, the number of living donors reached an all-time high with 6,485, exceeding the 6,081 donations that were given after death. More than 90% of the donors (5979) gave a kidney, about 500 donated livers, and about three dozen people gave part of a lung ("Most transplanted organs . . . ," 2002).

The supply of organs that can be used for transplantation has not been able to keep up with the demand. This concern resulted in the Secretary of Health and Human Services, Tommy Thompson announcing his "Gift of Life Donation Initiative" in April 2001. This initiative had five major elements to encourage organ donation. Among these was a model donor card, which included provisions for designating whether all organs and tissues may be donated, as well as lines for signatures by two witnesses (Fig. 10-5). This card may be downloaded from the Internet site *www.organdonor.gov/SecInitiative.htm*. Concomitantly, the number of bills in Congress that address the issue of organ transplant continues to grow.

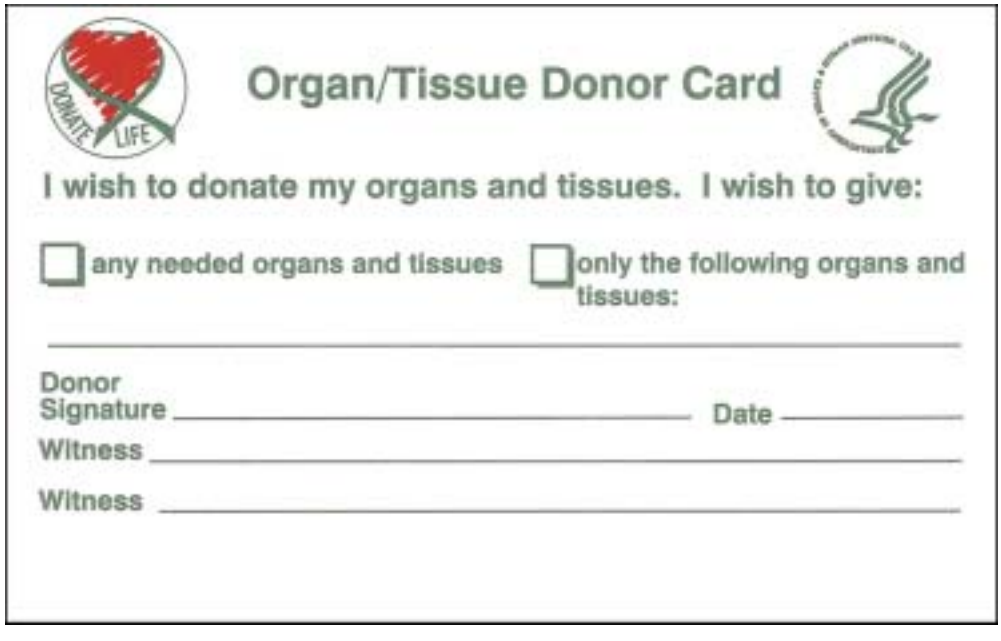

FIGURE 10-5 Organ/tissue donor card.

CONCERNS ABOUT PROCUREMENT

Organ procurement refers to all the activities involved in obtaining donated organs. The idea of consent becomes important when we talk about organ transplantation and procurement. It is preferable to have the consent obtained from the donor. This has been facilitated in many states by the Uniform Anatomical Gift Act, which was drafted by a committee of the National Conference of the Commissions of Uniform State Laws in July 1968, and now by the Model Donor Card. People who are willing to donate parts of their bodies after death may indicate the desire to do so in a will or other written documents, or by carrying a donor's card. Many states also provide a space on the driver's license where individuals can authorize permission for organ donations.

The next-of-kin also must grant permission for the removal of organs after death. However, the time factor is crucial; the deaths are often accidental, and the relatives are often so emotionally distressed that the process of obtaining permission may be uncomfortable. Hospitals that receive Medicare funds are mandated to have required request policies in place. Typically, they have developed a procurement team that has received special preparation related to requesting organ donations. These are persons skilled in recognizing the stress being felt by the family and experienced in providing information that will be important to them. A growing number of hospitals are designating a nurse as transplantation coordinator to facilitate this process.

An interesting and controversial case related to obtaining necessary material for transplantation occurred in California in 1990.

EXAMPLE

Transplantation

An 18-year-old woman, an only child, was diagnosed as having chronic myelogenous leukemia. Although this form of leukemia responds favorably to bone marrow transplants, no compatible donor could be found after testing the girl's family and contacting the National Marrow Donor Program. In desperation, the parents decided to have another child with the hope that the new baby would have genetically matching tissue type. This required that the father have a vasectomy reversed and that the mother, age 43, go through another pregnancy, which terminated in a cesarean section. The baby proved a good match and was able to provide donor tissue for her sister.

The case drew considerable attention as medical ethicists voiced concern about creating one child to save another. Citing Immanuel Kant, they argued that the baby was conceived, not as an end in itself, but for utilitarian purposes. Some medical ethicists argued in favor of the rights of the individuals involved, saying that it is not the concern of biomedical ethicists to intrude into matters affecting private citizens, especially when that intrusion approaches "intruding into a couple's bedroom." Still others say that striking cases must be brought before the public because an obligation to inform society exists.

Children and young people experience the most critical need for human organs. This has caused us to challenge previous decisions. A good example is that raised when considering organs removed from an anencephalic infant. An anencephalic infant is one born with only

enough brain to support such vital functions as heartbeat and respiration. It has been estimated that about 60% of these infants are stillborn, and of those born alive, only about 5% will live more than 3 days. Because anencephaly affects only the brain, other organs can be used for transplantation if the infant is kept alive on a respirator until an organ recipient is located. This challenges our definitions of death. How can current definitions of "brain" death be applied to a condition in which there is no brain as we normally recognize it?

ARTIFICIAL ORGANS

Other problems also arise regarding organ transplantations, especially because more people need organs than there are organs available. The skill of modern technology has resulted in the development and implantation of artificial organs such as the heart. Such technologic advances once were viewed as science fiction. As a result, historic cases such as the implantation of an artificial heart in Barney Clark in 1982 received a great deal of publicity. Over the years, the use of artificial organs has not proven effective for long-term use, but artificial organs have made it possible for individuals to live with the hope that a transplantable organ will become available. Work and research to develop better organs continues and recipients are living longer, although the promise is far less than that with donated organs. The use of artificial joints, heart valves, and other prostheses continues to grow and to be successful.

MINORITY GROUPS AND ORGAN DONATION

Another issue that has emerged is that of minority differences regarding organ donation. Of the persons awaiting an organ for transplantation, approximately 42% represent minorities (National MOTTEP, 2002). The risk of end-stage renal disease for African Americans and Native Americans is three to four times higher than for the white population (Kasiske et al, 1991). Although minority groups donate in proportion to their population distribution, minority organ donations lag behind those from the white population, with more than 74% of cadaver donations coming from whites, 12.4% from African Americans, 10% from Hispanics, and 1% from Asians (National MOTTEP, 2002). One of the reasons this presents a concern is that minorities form more than half of the kidney transplant waiting list. More minority donors are needed to increase the chances that a well-matched organ will be available to minorities awaiting transplants.

Several factors may impact reticence of minorities to donate organs. Some groups have identified religious beliefs and cultural customs as forbidding organ donation, although no major Western religion prohibits organ donation. Religious objection often stems from the high value attached to keeping the body intact ("Body and soul," 2002). African Americans listed distrust of the medical community, fear of premature death, and racism as major barriers. Hispanics experienced language barriers and identified the importance of having the entire extended family involved in all decision-making regarding donations. Puerto Ricans verbalized denial of death and fear of mutilation of the body as critical factors. Barriers to organ donation in Asian American cultures included the belief that the body should remain intact to the grave and lack of respect during the handling of the body after death. Although Native Americans are theoretically supportive of organ donations, their rate of donation is low, probably due to lack of knowledge (Wheeler & Cheung, 1996). Although no single approach to organ donation fits all groups, efforts to decrease barriers to donation are being instituted.

The first national program specifically designed to empower minority communities to become involved in education activities to increase the number of minority donors and transplant recipients has been started. The National Minority Organ/Tissue Transplant Education Program (MOTTEP) now has 15 sites across the country and represents African American, Hispanic/Latino, Native American, Asian, Pacific Island, and Alaskan Native populations. MOTTEP includes a health promotion and disease prevention component designed to reduce the incidence of conditions that can lead to organ failure. It can be reached at the Web site *http://www.nationalmottep.org*

Critical Thinking Activity

Have you signed an organ donation card? If not, discuss the reasons why you have chosen not to do so. If you have, discuss the reasons why you have. Is there a possibility you will change your mind? Why or why not? What solutions can you suggest to help the nation deal with the shortage of organs needed for transplantation?

CONCERNS ABOUT ALLOCATION

How will we determine who receives donated organs? Does "elitism" exist in their distribution—that is, does a white-collar worker have a better chance to receive an organ than a blue-collar worker? Medicaid and most insurance policies refuse to pay for the cost of many organ transplants, although Medicare usually covers the costs of corneal transplants and kidney transplants. Transplants are expensive procedures, often running into several hundreds of thousands of dollars. If money is required "up front," as it sometimes is, where can the needy person procure such funds? Other questions involve both donor and recipient. Should the donor or the donor's family have the right to say who will receive the organ? How can one "get in line" for an organ, and how can that need be made known? What about selling a healthy organ, such as a kidney?

Much has been written about the problem of selecting recipients for organ transplantation when the number of applicants exceeds the number of available organs. Many criteria have been suggested, and as one might anticipate, these criteria have arguments both pro and con; the criterion requiring medical acceptability is probably the only exception. Many transplants require that compatibility exist in the tissue and blood type of donor and recipient. It would not be logical to give a much-needed organ to a person whose body would automatically reject it.

The criterion of the recipient's social worth is probably one of the hardest to defend, although it was used in the Pacific Northwest in the early 1960s to decide who should be allowed to live by kidney dialysis. Social worth, including past and future potential, was considered, and even such factors as church membership and participation in community endeavors were considered.

Some suggest a form of random selection, once the criterion of medical acceptability has been met. This could be either a natural random selection of the first-come, first-served variety, or an artificial selection process such as a lottery. A criticism of this method is that it removes rational decision-making from the process.

We offer no suggestions to solve this problem but merely demonstrate the difficulty it presents. Even the issue of who should serve on the decision-making committee can be touchy. The problem of personal biases is a big concern.

In an effort to gather donations and disseminate information about individuals who need various organs, an Organ Procurement Program was started in Pittsburgh, Pennsylvania. This program was established to facilitate the matching of donor with recipient and to provide a central listing agency for those in need of transplants. Today, organ procurement agencies are located in all regions of the country. These groups carry out many activities related to organ procurement, including establishing groups for individuals who have received donated organs and their families, publishing newsletters, developing educational materials, increasing public awareness of the need for organs, and serving as a clearinghouse for organ procurement and matching. They are connected through the federally funded United Network for Organ Sharing.

CONCERNS ABOUT INDIVIDUAL PROPERTY RIGHTS

Concern for an individual's **property rights** regarding human tissues also has attracted attention. Developments in biotechnology allow profit-oriented companies to use human tissue to generate lucrative products, such as drugs, diagnostic tests, and other medically related materials. The modern legal system has consistently held that no property rights are attached to the human body (Swain & Marusyk, 1990).

EXAMPLE

Human Body Property Rights

In 1990, a Seattle man sued the University of California, two researchers, and two biotechnology and drug companies, because in 1976, he had sought treatment for hairy cell leukemia and subsequently had his spleen removed (which is the standard treatment). It was later discovered that the removed spleen contained unique blood cells that produced a rare blood protein, which then was used experimentally in the treatment of certain cancers and possibly AIDS. The patient was never told that his cells had great potential value, although he was brought from Seattle to Los Angeles frequently for blood and other tests. His cells were then developed into a self-perpetuating cell line to mass-produce the rare blood protein. The patient's suit claimed that the defendants wrongfully converted to their own use his personal property (ie, the blood cells) and that this was done without his consent.

Xenotransplantation

Xenotransplantation refers to the practice of using animal organs, cells, and tissues for transplantation into human beings. Some scientists believe that having a reliable supply of organs from pigs or other animals could solve the great shortage from human donors. It is in the stage of experimentation around the world.

Xenotransplantation usually involves organs or tissues from pigs and nonhuman primates. One case receiving national publicity was that of an AIDS patient in San Francisco who received the transplant of baboon bone marrow to bolster his weakening immune system. Since 1906, some 55 animal-to-human whole organ transplants have been attempted; none was successful (Fano et al, 1999). Cases that received particular attention were the 1984 transplant of a baboon heart into Baby Fae (who died 20 days later) and the 1992 transplant of a baboon liver into a 35-year-old man (who also died).

In addition to the obvious problems associated with immune system rejection, of particular concern to some is the possibility of transmitting serious animal viruses and other microbes, so-called zoonotic diseases, to people. Fano and associates (1999) report more than 20 known, potentially lethal viruses that can be transmitted from nonhuman primates to humans. This has prompted the use of pigs as the "donor" of choice, and has led to attempts to alter pigs genetically so that tissues would be more adaptable to transplantation. In August 2002, a British biotechnology company announced the creation of the first so-called "double knock-out" pigs, genetically engineered to lack both copies of a gene that causes rejection ("Cloned pigs . . . ," 2002).

Concerns in England over the communicability of bovine spongiform encephalopathy through the ingestion of meat from ill animals has prompted the discussion of the potential for all animal organs to transmit diseases that would appear only years later. Even raising animals in a sterile environment has its limitations because it is now being discovered that some diseases are transmitted from mother to fetus in utero. Some groups in England are urging the xenotransplantation project be abandoned and that research into xenotransplantation be stopped because of the social cost and because of on-going suffering of animals inherent in such an approach.

In September 1996, the federal government proposed strict safeguards to provide protection. Representatives from the Food and Drug Administration (FDA), the Centers for Disease Control and Prevention (CDC), and the National Institutes of Health (NIH) developed the guidelines. The guidelines urged that patients and their families be fully informed of potential risks, and further required that any planned procedure be thoroughly screened and approved by a series of local institutional review boards, and by the FDA. The recommendations also require that transplants take place at a clinical center associated with an accredited biology and microbiology laboratory.

The Human Genome Project

A **genome** may be defined as all the DNA in an organism, including the genes that carry information for making the proteins required by all organisms. These proteins determine such things as how the organism looks, how well its body metabolizes food and fights infection, and sometimes even how it behaves. Genomes have been studied for many reasons, including disease prevention, determination of the effects of radiation and chemicals on living species, and more recently, genetic therapy. DNA is made up of four similar chemicals called bases and abbreviated A, T, C, and G, and are repeated millions or billions of times throughout a genome. The order of As, Ts, Cs, and Gs is important because the order underlies all of life's diversity, including whether an organism is human or of another species.

The **Human Genome Project** (HGP) was first proposed by Nobel prize-winning virologist Renato Dulbecco in 1986. Coordinated by the Department of Energy (DOE) and the NIH, the project started in October 1990 and involved at least 18 countries in the international effort. The project was planned to last for 15 years; effective resource and technologic advances have accelerated the expected completion date to 2003. Several types of genome maps have already been completed, and a working draft of the entire human genome sequence was announced in June 2000. The analysis was published in February 2001.

The goals of the project are to:

- Identify all the approximate 30,000 genes in human DNA
- Determine the sequences of the 3 billion chemical base pairs that make up human DNA
- Store this information in data bases
- Improve tools for data analysis
- Transfer related technologies to the private sector
- Address the ethical, legal, and social issues (ELSI) that may arise from the project (Human Genome Project Information, 2002).

An additional part of the HGP includes parallel studies being carried out on several nonhuman organisms, including the *Escherichia coli* bacterium, the fruit fly, and the laboratory mouse. Studying nonhuman organisms' sequences can lead to an understanding of their natural capabilities, which can be applied toward solving challenges in health care, energy sources, agriculture, and environmental cleanup.

It is anticipated that knowledge about the effects of DNA variations among individuals can lead to new ways to diagnose, treat, and someday prevent the thousands of disorders that affect us. This could unlock a plethora of bioethical concerns. Once this technology has been developed, where does it end? How is the information handled regarding issues of privacy and confidentiality? What is the impact if third-party payers gain access to the information? What might be the advantages and disadvantages of knowing the diseases to which you are susceptible? With whom should that information be shared? What would be the effects of manipulating stature, intelligence, or sex? Does this project represent eugenics revisited? Who among health care providers will provide access to patients? Will the responsibility fall to the family practitioner, who will most likely be the first contact for those with a genetic disorder? How prepared are family practitioners for this type of care delivery?

In a study of family physicians' perspectives on genetics and the HGP conducted in the midwestern United States, many family physicians indicated that they felt educational opportunities to learn about genetics had been inadequate, and some indicated reluctance to gain the additional education that would be required. Will we see the advent of a new medical specialty in structural genomics? Will molecular medicine teams be developed in our society? Will new and expensive technology result, such as a program of high-throughput X-ray crystallography aimed at developing a comprehensive mechanistic understanding of normal and abnormal human and microbial physiology (Burley et al, 1999). The DOE and the NIH have devoted 3% to 5% of their annual HGP budgets toward studying these concerns. A few that have been identified include:

- Fairness in the use of genetic information by insurers, employers courts, schools and others
- Privacy and confidentiality of genetic information
- Psychological impact and stigmatization due to an individual's genetic differences
- Reproductive issues, including adequate informed consent for controversial procedures, reproductive rights, and use of genetic information in reproductive decision-making

- Clinical issues, including the education of doctors and other health service providers, patients, and the general public
- Uncertainties associated with gene tests for susceptibilities and complex conditions
- Conceptual and philosophic implications regarding human responsibility, free will versus genetic determinism, and concepts of health and disease
- Health and environmental issues concerning genetically modified foods and microbes
- Commercialization of products, including property rights and accessibility of data and materials (Human Genome Project Information, 2002b).

More information regarding these issues can be obtained from the Web site: *http://www.ornl.gov/hgmis*.

Gene Therapy

An estimated 4,000 disease genes have been identified that reside with the genome. Identification and isolation of defective genes, and their replacement with functional genes (gene therapy), could result in the elimination of diseases that have plagued society for generations. Several significant conditions currently under study are cystic fibrosis, Huntington's disease, myotonic dystrophy, gout, and adult polycystic kidney disease.

In the genetic lexicon, the gene is a length of DNA that codes for a particular protein. The average human gene is a little more than 1,000 nucleotides long and, in many inherited disorders, only one or a few of these nucleotides is incorrect. For example, in sickle cell anemia, a single nucleotide causes the structural deformity that results in the characteristically distorted shape of the sickled red blood cell that prohibits the cell from adequately carrying oxygen to the body's organs and tissues. Seventy percent of the cases of cystic fibrosis may be due to the deletion of three nucleotides (Kmiec, 1999).

Theoretically, **gene therapy** can take the form of somatic (body) or germ (egg and sperm) cells. Somatic gene therapy results in the recipient's genome being changed but the change is not passed down to the next generation. With germline gene therapy, not being actively investigated at the present time, the goal is to pass the change on to offspring. The genetic testing of eggs and the sex selection of embryos mentioned earlier in this chapter are a matter of selection; no cells are altered or changed.

Decisions on clinical applications of gene-therapy approaches are under the oversight of the federal government. The Office of Recombinant DNA Activities Advisory Committee (OAC) evaluates protocols and makes suggestions for approval to the director of the NIH. Gene therapy policy conferences and gene therapy conferences designed to provide public information regarding research progress have been instituted.

To date, gene therapy is primarily experimental and has experienced far more failures than successes. Positive results in mice do not necessarily promise positive outcomes for humans. Many of the basic problems with gene therapies have not been worked out. Finding a mechanism to insert the new gene into the body needs to be found. Scientists need a better understanding of how genes function. The problems associated with multigene disorders must be solved. Questions regarding the repair of genes versus the replacement of genes are yet to be answered. The high costs associated with this new technology present another concern.

However, gene therapy offers a wide array of possibilities and undoubtedly will gain momentum in the near future.

Stem Cell Research

A **stem cell** is a special kind of cell that is able to renew itself and give rise to specialized cell types. These cells, unlike most other cells in the body, such as those of the heart or skin, are not committed to conduct a specific function. The cell remains uncommitted until it receives a signal to develop into a specialized cell. Scientists are now looking at a type of stem cell that is called *pluripotent* because the cells have the potential to develop almost all of the more than 200 different known cell types. These cells, which originate from early human embryos, may have the potential to generate replacement cells for a wide array of tissues and organs, including the heart, the pancreas, and the nervous system (DHHS, 2001). Thus, they offer hope for patients with diseases such as Parkinson's disease, diabetes, chronic heart disease, end-stage kidney disease, liver failure, cancer, multiple sclerosis, Alzheimer's disease and those with spinal cord injuries. Many of these conditions shorten lives and no effective treatments have been found. In heart disease, for example, numerous heart cells are destroyed and the body cannot replace them. Doctors hope to inject patients with stem cells and then signal them to grow into new heart tissue ("The stem cell debate . . . ," 2001).

As progress was being made with tissue from early embryos, research was being conducted on adult stem cells. An adult stem cell is an undifferentiated cell that occurs in a differentiated tissue, renews itself, and becomes specialized. These adult stem cells are capable of making identical copies of themselves for the lifetime of the organisms. Sources of these cells include bone marrow, blood, the cornea and retina of the eye, brain, skeletal muscle, dental pulp, liver, skin, the lining of the gastrointestinal tract, and pancreas. They are rare and often difficult to identify (DHHS, 2001). Because of this, the stem cells of human embryos are considered by some to be more desirable.

However, to retrieve the needed cells, the embryo is destroyed because the needed cells lie in the center of the blastocyst, a cluster of about 150 cells has developed about 1 week after the ova is fertilized by a sperm. Thus we find ourselves with the same ethical question raised earlier in this chapter: Do blastocysts equal human life? Many people, including antiabortionists, believe the answer is yes. Others find the benefits to be so great they tend to view the blastocysts as potentially human but not quite there yet.

Because research of this nature needs federal funding and approval to move forward, stem cell debate is a national issue. In August 2001, President Bush approved federal funding of some human embryo-related research, but not for studies that allow any more embryos to be destroyed, stating that the government would pay only for experiments using stem cells that already had been drawn from embryos or that used adult stem cells. Although this pleased the National Right to Life Committee, it greatly disappointed prominent scientists who see stem cell research as the single most promising avenue of medical research ("Stem cell stalemate . . . ," 2001). The concern is that the existing lines of embryonic stem cells are too limited to achieve the desired research objectives and that adult stem cells do not have the same potential. Those who want to see this research pushed forward want to use some of the thousands of leftover frozen embryos in storage at fertility clinics. The frozen embryos were created by couples who intended to use them for in-vitro fertilizations. The embryos

can be left frozen for potential later use, donated to someone else who wants to have a child, or thrown out. Some privately funded research and research in other countries may continue with embryonic stem cells.

This is another issue to which there are no easy answers. However, as powerful and well-known individuals such as Nancy Reagan, Michael J. Fox, Mary Tyler Moore, and Christopher Reeve push for legislation to support research, we can be assured of hearing more about the retrieval of embryonic stem cells for research.

Critical Thinking Activity

Given the arguments for and against stem cell research, what position would you take? Why do you hold this position? What are your biases? Discuss your position with someone who holds the opposite point of view. What are that person's strongest arguments?

OTHER BIOETHICAL ISSUES

Although our discussion cannot be exhaustive of the topic, certain events occur frequently enough in the health care delivery system that we would be remiss in not mentioning them.

Truth-Telling and Health Care Providers

The issue of "to tell" or "not to tell" may not carry the emotional and bioethical impact that one experiences with concerns such as euthanasia, but it is often encountered in the health care environment. Although informed consent has forced a more straightforward approach between physician and client, the problem of having the patient fully understand the outcome of care still exists (see Chapter 9). Sometimes the question about telling the client the expected outcome of care results from a request made by a close relative, but most of the time it results from the persistence of past medical practices.

In such instances, the physician operates in a paternalistic role in relation to the client. Under this model of care, the locus of decision-making is moved away from the client and resides with the physician. "Benefit and do no harm to the patient" is the dictum often cited as the ethical basis for this approach. It rationalizes that complete knowledge of his or her condition would place greater stress on the client. More recent discussions of medical ethics explore the rights of clients, particularly their right to make their own medical decisions. These discussions emphasize that in our pluralistic society, which also has fostered medical specialization to keep up with advances in knowledge and technology, physicians may be unable to perceive the "best interests" of their clients and to act accordingly.

Physicians do not agree on how much information should be provided to patients regarding their conditions. We usually experience a major controversy relating to this issue when a client has a terminal diagnosis such as cancer. Physicians may be concerned that sharing bad news will result in unhappiness, anxiety, depression, and fear, and that the client suffering from a terminal illness will "give up." In some cultures, such as Japan, this approach is widely

considered appropriate and both physicians and families strongly believe that those who are ill should be protected from bad news.

Physicians who argue the other side of the issue state that there exists a common moral obligation to tell the truth. They believe that the anxiety of not knowing the accurate diagnosis is at least as great as knowing the truth, especially if the truth is shared in a humane manner. These physicians also argue that one needs to have control over one's life and, if the news is bad, to have time to get personal affairs in order.

Regulations regarding informed consent and more aggressive treatment for all life-threatening conditions have minimized situations in which patients are not provided full knowledge of their condition. However, these situations still arise. Sometimes care providers are challenged as to the best ethical and legal approach when a family is from a different cultural background and strongly disagrees with giving full information to a patient.

Thus far, we have discussed situations in which information regarding a terminal illness may be shared with the client and family. At least one other circumstance that involves telling the truth is worth mentioning, although many examples could be included. One that we often see in the obstetric area of the hospital deals with sharing information with the parents of a newborn who is critically ill or who has a malformation. Sometimes physicians may want to spare the mother unpleasant news until she is stronger. This occurs frequently enough for obstetric nurses to have labeled it *spare-the-mother syndrome*. In some instances, the physician may want to delay giving information until suspicions can be validated. If the doctor is waiting for the return of laboratory tests to confirm suspicions of genetic abnormalities, several days may be required. If good communication exists between nurse and physician, so that the nurse is well informed, the nurse can provide emotional support and meet the client's need for information.

Although to tell or not to tell (or to delay telling) is a problem that exists between client and physician, nurses often become involved. Because the nurse is in contact with the client for a more extended time, he or she may be put on the spot by the client's questions. The nurse may feel that hedging on a response compromises the ethics of nursing practice. In such instances, a conference, whether formal or impromptu, that would involve the physician, nurses, and other appropriate members of the health team, may help everyone deal with the situation. The nurse who is a novice in the health care system should realize that anyone may initiate a client care conference, although appropriate channels of communication should be followed in organizing it.

The question of whether "to tell" or "not to tell" has been applied to another issue in the health care delivery system in recent years. That controversy pits the rights to privacy of the individual who is HIV positive against society's right to be protected. Dr. Cary Savitch, who has treated AIDS patients since 1981, advocates universal testing. Dr. Savitch (1996, p. 140) states, "Controlling the epidemic is the only means to limit needless suffering and death. Controlling the epidemic will not come at the hands of a vaccine or miracle drug. Controlling the epidemic requires prevention. Prevention requires knowing who is communicable. Knowing who is communicable requires universal testing."

Many express concerns about privacy and confidentiality. If universal testing for AIDS is mandated, what would be next? Others argue that if health care providers exercise proper precautions, little danger exists. Still others would find the cost of universal testing too great to make it realistic. There is no agreement among health care providers, activists, civil libertarians, and all concerned citizens regarding this issue, and the controversy is certain to continue.

Ethical Concerns and Behavior Control

Many people experience extreme discomfort when contemplating research into human behavior and **behavior control**. Although it may be one thing to work with atoms, molecules, and genes, it seems quite another to look at the science of human behavior.

Some of the problem seems to center around the fact that people define "acceptable behavior" in different and sometimes conflicting ways. When is behavior deviant? When is the client mentally ill? An excellent example is that of homosexuality, which the American Psychiatric Association at one time listed as a mental illness. Although many people may not approve of homosexuality, they would not classify all homosexuals as being mentally ill. Increasingly, society looks on sexual orientation as a personal matter.

The world has benefited from the work of many people whose behavior might not be looked upon as normal. Van Gogh cut off his ear; Tchaikovsky had terrible periods of depression; Beethoven was known for his uncontrollable rages. Some have suggested that Florence Nightingale's flights into fantasy could better be described as neurosis. Should this behavior have been changed? If so, by what methods?

We now can change behavior by several methods. Certainly one of the most common methods in which nurses will be involved is the administration of pharmacologic agents. Psychotropics are now one of the largest classifications of drugs in the United States. Many of these such as antianxiety agents and antidepressants are prescribed for people who wish to modify their feelings and behaviors. Other chemicals, such as alcohol, marijuana, cocaine, and lysergic acid diethylamide (LSD), also change mood and/or behavior. Some of these are considered socially acceptable, whereas others are not. Some are socially acceptable to some people or to some cultures yet unacceptable to others.

Electroconvulsive therapy (ECT), known earlier as electric shock therapy (EST), has been used for years to treat severe depression. Although antidepressant drugs are more commonly used today, ECT is still used in many areas of the country for depression that does not respond to drugs. Opponents of this form of therapy, who see it as inhumane, are becoming an organized political force. Proponents point out that with the current safeguards, it can be an effective therapy.

Psychosurgery—for example, frontal lobotomy (portrayed in *One Flew Over the Cuckoo's Nest*)—was used in the 1930s. This is undoubtedly one of the most criticized treatment modalities because of its effect on the person. It is rarely used today, although another type of brain surgery is now being suggested for obsessive–compulsive disorder.

Psychotherapy can change other behaviors. Techniques include verbal and nonverbal communication between the client and the therapist. Although psychotherapy requires considerable time, it is widely used.

When are any of these methods justified? Who makes the decision? What behavior is beyond the realm of acceptability? Who determines this? How does behavior control mesh with our beliefs about the autonomy of the individual or with concepts of self-respect and dignity? The issues of power and coercion pose a concern at this point. Problems related to involuntary commitment have moved this from the arena of ethics to that of legal determinants.

Halleck (1981, p. 268) has defined behavior control as treatment "imposed on or offered to the patient that, to a large extent, is designed to satisfy the wishes of others. Such treatment may lead to the patient's behaving in a manner which satisfies his community or his society."

Halleck goes on to point out that the question of behavior control has become more critical because newer drugs and new behavior therapy (such as aversive therapy and desensitization) make it possible to change specific behavior more rapidly and effectively. Traditional psychotherapy, which works slowly, offers the patient time in which to contemplate the change and reject it if it is unacceptable.

Dworkin (1981, p. 278) has proposed a set of guidelines that preserve autonomy in behavior control, as briefly stated here. Although these guidelines are almost 20 years old, they continue to be recognized for the direction they provide.

- We should favor those methods of influencing behavior that support the self-respect and dignity of those who are being influenced.
- Methods of influence that destroy or decrease a person's ability to think rationally and in his or her own interest should not be used.
- Methods of influence that fundamentally affect the personal identity of the person should not be used.
- Methods of influence that deceive or keep relevant facts from the person should not be used.
- Modes of influence that are not physically intrusive are preferable to those that are (eg, drugs, psychosurgery, and electricity).
- A person should be able to resist the method of influence if he or she so desires, and changes of behavior that are reversible are preferable to those that are not.
- Methods that work through the cognitive and affective structure of a person are preferable to those that "short-circuit" his beliefs and desires and cause him to be passively receptive to the will of others.

Critical Thinking Activity

Review the guidelines for ethical treatment of psychiatric conditions. Which do you believe are the strongest, and why? Are there any that you question; if so, why? Are there any that you think should be added?

Rationing of Health Care

Perhaps no issue in health care will receive more attention in the next few decades than the **rationing of health care**. Technology has allowed people to live longer. New treatment modalities have become more expensive. Dollars do not exist within our current social system to make all forms of health care available to all who wish to receive it. What should be treated and what should not? Who should receive the treatment and who should not? Should age be a factor? Mental status? Ability to contribute to society?

Rationing is restricting the availability of some desired commodity to limited allotments. Most consider rationing to be a planned, thoughtful approach to a limited supply. Some would argue that we currently ration health care by restricting its availability to those with the financial means to pay, although none would argue that this is a carefully planned approach.

Some states have begun to address these issues. In 1989, the Oregon legislature passed several statutes that, among other things, created a process to establish health care priorities

so that Medicaid and state-encouraged private coverage could provide the most cost-effective and beneficial forms of care for the largest number of persons. Explicit in this legislation was the involvement of the public in the process of building consensus on the values to be used to guide health resource allocation decisions. Oregon has continued to lead the nation in health care reform, especially at the consumer involvement level.

In Vermont, a statewide public education and discussion project was initiated to explore public attitudes and values that underlie health care and the public's priorities in the allocation of health resources. The project focused on the need for individuals to make known their preferences with regard to personal treatment.

In New Jersey, a Citizens' Committee on Biomedical Ethics has taken the position that citizens have the right and responsibility to insist that their preferences and values influence the development of health care policies and the allocation of medical resources. They have launched a community health program to clarify the ethical and social issues surrounding the provision of health care in that state.

Other states are following these examples. Citizens are being asked to make informed decisions regarding health care. As a nurse, you have a vital role to play in the sharing of information regarding the delivery of health services. It is critical for you to anticipate some of the questions you may be asked and to analyze your own values (Fig. 10-6).

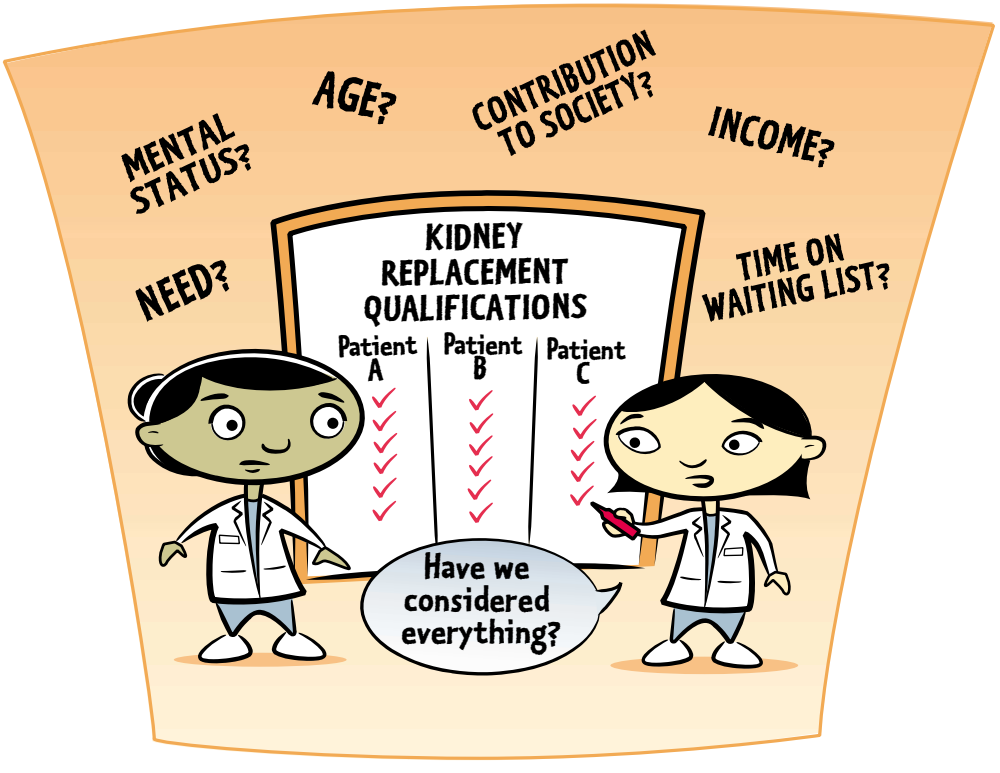

FIGURE 10-6 It is critical that you analyze your own values.

Critical Thinking Activity

What do you see as the major issues regarding the rationing of health care? Develop a list of the major health conditions for which you believe care should be funded. Identify those that should receive partial funding. List those that you believe should not be funded. Give a rationale for placing the various conditions on one of the three lists.

KEY CONCEPTS

- Bioethics is the study of ethical issues that result from technologic and scientific advances, especially in biology and medicine. The number of bioethical issues surrounding the delivery of health care is growing.
- Many bioethical issues can be divided into two major categories: those related to the beginning of life and those related to the end of life.
- Family planning (and the associated concern regarding age of consent) is one issue related to the beginning of life. Personal preferences and religious beliefs are critical determinants, and nurses should be prepared to meet the needs of all clients without imposing their personal values on clients.
- Abortion, amniocentesis, chorionic villus sampling, prenatal diagnosis, genetic screening, sterilization, the concept of eugenics, in vitro fertilization, artificial insemination, surrogate mothers, single parents, sperm banks, and the right to genetic information are additional topics presenting concerns.
- Fundamental bioethical issues concerning death are the changing definition of death and the decision about when it occurs.
- End-of-life issues include identifying futile treatment and establishing patient self-determination.
- Although many courts, based on individual circumstances, have accepted negative euthanasia, positive euthanasia remains very controversial.
- Surrounding the discussion of right-to-die are many issues, including those related to withholding treatment, withdrawing treatment, assisted death, and the right to refuse treatment.
- Bioethical concerns associated with the process of organ transplantation include procurement of organs, availability of organs for minorities, allocation of organs, individual property rights, and the appropriateness of xenotransplantations.
- The area of human genetic research has raised many ethical questions, including how this knowledge should be used, rights to privacy, and who in the health care delivery system carries the responsibility for making testing, diagnosis, and cost-effective care available to patients.
- Stem cell research, which holds great promise for diseases and conditions for which there is no cure, is also laden with bioethical concerns, particularly those related to whether a blastocyst should be considered a human life.
- Debate and controversy have long surrounded determining what degree of information should be shared with clients and their families.

- The area of behavior control is subject to bioethical review, and guidelines have been established to preserve autonomy in behavior control.
- Rationing of health care commands major attention now. Many states have begun to establish citizen committees to respond to this concern.

RELEVANT WEB SITES

American Journal of Bioethics, Bioethics Network: *www.bioethics.net*
Boston College, Nursing Ethics Network: *www.bc.edu/nursing/ethics*
Georgetown University, The Kennedy Institute of Ethics, National Reference Center for Bioethics Literature: *www.georgetown.edu/research/nrcbl/*
International Society of Nurses in Genetics: *http://nursing.creighton.edu.isong.*
John Hopkins University, Bioethics Institute: *www.med.jhu.edu/bioethics_institute*
Medical College of Wisconsin, Center for the Study of Bioethics, Bioethics Online Service: *www.mcw.edu/bioethics/*
Midwest Bioethics Center: *www.midbio.org/*
National Catholic Bioethics Center: *www.ncbcenter.org/*
National Coalition for Health Profession Education in Genetics: *www.nchpeg.org*.
President's Council on Bioethics: *www.bioethics.gov/*
Understanding Gene Testing: *www.accessexcellence.org/AE/AEPC/NIH*
United Network for Organ Sharing Transplantation Information Site: *www.unos.org/*
University of British Columbia, W. Maurice Young Centre for Applied Ethics: *www.ethics.ubc.ca/*
University of Southern California, Pacific Center for Health Policy and Ethics: *lawweb.usc.edu/Pacific_Center/*

REFERENCES

American Nurses Association. (1995a). *Position statement on foregoing medically provided nutrition and hydration.* Washington, DC: American Nurses Association.
American Nurses Association. (1995b). *Position statement on nursing and the Patient Self-Determination Act.* Washington, DC: American Nurses Association.
American Nurses Association. (1994). *Position statement on assisted suicide*. Washington, DC: American Nurses Association.
American Nurses Association. (1988). *Guidelines on withdrawing or withholding food and fluid*. Washington, DC: American Nurses Association.
Blackmun, H. (1981). Majority opinion in Roe vs Wade. In T. A. Mappes & J. S. Zembaty, *Biomedical ethics* (2nd ed.) (pp. 478–482). New York: McGraw-Hill.
"Body and soul." (2002 [October 27]). *Seattle Times*, p. A3.
Burkhardt, M. A. & Nathaniel, A. K. (2002). *Ethics & issues in contemporary nursing* (2nd ed.). Albany, NY: Delmar.
Burley, S. K., Almo, S. C., Bonanno J. B., Capel, M., Chance, M. R., Gaasterland, T., Lin, D., Sali, A., Studier, F. W. & Swaminathan, S. (1999). Structural genomics: Beyond the human genome project. *Nature Genetics 23*(2):151–157.

Capron, A. M. (1994). Grandma? No, I'm the mother! *Hastings Center Report 24*(2):24–25.
"Cloned pigs raise transplant hopes." (2002 [August 22]). [On-line]. Available: *http://news.bbc.co.uk/2/hi/science/nature/2210306.stm*.
Colby, W. H. (1990). Missouri stands alone. *Hastings Center Report 20*(5): 5–6.
Critical Data: U. S. Facts About Transplantation. (2002). UNOS Critical Data Main Page. [On-line]. Available: *http://www.unos.org/Newsroom/critdata_main.htm*. Accessed September 26, 2002.
Department of Health & Human Services. (2001 [June]) "Stem cells: Scientific progress and future research directions, executive summary". [On-line]. *http://www.nih.gov/new/stemcell/scireport.htm*. Accessed October *12*, 2002.
Dorning, M. (1994 [November 13]). Teen-agers refusal of treatment stirs debate. *San Diego Union Tribune* A-8.
Dworkin, G. (1981). Autonomy and behavior control. In T. A. Mappes & J. S. Zembaty. *Biomedical Ethics* (2nd ed.) (pp 273–280), New York: McGraw-Hill.
"European court throws out appeal for assisted suicide." (2002 [April 30]). *The Seattle Times*, p. A-12.
Fano, A., Cohen, M. J., Cramer, M., Greek, R. & Kaufman, S. R. (1999). Of pigs, primates, and plagues: A layperson's guide to the problems with animal-to-human organ transplants. [On-line]. Available at *www.mrmcmed.org/pigs.html*. Accessed December 22, 1999.
Fry, S. T. (1990). New ANA guidelines on withdrawing or withholding food and fluid from patients. In C. A. Lindeman & M. McAthie: *Readings: Nursing trends and issues*. (pp. 499–507). Springhouse, PA: Springhouse.
Gustafson, J. J. (1973 [Summer]). Mongolism, parental desires, and the right to life. *Perspectives in Biology and Medicine*, p. 529.
Halleck, S. L. (1981). Legal and ethical aspects of behavior control. In T. A. Mappes & Zembaty J. S.: *Biomedical ethics* (2nd ed.) (pp. 267–273). New York: McGraw-Hill.
"Hospital sued for 'wrongful life'." (1991). *American Journal of Nursing, 91*(5):111.
Hudson, T. (1994a). Advance directives: Still problematic for providers. *Hospitals and Health Networks 68(*6): 46, 48, 50.
Hudson, T. (1994b). Are futile-care policies the answer? *Hospitals and Health Networks 68*(4):26–32.
Human Genome Project Information. About the Human Genome Project (2002a). [On-line]. Available: *www.ornl.gov/ hgmis/project/about/html*.
Human Genome Project Information. Ethical, legal, and social issues (ELSI) of the Human Genome Project. (2002b) [On-line]. Available at *www.ornl.gov/hgmis/elsi/elsi.html*.
Judson, K. & Hicks, S. (1999). *Law & ethics for medical careers* (2nd ed.). New York: Glencoe/McGraw-Hill.
Kasiske, B. L, Neylan, J. F., Riggio, R. R. et al. (1991). The effect of race on access and outcome in transplantation. *New England Journal of Medicine* 324:302–307.
Kass, L. R. (1993). Is there a right to die? *Hastings Center Report 23*(1):34–43.
Killion, S. W. & Dempski, K. M. (2000). *Legal and ethical issues*. Thorofare, New Jersey: Slack, Inc.
Kmiec, E. G. (1999 [May-June)]. Targeted gene repair. *American Scientist,* [On-line]. Available at *www.amsci.org/amsci/articles/99articles/Kmiecrepair.html*. Accessed September 19, 2002.
Lombardo, P. (2002). Eugenics sterilization laws. [On-line]. Available at *http://www.eugenicsarchive.org/html/eugenics/essay_8.html*.
Macklin, R. (1991). Artificial means of reproduction and our understanding of the family. *Hastings Center Report 21*(1): 5–11.
"Most transplanted organs from live donors, U.S. says." (2002 [April 23]). *The Seattle Times*, p. A2.
National Minority Organ Tissue Transplant Educational Program. Statistics: MOTTEP Facts and Figures. (2002). [On-line]. Available at *http://www.nationalmottep.org.ststs.html*.
"Netherlands is first nation to fully legalize euthanasia." (2001 [April 11]). *The Herald,* p. 3A.
Nuland, S. B.(1996). An epidemic of discovery. *Time Special Issue*, Fall: 8–13.

"Oregon suicides steady, still sharply divisive." (2002 [February 10]). *The Seattle Times*, p. B1, 4.
O'Toole, M. (Ed.). (1992). *Miller-Keane encyclopedia and dictionary of medicine, nursing, and allied health* (5th ed.). Philadelphia: W.B. Saunders.
Pilbeam, S. P. (1998). *Mechanical ventilation: Physiological and clinical applications* (3rd ed.). St. Louis: Mosby.
Randall, V. R. (2002). Basis of distrust. [On-line]. Available at *http://academic.udayton.edu/health/05bioethics/slavery02.htm*.
Roan, S. (1997 [April 24]). Woman gives birth at 63: Ethical questions raised. *Los Angeles Times*, A1, A31.
Roe v. Wade, 410 U.S. 113 (1973).
Rothstein, M. A. (1990). The challenge of the new genetics. *National Forum 69*(4): 39–40.
Savitch, C. (1996). *The nutcracker is already dancing: The HIVs and the HIV-nots*. Ventura, CA: Teague House Press.
Schneiderman, L. F. & Jecker, N. (1993). Futility in practice. *Archives of Internal Medicine* 153:437–440.
Schroeder, S. (2002). Steven Schroeder reflects on the uninsured. Roberts Woods Johnson Foundation. [On-line]. Available at *http://www.rwjf.org/newsEvents/healthPolicy2.jhtml*.
Stem cell stalement. (2001 [August 10]). *The Herald*, p. A1.
Swain, M. S. & Marusyk, R. W. (1990). An alternative to property rights in human tissue. *Hastings Center Report 20*(5):12–15.
"The stem cell debate hinges on when human life begins." (2001 [August 10]). *The Herald*, p. A11.
totse.com. Age of consent in every state. [On-line]. Available at *http://www.totse.com/en/law/justice_for_all/aoc.html*. Accessed 10/16/02.
Veatch, R. M. (1976). *Death, dying and the biological revolution*. New Haven, CT: Yale University Press.
Wheeler, M. S. & Cheung, A. (1996). Minority attitudes toward organ donation. *Critical Care Nurse 16*(1):30–34. *http://womenshistory.about.com/library/ency/blwh_comstock.htm*. Accessed 10/16/02.