Social Activism and Health-Care Consumerism

If the medical activism discussed in Chapters 3 and 4 can be thought of as policy-making agitation of a trickle-down sort, then the grass-roots forces discussed here and in Chapter 6 might be thought of as activism of the percolator variety, bubbling forth from the mass of nonprofessionals upward. This chapter is about activism that flows from the general predisposition Americans have to embrace individual rights. In this context, the right to die can be understood not as some ghoulish aberration but as a natural extension of rights Americans already expect to enjoy. Chapter 6 will deal with the agitation for rights as they apply to the business of dying specifically.

Emergence of a Rights Culture

Americans have always cherished their civil rights, especially those protected by the first amendments to the U.S. Constitution—the revered Bill of Rights. But sensitivity about this subject increased substantially within the body politic during the 1960s when interest in an entirely new layer of individual rights sprang forth. This new genre of civil rights was not explicitly expressed anywhere in the Constitution’s words per se. Instead, they became part of the legal and cultural fabric of American society as “penumbral rights,” an amorphous set of guarantees that many came to think of as existing in the shadow of the Constitution. These guarantees took shape largely as promises that individuals would be treated fairly in their interactions with “the establishment,” if establishment is broadly defined to include all sorts of authority figures and power brokers in both the public and private sectors. The increasing predisposition of individuals to claim these rights is a phenomenon we refer to as the emergence of a rights culture.

The 1960s was a decade in which the establishment (i.e., middle- and upper-class Anglo-Saxon males who tended to hold the reins of political and economic
power) was perceived as evil, almost by definition, by many who were not a part of that establishment. Many lost faith in government because of the Vietnam War, which seemed to spin out of control with no end in sight. Activism in the area of race was another manifestation of an emergent rights culture, and Americans, primarily those of African-American descent, began questioning and often rejecting the status quo. The women's movement got an enormous boost in this decade, as well, as Americans—especially female Americans—began rejecting sexual mores and gender stereotypes that tended to relegate women in the United States to a second-class status.

These were the years when a number of other groups within American society also began to assert their claims to rights, including those who advocated the causes of farm workers, blue-collar laborers, prisoners, homosexuals, tenants, children, the poor, and disabled persons. Not surprisingly and certainly not coincidentally, these were also the fledgling years of the consumerism movement. This basic rights crusade, grounded in the complementary demands associated with product safety for consumers and product liability for corporations, cut across racial, gender, and age boundaries to radically alter the nature of the U.S. marketplace.

Producers were put on notice in the 1960s when President John Kennedy announced his "consumer bill of rights," a document that codified for the consumer the right to have safe products and product choice and the right to petition for the redress of consumer-oriented grievances. The document was an official reflection of the times, though, more than a bold new assertion for consumerist sentiments were already gelling in the country at the time. No longer would American consumers be satisfied with what laissez-faire capitalism was dishing out. Instead, they would demand greater levels of corporate responsibility in such areas as environmental protection, product safety, product labeling, and honesty in advertising. Health care was just one more area of consumer interest in which expectations were raised.

To ensure that the corporations would do their part, Americans began to demand more government oversight. As a result, the Food and Drug Administration (FDA) started playing a more activist role with regard to drug trials and product labeling. Ralph Nader's stinging indictment of the Chevrolet Corvair and the subsequent formation of consumer-rights advocacy organizations (groups that became known as "Nader's Raiders") were important policy forces, as well. Nader and his followers were skillful at manipulating the levers of power in Washington to ensure that government bureaucrats and federal legislators toed the line on product safety in ways unheard of just a decade before.

Then, in 1972, the consumer movement got another boost when the Consumer Product Safety Commission (CPSC) was created as an independent regulatory
agency. The CPSC was charged with the responsibility of reducing the risk of injury to consumers from products sold to them. In addition, the commission was empowered to conduct product-safety research and set safety standards in such areas as flammable fabrics and poison-protective packaging. Its other responsibilities included conducting consumer-education programs and establishing a clearinghouse for injury information. Today, it would be difficult to imagine a world in which the federal government did not engage in such activities. But at the time, all these activities—risk management, consumer education, and safety research—were revolutionary roles for the government to play.

A host of federal “truth in” regulations were also passed in these years: truth in advertising, truth in lending, truth in labeling, and truth in packaging were among them. Empowered with these new rules, consumers launched an onslaught of tort litigation that has carried through to the 1990s unabated. There was significant activity at the state level, as well, as state offices of the attorney general were transformed from entities almost entirely concerned with violent and organized crime into hotbeds of activity on the consumer-rights front. The change had more than a little to do with the realization that consumer expectations were running high and that there was a good deal of political hay to be made by bringing corporate scoundrels to justice.

In the end, the collective activity of fifty state offices of the attorney general, other state agencies involved with consumer interests, and the federal CPSC and other like-minded agencies created a whole new market environment for American producers and consumers. Slowly but surely, the old adage so appropriate in the freewheeling laissez-faire days of the earlier twentieth century—caveat emptor, let the buyer beware—began giving way as a descriptor of consumer-producer relations. Today, the aphorism caveat venditor—let the seller beware—reflects more accurately the character of the modern marketplace.

In retrospect, it is fair to say that by the 1970s, some of the more radical sentiments of the stormy 1960s had been mollified. Still, the smoldering embers of that turbulent decade remained: Even if the establishment was no longer thought of as necessarily evil by definition, neither was it deemed right by definition. Instead, the actions of members of the establishment would be judged on a case-by-case basis, receiving neither the immediate rejection of the 1960s nor the benefit of the doubt that was so freely accorded it in prior decades. Consumers, including consumers of health care, would no longer stand idly by, accepting without question whatever goods and services were being offered. They would demand that the government protect them, and they would insist on being able to protect themselves. Producers of all kinds of goods and services, including physicians and hospitals in the case of health care, would lose power in the process. Ultimately, this redistribution of power in the medical marketplace led Americans to start de-
manding more control over the way the health-care system treated them, both in life and in death.

Health-Care Consumerism

The emergence of a rights culture that fueled the consumerism movement in the 1960s quite naturally spread to the health-care arena. Consumerism called into question the traditional relationship between physician (seller) and patient (buyer). In the late 1960s and early 1970s, activists in the health-care rights movement were demanding that more attention be paid to informed consent, the right to view medical records, and the extension of due process protections when individuals were involuntarily committed to institutions. Each claim robbed from physicians some of the authority that they had exercised exclusively in days past.

The Physician-Patient Relationship

The relationship between Americans and their physicians is somewhat unique, according to Paul Starr (1982), because physicians have traditionally been held in high esteem. This is not always true in other cultures. In the former Soviet Union, for example, the fact that 70 percent of physicians were women did not reflect the advances that women had made in that society so much as it reflected the relatively low esteem in which doctors were held in that country. In contrast, American physicians have been the most respected of all professionals in the United States, at least since the turn of the century.

Doctors have mastered knowledge in an area of great importance to Americans—the preservation of life—and this expertise gives them a great power advantage from the start. As Marie Haug and Bebe Levin (1983, p. 11) note: “In a society where vigorous health is a central value, and where death is to be forestalled at all costs, power will accrue to persons whose skills are believed to conquer disease and prevent premature demise.” Command of an esoteric language has only added to the physician’s mystique.

The traditional imbalance in power between physician and patient is compounded by the fact that most individuals who come in contact with doctors are in a relatively weakened state to begin with, making them more vulnerable than they might otherwise be to the exercise of power and authority. They may be in great pain or in shock. Or they may be at their wits’ end, desperate for a medical fix. As such, patients are put into a subordinate role vis-à-vis their doctors.

This is true even during regular medical checkups. Due to advances in diagnostic technology, physicians can find all kinds of terrible things wrong even with seemingly healthy individuals, and that, too, puts the patient at a distinct power disadvantage. Clearly, the advent of high-technology medical equipment—both
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of the diagnostic and the rescue-medicine variety—has widened what Talcott Parsons has called the “competence gap,” from which physicians draw considerable authority and power.

At the same time, physician hegemony is on the wane. In the previous chapter, we charted the changes in physician behavior that led to an erosion of the trust that had characterized the doctor-patient relationship before the turn of the century. Here, we note how patients themselves have chipped away at physician autonomy through the medical consumerism movement. This new philosophy of patient empowerment challenged the doctor’s right to make unilateral decisions and demanded that power be shared in a relationship that shifts the focus from physician autonomy to physician obligation and from patient compliance to patient rights. It is a new kind of bond in which faith and trust have been replaced by caution and doubt (Haug and Levin, 1983, p. 10). As a result of this shift in philosophy, recipients of health care today are more likely to be “wary consumers” rather than “grateful supplicants” (Rothman, 1991, p. 128).

Part of this radical transformation in physician-patient relations can be attributed to improved education nationwide, as measured, in part, by the number of years of formal education completed. In addition, there is another, more informal dimension to education—education that is facilitated by the stream of popular literature on health that has emerged in the last few decades. Health and fitness magazines, consumer reports, books on every popular health subject imaginable, and medical columns in newspapers have advised increasingly health-conscious consumers about new treatment options and their side effects, old treatment protocols found to be ineffective or even dangerous, and new ailments that were formerly misdiagnosed as something else. These publications have also encouraged readers to press physicians for candid answers and to shop around for a second (or third or fourth) opinion if they are unsatisfied. All this information and encouragement has empowered patients by bringing the authority of the physician into question, putting doctors on the defensive for the first time since being challenged by their medical school supervisors.

The advances of medical technology and proliferation of treatment options have also cut into physician credibility. Many patients today have some form of chronic or degenerative illness, such as cancer, heart disease, diabetes, or kidney disease. Although much progress has been made in treating these ailments, there is still a measure of disagreement in the medical community with regard to the standards of care that should be rendered in specific cases. The proliferation of specialists only exacerbates the problem for each different specialist seems to put a different spin on diagnosis and treatment. Such disagreements lead to a further breakdown in the faith the patient has in any particular physician (Haug and Levin, 1983, p. 33). Long, drawn-out illnesses also give patients more time to think about and question their treatments. As noted in Chapter 3, George Washington
had only a few days to disagree with his caretakers before death arrived, but most of us will have months or even years to think about the care received while dying.

Then there are the medical ethicists who chime in with policy pronouncements about the importance of patient autonomy in editorials and news articles, during policy symposia that they arrange, and before congressional committees. One such opinionmaker is Willard Gaylin, president of the Hastings Institute, a center devoted to the study of medical-ethical issues. Gaylin testified that “patient-consumers must no longer trust exclusively the benevolence of the professional. ... Basic decisions must be returned to the hands of the patient population whose health care future will be affected. ... We should all share in the decision making” (cited in Rothman, 1991, p. 188).

The electronic media have played an important role, as well. Gone are the candycoated images of trustworthy doctors as packaged in the character of Dr. Welby. (Could there be a better, more seductive name for the doctor portrayed in this stereotype?) In the place of these fictional dramas about good doctors practicing good medicine, we now find real-life exposés about bad medicine, served up almost nightly on the news and covered more extensively on “60 Minutes,” “20/20,” “Frontline,” “48 Hours,” and the like. The daytime talk shows—hosted by Phil Donahue, Oprah Winfrey, Sally Jesse Raphael, and Geraldo Rivera—then add their explosive spin to the health-care issues currently in vogue. These television programs broadcast stories about physicians having sex with patients, overcharging, prescribing drugs with tragic side effects, conducting experiments on humans without fully informed consent, performing unnecessary surgeries, as well as absentee doctors (who are out on the golf course while residents perform their operations). Some programs narrow in on specific physicians who have committed other ethical transgressions, like the fertility specialist who, in 1991, confessed to using his own sperm to artificially inseminate over seventy patients without their knowledge.

Even though the overwhelming percentage of physicians may be selfless, ethical, upstanding practitioners, these stories of deviance cut deep into the faith Americans put in the medical profession, and that initiates a cycle of skepticism-based activity as these reports of abuse feed into themselves. Exposés increase doubts in the patient population, which, in turn, increase awareness and encourage individuals to raise issues of safety and trust. This then causes more complaints and revelations of more problems and ultimately produces even more exposés. And the cycle starts again. Once begun, this engine of policy activism is difficult to stop as long as there is fuel, and, apparently, there is fuel aplenty.

As a result, “doctor’s orders,” a command that had previously carried great weight in American society, is beginning to lose its power. Today, the compliant “you’re the doctor” acknowledgment of authority is being replaced by the more challenging notion (sometimes expressed but usually only thought) that “maybe I should get a second opinion.” In searching out these second opinions, some pa-
tients turn to paraprofessional and nontraditional health-care providers for assistance. This, too, cuts into traditional physician credibility and manifests its decline.

**Alternative Approaches to Health Care**

Haug and Levin (1983, p. 21) note how the growth of paraprofessional fields has been an important factor in the demystification of medicine. Tasks once done solely by physicians are now delegated to nurse practitioners, midwives, and physicians' assistants, especially in health maintenance organizations (HMOs), where cost control is a primary concern. The operating philosophy of the HMO requires providers to husband resources and deliver services at the lowest possible level of technical sophistication. That means greater use of paraprofessionals to perform the less technical procedures and tasks related to diagnosis and treatment. The HMO philosophy of capitated coverage—annual flat-fee coverage, as opposed to bills paid on a rolling, “fee-for-service” basis—may also mean increased patient self-care, with a special emphasis on disease prevention.

In both paraprofessional care and self-care, individuals become aware that someone other than a full-fledged physician can provide quality care, adding to the notion that maybe the legendary stature traditionally accorded the physician is not particularly well deserved, after all. In addition, it may be easier for patients to question a paraprofessional rather than a physician about their medical care. HMOs, nonexistent twenty years ago, cover nearly 20 percent of the population today. It would be surprising—indeed, incredible—if this exposure did not undermine faith in physicians to some degree.

There is also a surge of interest in caring for oneself that arises independently of the HMO philosophy. Part of this development can be traced to the 1974 best-seller *The Type A Behavior and Your Heart*, written by cardiologists Meyer Friedman and Ray Rosenman. These doctors argued that personality traits such as impatience and irritability increase a person's risk of heart disease, which led them and their readers to believe that the health of the heart could be changed by personality-altering behaviors. *The Relaxation Response*, a 1975 best-seller by Herbert Benson (another cardiologist) and Miriam Klipper, arrived just in time to follow up on Friedman and Rosenman's work. The first book described why some people are at risk for heart disease. The second, a behavioral guide to heart disease risk reduction, capitalized on the interest in transcendental meditation (TM) that had become something of a cultural fad in the 1970s.

In 1979, Norman Cousins, longtime editor of the *Saturday Review*, made a significant contribution to the self-care movement when he told of how taking vitamin C and watching comedies on television led to his seemingly miraculous recovery from what was thought to be an incurable disease. That same year, Jon Kabat-Zinn, a professor of medicine, established a stress-reduction clinic at the
University of Massachusetts Medical Center—the first hospital-based program to use a combination of medication and yoga to reduce stress. The use of prescription drugs at the clinic was a traditional approach that kept physicians firmly in control, but the yoga was something patients could do at home, without any prescription. This helped to bring yoga—like TM—into the mainstream of American life as a preventive, self-directed approach to health. Biofeedback, in which individuals are trained to become aware of their heart rate and blood pressure in order to control them through conscious mental effort, was another self-care alternative that became popular during these years.

More advances were made along these lines in the 1980s. Stores started putting blood pressure and pulse-monitoring machines in their lobbies, and bars started installing Breathalyzer machines. Also in this decade, the Physician’s Desk Reference (PDR) became available for purchase by the public (see, e.g., Physician’s Desk Reference, 1992). In years past, the PDR, a compendium of legal drugs available in the United States (including recommended doses, generic information, and potential side effects), was a carefully guarded trade secret of physicians. Now, patients armed with their own copies of the PDR are able to second-guess the physician, about both the dosage and the choice of drugs. The PDR also made it possible for patients to become more aware of potential side effects—yet another potential ground on which to call doctors into question.

The rise of the home-health-care business, an industry response to the escalating costs of institutional care, has also been a significant development in the popularization of medicine. Home health care, in which treatments and therapies are provided in the home (with the assistance of visiting paraprofessionals as needed), shifts the locus of control and responsibility from bureaucratic institutions to the domestic scene. More importantly, it shifts the locus of authority away from professional physicians and toward paraprofessionals and individuals—the patients and their relatives. Home health care has gone from an anomaly to a $3.2-billion industry in the last decade or so, and forecasters are calling for steady growth in the future (Freudenheim, 1992a). By providing health-monitoring equipment, intravenous nutrition and drugs, and other sorts of portable technology to individuals in their homes, these companies are helping to sever the already frayed tether of dependency between patient and doctor. Home health care takes the mystery out of treatment and puts control in the hands of the lay public, whose toleration for autocratic physicians cannot help but begin to ebb in the process.

Self-care resource groups have also proliferated in the last two decades. Networks, coalitions, advocacy groups, alliances, and associations of every size, shape, and persuasion have grown up around every health-care cause imaginable. Some of these groups provide educational materials and hold information sessions. Other groups focus on coping skills for patients and families. Some provide
a forum for sharing the trials and tribulations of a particular affliction. And others do a little bit of all these things.

Occasionally, groups will espouse a very broad mandate, such as those organizations that focus on women's health-care issues in general. Other groups concentrate their attention on specific afflictions—the Malignant Hyperthermia Association of America, for example, which educates and provides support specifically to those who suffer from malignant hyperthermia (MH), a potentially life-threatening sensitivity to anesthesia. Whatever the goal, however, and whatever the health issue, self-care resource groups empower individuals in battles with both their afflictions and their physicians.

In addition to self-care and paraprofessional care, there is also a surge of interest in "alternative medicine”—medical philosophies that fall outside the mainstream established by the American Medical Association. One development worth noting is the renewed interest in homeopathic medicine (Gorman, 1992).

Homeopathy, an approach to health care that originated with German physician Samuel Hahnemann (1755–1843), operates on what its practitioners call the "law of similars." The principle holds that a substance that causes the symptoms that the patient suffers from will cure the patient if given in extremely diluted solutions. Interestingly, although nobody knows how homeopathy works, practitioners and patients alike swear by its efficacy, citing anecdote after anecdote of successful treatment.

In the United States, interest in homeopathic approaches surged after the Civil War but then subsided appreciably after the turn of the twentieth century. In 1900, there were twenty-two homeopathic medical schools in the United States, but by 1918, that number had dropped to six, and now there are none. Interest in homeopathy seems to be rekindling today, however. Homeopathic drug companies report that, in some cases, sales have increased tenfold in the last decade or so. In that time, the sale of homeopathic "cures" has evolved into a $100-million business (currently, these "cures" are not subject to FDA approval). The number of individuals who claim to practice homeopathy has increased, as well, from a nationwide total of 100 in the early 1970s to 2,500 today. Three states—Connecticut, Arizona, and Nevada—now license individuals to practice homeopathy, and in most other states, homeopathy providers may advertise their services as long as they are also board certified as traditional health-care professionals. This resurgence of interest in homeopathy is important for two reasons. First, homeopathic defections in the patient and practitioner population suggest that at least some are dissatisfied enough with the traditional-care model that they are willing to swim against the tide and try something new, another sign of the decline in trust of traditional care. Second, part of the appeal of homeopathy derives, we suspect, from the close patient-practitioner relationship that the homeopathic philosophy calls for. Homeopaths are encouraged to learn all they can by listening closely to patients, who are allowed to give extended, uninterrupted re-
ports of their symptoms. Practitioners are trained to establish close relationships with their patients, and hour-long consults are not uncommon (Starr, 1982, p. 97). Obviously, this approach varies greatly from that of traditional physicians who are criticized for becoming too emotionally disconnected from their patients.

Patients who are unable to get relief from traditionally trained physicians have given testimony to the value of a wide variety of other alternative approaches to health care, as well. In naturopathy, for example, illness and disease are treated through exercise, diet, and other "natural" means rather than with drugs or surgery. Another alternative, osteopathy (founded by Missouri doctor Andrew Still in the 1890s) takes a very mechanistic approach to medical disorder. Dr. Still encouraged his followers to treat the heart as if it were an engine, the lungs as if they were a fanning machine, and the lobes of the brain as if they were an electric battery (Starr, 1982, p. 108). The body could be repaired, he argued, only by making sure that its parts were in proper relationships with one another. Accordingly, osteopaths emphasize physical manipulation and massage as therapeutic approaches to be used before resorting to drugs or more invasive therapies. Not coincidentally, chiropractic had its beginnings in the same decade as osteopathy, and though the intervening years have produced ups and downs in the field, the chiropractic approach seems to be as popular as ever today.

Acupuncture is yet another increasingly common, nontraditional alternative in health care. This approach was popularized in the United States by *New York Times* writer James Reston, who related his experiences with this ancient Chinese practice that involves inserting needles into the body at specific points and manipulating them to relieve pain and treat illness. More than 2,000 physicians now use acupuncture in conjunction with conventional medicine in the United States (Barasch, 1992).

Some 5,000 other individuals hang hypnotherapy shingles outside their offices. Hypnotherapy is a method of inducing a trancelike state, characterized by the patient's extreme suggestibility, to help the individual relax and control pain or overcome addictions like smoking and overeating. No one thoroughly understands the nature of hypnotherapy's effects, but this alternative, like the others, represents a rejection of traditional medical practice; taken together, these alternatives are now manifest as a multibillion-dollar rival to the traditional care model.

According to a survey reported in the *New England Journal of Medicine*, it is estimated that Americans spent close to $14 billion on alternative medicine in 1990 (Angier, 1993b). Approximately one-third of those surveyed claimed to have engaged in alternative therapies in that year, and one in ten claimed to have visited a practitioner of such therapies. Those under the care of an unorthodox practitioner (most typically, patients were well-educated, middle-income whites between twenty-five and forty-nine years of age) reported making an average of nineteen visits during the course of the year. Multiplied out, that represents a total of 425
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million visits—more than the number of trips made by all people to all primary-care physicians (e.g., general practitioners, family doctors, internists, and pediatricians) combined (Angier, 1993b).

The fact that the National Institutes of Health (NIH) opened an Office of Alternative Medicine further testifies to the increasing interest along these lines. According to Dr. Joe Jacobs, the new director of the office, the popularity of alternative medicine demonstrates the "hunger among Americans for a more humane and less invasive type of treatment than ordinarily practiced by standard doctors" (cited in Angier, 1993b). Jacobs believes it is important that "some of these alternative therapies take a holistic and caring view of the patient ... this is hard to achieve in a conventional medical setting, with your feet in stirrups" (cited in Angier, 1993b). Dr. Jules Hirsch of Rockefeller University in New York echoes the sentiment. The interest in alternative medicine, he argues, represents "a cry for new treatments and a criticism of the scientific community for being too cold and too removed from human needs" (cited in Angier, 1993a).

The new office at the NIH is expected to receive requests for funding research in such unorthodox fields as homeopathy, herbal medicine, electromagnetism (to treat arthritis), visualization and guided imagery (to help manage pain), and touch therapy (akin to the traditional laying on of hands). Admittedly, the first-year budget for the Office of Alternative Medicine—$2 million—is minuscule when compared to the total NIH research budget of over $10 billion. Still, the very creation of this office and the growing predisposition of Americans to reject conventional medicine in favor of alternative approaches are harbingers of import to the right-to-die debate. If more Americans are taking health care into their own hands, are they not more likely to take death into their own hands, as well?

The Impact of Organizations

To this point, we have looked at consumerism in health care as manifested in the decline of the physician-patient relationship and the rise of alternative forms of therapy. We turn now to evidence of consumerism as manifested in the activity of groups—primarily interest groups, professional associations, and government committees. The clearest and most explicit expression of health-care consumerism arising from the activity of groups is the Patient Bill of Rights, the end product of a study conducted by the National Welfare Rights Organization (NWRO) in 1970.

The Patient Bill of Rights, a list of twenty-six rights proposals, was presented to the Joint Commission on Accreditation for Hospital Organizations. The Joint Commission is the primary hospital-accreditation agency in the United States, and NWRO was hoping that its rights manifesto would be made a requirement for all hospitals that wished to retain their JCAHO accreditation. After negotiations, the Joint Commission incorporated a number of NWRO rights recommen-
dations into the preamble of its hospital-accreditation manual. Essentially, the new preamble called for hospitals to provide access to care to anyone, regardless of race, color, creed, national origin, or ability to pay. Further, it stated that all patients had the right to be told the truth about their medical condition.

This preamble served as the basis for the American Hospital Association's (AHA) Patient Bill of Rights, issued in 1972. The AHA version reiterated the Joint Commission's preamble and more generally stipulated that all patients had the right to respectful care. Importantly, the AHA proclamation enlarged on the JCAHO manual's treatment of informed consent by stipulating that truth telling must incorporate explanations that “the patient can reasonably be expected to understand” (cited in Rothman, 1991, p. 146). There were also provisions requiring that patient consent be obtained before proceeding with either treatment or experimentation.

In theory, the Joint Commission carries a great deal of weight since it can decertify a hospital, making the institution ineligible for reimbursement under Medicare or Medicaid. Initially, however, the Joint Commission did not exercise its power with regard to patients' rights. Including some of the NWRO positions in the preamble of its accreditation manual really only constituted a statement of a philosophy, not the establishment of hard-and-fast requirements. There were no procedures laid down for enforcement, nor were there any sanctions listed for failure to comply. The AHA document carried even less weight. It provided evidence that change was in the air, but like the Joint Commission preamble, the AHA statement was an expression of philosophy more than a rule of law—an indication of changing attitudes but not necessarily an impetus for changing behaviors. Clearly, however, Joint Commission and AHA attention to these concerns suggested that more rigorous requirements in the area of patients' rights would come into play in the future.

In early 1973, at about the same time the Joint Commission and the AHA were dabbling with patients' rights, Senator Edward Kennedy began holding committee hearings under the operating title “Quality of Health Care: Human Experimentation.” Despite the narrow focus suggested by this title, Kennedy's aim was to call all medical practice into question. Although the Kennedy Committee's report was weakened substantially before being made public, it was still strong enough to symbolize the end of the monopoly the medical profession had created for itself in the medical ethics venue (Rothman, 1991, p. 188). The doors to the decision-making process were flung wide open by testimony taken by the Kennedy study group, leading Bernard Barber to predict that the committee would “transform fundamental moral problems [in modern medicine] from a condition of relative professional neglect and occasional journalistic scandal to a condition of continuing public and professional visibility and legitimacy” (cited in Rothman, 1991, p. 188).
The Public Citizen's Health Research Group (PCHRG), one of Ralph Nader's many consumer-oriented organizations, helped to make sure, through the 1970s and beyond, that patients' rights would continue as a high-profile concern on the public-policy agenda (Rothman, 1991, p. 188). The PCHRG stirred the pot by publicizing investigations into medical practices that had gone unscrutinized, by publishing and disseminating its own reports along the same lines, and by testifying before Congress on controversial health-care issues like national health insurance, medical malpractice, unnecessary surgery, and measuring the quality of medical care patients receive.4

As much as Americans tend to worship advanced medical technology and those who use it, they seem to be less willing to consider physician-provided treatments as good by definition. And the demographics of U.S. society suggest that this trend will only continue. Baby boomers who cut their teeth during the antiestablishment days of the 1960s are now moving into middle age (the oldest of the lot will turn fifty in 1996). This generation is twice as large as the previous one, and its members will be, we suspect, much more likely to question authority and demand control over their medical care—both in living and in dying—than their parents were.

Those who do make those demands will be relieved to know that the Joint Commission has taken a stronger stand on the issue of patients' rights in recent years, to the point where, instead of being mentioned as a suggestion in the preamble of the certification manual, patient rights have now evolved into a primary and important part of all Joint Commission reviews. According to the 1992 JCAHO standards manual, hospitals are required to have formal procedures in place that protect the right of the patient to make decisions involving health care, in collaboration with his or her physician. This includes the right to refuse medical treatment, to make advanced directives, and to appoint a surrogate decision-maker (all such rights are exercisable to the extent permitted by state law). Further, the Joint Commission requires that, upon admitting a patient, the hospital must make a documented effort to determine if an advance directive exists and to help the individual without one to develop a directive if he or she desires (in the spirit of the Patient Self-Determination Act, which will be described more fully). Any advance directives produced or created as a result must be documented in the patient's record and periodically reviewed, according to commission guidelines.

Thus, the patients' rights movement has produced some tangible results in the twenty years since its humble beginnings. The various rights movements of the 1960s helped to set the stage. Then, as the relationship between physicians and patients began to break down, nontraditional forms of medical care became more prominent. Meanwhile, organizations like the NWRO, the Joint Commission, and the Kennedy Committee were identifying, for the first time, the nature of an appropriate relationship between a caregiver and a patient, with emphasis on the rights of the latter.
All these streams of health-care consumerism ultimately converge in a confluence of activism for patients’ rights that is probably nowhere as clearly manifest as in the women’s health movement. This movement illustrates well the trends of medical decisionmaking in the last few decades. And it may even suggest something about the trajectory of the right-to-die movement in particular.

The Women’s Health Movement

Medical consumerism is perhaps most robustly expressed in the area of women’s health care. It may be that the most dramatic changes have taken place in this arena precisely because this was where the most progress was needed. Indeed, the history of the interaction between women and their physicians is marked by dominance, deception, half-truths, and even abuse of the former by the latter. The Hippocratic medical tradition itself reinforced negative conceptions of women, their predispositions, and their capacities for rational thought. According to that tradition, a woman’s place was deemed to be strictly domestic in nature; she should not be agitating for her rights in the doctor’s office and certainly not practicing medicine.

Women and Medical Training

Male doctors deliberately and systematically excluded women from medical training in the United States at least until recently (The Boston Women’s Health Book Collective, 1984, p. 363). In the nineteenth century, the AMA issued the following statement in defense of its position that only men should be trained as physicians: “When a critical case demands independent action, and fearless judgement, man’s success depends on his virile courage, which the normal woman does not have nor is expected to have” (cited in Kevorkian, 1991, p. 207). In the twentieth century, the medical establishment built on this and other Hippocratic stereotypes by suggesting that women were unfit to be doctors because menstrual cycles caused emotional instabilities. Some argued that having women in the classroom would be an unwholesome distraction for men, and others worried that women would go on to marry and bear children, proving their training to be a waste (The Boston Women’s Health Book Collective, 1984, p. 570). In addition, many worried (maybe with good reason) that if women were admitted to the profession, female patients would prefer physicians of their own gender, especially for childbirth.

Men effectively barred the door to medical school through the 1950s, when only a trace of females could be found practicing medicine. But numbers grew steadily through the 1960s as the rights movement began opening all kinds of doors to those who had previously been discouraged from entering. Today, nearly one in every eight practicing physicians and more than one in four medical students is
female. This influx of women portends important changes for the doctor-patient relationship (see Chapter 4). Moreover, female physicians serve as strong role models for other women outside the profession who may otherwise have wondered if women really were capable of making medical decisions, either as physicians or as patients.

**Women as Patients**

The popular media's coverage of issues of particular importance to women has had a galvanizing effect on the women's health-care movement. Headlines about toxic shock syndrome (TSS, a potentially life-threatening malady brought on by the use of superabsorbent tampons), breast cancer (which one in eight women in America today will contract), silicon breast implants and hip implants, and faulty contraceptive devices (like the Dalkon Shield) have, in their way, normalized and popularized health care. Such subjects are now out of the closet and considered something that women can openly discuss and maybe even do something about.

The development and distribution of the birth control pill also had a dramatic effect on women as patients. First approved by the FDA in 1960 and nearly 100 percent effective if properly prescribed and administered, “the pill” was instrumental in empowering women. Availability of the pill drew women into the health-care system earlier and more often than they would have been otherwise, and at the same time, it gave them a degree of control over their bodies that they had not enjoyed in the past. It was now possible for sexually active women to plan pregnancies or avoid them altogether.

Then came Roe v. Wade, the U.S. Supreme Court's 1973 decision that determined that access to an abortion was constitutionally protected as a “penumbral” privacy right—one of those rights found to exist in the “shadow” of the U.S. Constitution. Roe empowered women—even those who chose not to have an abortion or those not needing an abortion—by reinforcing the notion that they could take medical decisionmaking into their own hands. Like the birth control pill, legalized abortion gave women more flexibility, more options, and more control over their own lives, and that emboldened them to expect and even demand more control over their own health care.

Widespread reports of doctors sexually abusing their female patients had an impact, as well, making women leery of male physicians. Even when physicians did not cross the bounds of sexual propriety, their behavior was perceived by many females as imperialistic and autocratic, leading women to regularly complain that their doctors had not listened to them or believed what they said. Too often, women reported, their male medical caretakers were offering tranquilizers and moral advice instead of sound medical care.

Even worse, some physicians systematically withheld knowledge, lied, and treated their female patients without consent. Failing to warn patients of the risks
Social Activism and Health-Care Consumerism

and side effects of treatments, overprescribing drugs, and overcharging in the process are among the indictments of male physicians brought by feminists in recent years. These feminists have urged rejection of the status quo in favor of increasing both patient rights and physician obligations (The Boston Women's Health Book Collective, 1984).

Obstetrics

Some of the most pointed feminist criticisms regarding the treatment of women as patients have been aimed at the way childbirth has become bureaucratized and medicalized in the twentieth century. First, the site of the birth has changed. In 1900, 95 percent of American babies were born at home, commonly with a midwife in attendance. But beginning in the 1920s, many states (with the encouragement of medical doctors) began outlawing the practice of midwifery (Rothman, 1991, p. 135). By 1960, 95 percent of all deliveries were taking place in hospitals, and a centuries-old tradition of domestic childbirth was all but lost.

Even more significant than the change in venue was the change in procedures associated with the delivery of a baby for the entire process had become extraordinarily medicalized. Both baby and mother benefitted greatly during high-risk births. But for many women experiencing an otherwise routine birth, all the added technology turned a natural event into a dehumanizing nightmare. Typically, the woman was forced to lie on her back with her legs spread and feet up in stirrups. Enemas, medical equipment (blood pressure cuffs around the biceps, contraction monitors taped to the abdomen, IVs inserted into the arm), and drugs (analgesia tranquilizers to minimize anxiety, barbiturates to induce sleep, and anesthesia to control pain) were all part of the picture, as well.

Often, if the attending physician did not feel the labor was progressing fast enough, he would break the bag of waters artificially by puncturing the amniotic sac with a small instrument shaped like a crochet hook and inserted through the cervix. Sometimes, electrode sensors would be inserted through the woman's uterus and attached to the baby's body by means of screws or metal clips. The mother's condition might be further monitored by another electrode, introduced into the cervix through a catheter in the vagina. If the delivery was still falling behind schedule, labor might be induced with an injection of Pitocin (The Boston Women's Health Book Collective, 1984, p. 382).

As the baby began to present itself, two more procedures often came into play. First, there was the ever-present possibility of a forceps-assisted delivery. Second, the physician would likely proceed with the most frequently performed obstetric operation in the West: the episiotomy—the only operation regularly effected on the body of a healthy woman without her consent. This scenario all presumes, of course, that the baby is delivered vaginally. The other option, even more medically intensive, is to deliver the baby through an incision in the mother's abdomen: the cesarean-section delivery. Twenty-five years
ago, only 5 percent of babies were born by cesarean section, and a decade before, hardly any were. Today, nearly one in four babies in the United States is born via the ubiquitous cesarean (compared with one in fifteen babies in Japan). The cesarean is increasingly popular among obstetricians at least in part, according to consumer groups, because it allows them to “manage” their “caseload” and maximize efficiency (and profit). This is true despite evidence that suggests that cesareans are more risky for the mother and that many, maybe most, are not even necessary.

In sum, more drugs and technologies are now used in the United States for “normal” births than anywhere else around the world. This reflects, in part, the desire to master, conquer, and control nature that has always been a defining characteristic of the American political culture (Wertz, cited in The Boston Women’s Health Book Collective, 1984, p. 362). At the same time, the medicalization of childbirth has tended to restrain and dehumanize the women such procedures are intended to benefit. Today’s women are demanding a more humane standard of care, one that adds their feelings and interests into the decision-making mix. Certainly, they want the best care for themselves and their babies. But, because the evidence now coming forth suggests that many interventions and procedures are done solely for the well-being of the physician, women are becoming increasingly suspicious of those who claim to be caring for them.

In an environment of declining trust, women are beginning to demand that their rights and prerogatives be respected, and this sets them up to be more challenging when it comes to making right-to-die decisions, as well. Given their experiences with medicalization in the delivery room, sexual abuse in the examining room, disinformation in the consultation room, and discrimination in medical school, it should come as no surprise that American women are primed to start demanding more control over health-care decisionmaking, both for themselves and for their children. If they are not, perhaps the cases of Angela Carder and Nancy Klein will make them think again.

The Case of Angela Carder. Angela Carder, twenty-seven years of age, had suffered from bone cancer nearly all her life. On two occasions, she had been told by doctors that she had only a few days to live, but Carder, one of the first children to survive Ewing’s sarcoma (a cancer of the connective tissue), had proved the experts wrong. By 1984, after being in remission for several years, Carder was married and had hopes of starting a family. With her doctor’s blessing, she became pregnant. But in June 1987, when she was twenty-six weeks pregnant, the cancer returned. With an inoperable tumor engulfing her lung, she was admitted to the George Washington University Medical Center in Washington, D.C., where, after examination, doctors determined her condition to be terminal.

Carder had indicated to her doctor at the beginning of her pregnancy that she wanted her own health, not the fetus’s, to come first. “She had battled too long to survive to give it all up at this point,” according to her mother, Nettie Stoner.
Carder’s longtime oncologist, who disagreed with the terminal prognosis rendered by the George Washington University physicians, recommended an aggressive treatment of radiation and chemotherapy. However, the doctors at the hospital, who believed Carder had only days to live, were against administering this treatment for it would likely endanger the developing fetus. They decided that if they could prolong Carder’s life for several weeks, rather than save it, they could offer at least some hope for the fetus. So, instead of moving ahead with a treatment to attack her cancer, doctors administered sedatives, a strategy used to postpone death. Carder tried to resist the doctors, “thrashing and twisting on the bed to fend them off.” According to her mother, she pleaded, “No, no, no. Don’t do that to me” (Faludi, 1991, p. 435).

At this point, the hospital administration became involved. Aware of a possible backlash from antiabortion activists for not attempting heroic measures to save even a severely compromised fetus, they weighed their options. Fearing that if the fetus was viable, the hospital would be held liable for its death, the administration recommended that the doctors perform a cesarean section in an attempt to save the fetus. But in Carder’s precarious state, it was highly unlikely that she would survive this kind of major surgery. She was heavily drugged at this point and virtually unconscious, making it difficult for her to make her own feelings about the hospital’s decision clear. Without waiting for the effects of Carder’s sedation to wear off and without notifying her family, the hospital requested the intervention of the courts.

Superior Court Judge Emmet Sullivan hastily convened a hearing in a hospital conference room. Those present included a legal team for the hospital, two city attorneys, a lawyer representing the fetus, and an attorney appointed by the court to represent Carder. In the meeting, the medical opinion of each physician in the obstetrical department was requested, and each doctor called recommended against the operation. Further questions asked by the judge focused almost solely around the welfare of the unborn fetus, with the health and welfare of Angela Carder becoming less and less central. After a brief recess, the judge ruled that “the court is of the view the fetus should be given an opportunity to live,” and since any delay in performing a surgical delivery increased the risk to the fetus, the cesarean was to be performed immediately.

Carder’s sedatives were just beginning to wear off when Dr. Louis Hamner of the obstetrical unit arrived to tell her of the decision. When first asked if she wanted the surgery, Carder indicated yes, but when Hamner returned to her room a half hour later, Carder clearly and repeatedly said, “I don’t want it done, I don’t want it done.” According to Hamner, her wishes on the matter were “quite clear to me” (Faludi, 1991, p. 435). Yet, when he reported this to those still in the “courtroom,” the judge replied, “The court is still not clear what her intent is” (Faludi, 1991, p. 435). Richard Love, one of the city’s lawyers, then argued that since the court had originally made the decision to operate on the basis that it
would be performed without her consent, her latest indication was immaterial (Faludi, 1991, p. 435). At this point, Carder’s court-appointed lawyer called the American Civil Liberties Union (ACLU) Reproductive Freedom Project, and the ACLU attorneys filed an emergency appeal for a stay. Due to the urgency of the matter, a three-judge panel from an appellate court was quickly assembled.

In that hearing, more doubts were raised over Carder’s mental capacity to make a coherent decision. The fetus’s attorney, Barbara Mishkin, argued that because of Carder’s condition, the “right of the fetus to live overrides any interest in the mother’s continued very short life.” In the end, the three-judge panel upheld the original decision and ordered the hospital to perform the cesarean section. Shortly after, doctors delivered a baby girl who lived only a little over two hours. Carder regained consciousness several hours later and cried when told her child did not survive. Soon after, she slipped into a coma, and two days later, she, too, died. Doctors admitted that the surgery most likely hastened Angela Carder’s death.

In April 1990, the Washington, D.C. Court of Appeals issued a decision (In re A. C.) affirming the right of a pregnant woman to make her own decisions about health care even if her choices endanger the fetus (“Let the Patient Decide,” 1990). Seven months later, in November 1990, the George Washington University Medical Center adopted a new policy that stated that “ethically difficult decisions for treatment of severely ill pregnant women and their fetuses will be made by the woman, her family, and her doctors, not by the courts” (Greenhouse, 1990). Carder’s mother issued a statement in response: “It’s been a terrible tragedy for us, but positive things have come from it” (Greenhouse, 1990).

Those “positive things” Carder’s mother talks about must include the hospital’s issuance of a written policy on pregnancy that respects the right of the mother to make decisions and, maybe more importantly, more general changes in attitudes that resulted from the case. Less than one year after the Carder incident, New Jersey passed the first (and, to date, the only) living-will law to give pregnant women the same rights granted in case law by the Washington, D.C. Court of Appeals. We do not have evidence of a causal link between the two events, but it is not hard to imagine that the Carder case helped to set the stage for New Jersey’s bold stroke of policy mediation in this area. (For more on New Jersey’s law, see Chapter 8.)

The Case of Nancy Klein. Nancy Klein and her family fared a bit better than Carder and her family had when faced with a similar situation, largely because her pregnancy was not as far along when catastrophic illness struck. Still, it took a court fight to settle the matter.

In February 1989, Klein lay in a coma in North Shore University Hospital on Long Island after suffering brain damage in a December 1988 automobile accident. She was seventeen weeks pregnant at the time. Her husband, Martin Klein, sought (with the support of his wife’s parents) to be appointed as Nancy’s tempo-
rary guardian for purposes of authorizing the physicians at the hospital to "interrupt the pregnancy ... and to perform such other medical procedures as may be necessary to preserve [Nancy Klein's] life" (538 N.Y.S.2d 274 [A.D.2 Dept. 1989]). Martin Klein was opposed in court by two strangers to the family who sought to prevent the proposed abortion by petitioning for guardianship of the four-month-old fetus.

Both the Supreme Court in Nassau County and the Appellate Division of the New York Supreme Court rejected the strangers' petition, citing *Roe v. Wade* and arguing that "a non-viable fetus, i.e., one less than twenty-four weeks old, is not a legally recognized 'person' for the purposes of proceedings such as these." Furthermore, the court stated, "the State has no compelling interest in the protection of the fetus prior to viability since the mother's constitutional right to privacy, which includes her right to terminate her pregnancy, is paramount at that stage. [Therefore, the] application [of those opposing Klein] is totally without merit." In an emotionally charged summary, the court added that "ultimately, the record confirms that these absolute strangers to the Klein family, whatever their motivation, have no place in the midst of this family tragedy" (538 N.Y.S.2d 274 [A.D.2 Dept. 1989]). The court also found that, absent any evidence of malicious intent (what the court calls "adverse interest"), case law clearly leads in the direction of granting family members guardianship whenever possible.

The Kleins' victory was a qualified one for the New York courts supported them, it appears, only because the fetus had not reached the magical viability point of twenty-four weeks. Thus, if Angela Carder had been in a New York hospital, the fact that she was twenty-six weeks pregnant would apparently have meant that she would have lost in court since her fetus was, in theory, viable. For present purposes, however, it is more important to note that such questions are now being raised in the courts and that both hospitals and states are beginning to make policy in this area. All this activism comes about, at least in part, because of the continued medicalization of health-care in America, which has already precipitated its share of rights activism in the last thirty years.

**Women Begin to Regain Control over Their Medical Destiny**

According to John Smith, the development of a vital feminism in the United States in the last quarter century has led to some significant changes in women's health care, including everything from "padded stirrups and speculum warmers in the examining room to childbirth education, the resurgence of midwifery, and a wider awareness of 'patients' rights' in general" (Smith, 1992, p. 2). In place of the traditional, profession-dominated medical culture, a therapeutic counterculture has emerged in women's health care, in which members of self-help groups coach each other through the travails of infertility, breast cancer, cervical cancer,
and sexual abuse. Women also are becoming more comfortable with monitoring their own health status (e.g., by doing breast self-exams and monitoring ovulation for times of peak fertility), all the while taking more responsibility for their own health.

In obstetrics, Lamaze and other "natural" childbirth methods have been advocated since the 1960s. Birthing rooms have become popular accoutrements of the modern American hospital, and now, the infant is allowed to stay with the mother after birth rather than being whisked away to the antiseptic nursery. Some hospitals put a crib in the mother's room to maximize the time mother and child can spend together. There also has been a resurgence in breast-feeding, another development (largely the result of efforts by Le Leche League) that empowers women to take care of themselves and their own.

Women's health issues outside the delivery room are coming to the fore, as well. Smith (1992, p. 14) notes, for example, that a million hysterectomies are conducted in the United States every year, and in nine out of ten cases, there is no medical imperative that the surgery be done. These operations are simply pushed on women, according to Smith (himself an obstetrician-gynecologist), by physicians who favor the aggressive-invasive approach to women's health-care issues. Consequently, approximately three-quarters of all American women have had their uteruses removed by age sixty-five, many unnecessarily. In light of this, Smith and others have recommended that women take control of these decisions themselves. At the very least, they should demand that physicians share decision-making authority with them—and maybe even with other physicians as the second opinion becomes a more realistic option for patients and a requirement of some health-care insurers.

In the end, the women's rights movement—a central and significant part of health-care consumerism (itself a spin-off of the more general civil rights movements ignited in the 1960s)—taught women to reject the "professional autonomy-patient compliance" model that characterized the roles traditionally played when female patients interacted with their physicians. As a result, women of today are well on the way to retrieving some measure of control over their own medical destinies, both in life and, ultimately, in death.

Medical Research and the Power of the Press

The power of the press was instrumental in converting outrage over women's health issues into something of a coherent mass movement. Headline stories about toxic shock syndrome, the Dalkon Shield, the side effects of birth control pills, and sexual abuse in the examining room encouraged women to demand for themselves more information, more choices, and more accountability in the pro-
vision of their health care. And the power of the press was equally important as a force of activism in other health areas, as well.

A Tradition of Influential Exposés

Sometimes, a series of stories and reports, published over time, add up to a significant and annealing force of movement activism. At other times, individual, blockbuster revelations seem to ignite a movement of one kind or another almost entirely on their own.

Upton Sinclair’s *The Jungle* was a work of the latter sort. His graphic description of the sausage-making process in the early part of the century was a primary catalyst behind a raft of food-quality regulations that were passed in the years that followed. Rachel Carson’s *Silent Spring* is another expose of this genre, one pointed to by Ralph Nader (1965) as a central, founding treatise of the environmental movement. Nader should know something about such things for his condemning expose of the Chevrolet Corvair, *Unsafe at Any Speed*, is often credited with launching the consumerism movement.

Nader, Carson, and Sinclair shared the unique quality of being able to stick their fingers in the collective public eye. Their works got people talking—and worried—about their own health and safety. Interest groups formed as agitation became organized and was channeled into various forms of activism that forced government to step into the breach in an effort to protect the rights of the general public. In each case, policy mediation could be traced to an identifiable collection of scathing words distributed for public consumption on the printed page.

It is with this general understanding of how important a single establishment-shaking work can be that we turn back to the field of medicine. Is there anything like the works of Sinclair, Carson, or Nader that has served as a catalyst in the health-care rights movement? One article, in particular, comes as close as any to fitting the bill.

Medical Research and Human Experimentation

The erosion of trust in doctors really began, argues Rothman (1991), with the erosion of trust in medical researchers. And that development only blossomed fully after a stinging indictment of medical research ethics, authored by Harvard Medical School professor Henry Beecher, was published in 1966. The article, entitled “Ethics and Clinical Research,” appeared in the *New England Journal of Medicine.*

Medical Research: A Historical Background. Until World War II, medical research was essentially a cottage industry, and human experimentation was limited to individuals and small groups. In those days, it was common for researchers to conduct small-scale trials on friends, neighbors, and family members. For exam-
ple, Englishman Edward Jenner, an eighteenth-century physician who did
ground-breaking research on a vaccination against smallpox, was reported to
have experimented on his son and another boy in the neighborhood. Occasion-
ally, partly as an act of good faith and partly out of conviction, these researchers
would even use themselves as guinea pigs. In 1767, Dr. John Hunter, the father of
modern surgery in the United Kingdom, slit his own penis with a lancet that had
been dipped in pus drawn from a patient infected with gonorrhea in an attempt
to study the hypothesized relationship between gonorrhea and syphilis (Klawans,
1992, pp. 110–112). A few years later, another European physician, James Simpson,
inhaled chloroform during an experiment to develop an anesthetic agent superior
to ether; he awoke to find himself lying flat on the floor (Rothman, 1991, p. 21).

The clinical use of humans in experimentation on a large scale did not really
come into play until the 1940s. Indeed, the Committee on Medical Research
(CMR) projects that were funded during World War II were among the first med-
ical experiments ever conducted in which humans were used in test and control
groups to determine, with some degree of statistical confidence, which drugs and
procedures were causing what reactions in the client population. Before advances
in biochemistry made it possible to isolate and monitor drug doses in trials, it
made little sense to conduct large-scale experiments. But rising levels of sophisti-
cation in this area, together with the pressing demands of a war (developing treat-
ments for dysentery and malaria, for example, were very high priorities for the
military), combined to make such experimentation both possible and necessary.

At that time, attitudes about the ethics of human experimentation were lax,
partly because such experiments were so novel, partly because they were consid-
ered matters of national security, and partly because so much success seemed to
be in the offing. A utilitarian calculus dominated in this environment: Ethical
transgressions (if they were even thought of as such) committed in the develop-
ment of new drugs and therapies through human experimentation were dis-
missed as inconsequential when compared to the potential benefits of such exper-
iments.

Consequently, all manner of clinical tests were done on large groups of usually
unsuspecting subjects without their consent during the 1940s. Orphanages, asy-
lums, and prisons were typically chosen for these trials, as the consideration of
ethical dilemmas raised by such experiments were suffused by the expediency of
war and the promise of great results. It was almost as if the acquiescence of indi-
viduals in these locations was expected as an obligation of citizenship since they
were not contributing to the war effort otherwise.

Even after the war years, however, when the national-security argument began
to fade and when human experimentation was no longer so novel, researchers
continued to play fast and loose with the ethics of their medical experiments on
humans. Emboldened by their wartime triumphs over smallpox, typhoid, tetan-
us, and yellow fever, clinical researchers forged ahead under the old “expedience
of war” rules, numb to the ethical objections that could be raised over experimenting on unwitting humans. As Rothman (1991, p. 79) puts it, a “license granted is not easily revoked,” and so researchers pressed on in the late 1940s and through the 1950s as if they had an ethical carte blanche.

**The 1960s.** The era of the laissez-faire laboratory (Rothman, 1991, p. 51) continued into the first years of the 1960s. Early in that decade, Dr. Louis Welt of the University of North Carolina Medical School surveyed eighty university departments regarding their practices and guidelines for human experimentation. Only eight of the sixty-six responding departments had documented their guidelines, and only twenty-four departments (less than half) had or favored the creation of review committees. In another study of fifty-two departments of medicine, only nine had formal procedures for approving research involving human subjects, and only five others indicated that they favored the creation of such procedures. Presumably, the remaining departments were either ambivalent about research protocols or rejected the notion outright. The Welt study concluded that the research community had “a general skepticism toward the development of ethical guidelines, codes, or sets of procedures concerning the conduct of research” (cited in Rothman, 1991, p. 60).

This same rationale seemed to be at work in most major research hospitals during the 1960s, including the flagship institution of the NIH—the Clinical Research Center (CRC). The CRC, a 500-bed, state-of-the-art research hospital in Bethesda, Maryland, was opened by the NIH in 1953. Patients were admitted as research subjects in the formal studies conducted at the institute. But as Rothman (1991, p. 54) states, “The NIH, at least before 1965, never put the matter quite so boldly.” Instead, bland and reassuring statements about the importance of patient welfare were offered. The CRC had no formal protocols designed to ensure that the patients’ best interests would not be sacrificed to the researchers’ own agendas. Indeed, the prospect that the well-being of humanity (the ends) and the well-being of the patient (the means) might often diverge was never officially broached by the research clinicians of the institute.

Not surprisingly, given this environment of ethical neglect, the CRC had no rigorous informed-consent requirements. Instead, the degree to which test procedures, potential benefits and risks, side effects, and possible complications were explained to patients was left entirely up to the discretion of individual researchers. Nor were researchers obliged to consult with their colleagues about the degree to which their experiments comported with ethical standards (as if there were any, beyond the individual conscience of the researcher involved). \(^6\)

Beyond allowing the CRC researchers to create, essentially without oversight, their own experimental protocols, the NIH also allowed those receiving external grants wide discretion. Indeed, grant recipients were not even required to have or report any procedures or guidelines governing the conduct of human-based re-
search at the time of the Beecher article. By 1965, the NIH was the single most important source of research grants for universities and medical schools in the world, supporting over 1,500 projects worth well over $1 billion. Yet, there was no stipulation that these research projects be carried out with even a modicum of sensitivity to the ethical dilemmas that human experimentation posed (Rothman, 1991, p. 59). Then came the Beecher exposé, which shined a glaring light on these researchers and their practices for the first time. And all of a sudden, the gilded age of research no longer seemed so golden.

The Beecher Indictment. Beecher’s article cited a series of cases in which human experimentation created, in his opinion, ethical problems of the first order. He wrote of one study in which penicillin was purposely withheld from servicemen so that alternative means of combatting streptococcal infection could be tested. None of the men in this experiment knew this, nor were they aware that their condition could deteriorate into rheumatic fever without treatment by penicillin. In the end, twenty-five men actually did contract this secondary disease.

In another example, live hepatitis viruses were fed to residents of a state institution for the mentally retarded in order to study the progression of the disease under “controlled” conditions. Elsewhere, physicians injected twenty-two elderly patients with cancerous cells to study the body’s immunological response. Newborns were the subject of another study. Here, researchers inserted catheters into the bladders of twenty-six babies less than forty-eight hours old, apparently without the consent of the parents, then took a series of X rays to study the function of the bladder as it filled and voided.

The research protocols questioned by Beecher were not unearthed as part of some elaborate, undercover investigation. Instead, the projects he questioned were discussed in published medical research literature, a fact that suggests the researchers thought they were operating well within the realm of standard and acceptable practice when they conducted and reported their work. This becomes even more clear in the unabashed reaction of other medical professionals to Beecher’s article. One of his own colleagues at Harvard was moved to write a scathing rebuttal in response to Beecher’s suggestion that informed consent be required before human experimentation is conducted. The colleague wrote: “Should informed consent be required? No! For the simple reason that it is not possible. ... Any teaching and research hospital must clearly identify itself as such ... to the patient upon admission. ... The fact that the patient is requesting admission to this hospital represents tacit consent” (cited in Rothman, 1991, p. 91).17

Others took a position with less of an edge but still disagreed with Beecher, using the old utilitarian calculus of “the greatest good for the greatest number.” It was well understood in the research community that true informed consent would be difficult to extract. In the case of the mentally disabled, questions were raised about whether informed consent was even possible. In the case of the men-
tally healthy, it was assumed that only those with dire illnesses would subject
themselves to experimentation and then only if the procedure offered some hope
for alleviating their specific conditions. Mainstream medical researchers claimed
that, if the CMR successes of the war years were any guide, a great deal of good
could (and had) come from human experimentation. “Even if a few lives were
sacrificed along the way, humanity would be better for it in the long run” seems to
be a fair representation of the prevailing ethos.

The Beecher article and other stories about the lack of ethical guidelines in hu­
man experimentation had a tremendous impact on attitudes in the nonmedical
community at the time, but medical researchers just did not seem to get it. They
had become experimental junkies in over two decades of experimentation, essen­
tially unencumbered by ethical considerations. But the public was no longer so
quick to grant medical researchers the benefit of the doubt. Amid the widespread
rejection of the establishment that was expressed in the tumultuous 1960s, Ameri­
cans began to call medical researchers into question. The Beecher article and
others that followed were picked up quickly by the popular press, and they had
the effect that might be anticipated—sparking the same kind and degree of out­
rage that followed the publication of The Jungle, Silent Spring, and Unsafe at Any
Speed.18

According to David Rothman (1991, p. 72), “Beecher’s article was a devastating
indictment of research ethics [that] helped inspire the movement that brought a
new set of rules and a new set of players to the medical decision making table.”
Some of that change was instituted from the top down, as a wounded NIH scram­
bled to limit the political damage from Beecher’s charges by proposing sweeping
new regulations on the documentation of informed consent and peer review of
ethical protocols. The FDA then got into the act, issuing strict new regulations re­

Perhaps more important than these top-down reforms was the sea change in
attitudes taking place in the United States from the bottom up. The political cul­
ture began running counter to the research culture in that decade of social unrest.
A loss of trust in discretionary authority in all its manifestations—religion, edu­
cation, family, and workplace—spilled over to affect the medical community, and
things have never been quite the same.19

The Funeral Business. It was no coincidence that the 1960s was also the decade
during which criticism of the funeral trade began to foment. Two books pub­
lished in 1963—The American Way of Death and The High Cost of Dying—were to
funeral directors what Beecher’s article was to medical researchers. The funeral
director, once one of the community’s more staid and respected citizens, now be­
came the subject of suspicion and skepticism as potential conflicts of interest were
laid bare alongside real-life cases of overcharging and misrepresentation. The sit­
uation deteriorated so quickly that the National Funeral Directors Association be-
gan a program of damage control, pushing its own enhanced standards of professional conduct on the membership along the way.

Meanwhile, memorial societies began to flourish as the public’s disenchantment with funeral directors grew. These new kinds of organizations offered members low-cost body-disposal services by negotiating with mortuaries and crematoriums on a volume basis, thereby effectively cutting out the funeral director altogether. Ultimately, the Federal Trade Commission (FTC) issued its Trade Regulation Rule on Funeral Industry Practices in 1984, based largely on a 1979 study conducted for the FTC. These new federal guidelines set rules regarding pricing, options, and decisions on what was legally required in the disposition of a body.

Informed consent, especially with regard to embalming (which in many states is not required by law) was also a part of what became known in the trade and elsewhere as the “Funeral Rule” (DeSpelder and Strickland, 1992, p. 207). To be sure, the wheels of government turned slowly: Twenty years had passed since *The American Way of Death* and *The High Cost of Dying* were published. But public attitudes and behaviors, as evidenced by the interest in memorial societies, had begun to change almost overnight, as did other attitudes about “business as usual” in the 1960s, those important and formative years of the consumer rights movement.

**The 1970s.** More research scandals surfaced as the 1960s melted into the 1970s. Things came to something of a head in 1974 when Senator Walter Mondale (D-Minnesota) began conducting a series of congressional hearings under the aegis of a newly formed National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research. Mondale had been trying for years to convene such a committee but did not have the support to do so until the press, on an anonymous tip from a Public Health Service (PHS) researcher, revealed the details of a decades-long study of blacks suffering from secondary syphilis in Macon County, Alabama.

PHS researchers had been traveling to rural Alabama regularly to study the progression of syphilis in the study group there, but they refused to provide any of those afflicted with penicillin, the standard treatment. During the Vietnam War, Health Service officials went so far as to instruct draft boards not to conscript these individuals, fearing they might receive treatment in the service. The PHS defended its actions (or inactions) by arguing that, with the advent of antibiotics, it would never again be possible to study the long-term, untreated effects of syphilis. But the public was outraged, and with support from Senators Hubert Humphrey, Jacob Javits, and Edward Kennedy, Mondale’s committee was finally set up, and it began to hold hearings.

The more hearings the committee held, the more scandals were uncovered. There were stories about how diethylstilbestrol (DES, used specifically to prevent miscarriages) and Depo-Provera (used to treat advanced uterine cancer and en-
dometriosis) were approved by the FDA, then prescribed as contraceptives despite evidence to suggest that both were carcinogens. There were stories about Mexican-American women who had gone to a San Antonio, Texas, clinic for contraceptives and unwittingly become part of a study to determine whether side effects of the contraceptive were physiological or psychological. Half the women were given placebos as part of a control group, and several promptly became pregnant (Rothman, 1991, p. 185).

Senators also heard the story of a University of Cincinnati General Hospital study, done in conjunction with the Department of Defense over the course of fifteen years, in which radiation was applied to patients with terminal cancer. The hospital claimed that consent had been granted, but administrators were never able to produce any documentation. Even more troubling, there seemed to be a clear demographic bias in the manner in which the hospital chose those who would be “treated”: The test group primarily consisted of indigent African-Americans with only grade-school educations. The committee also took testimony regarding a slew of stories about pharmaceutical companies that relied almost entirely on prisoners—recruited for as little as a dollar a day—for testing new drugs, without the FDA's knowledge (see Mitford, 1973).

These stories all augmented the public’s distrust of medical researchers and medical people in general that had begun building in the 1960s. Never again would the doctor be viewed in the same light as every aspect of the medical profession became the subject of suspicion by wary consumers. Medical research abuse had become a flash point for a much larger explosion of interest in the general population regarding health-care rights and wrongs. To be sure, regulatory responses with any bite to them tended to lag well behind the exposés that originally sparked active interest and outrage. But changes did come, largely as a result of the mass agitation provoked by the considerable publicity on professional ethics (or lack thereof) that the scholarly and popular presses provided.

**Summary: The Rights Culture and Changing Roles in Health-Care Decisionmaking**

The emergence of a rights culture in the United States has caused consumers to question the relationship between patients and their health-care providers. In the process, the patient-physician relationship has been transformed from a monologue into a dialogue, if not yet a partnership. Clearly, the increasingly consumerist American culture is a force of the first order in this transformation. The general public pays more attention to health issues today than ever before, and many people are taking it upon themselves to try new, alternative therapies, partly as a result.
Women in particular have become more aggressive in advancing the right to model treatment decisions and protocols to their own needs and preferences. And they are key to this whole transformation for another reason. Studies show that, overwhelmingly, women rather than men assume responsibility for the health of their offspring. Consequently, as women become more empowered in health-care issues, it is likely that more of an activist orientation will be passed down to the next generation.

The power of the press is a force of activism to be reckoned with, as well, as scandals that foster skepticism within the general population continued to be exposed. No profession, not even the medical profession, can withstand the steady assault of such negative exposure without losing credibility in the process. Power has begun to slip away from physicians, leaving patients in a stronger position to control their own medical destinies as a result. Ultimately, as individuals ask for and get more control over their own health care throughout life, it seems inevitable that they will do the same when it comes time to die. We turn now to a discussion of developments along these lines, in which a specific interest in an agreeable death is beginning to overcome the denial of death that otherwise prevails.