Policy Activism and Medical Technology: Emergence of the Right-to-Die Scenario

In surveying the right-to-die landscape, we see two variations of activism at work, pushing and prodding right-to-die questions onto the public-policy agenda in spite of the forces of restraint. The first sort of activism trickles down from the top, from the medical profession to the patient population. The manner in which hospitals and physicians treat their patients has proved to be an important source of right-to-die activism that we will discuss here and in Chapter 4.

Chapters 5 and 6 present our discussion of the activism that flows in the opposite direction, percolating from the bottom up. We take a grass-roots approach in our search for causes of right-to-die activism that arise almost independently of professional developments in the mainstream medical community. In Chapter 5, we assay the forces of social activism that are closely linked with other social movements, namely, consumerism and the “rights culture” more generally. Chapter 6 wraps up the discussion of activism with a survey of the forces that combine to form what one author has called “the happy-death movement.”

Technology plays a Janus-like role in our policy scenario. As discussed in Chapter 2, the increased availability of advanced medical technology feeds into the scientism that is central to American culture. As a result, Americans would rather deny death than contemplate decisions about the right to die. At the same time, however, technology creates scenarios that raise right-to-die questions. Advances in both diagnostic and rescue-medicine technology have helped to create a whole population of individuals who would have died quickly only a few decades ago. Today, the beneficiaries of advanced technology live on—sometimes in seriously degraded states—and that, we contend, tends to force death onto the public-policy agenda.
Policy Activism and Medical Technology

We also consider the role surging health-care costs play in stimulating interest in the right to die. As technology advances, as the size of the elderly population grows, and as costs skyrocket out of control, policymakers inevitably are increasingly forced to deal with questions of life and death. Whatever the answers, the very fact that questions are being asked suggests that the forces of restraint are being loosened up, making activism not only possible but likely to emerge.

Interventions Create “Would-Have-Dieds”

Interventions of both the diagnostic and rescue-medicine variety have created an entirely new group of individuals: the “would-have-dieds,” people who would have died in earlier days. In the past, they would have contracted illnesses without much warning and slipped over the edge of eternity with some dispatch. But today, with the assistance of medical technology, Americans seem able to cheat death, at least in the short term.

Two great revolutions have taken place in American medical technology in the last thirty years (Wildavsky, 1977, pp. 105–124), both of which create their own special population of would-have-dieds. First, there has been a quantum leap in the sophistication and accuracy of diagnostic technology that makes it possible for medical professionals to anticipate, with considerable accuracy, the development of medically threatening conditions. These conditions, if detected early enough, can lead practitioner and patient to remedial strategies well before life is threatened. Beneficiaries of this technology will die another day, and their deaths are more likely to be the result of old age, chronic illness, degenerating health, and, quite possibly, a seriously degraded quality of life in which the lines between life and death are blurred.

The second great revolution has come in rescue medicine. When diagnostic procedures fail, for lack of accuracy or lack of use, to anticipate the onset of a life-threatening medical condition or when serious accidents strike, advances in medical technology make it possible to “rescue” individuals, pulling them back from the brink of death. For example, primary organ failure is no longer the death warrant that it was just a few decades ago. Indeed, many people now rebound from heart, lung, or kidney failure to live on for years and even decades; minutes and hours of life were the most one could hope for when organs failed just a few decades ago. For some of these people, right-to-die questions will be raised only later in life. But other “rescue-medicine would-have-dieds” pose questions involving the right to die immediately. This happens when the biological life has been saved but the resulting quality of life is seriously degraded, that is, when the rescue is incomplete.
Advances in Diagnostics

Tremendous advances in diagnostic testing technologies have been made in this century. The discovery of X rays provided the first real breakthrough over half a century ago. But electronic monitoring of the brain with electroencephalographs (EEGs) and of the heart with electrocardiograms (ECGs), two other diagnostic tools that have proved invaluable to the modern physician, has become commonplace more recently. Indeed, much of the diagnostic technology used today was developed, refined, and marketed publicly only in the last thirty years or so. With the help of these technologies, diagnoses are now made earlier and more accurately, offering a much better chance of successful medical intervention.

Computerized axial tomography (popularly known as a CAT scan or CT scan) is typical of the new wave of computer-assisted imagery that has opened up the inside of the human body for more clinically detailed inspection. Ultrasound, in which high-frequency sound waves are bounced off the body to form echo patterns, is another imaging technology that has been widely used in recent decades. Magnetic resonance imaging (MRI) is among the newest imaging technologies: Although most American hospitals of any size have an MRI machine today, there were only seventy-eight units worldwide as recently as 1984.

Advances in computerization have also led to many advances in scope technology and instrument miniaturization. Today, endoscopies (miniaturized television cameras inserted through the mouth to view the stomach and duodenum area) and colonoscopies (similar equipment inserted through the colon to view the large intestine all the way up to the lower chest area) are done in the doctor’s office or on an outpatient basis without much fanfare. And with only a little extra effort, doctors can perform angioplasty, one of the most common heart procedures done in America today. Miniaturization has also brought a whole new classification of operations, known as microsurgery. Athletes with faulty joints were the first beneficiaries, but now such procedures are commonly used in the general population for everything from knee surgery to gall bladder removal.

The diagnostic laboratory is another site where great strides have been made. Advances have been especially pronounced in the areas of hematology (blood studies), general body chemistry, and clinical microbiology. Before the turn of the century, clinical laboratory analysis was unheard of. Today, American physicians order ten billion lab tests annually—about fifty per person per year (Bronzino, Smith, and Wade, 1990, p. 284). Not only do computers make the basic analyses possible, they are now also used to sort, verify, store, and retrieve information. Consequently, more kinds of tests can be run (looking for trace elements, amino acids, cholesterol levels, and the presence of other complex molecules, for example), and the results are more accurate and the analyses more accessible to the clinical diagnostician.
Physicians have the ability to learn more about the individual human condition than ever before, thanks to the diagnostic medicine that has made breast X rays, Pap smears, blood-pressure monitoring, and cholesterol screening an accepted part of everyday life for millions of Americans. Physicians know more about their patient’s condition, and they know it earlier. They can also monitor the patient’s reaction to different clinical interventions on an almost real-time basis as a result of the strides in monitoring technologies.

Clearly, these advances in medical technology have improved the health of the general population. But at the same time, as formerly fatal diseases are detected and treated early on, medicine will increasingly be faced with an older population whose disabilities are more chronic, more degenerative, and more difficult to defeat. And the would-have-dieds can be expected to take center stage in the right-to-die debate as they age, as their conditions deteriorate, and as hope of a meaningful, productive existence fades in the twilight of their lives. Advanced diagnostics enable individuals to live longer lives, but these same technologies are also responsible for sentencing many to a more lingering death later in life when right-to-die questions are more likely to be raised.

**Advances in Rescue Medicine**

Perhaps even greater strides have been made in the field of rescue medicine in recent years.

Two hundred years ago, the ministrations of medical professionals were as likely to hasten death as to forestall it. Lewis Thomas (1987, cited in Bronzino, Smith, and Wade, 1990, p. 521) paints this rather gruesome picture:

> By the end of the eighteenth century, getting ill and coming under the care of an energetic physician had become an athletic challenge. The dominant idea then was ... that disease in general was caused by an imbalance in the distribution of fluids within the body. Bleeding, cupping, the application of blistering ointments to the skin over the affected organs, accompanied by violent purging with mercurial or plant cathartics, were the standard features of therapy for any serious illness. The bleeding often involved the removal of a quart or more of blood at one sitting, and the appearance of bluish pallor, a feeble pulse, and profound weakness were taken as signs that the treatment might be having the desired effect.6

The account of George Washington’s death provides a graphic case in point. Washington, “by all accounts a hale and hearty man in his mid-sixties,” developed a sore throat after a tiring horseback ride in the snow on December 12, 1799. A blistering poultice was applied to his neck, and he was repeatedly asked to gargle with a mixture of vinegar, molasses, and butter. Meanwhile, caretakers drew off about five pints of blood, probably half his total blood volume. He died two days later. Among his last words were, “I thank you for your attentions, but I pray you
to take no more trouble about me. Let me go off quietly." Indications suggest that what Washington really had was a case of strep throat: It was the shock caused by blood loss that most likely killed him (Bronzino, Smith, and Wade, 1990, p. 521).

The primitive state of premodern medicine precipitated brief encounters with death during which few questions about the appropriate response (save for acceptance) had a chance to germinate. Medical technology based on crude and often misguided principles, the home-based health-care model that emphasized palliation more than cure, and the late detection of fatal conditions (most people with chronic, degenerative conditions were dying quite a while before anyone knew it) all led to a relatively short period of infirmity before death took its toll. The simple understanding of death as the lack of a heartbeat, and the high incidence of acute disease and serious injury are other factors that led to a relatively brief deathbed scene (if one even made it to the bed). This all caused most people to adopt a fatalistic acceptance of death (Lofland, 1978, p. 18). After all, what other options were there?

Today, the progress of intervention technology has fueled a curative, activist orientation among health-care professionals who place a high value on prolonging life. As a result, individuals are rescued from a brief encounter with death only to suffer a lingering exit later in life.

Kidney Technology. Some of the earliest and most dramatic advances in rescue medicine have been made in the area of organ failure. Three decades ago, people died if their major organs failed. But now, with some luck and a third party willing to pay, organ failure can be transformed from a death warrant into an entirely manageable condition.

The first of the modern organ augmentation technologies came with the development of the kidney machine at the end of World War II. The very earliest dialysis machines were cumbersome, experimental contraptions that really did not do much to extend the life of those with end-stage renal disease (ESRD). The real turning point for ESRD came with advances made by a team of Seattle doctors led by Dr. Belding Scribner in the early 1960s. Scribner and his colleagues developed a kidney shunt that could be implanted in the body permanently, making it possible for ESRD patients to literally “plug in” to dialysis machines. Dialysis had been available for short-term kidney failure since the early 1950s, but with improved machinery and implanted shunts, it became a long-term therapy with widespread application.

Then came the development of cyclosporine and other immunosuppressive drugs, also in the 1960s, making kidney transplants a realistic long-term alternative to dialysis. By the end of that decade, kidney transplants had become commonplace, and by 1985, physicians were transplanting upwards of 8,000 kidneys a year. Of course, that means that kidney transplantation is responsible for adding 8,000 names to the would-have-died list annually. And many of these res-
cue-medicine would-have-dieds—just like diagnostic would-have-dieds—must
live through a slower, more degenerating death some years down the road, when
ethical questions about the right to die inevitably are raised.

Advances in ESRD treatments raised real-time ethical problems, as well. For
example, dialysis was expensive when first developed, and only a few machines
were available to serve the many patients who could benefit from treatment. Who
would decide who should have access to this lifesaving technology? And what cri-
teria would be used? These were the kinds of questions that physicians and re-
searchers had traditionally decided among themselves, within the professional
fraternity. But the Seattle physicians who pioneered dialysis procedures in the
early 1960s seemed uniquely aware of the sensitive nature of the resource-alloca-
tion decisions that would have to be made. This sensitivity is evidenced by their
decision to distribute responsibility beyond the medical profession by empower-
ing a new kind of medical decision-making structure: the ethics committee.

This committee, composed of community members, would be asked to decide
what individual characteristics to consider when selecting candidates for treat-
ment. Even after the physicians excluded out-of-state residents (a questionable
criterion in itself), children, and patients over the age of forty-five, there were
four potential candidates for every dialysis machine available. What should be
done? Was it appropriate to screen individuals on the basis of parenthood, profes-
sion, or some amorphous “worth to society” classification? Or should medical
suitability be the sole criterion for deciding who would get dialysis? Should the
ability to pay be a factor?

In effect, by creating an ethics committee to decide such life-and-death ques-
tions, the Seattle physicians were throwing up their hands and acknowledging
openly (maybe for the first time) that medical professionals no longer had or
wanted to have a corner on the decision-making market. Once that gate was
opened, however—once doctors forfeited their hegemony over medical decision-
making and conceded their fallibility (or at least their insecurity) about making
life-and-death decisions—there would be no turning back. Beginning with
Scribner’s ethics committee, the general public became increasingly comfortable
with the notion that people outside the medical fraternity were capable of provid-
ing some input regarding life-and-death situations. Medical decisionmaking
would never again be quite the same.

Kidney transplantation raised its own set of ethical dilemmas in which not one,
but two lives would be seen as hanging in the balance: the life of the donor and
the life of the recipient. Interest in dying donors would fuel public-policy con-
cerns in developing brain-death criteria; when is it safe, for example, to harvest
the organs from a dying donor if time is of the essence? Interest in healthy donors
would raise ethical issues, as well. Would they be coerced by family members to
give up one of their kidneys to save the life of another family member? Would
some individuals be induced by financial exigency to sell a kidney on the black
market in order to raise some quick cash? What about parents who purposely
conceive a child in order to harvest organs or other tissue to save the life of another offspring? These kinds of issues simply touched too many raw nerves to be decided within the medical profession. Members of the general public—ethics committee members, the media, judges, legislators, and interest-group activists, to name a few—would find themselves sucked into the vortex of difficult resource-management questions raised by kidney technology.

Hearts and Lungs. Although not as many ethical issues arise when it comes to hearts and lungs, progress in the technology used to augment the functioning of both organs has added considerably to the would-have-died population. As such, we cannot overlook the potential of advances in this area to stimulate right-to-die activism.

Pacemakers, developed in the 1960s, have certainly done their part in this regard. A half million Americans are walking around today with surgically implanted pacemakers, and implantation operations are being done at a rate of 200,000 a year, making this the most common cardiovascular therapy in America. Half of those with implants are living eight years or more, and all who live have been spared a brief encounter with death.

Portable defibrillation equipment has also added substantially to the would-have-died rolls. Also a product of the 1960s, electronic defibrillators are now available in most ambulances and are largely responsible for the dramatic increase in heart attack survival rates in recent years. Only about one in ten individuals rescued with electronic defibrillation ever leave the hospital alive, but all who are rescued in this way are saved for another, later death.

Respiration technology, featuring artificial organs that pull those with lung failure back from the brink of death, has also played a role here. Iron lungs were first developed in the 1950s as an aid to polio victims. These large and cumbersome “tanks” are not nearly as common today as the more practical, positive-pressure ventilators that were developed in that watershed decade for medical advances, the 1960s. With these machines, a flexible plastic hose is “intubated” through the patient’s nose or mouth or placed permanently through the trachea to provide the breath of life to those with malfunctioning lungs.

All these advanced medical procedures and technologies—dialysis, organ transplants, defibrillation, and artificial respiration, to name just a few—have two things in common. First, they were all developed in the last thirty years, and second, they all create a population of would-have-died individuals and ultimately prompt consideration of right-to-die issues.

Interventions Create “May-Have-Dieds”

Sometimes, rescue medicine falls short of its goal: to return the patient to a reasonable quality of life. Sometimes, all it does is preserve life in a technical, biologi-
cal sense, with both the current quality of life and the chances for an improve­ment in quality of life diminished to the vanishing point. Sometimes, all the rescue medicine in the world can only maintain an individual in what is clinically referred to as a "persistent vegetative state" (PVS). The PVS condition has been a factor in fully 40 percent of all right-to-die cases aired in state and federal courts to date (see Chapter 7), providing empirical evidence that right-to-die activism has been precipitated by recent advances in medical technology. Progress in neonatology that helps severely ill children survive, at least in the short run, has also been the subject of widespread ethical and legal debate.

**The Persistent Vegetative State**

The persistent vegetative state is characterized by massive and irreversible brain damage that leaves the individual unable to sense or respond to his or her surroundings. The cerebral cortex, sometimes referred to as the "gray matter" and considered the seat of all emotions, sensations, and understanding that distinguish human from subhuman life, no longer functions in patients diagnosed as being in a PVS. Such individuals may experience sleep cycles, and while "awake," they may blink their eyes and contort different parts of their bodies, but they are unable to sense joy or pain. Indeed, PVS patients cannot process or respond to any of the stimuli the surrounding world provides. Unable to swallow, such individuals are usually fed and hydrated through a tube surgically implanted in the stomach wall. This sort of artificial nutrition and hydration (ANH) has itself become commonly available only in the last twenty years or so.

It has been estimated that approximately 14,000 individuals are maintained in a PVS in the United States at present, and most could be maintained in that condition indefinitely.\(^\text{10}\) Most typically, PVS results from either head injury or hypoxia (a condition caused by a prolonged lack of oxygen to the brain), although some instances of PVS also have been induced by hypoglycemia (insulin overdose). Clinicians contend that patients who exhibit no response to their environment for a month or more are extremely unlikely to ever regain consciousness.\(^\text{11}\)

Certainly, opinions will vary, but many argue that the slim hope of returning to a severely degraded existence, when combined with the acute financial and emotional burdens imposed on the patient's family (individuals whose well-being was presumably important to the now-unconscious patient), makes PVS one of the most disturbing and compelling right-to-die scenarios created by advanced medical technology.

Right-to-die questions are even raised when the patient is not technically in a PVS. In particular, we are thinking of those who, near the end of life, lie tubed and restrained in a strange place, surrounded by foreign equipment and unfamiliar faces. According to Henry Glick (1992, p. 209), as many as a million Americans are now being artificially sustained by medical machinery in various states of uncon-
sciousness. Bronzino, Smith, and Wade (1990, p. 544) bring the issue into focus when they point out that:

Clearly there are circumstances where this kind of vigorous struggle is appropriate and in keeping with medicine's longstanding humanitarian commitments. But when it becomes the predominant response to death, as many believe it has, genuine problems are posed. The most worrisome is the danger—which already may be a reality—that a whole class of patients, particularly elderly patients whose lives are at a natural and inescapable end, will be kept alive by mechanical means long beyond what can be of any benefit to them. ... Technology is particularly well suited to keeping the body going when life is threatened. But it is not particularly well suited to the needs of persons who are not benefitted by having their bodies kept alive.

In times of illness, when one is likely to be insecure and vulnerable, the patient may end up feeling assaulted by the same technology that, in health, had been revered. Conscious patients may complain about the humiliation associated with being treated as inanimate objects that are poked, prodded, stuck, eviscerated, implanted, and evacuated according to schedules set by someone else. Unconscious patients simply stare while members of the family feel the humiliation. As medical ethicist Joseph Fletcher puts it, "The classical deathbed scene, with its loving partings and solemn words, is practically a thing of the past. In its stead is a sedated, comatose, betubed object, manipulated and subconscious, if not subhuman" (cited in Cohn, 1989). And as medical technology creates a natural constituency of may-have-dieds and their families, the right to die is added to the public agenda.

**Neonates**

Rescue medicine also has made great progress in the world of neonatal health care. Indeed, caring for premature, low-birth-weight babies is one area in which some of the greatest strides have been made. In 1961, newborns in the two- to three-pound range had only a 50 percent survival rate. Today, 80 percent survive, and those who do have fewer medical complications. The very low-weight babies—those under two pounds—had only a 10 percent chance of survival thirty years ago; today, half of them live.

**When to Continue Treatment, When to Withdraw?** Neonatalists may have been less interested than those in the organ transplant world in having their own resource-management decisions opened up to public scrutiny, at least at first. As David Rothman (1991, p. 160) notes,

Issues of life and death remained relatively obscure in the 1960s, largely because doctors, inside the closed world of the intensive care units, turned off the machines when they believed the patient's death was imminent and irreversible. "Very few hospitals," reported a committee of neurologists in 1969, "had any regulations on the matter of
discontinuing the medical aids to respiration and circulation. No one has encountered any medicolegal difficulties. Very few have sought legal opinions.” The intensive care units were a private domain, whatever the formal definition of death, and doctors exercised their discretion.

All this changed in 1969, however, with the exposure of the Johns Hopkins University Hospital case in which a baby was allowed to starve to death. The case involved a newborn infant who was transferred to Johns Hopkins for surgery to correct an intestinal blockage. The parents, upon being informed that their child suffered from mental retardation, refused to give permission for the surgery. Consequently, “the infant was moved to a corner of the nursery, and over a period of fifteen days, starved to death” (Rothman, 1991, p. 191). According to Johns Hopkins physicians, this was common practice for children with spina bifida, a congenital condition in which a gap in the spinal column causes paralysis, incontinence, and, frequently, mental retardation. Babies with this condition simply were not treated aggressively. Often, they never even left the delivery room; their charts would read “stillbirth.”

A few physicians were deeply troubled by the Hopkins incident, however, and re-created the scenario in a film that was ultimately shown on national television, accompanied by inflammatory newspaper headlines like “Drs Watch as Sick Baby Starves.” The story (as retold by the media) laid bare the inner sanctum of physician decisionmaking for all to see and judge, and many Americans did both. As a result of the widespread publicity, symposia and conferences were held all over the country to debate the issues surrounding the case. Significantly, these conferences were not dominated by physicians as they might have been ten years before. Instead, philosophers and ethicists, theologians, lawyers, patient advocates, public-policy analysts, and private individuals could all be found elbowing their way to the table.

A few years later, a situation that was the flip side of the Hopkins case was brought to the public’s attention by the parents of a one-pound, twelve-ounce infant boy, delivered after only twenty-four and a half weeks of gestation. Robert and Peggy Stinson coauthored *The Long Dying of Baby Andrew* in 1976 to express their outrage at having no control over the fate of their severely ill offspring after he was admitted to the neonatal intensive care unit (ICU) at a teaching hospital in Philadelphia. They requested that heroics be stopped but were tagged as uncooperative parents by the teams of interns who rotated through the ICU every month or so. And so it went: Baby Andrew lived, with the help of the best technology, for six months, but his story, as told by his parents and reported in the media, had a much longer life and a much more telling impact.

Not all agreed with the Stinsons’ decision or even with their account of what took place. But few could argue with one conclusion drawn from their story: “It’s not the technology per se that inspires fear—it’s the mentality of the people employing it. Fallible people lose sight of their fallibility in the scramble to push back
the frontiers of knowledge, to redesign nature and to outwit death” (cited in Rothman, 1991, p. 215). The blurb on the jacket of the Stinsons’ book, by Hastings Center cofounder and director Daniel Callahan, described the incident more succinctly as “technological enthusiasm” prevailing over “human care.” Agree or not, it was clear that such cases would continue to be aired in public and that the right to die would slowly come to the forefront as a result.

**A Special Case: Anencephaly.** Some children born with organs that are malformed, partially formed, or, in some cases, entirely missing can still have a fighting chance for life, thanks to the transplant and life-support technology available in modern neonatal intensive care units in the United States. But not much can be done for anencephalic children—those born with underdeveloped brains. There are about 4,000 such births a year, about 1 for every 850 healthy births. For infants born with anencephaly, some portion of the brain stem may exist, but the largest part of the brain, the cortex, is either severely underdeveloped or absent altogether. The expected life span of anencephalic children is extremely short: The vast majority are stillborn, and of those who are born alive, fully 95 percent die within a week (Krauthammer, 1992). Only a very few of these babies survive for more than a few months.

Nearly all severely anencephalic babies are maintained in something akin to a persistent vegetative state. Like their adult counterparts, these infants have no ability to sense their environment. The maintenance technology is well developed, and that allows anencephalic children to live on even when a caring family is not sure that the life being maintained is worth living. And so, the right-to-die question pops up once again.

Another right-to-die issue mixes the rights of anencephalic children with the needs of potential organ recipients, both situations produced by modern medical miracles. The case of Theresa Ann Campo Pearson is illustrative.

A month before the Campo baby was due to be born, routine prenatal tests revealed that she suffered from anencephaly. With this knowledge, the parents, Laura Campo and Justin Pearson of Ft. Lauderdale, Florida, decided to proceed with the pregnancy, already in its eighth month. Knowing their baby had no chance to live, they had decided to attempt to donate their baby’s organs to those needing transplants. On March 21, 1992, at the Broward General Medical Center, Theresa Ann was born. As expected, her brain was severely underdeveloped; it included a partially formed stem, which controlled her breathing and her heartbeat, but nothing else. There was no cortex, and an incomplete skull left a gap where several bones should have been. Although her body and organs were fully formed and healthy, Theresa Ann was incapable of experiencing consciousness, pain, emotion, or thought without the cortex of her brain. In effect, her condition was the congenital counterpart of a persistent vegetative state. Also, like any other anencephalic infant, Theresa Ann’s life span was expected to be only several weeks at the most.
The baby’s parents were confident in their decision to donate her organs to others in need of pediatric transplants, but legal restrictions challenged their ability to carry out that decision. Before Theresa Ann could be considered eligible to donate her organs in her home state of Florida, she first needed to be declared legally brain dead. As in most states, the legal definition of death in Florida requires the “irreversible cessation of all functions of the entire brain, including the brain stem” (“Baby Born Without Brain Dies,” 1992). Because Theresa Ann technically did have some brain activity in her partially formed brain stem (controlling reflexive movements), she was considered ineligible as a donor. The parents knew Theresa Ann was terminally ill with no chance for a meaningful life and were hoping that their child could leave her “mark on society in this world and hopefully allow another child to live” (“Organ Donations Barred by Judge,” 1992). To keep that hope alive, they decided to take their case to court.

Theresa Ann’s parents went to court alone, however. Fearing potential ethical and moral controversy, medical and legal professionals involved in organ-donor and transplant organizations declined to join the family’s legal effort. Although commending the parents’ intent, doctors were afraid they might be accused of being too quick with the knife, an accusation that would only reinforce the already widespread misperception that the procurement of organs was sometimes performed before a person was really dead. Joining Campo and Pearson in an effort to change brain-death policy would only serve to further undermine the public’s trust in the nation’s organ-donor program, they thought, and that program was already facing difficulties in securing donations (Chartrand, 1992).

Meanwhile, as the Campo-Pearson legal challenge involving Theresa Ann played out in the Florida courts, Theresa Ann’s condition was allowed to decline, along with the viability of her organs from a transplant standpoint. Finally, a circuit court judge decided to refuse to waive the brain-death definition. A few days later, the Florida State Supreme Court rejected the family’s appeal for an emergency hearing, claiming it did not have the constitutional authority to hear the case. Theresa Ann was subsequently removed from a ventilator, which she had been placed on to sustain her when her vital organs began to fail. Later that afternoon, at 3:45 P.M. on March 31, 1992, Theresa Ann Campo Pearson died of respiratory failure. She was nine days old. As feared, her organs had deteriorated beyond the point of usefulness: In spite of all of her parents’ efforts, not one organ could be donated to any of the more than 30,000 patients on the national organ donation list (Kolata, 1992a; “Waiting List Soars,” 1993).

Settling the May-Have-Died Question

The Campo case and the situation of the 14,000 PVS patients in the United States raise an important question: What does it mean to be “alive” when medical technology can take the place of vital organs despite an irreversibly nonfunctioning
brain? Those in a PVS and severely brain-impaired neonates do not live life as we know it. Instead, they exist in only the most marginal of human conditions, unable to sense the world around them and without realistic hope for improvement. But can they be considered dead from a medical, legal, or ethical perspective? The ethicists are still debating the issue, and, for the most part, the answer from legal and medical circles is a conservative one: They are alive as long as any brain activity exists at any level.

It was long believed that the heart was both the seat of the soul and the key to life (Kastenbaum and Kastenbaum, 1989, pp. 32–36). This is clearly reflected in the fact that the heart is the human organ most written and sung about as the source of our humanity. Conversational language and popular sayings also reflect this long-standing conception (“she has a heart of gold,” “his heart is in the right place”). But this did not resolve the issue of when death occurred for premoderns for the prospect of burying the dead alive, even though the heart has stopped beating, has haunted humans for centuries. Indeed, the traditional deathwatch, where friends and family watch over the apparently dead body for some extended period of time, has its genesis in this fear.

As mentioned in Chapter 2, the predeath watch was designed to comfort the dying patient, while at the same time giving family and friends an opportunity to make peace with the soon-to-be-deceased person (lest a restless ghost come back to haunt them). But the postmortem watch was intended to give the apparently dead individual one last chance to show some sign of revival. As if this were not security enough, it was not uncommon for nineteenth-century coffins to be equipped with elaborate rope-and-bell mechanisms, contraptions that would allow a seemingly dead individual to signal those above ground that he or she had been prematurely interred. Lack of heartbeat and breath were taken as the obvious signs of death then, just as they are today, but enough cases of spontaneous resuscitation had been rumored and recorded to give premoderns some pause.

Still, it was only recently that attention officially shifted to the brain as the organ that could ultimately signal death. This shift took place for at least two reasons: the advent of the EEG, which made monitoring of the brain’s functioning possible, and the advent of organ transplants, which made monitoring of brain activity necessary. Thus, brain death was something that could be and needed to be established. To be sure, the vast majority of deaths are still certified by checking for pulse and respiration. But in the case of may-have-dieds, especially if the individual is slated to donate organs, cessation of brain activity has become the more widely accepted standard.

The concept of brain death stems from a 1959 article by two French neurophysiologists, Mallaret and Goulon. These physicians studied patients on artificial life supports who showed no electrical brain activity and were therefore considered to be “beyond coma” (Kastenbaum and Kastenbaum, 1989, p. 34). Studies involving the brain-death concept continued throughout the 1960s, but no definitive stan-
standards emerged until a committee of Harvard Medical School faculty members convened in 1968—nine years after the French published their study—to codify clear, brain-oriented criteria of death.

The Harvard criteria included a four-part test for clinical death. The first three parts had to do with the more standard definitions of death (i.e., the individual should be unresponsive to stimuli, unable to move or breathe independently, and lack observable reflexes), and the last criterion dealt with the new brain-death concept itself. According to the Harvard criteria, to be declared dead an individual should display an absence of brain activity, signified by two flat EEGs (showing an absence of “peaks and valleys” that indicate electrophysiological activity) taken twenty-four hours apart.

This four-part test was slowly absorbed as a standard protocol of medical practice during the 1970s. And in 1981, a slightly modified variation of Harvard’s test was adopted as the Uniform Determination of Death Act (UDDA) by the President’s Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research (1981). In its report, the commission recommended adoption of the UDDA as a public-policy standard of practice for the United States. Subsequently, the National Conference of Commissioners on Uniform State Laws, working in collaboration with the American Bar Association (ABA) and the American Medical Association (AMA), passed a very similar code. Most states took this policy lead and adopted some form of the uniform code as the legal standard for their own laws.

This did not settle the matter, however, for a good deal of controversy remains with regard to what specific brain area should be monitored for electrical activity. Like premoderns who held deathwatches and built coffins rigged with alarm bells, many postmoderns—the Harvard group, the uniform commissioners, the AMA, and the ABA—continue to advance a conservative, “comprehensive brain-death” criterion, just to be sure. This standard requires that electrical activity be absent from each region of the brain, including the cerebral cortex (the thinking center), the cerebellum (a small lobe at the base of the brain that controls balance and the coordination of voluntary movement), and the brain stem (which connects the base of the brain to the spinal cord and is responsible for regulating respiration, heart action, swallowing, and other such reflex functions). Activity in any one of these areas would be evidence of life, according to the comprehensive brain-death standard.

Others argue, however, that individuals with an inoperative cortex are unable to think or sense their surroundings as part of a conscious experience and have therefore lost their characteristic humanity. According to this more liberal interpretation, an individual with a dead cortex can be considered physiologically dead even though some reflex activity remains. The conservatives have prevailed to this point almost without exception, and the comprehensive brain-death approach informs the legal codes of most states. It was the standard applied in the case of
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baby Campo, and it is the interpretation most commonly accepted in hospitals across the country, as well. In the larger scheme of things, however, the very fact that the issue is debated at all is important evidence that right-to-die activism is afoot, despite all the cultural forces of restraint that operate in American society today. Advances in medical technology have created a population of may-have-dieds, and that has made death an important subject of public-policy concern.

Who Will Pay?

With who-gets-what-treatment questions flying in every direction by the 1970s, it was only natural that the question of who would pay should emerge. End-stage renal disease provided the first large-scale opportunity to ask that question. The perfecting of permanently implanted shunts early in the 1960s made dialysis practical as a long-term way of life for thousands. Later in the decade, the development of immunosuppressant drugs made transplants a viable option, as well. But dialysis and transplant technology were (and still are) extraordinarily expensive. And that led to a further question: Would Americans stand idly by while thousands died from a treatable condition for lack of money?

The Case of ESRD

Not surprisingly, given their characteristically weak-kneed reaction to dilemmas that deal with death at any level, Americans, speaking through the policy process, answered this question in the negative. Rather than decide which individuals to subsidize and which to let go, Americans tried to sidestep this discussion entirely by making ESRD technology universally available. And so, both dialysis and transplantation became the first “extreme” medical technologies that government subsidized as an entitlement.

Approximately 70,000 Americans receive either kidney dialysis or kidney transplants in any given year, and much of this care is funded by Medicare (the tab runs about $2 billion per year). Although Medicare is designed primarily as a public health-care plan for the elderly, the age rules were suspended for those with kidney disease: Anyone with ESRD potentially qualifies for coverage. Although kidney patients constitute only about one-quarter of 1 percent of all Medicare beneficiaries, they consume 10 percent of inpatient expenditures and 13 percent of outpatient expenditures annually (Evans, cited in Blank, 1988, p. 6).

From the very start, Congress seemed bent on avoiding life-and-death questions altogether by spending whatever was necessary to cover everyone—death denial and policy restraint at its finest. It is more important for our present purposes, however, to note that questions about the medical management of death have at least been raised and discussed at the federal level of government. This
suggests that a new threshold has been crossed: Medical management of life and death is an item falling squarely on the public-policy agenda.

The ESRD experience also set the stage for government to start asking tough questions about the distribution of its health-care resources. Few could argue the absolute benefits of providing dialysis and transplants to those who would otherwise die. But in a world of increasingly scarce resources, the ESRD experience made it clear that the federal government could not provide everything that was technologically feasible to everyone who could potentially benefit. Life-and-death decisions would have to be made consciously at some point, and death would have to be managed, like it or not, because the Medicare budget simply would not accommodate many more stretches like the one it made in covering ESRD.

The Elderly

Like ESRD patients, the elderly also consume a disproportionate amount of public health-care resources. On average, public-sector spending on health care for those in the twilight of life far outstrips public-sector support for those below the age of sixty-five.\(^{15}\) On the one hand, increased levels of spending on the elderly are to be expected because older people have a higher morbidity rate. On the other hand, however, the government underwrites only 27 percent of health-care costs for those under sixty-five but covers fully 64 percent of costs for those over sixty-five (Hahn and Lefkowitz, 1992, p. 13). It is this differential in percentages of support—not necessarily the differential in absolute spending—that has led some to take a closer look at the kinds of services all these outlays are buying.

High-tech Care. Much of the spending for elderly health care is devoted to routine procedures under Medicare and reimbursement for long-term care under Medicaid. But a significant percentage of this spending goes for procedures that do little more than forestall an inevitable death. According to the Health Care Financing Administration (HCFA), 28 percent of the Medicare budget (about $30 billion annually) is spent on individuals in their last year of life, primarily in the final thirty days (N. Clark, 1992). Admittedly, even from a probability standpoint, it is not easy to determine who is in the last thirty days of life. And certainly, a share of the outlays in the last thirty days are devoted to providing comfort care. Still, a significant portion of that spending (conservative estimates put the number at around $5 billion) is devoted to providing those at the end of life with the latest in state-of-the-art medical care.\(^{16}\)

Other studies conducted by HCFA reveal that Medicare reimbursements are consistently six times higher for those who die in a hospital than for those who survive hospitalization, a fact attributed by some to the high-tech services provided dying patients in their last weeks and days of life. Ultimately, it seems that health-care spending in the United States is skewed to a degree toward the seri-
ously ill elderly—individuals who will die regardless of interventions. In the eyes of some, this is a luxury that the health-care finance system is less and less able to afford. As a result, fairly or not, life-and-death issues are being raised in the context of debates about how much health care the elderly are entitled to receive.17

One critic of the status quo, Richard D. Lamm (a former governor of Colorado), put the point sharply in 1984 when he stated in a public address that elderly, terminally ill persons have a “duty to die and get out of the way. Let the other society, our kids, build a reasonable life” (Worsnop, 1992, p. 149). Others have been more cautious in advancing the same conclusion. In 1977, a year after California took the plunge as the first state to pass a living-will law, Robert A. Derzon, chief administrator of HCFA at the time, opined that “cost-savings from a nationwide push toward living wills is likely to be enormous” (Worsnop, 1992, p. 148).

Thomas H. Murray, director of the Center for Biomedical Ethics at Case Western Reserve University in Cleveland, agrees that right-to-die developments could potentially help control health-care spending, although he also worries about the abuses that such developments could invite (Worsnop, 1992, p. 150). The bottom line, regardless of which direction the debate goes from here, is that the United States spends enormous amounts on those at the end of life, while other health-care needs go begging. That has led some to explore the right-to-die argument for relief, thereby creating a measure of right-to-die activism within some circles.

**Nursing-Home Care.** Clearly, whether one agrees with Lamm’s hard-line, “duty to die” assessment or not, the elderly are putting a strain on the health-care system today. Only about 5 percent of the nation’s 28 million elderly are in nursing homes at any one time (Eckholm, 1990), but total public outlays for nursing-home care have more than doubled from $11 billion in 1980 to $25 billion in 1990. These outlays are projected to double again in the 1990s, reaching $53 billion ($193 per capita annually) by the year 2000 (Callahan, 1990, p. 273). This is a strain that, rightly or wrongly, will inevitably prompt questions about the right to die among nursing-home residents, members of their families, and the tax-paying public more generally.

Projected demographic shifts and health-care trends only promise to magnify the strain on the health-care system in the years to come. In 1970, 10 percent of Americans were over sixty-five; now that number is up to 12.5 percent and climbing steadily. By 2010, the percentage of Americans over the age of sixty-five could reach 20 percent as baby boomers swell the ranks of the nation’s elderly population. A small minority of this entire age group will require nursing-home care, but 23 percent of those over the age of eighty-five—the fastest-growing of all age groups in the United States today18—will find themselves residing in such institutions.

**Dementia.** More important than the raw increase in numbers, however, may be the degree of infirmity experienced by this elderly population. Not only are the
superannuated more likely to require nursing-home care, they are also much more likely to suffer from advanced stages of dementia. Only about 10 percent of elderly Americans suffer some form of mental disability, but Peter J. Cross and Barry J. Gurland (cited in Blank, 1988, p. 127) estimate that between 20 percent and 30 percent of those eighty-five and older will suffer some form of such afflictions (the National Institute on Aging and the Alzheimer’s Association peg the level at 50 percent). If current trends hold true, another half million individuals with terminal dementia will be added to the list of 1.5 million patients in that condition already in the United States (Blank, 1988, pp. 125–126).

Dementia (a chronic illness category in which Alzheimer’s disease is the most common variety) is a serious disease that now ranks as the fourth leading killer of adults, with a tally of 100,000 deaths annually. To be sure, the cost of caring for individual patients in this condition is not particularly high when compared with the kinds of high-tech treatments now employed as a matter of course in many American hospitals. Nonetheless, the combined costs of caring for those suffering from such afflictions is considerable, varying from an estimated low of $24 billion (Office of Technology Assessment, cited in Blank, 1988, p. 126) to a high of $88 billion (Gelman and Hager, 1989, p. 45).

Dementia is an irreversible process that becomes increasingly expensive to treat as the quality of the patient’s life erodes. It is a debilitating, often dehumanizing condition for which there is no known cure. It slowly robs the individual of memory and the capacity to function, making him or her increasingly dependent on others for the daily necessities of life, including feeding and toileting, in what some have described as an “endless funeral.” Ultimately, the overall costs of caring for growing numbers of patients suffering from dementia, combined with the mentally and physically dehumanizing and irreversible nature of the condition, are leading some to ask if incurring greater expenses to maintain an irreversibly degrading and dehumanizing quality of life makes sense anymore. Many are beginning to wonder, as America ages and the ranks of the infirm elderly swell, if this situation does not invite—and even demand—a serious public-policy discussion about life and death, including the right to die.

Costing Out the PVS Problem

Certainly, health-care spending that raises right-to-die questions is not limited to geriatric care. It seems that seriously ill Americans in general receive more than what is considered a fair share of health-care resources in other countries. According to 1982 figures, the United States devoted 15 percent of expenditures to support care rendered in the ICUs of American hospitals, where 5 percent of the 1.4 million hospital beds are located. That contrasts sharply with Great Britain, where only 3 percent to 4 percent of outlays are expended for intensive-care procedures and only 1 percent of beds are devoted to the ICU.
There is, in addition, a small but growing population of individuals mired in the limbo referred to as a persistent vegetative state. Generally, estimates of the current PVS population in the United States hover around the 14,000 mark. Whatever the exact figure, however, it is clear that this group of individuals—for whom care can be very expensive, with little if any chance that medical interventions will have any positive effect—is growing in number.

Estimating the cost of care per PVS patient at $50,000 per year (a conservative guess if much advanced technology is required), this group consumes about $7 billion in resources annually. As already noted, those in a PVS do not meet the standard brain-death criteria now in use, so they are kept alive by artificial means indefinitely, usually at the request and sometimes the demand of the family (Blank, 1988, p. 131). Historically, physicians have chosen to treat these patients aggressively, and insurers have simply paid the bills without question, disbursing the costs among policyholders in the form of higher premiums and higher deductibles. Some patients in a PVS with ESRD are even transported three times a week from a long-term care facility to a medical center to be dialyzed, even though they have no sense of what is going on around them and no hope of recovery. More and more, however, physicians are taking a more critical look at the care they provide. The case of Helga Wanglie is illustrative.

Helga Wanglie was eighty-six when she slipped on a rug in her Minneapolis home, falling and breaking her hip in December 1989. After being successfully treated, she was discharged from Hennepin County Medical Center and moved to a nursing home. However, in January 1990, she developed respiratory complications and was readmitted to the hospital so that she could be placed on a respirator. In this condition, she was still aware of her surroundings, able to acknowledge pain and suffering, and able to recognize her family. In early May, after five months of unsuccessful attempts to wean her from the respirator, she was transferred to a long-term care facility that specialized in treating respirator-dependent patients. She subsequently suffered a heart attack there.

Though resuscitated, Wanglie had been deprived of oxygen for several minutes during the attack, leaving her with severe and irreversible brain damage. On May 31, 1990, she was readmitted to the hospital, where she continued to use a respirator. She also received antibiotics for recurrent pneumonia, along with artificially provided food and fluids through a tube implanted into her stomach. After repeated evaluations, her condition was diagnosed as PVS with the complication of permanent respirator dependency (Cranford, 1991, p. 23). In this condition, Wanglie was totally unaware of her surroundings and unable to recognize her loved ones, including her eighty-seven-year-old husband of fifty-three years, Oliver. Doctors who examined her said there was no hope that she would ever regain consciousness (Walsh, 1991).

Like most Americans, Wanglie had left no previous written record of what kind of care she wanted, and due to her unresponsive condition, she was no longer in a
position to indicate her preferences. Because of her dismal prognosis, the medical staff suggested that the family reevaluate continuing the extensive care required to prolong her existence. Relatives claimed to understand Wanglie's virtually nonexistent chances for recovery, but nevertheless, they opposed termination of treatment, "hoping for a miracle" (Walsh, 1991). Angered by the medical staff and others who saw her continued treatment as futile, her husband stated, "She told me many times that if anything happened to her, she didn't want anybody or anything to shorten her life. I intend to keep that promise" ("Doctors Want to Pull Plug," 1990).

Doctors responded to the Wanglie family's intransigence by affirming their commitment to saving and preserving life when possible, while countering that, in Helga Wanglie's case, they would have to go beyond the limit of "reasonable care" to maintain her existence. In short, medical staff members and hospital administrators agreed that continued treatment would not be "in the patient's personal or medical interest" (Walsh, 1991). Since the family remained unconvinced, hospital administrators and the medical staff, in an unprecedented move, took the case to court, where they requested the appointment of an independent guardian. An editorial in the *New England Journal of Medicine*, which supported the institution's position, opined that "the hospital's plea [was] born of realism, not hubris. ... It advances the claim that physicians should not be slaves to technology, any more than patients should be its prisoners. They should be free to deliver, and act on, an honest and time-honored message: 'Sorry, there's nothing more we can do'" (Miles, 1991, p. 514). Oliver Wanglie, a retired lawyer, filed a countersuit against the hospital with the support of his family, requesting that he be named guardian.

In a May 1991 hearing before Probate Judge Patricia L. Belois, Steven H. Miles provided testimony for the parties bringing suit against Oliver Wanglie. According to Miles, the physician who served as ethical consultant to the hospital in the case, family members are the "preferred surrogates" for comatose patients. At the same time, he noted, "physicians have a duty to overrule families in certain circumstances. I believe a doctor cannot be obligated and should not be obligated to provide medical care which cannot serve a patient's personal, medical interest" (Walsh, 1991).

The Wanglies persisted, however, in demanding that all medical treatment to keep Helga alive be continued. Describing her as a devout Lutheran who reportedly told relatives that she favored every effort to maintain life, her family claimed to be certain that, by insisting that life-support measures be continued, they were fulfilling her wishes. Oliver Wanglie argued that no one was better suited than he to decide his wife's fate and that the belief in sustaining life at all costs was something they had discussed and shared ("Judge Rejects Request," 1991). William Lubov, the court-appointed attorney for Helga Wanglie contended, in classic, individualistic form, "I couldn't disagree with the opinion of the family more, but I
feel even more strongly that the right of the individual to choose is paramount” (Walsh, 1991).

In a ruling issued July 1, 1991, Judge B elois of the Hennepin County Court re­jected the hospital’s position and gave Oliver Wanglie guardianship over his wife, who was then eighty-seven. Helga Wanglie and her family won the legal battle, but shortly thereafter, she lost her battle for life: She died of multisystem organ failure on Independence Day, 1991. Her medical bill was approximately $750,000.

The insurance company in the Wanglie case, fearing negative publicity, decided to assume responsibility for these costs without a fight. But more and more health insurers are beginning to take a critical look at the kinds of care they are willing to underwrite. There has been a surge of interest in managed care and coverage cut­backs in recent years that may ultimately nudge the PVS population out of line for coverage, leaving Medicaid (after the family spends down their assets to the pov­erty level) as the sole source of continued support. Again, with pressures on pub­lic health-care budgets already strong, right-to-die questions—and maybe even Lamm’s more radical “obligation-to-die” questions—cannot help but arise.

Malpractice

Malpractice is another element of the cost containment crisis in U.S. health care that might eventually lead individuals and policymakers to consider right-to-die alternatives. According to the AMA, only a little over three malpractice actions were filed per year for every 100 physicians in 1982. But by 1989, that number had more than doubled, jumping to 7.4 claims per year for every 100 physicians. Jury awards have skyrocketed, as well: The average jury award to plaintiffs for mal­practice actions is now $300,000. To compensate for this, insurance companies boosted malpractice premiums in that same time period by 167 percent (Olen, 1991). Today, physicians collectively pay about $4 billion a year for medical mal­practice coverage, and hospitals pay another $2 billion for the same purpose.

The average fee paid by individual American physicians for liability insurance in today’s market tops the $15,000 mark, with specialists paying much higher rates. For example, Chicago obstetricians and neurosurgeons pay upwards of $150,000 per year (Domenici and Koop, 1991). Eleven cents of every dollar paid to a doctor goes for such insurance, and the AMA estimates that another $15.1 billion (about 2.5 percent of all medical spending) is spent every year on “defensive med­icine”—therapies and tests that are ordered more out of concern about a poten­tial malpractice suit than out medical necessity.

This has all led some in the medical community to start sharing treatment plan decisionmaking with their patients. Putting patients more directly in control of treatment decisions may take some of the burden off the physicians, and presum­ably this would reduce some of the doctors’ liability in the process. When the medical decision-making structure is opened up, the family and the patient be-
come coauthors of the treatment plans that are chosen. As such, family members may be less likely to cry foul when things do not turn out as planned. And even if they do cry foul, they may be less likely to win their cases in court if judges and juries find the plaintiffs’ fingerprints are all over the medical record.

Ultimately, shared decisionmaking may cause malpractice premiums to stabilize. It may even lead to an attenuation of defensive medical practices. Both are potential benefits that will be difficult to resist in the years to come. But however that plays out, we should note, for present purposes, that inviting patients into the medical decision-making matrix on a regular basis cannot help but fuel a measure of right-to-die activism. If patients get used to being asked if they want to go ahead with procedure A or surgery B, they cannot help but become more interested in making choices at the very end of life, when they must decide whether they will continue to live or not.

Summary: Medical Technology and the Emergence of the Right-to-Die Scenario

The emergence of kidney dialysis and organ donation dilemmas, together with the definition of death and neonatal-care conundrums, forces discussion of death as a matter of public policy. Academics, the press, state legislators, and the American people have come to expect that these sorts of situations will be fair game as a matter of public discourse. Add into the mix the raft of new ethical dilemmas (surrogate motherhood, the disposition of frozen embryos when parents die or divorce, “morning after” birth control pills, and so on), and we end up with a society just ripe for public policymaking in the medical ethics arena.

Indeed, the whole business of ethics in medicine has become so volatile and the interest is so intense that a whole new academic animal—the bioethicist—emerged to deal with the conundrums that seem to pop up almost daily, beginning in the 1960s. Bioethicists would demand seats at the decision-making tables around the country as policies were formed to address medical-ethical dilemmas, and they would create their own decision forums by founding centers and schools of public-policy study and analysis. Ultimately, these academics would begin to set the ethics agenda for the nation at large as the years progressed.

Certainly, much of the foment regarding ethical questions about life and death can be traced to the fantastic advances in medical technology that have taken place in the last thirty years. But costs are also cropping up, promoting activism, as well. In fact, more money is spent on health care in the United States than anywhere else in the world. Fourteen percent of America’s mammoth gross national product (GNP)—about one dollar out of every seven—is spent on health care.
Our nearest spending competitor is Canada, where only about 9 percent of the gross domestic product (GDP) is devoted to health care. To some, the U.S. rate of increase in spending is even more frightening: Health-care spending has grown half again as fast as the rate of inflation in most years since the 1970s, and there seems to be no end in sight to that phenomenon (Melville, 1992, p. 14).

Especially troubling to some is the fact that a disproportionate amount of that spending goes toward maintaining and occasionally trying to rescue those at the very end of life. This is not particularly surprising, considering how much Americans seem obsessed with the denial of death. Ironically, however, health-care dollars spent during the last days and weeks of life are partly responsible for the increasing interest we have witnessed in right-to-die issues in recent years. Some have begun to question the amount of money spent on rescue medicine for the dying when health-care costs are spiraling out of control and when other medical needs (e.g., prenatal care and preventive medicine) are so apt to go unaddressed. A look into the future suggests that, unless spending priorities are changed, the situation will deteriorate even further as the baby-boom generation passes from middle age into the more medically dependent years of retirement. There should be no doubt that baby boomers will increase the drain on the health-care budget when they retire, just as they increased the drain on the education budgets when they went to school in the 1960s and 1970s.

In the end, whether explicitly acknowledged or not, the underlying pressures of cost containment will provide a good deal of impetus for raising right-to-die questions in the coming years. As George Lundberg notes, “There will never be sufficient money or services to provide everyone with the care they may want” (cited in Rothman, 1992, p. 32). Likewise, John Kilner discounts the popular American myth that there are enough resources to underwrite the cost of treating every terminal disease. Choices must be made, he argues, and better sooner than later. Following up, Callahan (1990, p. 21) notes that “the very nature of medical progress is to pull to itself many more resources than should rationally be spent on it.” Rationing is inevitable, these authors contend, and those who are already on death’s doorstep for one reason or another are the logical source for potential savings because expenditures here are (arguably) not nearly as important in the big picture as expenditures on those who potentially have many productive years of life ahead of them.

Underlying all this is a debate between individual rights and entitlements versus the collective good. It should be no surprise that the right-to-die debate is so problematic in the United States, where public policy and tradition usually favor individual liberty and downplay social goods. When it comes to death, the expectation that individuals have everything coming to them is the prevailing ethos, all in accordance with individualism and the entitlement syndrome (e.g., as with
Medicare covering dialysis and transplants). Meanwhile, the collective well-being associated with the judicious discussion of death-related issues tends to take a back seat. A number of authors are now sensing a sea change in attitudes, though, with more and more people finding aggressive medical interventions less acceptable than a quiet and humane death (Rothman, 1992, p. 37). As society learns to accept and live within limits, it seems only logical to assume that the right to die will likely come into much clearer focus as a viable alternative for both individuals and policymakers alike.