

Chapter 2

The Context of the Report

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The Context of the Report

INTRODUCTION

This chapter provides an overview of the technological developments, treatment settings, public attitudes and opinions, government policies, and demographic changes that are the historical and societal context for this OTA report. The chapter presents background information that is common to the other chapters and is the basis for the congressional concerns that led to the assessment. None of the topics is analyzed in detail, although each could be the focus of a full assessment.

In the early 1900s, there were few effective treatments for life-threatening diseases. Medical care consisted primarily of palliative treatments derived from clinical experience and intuition and intended to mitigate the effects of diseases that were considered natural and inevitable. Since then, advances in biomedical science and technology have produced effective treatments for some diseases, enabling doctors to keep people alive who would certainly have died previously. The use of these treatments, particularly antibiotics, has altered life expectancy and the age distribution of our population. The availability of the treatments has had far-reaching effects on medical practice and on attitudes and expectations about illness, death, and dying.

In part because of the availability of increasingly complex medical treatments, more people are treated in hospitals now than 50 years ago, and more die there. More physicians, nurses, and other health care professionals are involved in the care of each patient and are thus aware of and potentially involved in treatment decisions. More people are cared for in nursing homes and by home health agencies and outpatient clinics than ever before, and more health care professionals and others in these multiperson settings are aware of and potentially involved in life-and-death decisions for these patients. Thus, decisions that would once have been made privately by an individual physician, who might or might not have consulted with the patient or family, are now made in the view of many different people who have diverse opin-

ions and beliefs about the decision and the decisionmaking process.

The inherent difficulty of life-and-death decisions involving medical technologies and the increasingly public nature of the decisionmaking process have led to intense clinical, legal, and ethical debate; to court cases that define the rights of patients to refuse treatment and the role of families, physicians, and health care institutions in the decisionmaking process; to State legislation on advance directives and surrogate decisionmaking; and to the formulation of guidelines for decisionmaking by government-appointed task forces and commissions, professional associations, citizens groups, and others. Much of this debate and the relevant court cases, legislation, and guidelines address questions about possible overtreatment and about appropriate procedures for deciding whether or when life-sustaining treatment should be withheld or withdrawn.

Concurrently, rising health care costs and expenditures have generated widespread public concern and have led to changes in medical practices and in private insurance and public programs that pay for medical care—changes intended to limit health care costs and spending. The pressure for cost containment has added another dimension to the debate about life-sustaining technologies.

In the past, a decision to use or withhold a life-sustaining treatment for an individual patient was based on consideration of the patient's physical condition, legal and ethical constraints, and, in some cases, the wishes of the patient and family. The cost of medical care has always been a consideration for patients who are uninsured, but most people, particularly elderly people, are insured, and most are covered for life-sustaining treatments (although sometimes only when the treatments are provided in a hospital). Thus, elderly patients, their families, and physicians have generally been insulated from cost considerations with regard to life-sustaining treatments. Since

about 95 percent of elderly people are covered by Medicare, and some are also eligible for Medicaid, Veterans Administration (VA), or other publicly funded programs, the cost of life-sustaining treatments for them has been primarily a public cost.

Some ethicists have theorized about the relationship between individual treatment decisions and allocation of scarce resources on a societal level (see ch. 4). Likewise, government-appointed task forces and commissions that have issued guidelines for decisionmaking have concluded that health care institutions and individual clinicians can justifiably limit certain treatment options on an institutional basis in order to allocate scarce resources more equitably (136,153). In the past, however, the public cost of care has generally not been a factor in individual treatment decisions. Nor have the courts that have ruled on cases involving withholding and withdrawal of life-sustaining treatment recognized the public cost of the treatment as a valid consideration in individual treatment decisions.

Recent changes in Medicare and other public programs have created institutional pressures on physicians and other health care professionals to reduce costs and thus have introduced consider-

ation of the public cost of care into individual treatment decisions on a wide scale. These changes have led to new concerns about possible undertreatment and limitations on access to appropriate care—concerns that are superimposed on the unresolved questions about possible overtreatment and about procedures for deciding whether or when life-sustaining treatment should be withheld or withdrawn.

Along with the increased awareness and alarm about health care costs and expenditures, there is a growing recognition among government officials, policy analysts, and the public of the growth of the elderly population, both in absolute numbers and as a proportion of the whole population. Elderly people are more likely to experience life-threatening illnesses than younger people. Health care costs are generally higher for elderly than for younger people, and a significant percentage of the medical care of elderly people is publicly funded. Finally, since elderly people are the primary group covered by Medicare, they are also the group affected by changes in Medicare policies. These factors and others discussed in this chapter have focused public attention and congressional concern on the use of life-sustaining technologies for the elderly.

CHANGING TECHNOLOGY

Advances in life-sustaining medical technology during this century have built on knowledge accumulated during preceding centuries, but the pace of discovery and technological change in recent decades is unprecedented. Major advances began in the 1920s with the isolation of insulin for treatment of diabetes, the invention of the first mechanical ventilator (the “iron lung”), and the discovery of penicillin. Sulfa drugs were first used in the 1930s. The first artificial kidney was used during World War II, although long-term kidney dialysis was not possible until the 1960s.

The 1950s saw the first open-heart surgery, discovery of the polio vaccine, and rapid development of mechanical ventilators. The first intensive care units (ICUS) were established in this period.

In the 1960s, cardiopulmonary resuscitation (CPR), coronary artery bypass surgery, kidney transplants, total parenteral nutrition, and radiotherapy and chemotherapy for cancer were introduced. Coronary care units (CCUs) were established. The first heart transplant occurred in 1967.

The 1970s brought continued progress in the treatment of cancer, heart disease, heart attack, and stroke. With the introduction of the drug cyclosporine in 1979, the biggest obstacle to successful transplantation—immunological rejection—was reduced. The first liver transplant occurred in the 1970s, and heart and kidney transplants became more common. In 1985, about 600 people received liver transplants; 700 received heart transplants; and about 8,000 received kidney transplants (30). In 1982, an artificial heart was placed in a living patient for the first time.

The pace of technological change is increasing. Although it is impossible to predict the next breakthrough, new technologies to treat life-threatening diseases are constantly being developed. In 1984-85, OTA polled academic researchers, trade associations, medical device companies, and government analysts to identify medical technologies likely to appear in the next 5 to 15 years. Responses to the poll indicate that future developments in life-sustaining treatments may occur in the areas of artificial organs and transplanted organs and tissues; cancer vaccines; implantable drug delivery systems for cancer and other diseases; and immunosuppressive drugs. Improvements in medical imaging and other diagnostic and information technologies are expected to improve diagnostic accuracy and medical decisionmaking (201).

Some analysts say that we now have, or will soon have, the capability to maintain biological existence indefinitely (55). Others say that the timing of death—once a matter of fate—is now a matter of human choice (132,136)153).

Technology Development and Diffusion

New medical technologies, including life-sustaining technologies, are developed as an outgrowth of basic biomedical and applied research and targeted development (see fig. 2-1). Some are made

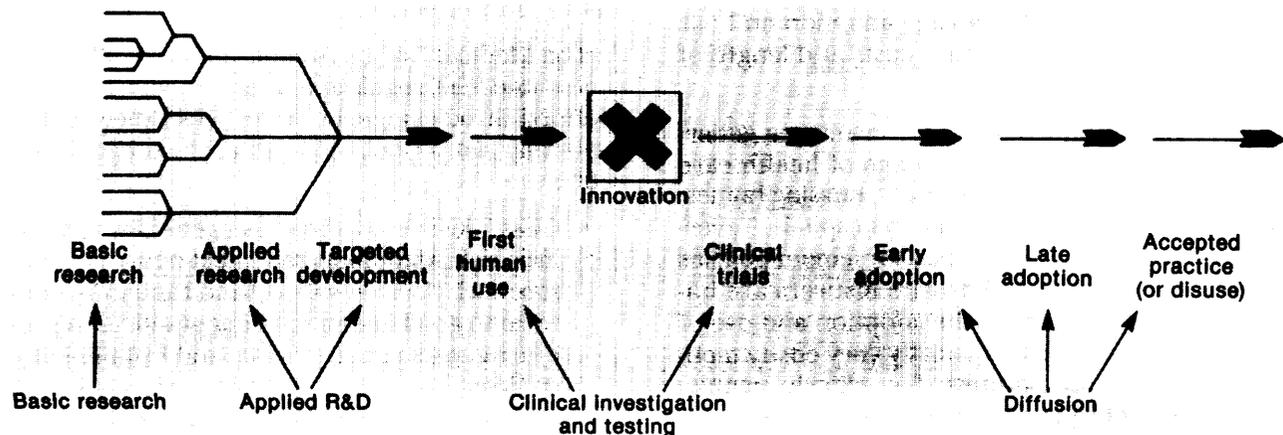
possible by engineering breakthroughs that allow, for example, miniaturization of devices or the use of a new power source.

The Federal Government pays for about half of all health-related research and development. Basic biomedical research is supported primarily by the National Institutes of Health (NIH), but other agencies of the Department of Health and Human Services (DHHS), the Department of Defense, the Department of Energy, the VA, and other Federal agencies also fund health-related research (231).

Private industry and nonprofit organizations pay for the other half of health-related research and development. Most applied research and targeted development is supported by private industry (199). Nonprofit organizations, such as the American Heart Association and the American Cancer Society, fund both basic and applied biomedical research.

Since the Federal Government pays for such a large proportion of health-related research, funding decisions by Federal agencies influence the direction of research and the areas in which development of new technologies is most likely. Massive Federal funding for research on heart disease in the 1960s and 1970s, for example, was an important factor in the subsequent development of new technologies for treatment of cardiovascular disease.

Figure 2-1.—Technology Development and Diffusion



SOURCE: U.S. ©, Office of Technology Assessment, *Development of Medical Technology: Opportunities for Assessment* (Washington, DC: U.S. Government Printing Office, 1976).

Diffusion of new technologies into the health care system results from decisions to adopt a technology by physicians, hospital administrators, and others and decisions to use the technology by physicians and, to some extent, patients and their families. Whether reimbursement for the technology is available obviously affects these decisions (37)199). Since about 90 percent of hospital care for persons of all ages is paid by private insurance and public programs, the coverage and reimbursement policies of private insurance and public programs strongly influence which technologies are adopted and used in hospitals. Medicare pays for about three quarters of the hospital care of elderly people. The remaining one quarter is divided about evenly between other public programs, primarily Medicaid and the VA, and private sources, including private insurance and direct payments by individuals (205). As a result, Medicare policies and the policies of other public programs and private insurers influence which technologies are adopted and used for elderly people (199,200).

Until recently, Medicare, most other public programs, and private insurers reimbursed hospitals on the basis of costs they incurred in treating patients. Cost-based reimbursement generally encouraged the use of medical technologies. Medicare's Part A prospective payment system (PPS), introduced in 1983, reimburses hospitals at a fixed rate per case, based primarily on the patient's diagnosis, PPS, which is discussed at greater length later in this chapter, is expected to encourage adoption and use of technologies that reduce costs and length of stay, and discourage adoption and use of technologies that increase costs and length of stay (199)200).

Public programs and private insurance generally pay for a smaller percentage of health care expenditures in outpatient clinics, nursing homes, and in the patient's home than in hospitals. Nevertheless, the coverage and reimbursement policies of public programs and private insurers are important determinants of the adoption and use of medical technologies, especially very costly technologies, in these settings. For elderly people, Medicare coverage and reimbursement policies are most important.

The methods used by public programs and private insurance to pay for physician services also affect adoption and use of medical technologies. Medicare's current fee-for-service method of paying for physician services encourages physicians to use medical technologies because they are paid for each service performed. Similar payment methods of other public programs and private insurance also encourage adoption and use of medical technologies. Alternate methods, such as the per capita payment method used by health maintenance organizations (HMOs), may discourage adoption and use of some technologies (203).

The policies of public programs and private insurers that affect the adoption and use of medical technologies also influence the decisions of medical device and drug manufacturers about areas of research and product development. The financial incentives created by PPS, for example, are expected to encourage research and development of technologies that reduce a patient's length of stay and reduce the cost of a patient's hospitalization to the hospital.

Government Regulation, Coverage Decisions, and Technology Assessment

Drugs and medical devices are regulated by the Food and Drug Administration (FDA). Medical procedures are not regulated by FDA, but the process by which they are approved for coverage by Medicare may involve an assessment of their safety and effectiveness.

The Medical Device Amendments of 1976 that mandated FDA regulation of new medical devices defined three categories of devices based on the potential risk associated with each category (23, 200):

- Class I devices are those that generally present little risk. Manufacturers must notify FDA before such devices are marketed and must conform to good manufacturing practices in producing, packaging, storing, and installing the devices.
- Class II devices are those for which performance standards must be met, according to the

1976 legislation. Most Class II devices are now regulated as if they were Class I devices, however, because the required performance standards have not been developed.

- Class III devices are those that support life and those whose use involves a relatively high risk of illness or injury. Manufacturers are required to demonstrate the safety and effectiveness of Class III devices before they are marketed.

A 1984 OTA report on medical devices discussed the FDA regulatory process in detail and concluded that the effectiveness of the process could not be determined because of lack of reliable information about the incidence of illness, injuries, or other problems associated with the use of medical devices (199). Since then, new regulations have required manufacturers to report problems with medical devices to FDA. The Health Industry Manufacturers Association has complained that the reporting requirements are vague, thus compliance is difficult (54). Whether the requirements ensure that serious problems in the safety and effectiveness of medical devices will come to FDA's attention is unclear.

Medicare, other government programs, and private insurers generally do not cover drugs or medical devices that have not been approved by FDA. In addition, by law Medicare can only cover medical technologies that are "reasonable and necessary" for diagnosis, treatment, or improved functioning of a malformed body part. Beyond these basic requirements, which are themselves subject to varied interpretation, the criteria and procedures for determining which medical technologies will be covered by Medicare are even less clear.

Some coverage decisions are made at the national level by the Health Care Financing Administration (HCFA). Most, however, are made by Medicare intermediaries and carriers (the contractors who process Medicare claims in each geographic area). Thus, coverage decisions may vary from one region to another. Sometimes they are made on a case-by-case basis. National coverage policies have evolved primarily in response to questions from individual contractors about paying for a specific technology, HCFA decisions about

coverage have limited legal or regulatory authority though, and contractors may or may not comply with them (199,200).'

Some Medicare coverage decisions are based on recommendations of the Office of Health Technology Assessment (OHTA) in the National Center for Health Services Research and Health Care Technology Assessment. OHTA assesses the safety and effectiveness of medical devices and procedures (127), but it evaluates only a small proportion of the thousands of new technologies introduced each year.

Some devices that FDA has approved for marketing are not recommended for Medicare coverage by OHTA, often because of a lack of demonstrated effectiveness. HCFA is not required to follow OHTA recommendations, however, and some OHTA recommendations have been overridden (37).

A recent report on technology assessment and Medicare coverage decisions (112) recommended many changes in the way that these decisions are made, including the development of a uniform national process for coverage decisions, an expanded role for OHTA in technology assessment and coverage decisions, and the establishment of a national panel of experts to assist with the evaluation of medical and cost data to determine cost-effectiveness. In April 1987, HCFA requested public comment on new procedures for making coverage decisions (62).

The Prospective Payment Assessment Commission (ProPAC), an agency established by Congress to monitor PPS, advises DHHS about adjustments in hospital reimbursement rates, including adjustments required because of technological changes. For this reason, it is charged with conducting and sponsoring medical technology assessments. Thus far, however, ProPAC has done little technology assessment, primarily because of budget limitations, and relies instead on published literature

¹Some medical device manufacturers believe that the arbitrary nature of Medicare procedures for determining coverage discourages private sector commitment to expensive R&D efforts on devices that might be beneficial, especially devices targeted for nonhospital settings (49).

and other available information about safety and effectiveness to back up its recommendations (148).

NIH sponsors clinical trials to assess new technologies. NIH also sponsors consensus development conferences that are intended to resolve questions about the clinical application of medical technologies. A panel, including research scientists, physicians, nurses, patients, lawyers, ethicists, economists, and others, evaluates available information about a medical technology and then issues a consensus statement. Since the initiation of the consensus development process in 1977, conferences have been held on about 60 topics, including coronary artery bypass surgery (March 1981), critical care medicine (March 1983), and management of pain (May 1986). With its focus on clinical applications, the NIH consensus development process goes beyond determination of safety and effectiveness to address questions about how the technology should be used and which types of patients it will benefit.

In addition to OHTA and NIH, several States and at least 45 private groups also have medical technology assessment programs. The American Medical Association sponsors a Diagnostic and Therapeutic Technology Assessment Project, for example, and the American College of Physicians sponsors a Clinical Efficacy Assessment Project. The American Hospital Association, the Blue Cross and Blue Shield Association of America, other insurers, manufacturers, and universities also conduct medical technology assessments (37,127,148).

TREATMENT SETTINGS

Hospitals and intensive Care Units

Over the past 20 to 40 years, the use of hospitals as a setting for life-sustaining treatment and as a place to die has increased. One reason for this change is that the special equipment, highly trained staff, and intensive monitoring needed by patients receiving complex medical technologies are usually only available in hospitals.

Hospital ICUs were first setup in the 1950s primarily to provide the intensive monitoring required by the large number of polio patients re-

Despite these assessment activities, some analysts complain that new technologies are introduced into the health care system too soon, before there has been adequate evaluation of their safety, effectiveness, and appropriateness for specified applications (36,91). Other analysts suggest that the lengthy period required for assessment, approval, and coverage of new technologies may hamper timely diffusion of valuable new technologies. One recent review found that an average of 62 months elapsed between the beginning of the FDA regulatory process and final approval of new devices for marketing. OHTA assessments required an average of 26 months (37).

The Institute of Medicine recently established a Council on Health Care Technology to encourage the development and use of health care technology assessment. The new Council will serve as an information clearinghouse on technology assessment. It will identify and develop assessment criteria and methods, promote training and education in technology assessment, and coordinate and contract for technology assessments (87).

Some observers have suggested that one way of lessening the problem of allocating scarce resources on a societal level and improving individual treatment decisions is to provide physicians with more and better information about the effectiveness of specific technologies (66,91,168). This report discusses whether such information is available with regard to elderly patients and the five technologies OTA studied.

ceiving mechanical ventilation (27). By 1958, about one-fourth of all community hospitals with more than 300 beds had an ICU. Now at least 80 percent of hospitals have an ICU (27).

Another reason for the increased use of hospitals is the financial incentives for inpatient as opposed to outpatient treatment created by the Medicare and Medicaid programs enacted in 1965. Although little information is available about the use of hospitals for life-sustaining or terminal care in the first decades of this century, and data for

later periods are incomplete and frequently not comparable, it can be shown that the greatest increase in hospital use in the last year of life occurred in the mid to late 1960s, after the introduction of Medicare and Medicaid (170).

A third reason for the increased use of hospitals as a setting for care of severely and terminally ill people is that, unlike 40 to 50 years ago, many Americans today have had little direct experience taking care of a very sick or dying person. For this and other reasons, they may be unwilling or unable to care for such persons at home (51).

The shift to hospitals and other institutions as a place to die began about the time of or just after World War II. The percentage of people of all ages who die in hospitals or other institutions increased from 37 percent in 1937, to 50 percent in 1948, and 61 percent in 1961 (170). By the 1970s, more than 70 percent of all deaths occurred in hospitals or other institutions (25,108), and the percentage may be even higher now (51,73).

Among elderly people, the percentage of persons who die in hospitals decreases with age. In 1984, of all persons age 65 to 74 who died, 68 percent died in hospitals, compared to 62 percent of those age 75 to 84 who died, and about 50 percent of those over age 85 who died (217). Conversely, the percentage of persons who die in nursing homes increases with age.

The use of hospitals and ICUs for the care of severely and terminally ill people has two important implications for decisions about life-sustaining technologies. First, there is a general presumption in favor of aggressive treatment in these settings. Factors that contribute to that presumption are the availability of equipment and skilled staff in hospitals, the fact that hospitals and ICUs are established to treat illness, the attitudes and training of many physicians and other health care professionals, and the perceived vulnerability of these institutions to malpractice charges for failure to treat.

Secondly, decisionmaking is often more complex in multiperson settings than when only a single physician, patient, and family are involved. Although final authority for treatment decisions in

hospitals and ICUs may rest with the patient's personal physician, the patient, and the family, many other people, including consulting and staff physicians, residents, nurses, and allied health professionals, may have information about specific patients and expertise that are relevant to treatment decisions. Representatives of the institution, including administrators and lawyers, may have both information and concerns about the impact of these decisions on the institution. Clergymen and other professional and lay counselors are also often involved.

Sometimes these other health care professionals, institutional representatives, and counselors play as great or greater roles in implementing decisions about life-sustaining treatments and responding to their effects than the patient's primary physician or family. Nurses are a good example (141, 185). According to one observer:

The nurses do not set the course of treatment, or decide when the treatment must end. The nurses make no life-or-death choices for these patients—not publicly anyway.

All the nurses do is cope with them, full time, over and over again. All the nurses do is look square in the face, longer and more directly than anybody else in medicine or the law, at the effect of decisions that other people make (70).

When the knowledge, perspectives, and values of nurses and other persons involved in the care of patients are not incorporated into the decision-making process, conflict may arise with regard to individual treatment decisions, professional roles, institutional policies, or all three (116,141, 187)229,232). Such conflict generates pressure for professional and institutional guidelines for decisionmaking and sometimes erupts into legal battles.

Nursing Homes

Nursing homes are a common treatment setting for severely debilitated and terminally ill elderly people, and thus a place where decisions about life-sustaining treatments are made. Use of nursing homes has increased considerably since Medicaid, and to a lesser extent Medicare, reimbursement became available. The percentage of all elderly people living in nursing homes and homes

for the aged grew from less than 2 percent in 1950 to about 5 percent in 1980 (107).

Nearly one-fourth of those over age 85 are in nursing homes at any one time, and many very old people die in nursing homes. In 1978, for example, 38 percent of decedents over age 85 died in nursing homes, compared to only 9 percent of decedents age 65 to 74 and 23 percent of decedents age 75 to 84 (119).

As in hospitals and ICUs, many different people are involved in the care of nursing home residents and are thus aware of and potentially involved in treatment decisions. This situation may lead to some of the same decisionmaking problems in nursing homes as in hospitals.

Little is known about the presumption for or against life-sustaining treatment in nursing homes. Anecdotal evidence suggests that some nursing homes present themselves to residents, families, and the community as health care institutions intent on rehabilitation of their residents. Some of these facilities seek to minimize the awareness of death in the facility and prefer to transfer residents to a hospital when death seems imminent.

Other nursing homes see themselves more as a home for the resident. These facilities may prefer not to transfer severely debilitated or terminally ill residents to a hospital when death seems to be imminent and may instead emphasize supportive care in the nursing home. Even in these facilities, however, fear of legal ramifications may result in decisions to provide life-sustaining treatment for such residents, sometimes in opposition to the resident's wishes, as the following example suggests:

For several years, an elderly lady has been living alone in an apartment with homemaker services (cooking, cleaning, and laundry) provided by a local home care agency. The lady has become frail and is sometimes forgetful. Her two daughters would like to have her admitted to a nursing home where she would be safer. However, the lady does not want any aggressive medical care

if she becomes seriously debilitated, and she says she definitely does not want to be tube-fed.

A social worker at the nursing home she and her daughters selected has advised them that although the facility would like to comply with the elderly lady's wishes, the staff believes that state law requires tube feeding in almost all cases when the resident is not eating, and the facility would probably have to provide it. The lady and her daughters agree that under these circumstances she is better off in the apartment for as long as she can manage, even if she is not entirely safe there.

Home Health Care

Over the past 10 years, home health care has become increasingly common, partly because of the recognition that it can be less costly than hospital or nursing home care; partly because most people prefer to remain in their own homes; and partly because technological developments now make it possible to provide many life-sustaining treatments, including mechanical ventilation, dialysis, nutritional support, and intravenous antibiotics in the home (99).

Home health care has become "big business" with estimates for all home health care products and services of \$2 to \$4 billion annually. Continued growth is expected as a result of PPS and other public and private cost-containment measures that are resulting in shorter hospital stays and earlier discharges (22)38,59).

Some observers fear that the involvement of private businesses and the potential for financial profit in home health care will lead to overuse of life-sustaining technologies in the home for severely debilitated or terminally ill persons who may not benefit from them. Others fear that lack of reimbursement for some life-sustaining treatments provided in the home may wrongly restrict their use. The report addresses the relationship among treatment setting, patient selection criteria, the availability of reimbursement, and the use of the five technologies OTA studied.

PERSPECTIVES ON LIFE-SUSTAINING TECHNOLOGIES AND RELATED ISSUES

New life-sustaining technologies are generally greeted with wonder and appreciation. Case histories of people whose lives they have saved are reported in the media, and the scientists, engineers, clinicians, and patients involved in their development and first use are regarded as heroes. Recognition of problems associated with the technologies or their use for certain purposes comes later.

This section reviews people's opinions, beliefs, and attitudes about life-sustaining technologies and related issues as they have been reported in the media, public opinion polls, and elsewhere. Inclusion of statements and ideas in this section does not imply their endorsement by OTA. Nor does it suggest that they are widely held, except where specific public opinion polls are cited. Likewise, the inclusion of case examples does not imply that such situations occur frequently.

When these opinions, ideas, and case examples are reported in the media, they generate public and congressional concern about life-sustaining technologies. They are cited here to describe the *context* of the debate about these technologies, to illustrate the diversity and intensity of opinions, and to frame the issues that are addressed in other chapters.

Opinions About Life-Sustaining Technologies

In recent years, very negative opinions have been expressed about the life-sustaining technologies discussed in this report. They are viewed by some people as needlessly prolonging the dying process, and many instances of poor outcome and patient suffering associated with their use have been reported. For example:

- One man told the President Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research that his 89-year-old mother's ribs were broken during a successful resuscitation attempt by a hospital emergency room team. "She never said another word, but moaned in pain the

whole time. I think this was a moral abomination" (60).

- A newspaper article described an 82-year-old woman who was put on a mechanical ventilator following bypass surgery. She could not talk because of the tubes in her throat but wrote notes to her daughter, saying "Please let me die." The tubes were not removed, and when she tried to pull them out herself, her hands were strapped to the bed (122).
- Another article described a 77-year-old retired school teacher who was admitted to a hospital with end stage kidney and respiratory disease and placed on dialysis and a mechanical ventilator. After her death, her husband said that if he had known what was going to happen, he would not have brought her to the hospital. "She didn't take anything by mouth so they fed her with an N.G. (nasogastric) tube. She was constantly pulling at the tape, trying to pull it out. She pulled it out twice. They put it in a third time. It was a heart-breaking experience" (96).

Mercy killings and suicides associated with the use of life-sustaining treatments have also been reported:

- In October 1984, a comatose 84-year-old woman on a respirator in a Washington, DC, hospital was stabbed to death by her 24-year-old grandson. A newspaper report stated that the family had been "bitterly divided about whether to remove her from the machines that were keeping her alive" (126).
- A newspaper article reported one physician's observation that a surprisingly high number of dialysis patients are involved in fatal one-car crashes into bridges and abutments—deaths that are classified as accidents rather than suicides (124).

Statistics and anecdotes demonstrating positive outcomes of life-sustaining technologies are available and are cited throughout this report. Moreover, negative attitudes about life-sustaining technologies may not be related to the technologies themselves, but rather to their use and outcome

for individual patients. Many people acknowledge that the same technologies that they view as unnecessarily prolonging the suffering of a relative or friend can also restore life and good or satisfactory functioning for other patients.

The negative attitudes expressed in the anecdotes suggest, however, that there may be aspects of some life-sustaining treatments that are unnecessarily painful or uncomfortable for patients. Technological improvements that might lessen patient suffering associated with the treatments could change some people's opinions about them. Aspects of each of the technologies that may be particularly burdensome are noted in the report.

Perspectives on Withholding and Withdrawing Life-Sustaining Treatment

Some people believe that the process of dying may be more fearful than death itself and that in some cases, "death is not the enemy" (102). These individuals oppose the use of life-sustaining treatments in such cases and instead advocate withholding or withdrawing treatment to allow death to occur "naturally" (19,101,111,222).

Advocacy of natural death, or "death with dignity" as it is often called, could not have existed prior to the development and widespread use of the technologies discussed in this report. At present, the movement for "death with dignity"—i.e., without machines, monitors, or tubes and without the frantic final attempts to sustain life that sometimes occur in hospitals and ICUs and to a lesser extent in other health care settings—appears to be growing. The expansion of hospice programs in this country and a growing interest in palliative or supportive care attest to the appeal of the "death with dignity" concept. Many advocates of "death with dignity" also support the concept of "the right to die"—i.e., the individual's right to refuse any treatment even if the outcome is death.

In contrast, other individuals and groups generally oppose withholding or withdrawing life-sustaining treatment except when a patient is terminally ill and expected to die imminently. In their view, it is morally wrong to withhold or withdraw

life-sustaining treatment from patients who may be comatose, severely debilitated, or terminally ill **but are not expected to die imminently**. This position is often called "the right to life" position. Many advocates of "the right to life" and others regard withholding or withdrawal of life-sustaining treatment from patients who are not expected to die imminently as discrimination against handicapped or disabled people (52,83).

Recent growth in the movement for "death with dignity" or "the right to die" is alarming to advocates of "the right to life." They believe that implementation of the "death with dignity" concept has resulted in or will result in denial of potentially beneficial treatment, particularly for patients who are mentally retarded, confused, or unable to demand treatment for themselves for any reason. Advocates of "the right to life" also fear that "the right to die" will become a "duty to die" for elderly and handicapped people (52,83). Some individuals and groups believe that nursing home residents are particularly at risk of being denied potentially beneficial treatment as a result of "the right to die" movement and other factors (83,96).

Public opinion polls indicate that about 75 percent of the public supports the idea that life-sustaining treatments may be withheld or withdrawn in some circumstances. Survey questions have been worded differently and thus are not strictly comparable; some stress that the patient is terminally ill or that the life-sustaining treatment is futile; others emphasize that the patient and/or the family has requested withholding or withdrawal.

A 1986 American Medical Association (AMA) poll asked, for example:

Would you favor or oppose withdrawing life support systems, including food and water, from hopelessly ill or irreversibly comatose patients if they or their families request it?

Seventy-three percent of the 1,510 respondents favored withdrawing treatment in these circumstances; 15 percent were opposed, and 12 percent were unsure (11); 75 percent of those under age 65 favored the option, compared to 64 percent of those over age 65.

Another poll asked:

Medical technology now enables doctors to prolong the lives of many people who are terminally ill. Do you believe doctors should stop using these machines if the patient asks, even if that means the patient will die?

Seventy-seven percent of respondents answered yes; 15 percent, no; and 8 percent said they did not know. Higher income and higher education were associated with affirmative answers. Moreover, only 60 percent of blacks answered yes, compared to about 80 percent of whites (122). Other polls have also indicated a significant difference in attitudes on these issues between blacks and whites (31).

Many caveats have been raised about the validity of survey findings in this complex area. The most important question is whether the findings reflect what individuals would choose for themselves if they were the patient described in the case situation. Neither of the surveys cited above asked what respondents would want for themselves.

One study in an outpatient medical center (113) asked respondents to suppose that they had such a severe memory loss that they could not identify people, remember where they were, or care for themselves, and that there was no chance of recovery. Sixty-two percent of the 152 respondents said they had thought a lot or a moderate amount about what treatment they would want in such a situation. Of these individuals, 73 percent said they would not want intensive care; 71 percent said they would not want CPR; 75 percent said they would not want tube feeding; and 53 percent said they would not want antibiotics for pneumonia. Patients over age 65 were more likely than those under age 65 to say they would not want tube feeding.

Anecdotal evidence suggests, however, that some patients who say that they would request withholding or withdrawal of life-sustaining treatments may not do so when actually faced with such a decision, OTA is not aware of any research that addresses this question.

The mass media and widely read professional journals contain commentaries criticizing physi-

cians for their attitudes and handling of situations in which withholding or withdrawal of treatment may be appropriate. The criticisms are often based on anecdotes, and it is usually unclear whether the author believes that the problems occur regularly or rarely.

Physicians have been criticized in such commentaries for their reluctance or refusal to withhold or withdraw life-sustaining treatments and for their determination to postpone death until the last possible moment. It is said that physicians regard the death of a patient as a personal failure, that they sometimes do not consider the patient experience of the treatment in decisions to initiate or continue it, and that they maybe '(seduced by technology' (47,65,80,81,164,219). Physicians and other health care professionals have also been criticized for pressuring families to consent to life-sustaining treatments for a severely debilitated or terminally ill relative against the better judgment of the family (135,164).

It has been suggested that a physician's need to treat may arise in part from a deep-seated fear of dying and that the same fear may cause some physicians and other health care professionals to withdraw from dying patients. It is said that this tendency to withdraw from a dying patient—experienced by the patient as abandonment—may be intensified when life-sustaining treatment has been withheld or withdrawn thus signifying that the patient's condition is considered hopeless (80, 100,186,219).

Physicians have also been criticized for practicing "defensive medicine"—i.e., providing all possible treatments regardless of their value to the patient in order to avoid a possible lawsuit.

Lack of physician training in how to care for dying patients whose diseases cannot be cured is said to leave some physicians feeling helpless when faced with such patients (80,89,100)219) (see also ch, 10). One physician reported this experience during a 1984 hospital strike:

One night, at 2:00 AM, while working as a nurse's aid, I was called to a patient under my care who had breast cancer with diffuse metastasis. She was on high doses of analgesics and nar-

...but her brain was becoming refractory (not readily yielding to treatment). I was called in and her as a physician she had permission to risk cessation. There was not much I could do to relieve her discomfort except to start a morphine drip.

Feeling helpless and frustrated, I called the nurse for assistance with this clinical problem. The nurse had the patient's hand, then plumped her pillow and repositioned her feet, managed the back of her head and asked the nurse of her grandmother. Thus I was, with the body of clinical medical knowledge to call upon, but inadequately trained in the requirements of compassion and empathy. Eventually the nurse scrubbed the patient, had her close her eyes, and she fell into golden slumber without the need for further narcotics (180).

In some instances, the feeling of helplessness caused by lack of an effective medical remedy for the patient's problem may lead physicians to initiate life-sustaining treatments that may not benefit the patient.

While recognizing the validity of some of these criticisms, physicians and others raise many counter arguments. First, they point out that it is frequently difficult to formulate an accurate diagnosis and prognosis and to determine how a particular patient will respond to a given treatment. In the face of this uncertainty, many physicians prefer to "err on the side of life" and initiate treatment (90,110,140,225).

Some physicians and others point out that there is almost always some chance a patient's condition will improve. In a recent, widely publicized case, for example, a 44-year-old woman who had been in a coma for 6 weeks and experienced cardiac arrest, a collapsed lung, and pneumonia, suddenly came out of the coma, 6 days after a Maryland judge denied her husband's petition to terminate life-sustaining treatment (4).

A physician reported a similar case:

A 70-year-old man was admitted to a coronary care unit after he was found unresponsive at home. The doctor, knowing that the patient had had a massive heart attack 3 years earlier and seeing his current condition, advised the family that he

would probably die, that if he lived, he would have severe brain damage, and that therefore aggressive treatment should probably not be used.

While the doctor was talking to the family, however, the hospital staff ordered aggressive life-sustaining treatment. When the doctor learned of this, he was distressed but did not change the orders. The patient remained comatose that night. By the next morning, however, he had removed the mechanical ventilator tubing and was talking, although his thinking was not clear. Four years later, the doctor reports, "the patient now visits my parents every couple of months for a check on his blood pressure and to monitor the propranolol he is taking to prevent sudden death" (35).

Even though such cases are rare, they intensify the doubts of physicians and others about withdrawing treatment.

Physicians point out that treatment of severely debilitated and terminally ill patients is a process—not a single event during which a life-or-death decision is made. Daily care of such patients involves many decisions, each affecting whether the patient will survive. Even when prognosis is very poor, physicians have difficulty knowing exactly when to stop aggressive care and begin palliative or supportive care.

Some physicians and others believe that physicians have a duty to prolong life; that it is unethical for them to withhold or withdraw life-sustaining treatment; and that such behavior destroys the trust that underlies the physician-patient relationship. Others believe that continuing treatments that do not benefit the patient or treatments that are against the wishes of the patient destroys this trust.

A survey of the attitudes of 250 physicians, nurses, and social workers at three VA medical centers suggest that some life-sustaining treatments are more difficult to withhold or withdraw than others. The study found that these health care professionals were most comfortable with Do-Not-Resuscitate (DNR) orders and withholding surgery and most uncomfortable with decisions to withhold nutritional support and hydration. In the middle range were decisions to withhold an-

tibiotics. Withholding treatment was perceived as less difficult than withdrawing it (230).

Some physicians and other health care professionals are reluctant to withhold or withdraw life-sustaining treatment because they have experienced instances in which terminally ill or severely debilitated patients who seem to be suffering greatly and perhaps wanting to die, in fact want continued treatment (69,78,90). One newspaper reported the following incident:

A 77-year-old woman dying of lung disease in the intensive care unit of a New York City Hospital had been on a mechanical ventilator for six months. No treatment was known that could improve her condition, and it was expected that she would be dependent on the ventilator until she died. Physicians in the ICU regarded her life as very difficult and believed that she might prefer to have the ventilator removed and die.

The doctor raised the issue with her. "Now, I don't want this to upset you. Nothing has changed in your situation. But we have to ask you this now so we will be better able to handle your care."

She was not able to speak because of the ventilator, but she smiled.

"We are not optimistic we can take you off the ventilator," he continued. "We've known that for a while, and we're looking to send you to a nursing home. But we need to know, if something unexpected should happen, if you should have an irregular heartbeat, do you want us to resuscitate you?"

The frail woman paused for a moment. And then she nodded.

"You understand what I am asking?"

She nodded again.

"As it stands, you want everything done?"

To the surprise of the doctor and two others's standing at her bedside, she nodded yes again (97).

Some physicians and other health care professionals may also be reluctant to withhold or withdraw life-sustaining treatment because they have experienced instances in which patients decided against treatment because they were depressed, in pain, or in significant discomfort, but when these problems were relieved, the patients decided in favor of treatment. Others may have experienced instances in which patients refused life-

sustaining treatment because they feared the procedures or equipment but changed their minds when the procedures were explained (90). Instances in which patients change their minds for these or any other reason tend to reinforce the general preference of health care professionals to "err on the side of life."

Opinions About "Quality of Life" as a Factor in Decisions About Life-Sustaining Treatment

Opinions about whether "quality of life" should be a factor in decisions about life-sustaining treatment vary depending on what is meant by the term, but its meaning is seldom made explicit. The term may refer to:

- an individual's view about the quality of his or her own life,
- an observer's assumption about how the individual views the quality of his or her own life, or
- an observer's evaluation of the quality of the individual's life.

From any of these three points of view, a judgment about an individual's "quality of life" may be based on physical, mental, emotional, or social characteristics of the individual or his or her environment. Severe cognitive impairment and patient physical or emotional suffering are frequently mentioned as aspects of poor "quality of life."

Whether "quality of life" should be considered in decisions about life-sustaining treatments is probably the point of greatest disagreement between advocates of "death with dignity" and advocates of "the right to life." In the opinion of advocates of "death with dignity," "quality of life" **from the patient's point of view** should be a primary consideration in decisions about life-sustaining treatment.

Advocates of "the right to life" argue, in contrast, that opinions about "quality of life" are, or tend to become, judgments about the value of life, and that treatment decisions based on "quality of life" devalue it. According to one spokesperson for this position:

“Quality of life” talk abandons the substantive concept of “life” in its focus on “quality,” suggesting the extreme position that a life of poor health quality is probably not even a properly human life at all; not worth living, and not worth keeping alive (149).

This position is usually based on an underlying conviction about the sanctity of life. For example, in testifying before the Senate Subcommittee on Family and Human Resources, Paul Ramsey said:

Our nation is in a deep moral crisis, a crisis of which road to take, the high road of faithfulness to a fundamental principle of Western morality—**the equality of life**—or the low road of discretionary judgments concerning the **quality of a life**, permitting private persons to assess that life’s inherent **capability or worthiness** to be treated equally, protected equally, as any other life would be treated and protected.

In our moral heritage, **equality of life** stems from the traditions of the religions of Western culture, whose teaching is that each of us has his **title** to life from God, from not only nature but nature’s God, and certainly not from any State’s or societal or private judgment that that life may or may not be entitled to equal care and protection. **In my view, the equality** of life can be sustained as a fundamental principle by acceptable notions of the equal dignity, equal claims, of any life in a valid, **truly humanistic** morality (159).

Advocates of “the right to life” believe that allowing “quality of life” considerations in decisions about life-sustaining treatment for any persons in the society creates a dangerous precedent that could ultimately threaten the fundamental rights of handicapped people of all ages and subject them to abandonment, abuse, and medical neglect (24, 79)149).

Little is known about the attitudes of physicians and other health care professionals toward the use of “quality of life” as a factor in health care decisions. One study asked physicians to indicate how they would treat a hypothetical patient—a 69-year-old nursing home resident in severe respiratory failure—and what factors in the case influenced their decision. Results of the study show that 37 percent of the physicians based their decision at least in part on the patient’s “quality of

life,” including 49 percent of physicians who said they would withhold mechanical ventilation but only 29 percent of those who said they would provide the treatment. The researchers note, however, that the physicians varied greatly in their opinions about the “quality of life” of the hypothetical patient (147).

Because of the lack of a clear and accepted definition of “quality of life” and because of the value judgments it introduces into the decisionmaking process, some people believe that “quality of life” should not be a factor in decisions about life-sustaining treatment and that such decisions should be based only on factors such as expected medical outcome. Others believe that “quality of life” is an important component of outcome and thus a necessary factor in treatment decisions.

The difficulty of determining whether “quality of life” should be a factor in decisions about life-sustaining treatment is summed up in the following comment of one observer:

I am struck by how many in my limited circle of acquaintances are willing to use and apply measures of the quality of life, and how few of them are comfortable with a serious and sustained probing of precisely what it is. Many of us are apt to respond as Fats Waller did when asked to explain the nature of jazz. “Man,” he said, “if you don’t **know** what it is, don’t mess with it.” In the context of geriatric care, we cannot leave it there—though perhaps it will turn out that we ought not to mess with it (175).

Chapters 5 through 9 discuss what is known about the use of factors that are sometimes said to constitute “quality of life” in decisions about the five technologies OTA studied.

Attitudes About the Patient's Role in Decisions About Life-Sustaining Treatment

Intertwined with opinions about life-sustaining technologies, withholding and withdrawal, and “quality of life”—but not synonymous with such opinions—are attitudes about the patient’s role in decisions about life-sustaining treatment. These attitudes exist within the context of general societal attitudes about the importance of patient

autonomy and patient involvement in decisions about all kinds of medical care. These general societal attitudes may be based on:

1. growing awareness that decisions made without the patient's input may not reflect his or her wishes or best interests;
2. widespread skepticism about what is seen as the traditional paternalistic role of physicians;
3. court rulings that support patient autonomy in decisions about medical treatment (see ch. 3); and
4. societal concerns about individual rights, civil rights, and consumer rights that, although not directly related to medical decisionmaking, still affect attitudes about it (91,228).

In this general context, physicians have been criticized for failing to discuss treatment decisions of all kinds with their patients. The extent of this problem is unclear. A 1982 survey, conducted for the President Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research, found that the vast majority of physicians (84 to 98 percent) said they usually discuss diagnosis, prognosis, and the pros and cons of treatment with their patients. A smaller, but still significant proportion of adults interviewed for the same survey (68 to 78 percent) agreed that their physicians usually discuss these matters with them (118). No data are available to determine whether physicians discuss decisions about life-sustaining treatments with patients more or less often than decisions about other treatments.

Many hypotheses have been advanced as to why some physicians do not discuss treatment decisions with some of their patients. Survey data show that physicians believe that about 20 percent of their patients are incapable of understanding treatment options and that other patients who are capable of understanding are, nevertheless, incapable of coping with information about their condition and treatment for it (118).

One observer points out that in the past physicians had few specific remedies for diseases and relied on hope and reassurance to comfort their patients. These approaches depend on patient trust, and physicians learned not to undermine trust by disclosing their uncertainty about diagnosis, prognosis, or appropriate treatment. Ac-

ording to this view, some physicians may fail to discuss treatment decisions with patients because of reluctance to acknowledge uncertainty (95).

Although most people believe physicians are sometimes justified in withholding information from patients or overriding a patient's decision about treatment, in general, people strongly support the autonomy of the patient in the decision-making process (118). A 1985 poll of 1,500 Americans age 45 and over found that only 14 percent agreed with the statement, "A person who has a fatal illness with no possibility of recovery should receive all available types of life support to keep them alive *regardless of their own wishes*" (emphasis added). Eighty-one percent disagreed, and 4 percent did not know. No significant differences were found by age (5-year intervals to age 85) (155).

In response to a second statement, '(People who have made their wishes known about life support treatments should have their wishes followed, regardless of the opinions of physicians or family members, ' 81 percent of respondents agreed, 13 percent disagreed, and 6 percent did not know (155).²

As discussed earlier, questions have been raised about the validity of survey findings in this area. Critics point out that the findings may reflect the respondents' attitudes about patient autonomy in general and not necessarily the way respondents want decisions made for themselves.

In fact, many health care professionals doubt that the majority of patients actually want to make decisions about medical treatments themselves. One study of patient participation in decisions about treatment for hypertension supports this view. Although most of the subjects wanted information about their condition and its treatment, 78 percent preferred that a physician or nurse practitioner make the decision about treatment, and less than half of these even wanted the physician or nurse practitioner to consider their opinions. Only 19 percent wanted to participate equally in decisionmaking, and only 3 percent wanted to make the decision themselves. Higher income and

²OTA appreciates the generosity of the American Association of Retired Persons (AARP) in including these questions in its 1985 poll and providing the results for use in this report.

education were correlated with an individual's desire to participate equally in decisionmaking (178).

Results of another survey showed that fewer elderly than younger people wanted to make decisions about their own treatment in the event that they are "seriously ill" (see table 2-1). While 43 percent of respondents of all ages said they wanted to make the final choice, only 23 percent of those over 65 wanted to do so (118).

Views on Surrogate Decisionmaking

Survey data indicate that most people want a family member to make treatment decisions for them if they are decisionally incapable (see table 2-2). Yet a significant percentage would rather have their physician or a friend or lawyer make decisions for them in such situations (118).

Some physicians believe that asking families for a decision about life-sustaining treatment is too stressful for the family and that families should not be asked to make these decisions. Others point out that the decisions of family members do not always reflect the patient's wishes or best interests. In some cases, family members insist on aggressive treatment that is considered inappropriate by the physician and other health care professionals. In other cases, family members decide that treatment should be withheld or withdrawn for reasons that may be related to the needs of the family rather than the wishes or best interests of the patient. As a result, many physicians

Table 2-1.—Responsibility for Decisions About Medical Treatment, Louis Harris Poll, 1982

Question: If you were seriously ill, would you want the responsibility of making the final choices about your medical treatment or would you want your doctor to make them for you?

Response:	Age				
	All ages	18-34 years	35-50 years	51-64 years	65 and over
Patient makes final choices	43	56	45	29	23
Doctor makes final choices	38	28	36	47	60
Both	14	15	17	12	12
Not sure	4	3	3	6	2

SOURCE: Louis Harris & Associates, "Views of Informed Consent and Decisionmaking: Parallel Surveys of Physicians and the Public," President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research, *Making Health Care Decisions*, vol. III (Washington, DC: U.S. Government Printing Office, 1982).

Table 2.2.—Who Should Make Treatment Decisions When the Patient is Too Sick To Decide, Louis Harris Poll, 1982

Question: If you were too sick to make an important decision about your medical care, who would you want to make the final decision for you—a family member, a close friend, your doctor, or a lawyer appointed to protect your interests?

Response	Percent
A family member	57
A close friend	2
Your doctor	31
A lawyer	2
Doctor and family/friend	6
Other	^a
Not sure	1

^aLess than 0.5 percent.

SOURCE: Louis Harris & Associates, "Views of Informed Consent and Decisionmaking: Parallel Surveys of Physicians and the Public," President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research, *Making Health Care Decisions*, vol. II (Washington, DC: U.S. Government Printing Office, 1982).

and others believe that families should not have an absolute right to make these decisions (33,76, 90,110,116,172)177). According to two proponents of this viewpoint:

We submit that the family's rights vis-a-vis the medical care of an adult are limited to ensuring that the wishes of the patient are fulfilled and to expressing their considered judgment regarding what is in the best interest of the patient, given their presumably more intimate knowledge of the patient and his life and values. None of this, however, entails the proposition that a physician ought to acquiesce to any and every desire expressed by a family concerning the appropriate medical care for an incompetent patient.

However sensitive the physician must be to the emotions and concerns of family members, he ought to remember that his covenant is with the patient, not the family. It is a covenant to pursue the welfare of the patient, not the welfare of society or even the welfare of the family. When the patient cannot speak for himself, we believe that the physician must, to the best of his or her abilities, speak for the patient (172).

The foregoing discussion raises many questions about how decisions about life-sustaining treatments are actually made, the usual roles of physicians, other health care professionals, and families, and the extent to which patients are or could be involved in the decisionmaking process. Because of the complexity of the clinical, legal, and

ethical issues surrounding surrogate decisionmaking, OTA commissioned three papers on this topic and sponsored a workshop on “Making Medical Decisions for Mentally Impaired Adults.” Some conclusions of the workshop and the commissioned papers are incorporated in this report. For a more detailed and comprehensive presentation of the issues, the reader is referred to the papers that will be published by *Milbank Memorial Fund Quarterly* (50) or can be obtained from the National Technical Information Service (see app. A).

Opinions About Euthanasia

Euthanasia, or mercy killing, is an act intended to cause the death of a person who is suffering from what is believed to be an incurable condition. The manner of death is intended to be painless or at least to result in less suffering for the individual than continuation of his or her existence as it is.

Many people make a distinction between an act such as giving a patient a drug that causes death, which they call euthanasia, and withholding or withdrawing life-sustaining treatments, which they do not call euthanasia. Other people refer to an act such as giving a patient a drug to cause death as “active euthanasia” and distinguish it from withholding or withdrawing life-sustaining treatment, which they call “passive euthanasia”; many of these people believe that there are significant legal and ethical differences between active and passive euthanasia. A third group of people believes that the distinction between active and passive euthanasia is not meaningful and that both practices are morally wrong.

With regard to what is sometimes called “active euthanasia,” the National Opinion Research Center has asked the following question periodically since 1947:

When a person has a disease that cannot be cured, do you think doctors should be allowed by law to end the patient’s life by some painless means if the patient and his family request it?

In 1947, 37 percent of respondents said yes. By 1973, slightly over half said yes, and in 1983, 63 percent said yes (122). Similarly, 61 percent of re-

spondents to a 1985 Harris poll agreed that a “patient who is terminally ill, with no cure in sight, ought to have the right to tell his doctor to put him out of his misery” (181).

In contrast to these attitudes, most religions and most ethical traditions oppose euthanasia (103) (see ch. 4). The American Medical Association prohibits any involvement of physicians in euthanasia (9), and survey results indicate that far fewer physicians than other adults consider euthanasia acceptable. For example, one survey asked:

Imagine that a dying patient in severe distress, which cannot be relieved, asks to have his life ended. Under these circumstances, is it ethically permissible to comply with the patient’s wishes?

Only 4 percent of physicians said yes, and only 2 percent said they would be likely to comply with such a request (118). On the other hand, more than 80 percent of physicians agreed that it is ethically permissible to administer pain relieving drugs to a dying patient in severe distress, even if the required dose would shorten the patient’s life.

Euthanasia, or mercy killing, is most likely to occur when patients are believed to be incurably ill and suffering but unlikely to die imminently. Recent newspaper articles have reported the following:

- A 68-year-old woman in Lynchburg, VA, stabbed her 72-year-old husband to death with an icepick because he was “confused and screaming with pain” caused by cancer (21).
- An elderly Florida man shot his wife to death in the nursing home where she lived because she had Alzheimer’s disease and spent much of her time screaming (122).
- An 86-year-old man shot his wife to death in her hospital bed because she had Alzheimer’s disease. He then shot and killed himself (123).
- A woman in La Jolla, CA, strangled her 92-year-old husband in his sleep because he was bedridden, suffering from emphysema, arteriosclerosis, strokes, and hallucinations (122).

In general, mercy killing is considered only when a patient is not receiving a life-sustaining treatment that could be withheld or withdrawn. Allan Otten, a correspondent for the Wall Street

Journal, describes such a situation in an article entitled "Can't We Put My Mother to Sleep?"

Every few days now, I go to visit my 90 year old mother in a nearby nursing home, more to save my own conscience probably than to do her any meaningful service. For her, in fact, there is little I can do. She lies on her side in bed, legs drawn rigidly into the fetal position, blinks at me uncomprehensively as I prattle on about family doings, and rarely utters a sound except a shriek of pain when the attendants turn her from one side to the other in their constant battle to heal her horrible bedsores. She must be hand-fed, and her incontinency requires a urethral catheter.

Why do we treat our aged and loved animals better than we treat our aged and loved human beings? Shouldn't a humane, caring society—as ours is supposed to be—begin to consider ways to put my long-suffering mother, and the steadily growing number of miserable others like her, peacefully to sleep (146)?

Otten says that he was told by several doctors and ethicists to take his mother home, bathe her, keep her comfortable, and just let her die. He asks in response whether "it must be done this slow, hard way" and whether "(a pill, injection, or other humane method" could be found to end her suffering (146).

Reports like this one speak to the intense anguish that some people feel about what they perceive as the prolonged suffering of a relative or friend. Responses to Mr. Otten's article ranged from sympathy and support to outrage that he would want "to kill his 90-year-old mother" (72, 224),

Mercy killing is illegal, but most people have not been prosecuted for it, or if prosecuted, they have been acquitted or given probation. There are exceptions, however, and a few individuals have been prosecuted and convicted (17).

Euthanasia seems to be more widely accepted and perhaps more widely practiced in some other countries than in the United States. In 1984, a group of French doctors announced that they had helped some patients to die by active measures, including the use of medications. Their declaration stated:

The moment has come for medical training and institutions to respond to the demand for quality in the last period of life and a death that prevents suffering and preserves dignity (29).

Simultaneously, results of a poll were published showing that 80 percent of French doctors favor euthanasia for hopelessly ill patients (29).

In the Netherlands, the Dutch Association for Voluntary Euthanasia has a group of volunteers to answer questions and give advice about euthanasia and a group of doctors who are in principle willing to perform euthanasia. The association insists that the patient must wish to die himself or must be unconscious. It has published a booklet detailing the drugs that can be used for mercy killing (2). Euthanasia is illegal in the Netherlands, but few doctors who perform euthanasia are prosecuted. In 1985, the Dutch Government Commission on Euthanasia recommended national legislation that would exempt physicians from prosecution for euthanasia if mandated procedures are followed. This legislation has not been enacted (42).

The diversity of opinions and attitudes just described with regard to life-sustaining technologies, withholding and withdrawing treatment, "quality of life" as a factor in treatment decisions, patient autonomy, surrogate decisionmaking, and euthanasia suggest that individuals involved in a decision about life-sustaining treatment are likely to differ in their perceptions of the situation and their beliefs about how the decision should be made and what the decision should be. Such differences of opinion can occur in decisionmaking situations that involve only a physician and a patient or a single family member. They are more likely to occur, however, when more people are involved, as they often are in hospitals, nursing homes, and other multiperson treatment settings.

Many people feel very strongly about one or more of the issues discussed in this section. This intensity of feeling may be based on strong religious or moral convictions, prior experience, professional training and socialization, or deeply ingrained cultural values and mores. The seriousness and potential finality of decisions about life-sustaining treatment and the emotionally charged atmosphere that usually surrounds severe illness

and the possibility of an individual's death further intensify these strong feelings and beliefs. Even individuals who do not feel strongly about these issues in the abstract frequently develop strong opinions in decisionmaking situations that

involve them personally. Thus, decisions about life-sustaining treatments are likely to take place in the context of intense and divergent feelings, beliefs, and attitudes of participants and potential participants.

SOCIETAL RESPONSES TO THE DILEMMAS ASSOCIATED WITH LIFE-SUSTAINING TECHNOLOGIES

Although life-sustaining technologies have had a positive effect in general, the dilemmas associated with their use in some cases have given rise to legal and ethical debate; court rulings; new methods for the determination of death; State legislation for living wills and methods for designating a surrogate decisionmaker; guidelines for decisionmaking formulated by government-appointed task forces and commissions, citizens' groups, professional associations, and others; institutional policies for decisionmaking and institutional ethics committees; Federal regulations; and hospice programs. This section reviews each of these developments briefly as background for subsequent chapters.

Legal and Ethical Debate

Some issues raised in this report have been discussed since ancient times, but legal and ethical debate about issues related to the use of life-sustaining treatments has intensified since the 1950s as a result of the introduction of new medical technologies. Since then a large body of knowledge has been developed, consisting in part of legal concepts and legal analysis and in part of ethical principles and ethical analysis (see chs. 3 and 4). Legal and ethical aspects of the debate about life-sustaining treatments are interrelated. Moreover, legal and ethical analysis has stimulated many of the other developments discussed in this section and in turn has been stimulated by them.

Observers have noted that each new technology seems to raise new and to some extent unexpected legal and ethical issues (32,33). Yet most of the debate about these issues has not focused on specific technologies. In addition, although there are exceptions, most legal and ethical anal-

ysis of these issues has not focused on elderly people as a distinct group.

Finally, until recently, legal and ethical debate has focused more on decisions about withholding and withdrawal—i.e., when it is legal or ethical to withhold or withdraw life-sustaining treatment—than on questions of access or right to treatment—i.e., what treatment is society legally or ethically obligated to make available. As concern has grown about the impact of cost containment measures on access to care, however, legal and ethical debate has focused increasingly on questions of access and right to treatment.

Court Cases

The first court case to focus national attention on the issue of withdrawing life-sustaining treatment was that of Karen Quinlan, a 21-year-old woman who was comatose and receiving mechanical ventilation. In 1976, the New Jersey Supreme Court ruled that her father could request removal of the ventilator on her behalf (88). (When it was removed, she began to breathe on her own and lived another 10 years.)

Since the landmark Quinlan ruling, many other cases involving life-sustaining treatments have been decided. Table 2-3 lists the cases OTA is aware of that involve elderly people. Many of these cases are discussed in other chapters of the report. Legal cases are not usually categorized by the age of the individual involved, and this table is not intended to suggest that different legal principles apply or should apply to elderly people. It is rather intended to show which technologies are represented in cases involving elderly people and the apparent change in this aspect of such cases over the past 10 years.

It is clear from table 2-3 that from 1980 to 1985 most cases involved the use of mechanical ventilation. The first rulings on cases involving nutritional support for elderly patients were handed

down in 1984. One case involving nutritional support was decided in 1985; there were eight cases in 1986, and two as of early 1987. These figures indicate that the legal issues associated with the

Table 2-3.—Legal Cases Involving Decisions About Withholding or Withdrawal of Life-Sustaining Treatment From Elderly Patients

State	Patient's age	Case	Technology
1977:			
Massachusetts,	67	<i>Superintendent of Belchertown State School v. Saikewicz</i>	Chemotherapy
1978:			
Massachusetts,	67	<i>In re Dinnerstein</i>	Resuscitation
Massachusetts,	77	<i>Lane v. Candura</i>	Amputation of gangrenous leg
New Jersey	72	<i>In re Quackenbush</i>	Amputation of gangrenous legs
Tennessee	72	<i>State Department of Human Service v. Northern,</i>	Amputation of gangrenous feet
1980:			
Massachusetts,	78	<i>In re Spring.</i>	Dialysis
Ohio	70	<i>Leach v. Akron General Medical Center^a</i>	Mechanical ventilation
Florida	73	<i>Satz v. Perlmutter</i>	Mechanical ventilation
1981:			
New York	83	<i>In re Eichner,</i>	Mechanical ventilation
California	67	<i>Foster v. Tourtellotte.</i>	Mechanical ventilation
1983:			
New Mexico	65+ ^b	<i>New Mexico ex rel. Smith v. Fort</i>	Dialysis
Washington	69	<i>In re Colder,</i>	Mechanical ventilation
Texas	65+ ^b	<i>In re Guardianship Estate of Peterson</i>	Mechanical ventilation
1984:			
New York	88	<i>In re Moschella</i>	Mechanical ventilation
California	70	<i>Bartling v. Superior Court</i>	Mechanical ventilation
Florida	65+ ^b	<i>John F. Kennedy Memorial Hospital Inc. v. Bludworth</i>	Mechanical ventilation
Ohio	70	<i>Leach v. Shapiro^c</i>	Treatment against patient wishes/ mechanical ventilation
Arizona	82	<i>Lurie v. Samaritan Health Service</i>	Mechanical ventilation
Massachusetts	92	<i>In re Hier,</i>	Nutritional support
New York	85	<i>In the Matter of Application of Plaza Health and Rehabilitation Center,</i>	Nutritional support
1985:			
Washington, DC	71	<i>Tune v. Walter Reed Army Medical Center</i>	Mechanical ventilation
New Jersey	83	<i>In re Conroy</i>	Nutritional support
New York	70	<i>Saunders v. State</i>	Living will ^d
1986:			
New York	83	<i>In re Triarsi.</i>	Mechanical ventilation
New York	79	<i>In re Vogel.</i>	Nutritional support
New York	83	<i>In re Application of Kerr (O'Brien).</i>	Nutritional support
New Jersey	90	<i>In re Visbeck,</i>	Nutritional support
Hawaii	73	<i>Wilcox v. Hawaii</i>	Nutritional support
Florida	73	<i>Corbett v. D'Alessandro</i>	Nutritional support
Virginia	65+ ^b	<i>Hazelton v. Powhatan Nursing Home, Inc.</i>	Nutritional support
Arizona	70	<i>Rasmussen. Fleming</i>	Nutritional support/resuscitation
Ohio	79	<i>Galin v. University Hospitals</i>	Treatment against patient wishes/ resuscitation
California	75	<i>Cantor v. Weiss.</i>	Nutritional support
1987:			
New York	79	<i>Workman's Circle Home and Infirmary for the Aged v. Fink</i>	Nutritional support
California	92	<i>Gary v. California.</i>	Nutritional support
New Jersey	91	<i>McVey v. Englewood Hospital Association</i>	Treatment against patient wishes/ mechanical ventilation

^aThe 1980 case *Leach v Akron General Medical Center* concerned a petition by Mrs. Leach's husband for an order to discontinue mechanical ventilation for her. The 1984 case *Leach v Shapiro* involved an action for damages against the doctor and hospital for the time Mrs. Leach was on mechanical ventilation. Both cases are discussed in ch 3.

^bThe precise age of the patients in these cases is not known, although they are known to be over 65.

^cThe Patient sought prior judicial validation of her living will so that it could be carried out without delay if her condition deteriorated to the point at which she would want to refuse life-sustaining treatment.

use of nutritional support are now most controversial.

Most recent court decisions in cases of younger patients also involve the use of nutritional support. Some cases of younger people are discussed in other chapters.

Determination of Death

Standards for the determination of death are relevant to decisions about life-sustaining treatment because everyone agrees that such treatment should not be used for persons who are already dead. Two decades ago, the accepted standard for determining death was the permanent absence of respiration and circulation. Since then, determination of death has become more complex because respiration and circulation can be maintained by artificial means even when the brain centers that control respiration no longer function and the whole brain, including the brain stem, is dead (106,151). The concept of brain death evolved as a solution to this problem.

In 1968, an Ad Hoc Committee of the Harvard Medical School issued an influential report defining what the Committee called “irreversible coma” and listing four clinical criteria for determining it: 1) unresponsiveness and unresponsiveness to even the most painful external stimuli; 2) no spontaneous movements or breathing; 3) no reflexes; and 4) a flat electroencephalogram. It was stressed that these four conditions should remain unchanged for at least 24 hours and exist in the absence of hypothermia and central nervous system depressants (1). These criteria have been widely used to determine brain death. One problem has been the Harvard Committee’s use of the term “irreversible coma,” which suggests to some people that the criteria indicate permanent unconsciousness rather than brain death (92,151).

Beginning in 1970, many States enacted legislation recognizing brain death, but lack of uniformity in the wording of these statutes, and thus lack of agreement about when death had occurred led to many proposals for a uniform legal definition of death. When the President’s Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research was created in 1978, the problem of defining death was included

in its mandated studies. In 1981, the Commission recommended a model State statute, the Uniform Determination of Death Act, that defined death as follows:

An individual who has sustained either (1) irreversible cessation of circulatory and respiratory functions, or (2) irreversible cessation of all functions of the entire brain, including the brain stem, is dead (151).

The Commission concluded that the “determination of death must be made in accordance with accepted medical standards” (151) but that the standards should not be included in State statutes or regulations because the tests for determining death may change with the advent of new research and technologies. The Commission’s report, *Defining Death*, includes as an appendix clinical guidelines for determining death formulated by the Commission’s medical consultants.

Despite the recommendations of the President’s Commission, controversy and confusion about some aspects of the determination of death persist. Moreover, some religious groups, such as Orthodox Jews, oppose the concept of brain death because it violates their belief that a person is alive until his or her heart and lungs have stopped functioning.

State Legislation Authorizing Living Wills and Methods for Designating a Surrogate Decisionmaker

In response to the dilemmas associated with decisions about life-sustaining treatment for persons who are not decisionally capable, some States have passed legislation authorizing living wills—documents that give directions from an individual about that person’s preferences about life-sustaining treatments in the event that he or she becomes decisionally incapable in the future. The first living will legislation was enacted by California in 1976, and seven States followed suit in 1977. During the next 6 years, only six States and the District of Columbia enacted living will legislation. In 1984, the pace picked up, partly because of growing public support for the terminally ill person’s right to refuse unwanted treatment and partly because of an apparent softening in the Catholic Church’s opposition to such legislation.

Between 1984 and 1986, 24 States passed living will statutes. Thus, 38 States and the District of Columbia now have such statutes.

Living will statutes in some States allow individuals to appoint a surrogate—a relative, friend, lawyer, physician, or other person—to make health care decisions for them if they become decisionally incapable. In addition, all 50 States and the District of Columbia, have durable power of attorney statutes that allow individuals to appoint a surrogate decisionmaker. General durable power of attorney statutes were enacted primarily to authorize proxies for financial and property decisions, however, and there is some uncertainty about whether they also authorize health care decisions. In response to this uncertainty, 15 States have enacted legislation that specifically authorizes durable powers of attorney for health care (43).

Since 1976, 15 States have enacted family consent laws that give family members legal authority to make health care decisions for terminally ill or incapacitated adults (137). In States without family consent statutes or specific court decisions, there is still no legal authority for the widespread practice of allowing family members to speak for individuals who are not decisionally capable.

State guardianship laws allow a court to appoint someone to make decisions for persons who are adjudicated incompetent. Many guardianship laws, like general durable power of attorney statutes, predate concerns about the use of life-sustaining treatment for persons who are not decisionally capable and may not address these concerns adequately.

Living wills, durable powers of attorney, family consent laws, and guardianship laws are discussed in chapter 3.

Guidelines for Decisionmaking

In 1983, the President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research published its report ***Deciding To Forego Life-Sustaining Treatment***. Based on the results of public meetings and the commission's earlier work on informed con-

sent (152), defining death (151), and access to health care (154), the report discusses: the elements of good decisionmaking, factors that constrain the patient decision, and special problems of patients who are decisionally incapable or permanently comatose (153). Some conclusions of the report are as follows:

- The voluntary choice of competent patients should determine whether or not life-sustaining treatments are given.
- Health care institutions and professionals should try to enhance patients' abilities to make decisions on their own behalf.
- Health care professionals should generally maintain a presumption in favor of life-sustaining treatment, while recognizing that competent patients may refuse treatment.
- Health care professionals may decline to provide a given treatment option if it would violate their conscience or professional judgment, but in doing so, they may not abandon the patient.
- Health care institutions or society may justifiably restrict the availability of certain treatment options in order to enhance equitable allocation of limited resources.
- An appropriate surrogate, ordinarily a family member, should be named to make decisions for patients who are not decisionally capable.
- Primary responsibility for ensuring that morally justified processes of decisionmaking are followed lies with physicians. However, health care institutions should develop policies to enhance patients' competence and provide for the designation of surrogates.
- Special attention should be paid to providing respectful, responsive, competent care for people who choose to forgo life-sustaining treatment.

The 1983 report of the President's Commission supports the establishment of institutional ethics committees and passage of State legislation authorizing living wills and durable powers of attorney for health care (153). It has had a strong impact on thinking about these issues over the past 4 years. Some "right to life" advocates object to the report, however, because they believe it is biased toward the "death with dignity" position.

Several State task forces and commissions have also studied or are studying issues associated with the use of life-sustaining treatment. For example:

- In Minnesota, in 1984, the State Coalition on Health Care Costs published its report, *The Price of Life: Ethics and Economics (136)*, that discusses individual treatment decisions, allocation of health care resources, and rationing.
- In New York, a State Task Force on Life and the Law is studying the problem of discontinuing life-sustaining therapies for terminally ill people and other issues raised by new medical technologies.
- In New Jersey, a State Commission on Legal and Ethical Problems in the Delivery of Health Care is studying issues related to decisions about life-sustaining technologies and allocation of health care resources.

In other States, citizens' groups and groups associated with quasi-governmental Health Systems Agencies are also studying these issues. From 1982 to 1984, the Oregon Health Decisions Project, a privately funded project linked to the State citizens' advisory council on health policy, held meetings in local communities and with professional groups to develop guidelines for health care decisions and proposals to improve medical decision-making in the State. The project resulted in a 1984 meeting at which delegates approved a document entitled *Society Must Decide, that delineates principles and specific policy recommendations for patient autonomy, access to services, cost control, and resource allocation (46)*. Similar projects are underway in Idaho, New Jersey, Wisconsin, Washington, and Orange County, California. In Colorado, the State Hospital Association has developed an educational game called "(Critical Choices" to simulate difficult ethical dilemmas in health care decisionmaking (218).

Professional societies have also issued guidelines for decisionmaking. In 1982, the Judicial Council of the American Medical Association issued a statement on quality of life and care of the terminally ill. It said in part:

In the making of decisions for the treatment of . . . persons who are severely deteriorated victims of injury, illness, or advanced age, the primary

consideration should be what is best for the individual patient and not the avoidance of a burden to the family or to society. Quality of life is a factor to be considered in determining what is best for the individual.

The social commitment of the physician is to prolong life and relieve suffering . . . For humane reasons, with informed consent a physician may do what is medically necessary to alleviate severe pain, or cease or omit treatment to let a terminally ill patient die, but he should not intentionally cause death . . . Where a terminally ill patient's coma is beyond doubt irreversible and there are adequate safeguards to confirm the accuracy of the diagnosis, all means of life support may be discontinued (9).

In 1986, the AMA Council on Ethical and Judicial Affairs amended this statement to add that nutrition, hydration, and medications are among the "life-prolonging" treatments that may be withheld or withdrawn from persons who are terminally ill and persons who are irreversibly comatose even if death is not imminent (10).

In 1985, the Minnesota Medical Association issued a statement, "Health Care for the Elderly—A Minnesota Physician's Perspective," that discusses the roles and responsibilities of patients and physicians in decisions about life-sustaining treatments (105). Many other State and local medical associations have also issued guidelines for decisions about these treatments (12,13,15,117).

In 1984, the American Geriatrics Society issued a statement endorsing the patient's role in decisionmaking and the use of advance directives. It stated that "the patient's interests are not always best served by applying all theoretically beneficial treatments" and that patients should be offered a full range of treatment options, "including the option of supportive care for patients who are dying" (5).

Organizations that represent hospitals, nursing homes, and other health care facilities have also issued statements about patients and physicians rights and responsibilities in making medical decisions, but these organizations have generally stopped short of defining specific procedures that should be followed in making such decisions. The American Hospital Association's "Patient's Bill of Rights" (8), issued in 1973, endorses the patient's

right to receive information about his or her diagnosis, treatment, and prognosis, and “to refuse treatment to the extent permitted by law.” The American Hospital Association has encouraged the development of institutional policies for decision-making (3,160).

In 1982, the American Health Care Association, an association that represents nursing homes, issued a report on methods for designating a surrogate and making medical decisions for questionably competent nursing home residents (6). In 1984, the Association circulated a report on “Health Care Decisionmaking in Long-Term Care Facilities” which encourages the development of institutional policies for “life-and-death” decisions and discusses the considerations that should be included in such policies (7).

This OTA report does not analyze the views of different religious groups about life-sustaining treatments. It is important to note, however, that many different groups have issued statements on the subject that have profound impact on the attitudes and beliefs of their members. The statements of the Catholic Church have had a particularly strong impact. They include Pope Pius XII’s 1957 statement on ordinary v. extraordinary treatments (150) and the “Declarations on Euthanasia” issued by the Sacred Congregation for the Doctrine of the Faith in 1980 (166) (see ch. 4).

In 1983, the Law Reform Commission of Canada released a report, *Euthanasia, Aiding Suicide, and Cessation of Treatment*, that recommends that euthanasia (the intentional killing of a person for compassionate motives) and aiding suicide remain illegal in Canada. The report also states that competent patients have a right to refuse any medical treatment and that treating patients against their will is assault under criminal and civil law in Canada (104). It states that a presumption in favor of treatment should be maintained but that “quality of life” can be considered in treatment decisions, and that a patient’s incompetence does not require that physicians provide aggressive treatment in all circumstances. Finally, the report concludes that physicians, rather than courts, ethics committees, or families, should be legally responsible for ensuring that the patient’s rights and best interests are upheld in the decisionmaking process (48,104,177).

Institutional Policies

In response to a perceived need in individual facilities and to the recommendations of national and State commissions and professional associations, some hospitals and nursing homes have developed institutional policies for decisions about life-sustaining treatment. Institutional policies can specify that certain treatments are routinely used or not used for certain kinds of patients; they can designate a procedure for making treatment decisions; or both. Most existing institutional policies for decisionmaking address only decisions about resuscitation. A 1986 survey by the Joint Commission on Accreditation of Hospitals (JCAH) found that 57 percent of hospitals, 20 percent of nursing homes, and 43 percent of hospices had formal policies for decisions about resuscitation (115) (see ch. 5 for a discussion of institutional policies for decisions about resuscitation). Only 20 percent of hospitals, 15 percent of nursing homes, and 21 percent of hospices had formal institutional policies for decisions about other life-sustaining treatments.

A 1983 survey of hospitals in Minnesota found that 86 percent had policies allowing physicians to write Do-Not-Resuscitate (DNR) orders, and 44 percent had written protocols defining how DNR decisions should be made. Forty-eight percent of hospitals had policies allowing physicians to write orders limiting treatments other than resuscitation, but only 8 percent had written protocols defining how these decisions should be made (133).

A similar survey of nursing homes in Minnesota in 1984 found that 66 percent had policies allowing DNR orders; 73 percent had policies allowing limited treatment orders; and 18 percent had neither. Very few facilities had written protocols defining either the content of DNR and limited treatment orders or procedures for deciding on such orders (134).

Some nursing homes have formal procedures for ascertaining residents’ treatment preferences. At one Baltimore facility, for example, the staff determines within the first week after-admission whether the resident is capable of participating in decisions about his or her care. Soon thereafter, decisionally capable residents are asked:

While you are here, there may come a time when you become too ill to communicate with us about your medical care. Are there any specific instructions you might want us to follow at such a time? (109).

Resident responses provide a basis for further discussion of treatment preferences. These are reviewed every 2 months and whenever there is a change in the resident's condition. For those who are not capable of decisionmaking, families are involved, but not until a treatment decision is needed, because the staff believes that families should not have to make these decisions without specifics on which to base them. A multidisciplinary team is available to assist patients, families, or staff in these decisions if needed (109).

Recently, some nursing homes have begun asking residents on admission or later in their stay whether they want to execute a living will or durable power of attorney. At the Hebrew Home of Greater Washington in Rockville, Maryland, for example, social workers are meeting with groups of residents who are considered decisionally capable to talk about living wills and durable powers of attorney. Those who express interest are approached later individually to determine whether they want to execute such a document (63).

Institutional Ethics Committees

Institutional ethics committees are multidisciplinary groups established within a hospital or nursing home to address ethical dilemmas that arise in the facility (45). Ethics committees were largely unknown in this country prior to 1976, when the New Jersey Supreme Court in its decision on the Quinlan case cited an article about ethics committees by Karen Teel (184) and said that life-sustaining treatment could be withdrawn if an ethics committee agreed that there was no possibility of Karen Quinlan ever returning to a "cognitive, sapient state" (88). Despite this statement of the Court, few hospitals established ethics committees (45).

Impetus for the establishment of ethics committees came in 1983 and 1984 as a result of three developments: 1) a case in Los Angeles in which two physicians were charged with murder for withdrawing intravenous nutritional support from

a comatose patient (see ch. 3); 2) endorsement of ethics committees in the President's Commission report, *Deciding to Forego Life-Sustaining Treatment (153)*; and 3) publication of Federal regulations on treatment of handicapped infants that strongly endorse the establishment of infant care review committees (45). It is estimated that half to three-quarters of all hospitals now have an ethics committee (44)68)) and some nursing homes have ethics committees (226). (See ch. 3 for a discussion of the functions of ethics committees and differences of opinion about their role vis-a-vis the legal system).

The Baby Doe Regulations

From 1982 to 1986, controversy about the appropriate role of the Federal Government in decisions about life-sustaining treatment for individual patients was focused on the Baby Doe regulations, described below. Some observers suggested that if these regulations were upheld in court, similar regulations for elderly people, sometimes referred to as "Granny Doe" regulations, might be forthcoming (18,139). Since the Baby Doe regulations were based on Section 504 of the Handicapped Rehabilitation Act of 1973—legislation that forbids discrimination against handicapped persons of all ages in programs that receive Federal money—similar regulations for elderly people were certainly a possibility.

The Baby Doe regulations based on the Handicapped Rehabilitation Act of 1973 were struck down by the U.S. Supreme Court in June 1986. New Baby Doe regulations based on 1984 Amendments to the Child Abuse Prevention and Treatment Act are now in effect. A brief review of the regulatory and legislative history of the Baby Doe regulations is provided here because of its relevance to questions about the potential role of the Federal Government in treatment decisions for elderly people.

In April 1982, a baby was born in Bloomington, Indiana, with Down's syndrome and esophageal atresia, a defect that prevents normal feeding. His parents refused consent for corrective surgery. A circuit court judge upheld the refusal, the Indiana Supreme decided not to intervene, and the baby died. A month later, the Reagan Administration notified hospitals that Section 504 of the

Rehabilitation Act of 1973 required them to provide life-sustaining treatment for handicapped newborns (139,161).

In March 1983, DHHS proposed several procedures to implement Section 504 of the Rehabilitation Act of 1983. They included: a requirement that hospitals post notices warning against “discriminatory failure to feed and care for handicapped infants” (61); a toll-free number—the Baby Doe Hotline—to allow anyone to report suspected denial of treatment to newborns to the Federal Office for Civil Rights; and “Special Assignment Baby Doe Squads” to investigate such reports (139).

Health care, medical, and nursing associations strongly opposed the procedures, and they were subsequently struck down, revised by DHHS, and reissued in July 1983. In response to continued criticism by professional groups, DHHS revised the regulations again and reissued them in January 1984. The new regulations, which encouraged hospitals to establish infant care review committees as a first forum for review of treatment decisions were less objectionable to health care professionals (139).

Meanwhile, in New York in October 1983, another baby, Baby Jane Doe, was born suffering from spina bifida and other impairments. Her parents refused surgery to enclose her spinal column, and an unrelated individual brought suit to have the surgery done. A lower court authorized the surgery, but that order was reversed by the appellate court. Nevertheless, DHHS sought access to Baby Jane Doe’s medical records to determine whether there had been a violation of the Baby Doe regulations.

In 1984, the U.S. Court of Appeals for the Second Circuit affirmed lower court decisions that denied the Federal Government access to the medical records. The Court concluded that Baby Jane Doe did not meet the definition of “handicapped individual” in the Rehabilitation Act of 1973 and that the act was never intended by Congress to authorize Federal intervention in individual treatment decisions (16,18).

The Federal Government did not appeal this decision, but the American Hospital Association, the American Medical Association, and other groups

used it to appeal the Baby Doe regulations. The regulations were struck down in June 1984—a decision that was affirmed by the U.S. Supreme Court in June 1986 (16)18).

In the meantime, Congress had passed the 1984 Amendments to the Child Abuse Prevention and Treatment Act. The amendments define medical neglect to include withholding “medically indicated treatment” from “disabled infants with life-threatening conditions” and require State protective service agencies that receive Federal child protective service grant funds to investigate reports of medical neglect, so defined. In April 1985, DHHS issued new regulations, also referred to as Baby Doe regulations, to implement this legislation (139). Because the new Baby Doe regulations are based on legislation that applies only to children, they could not be extended to cover treatment of elderly persons. Federal legislation like the Child Abuse Prevention and Treatment Act but for elderly people remains a possibility, however.

Hospice

Hospice programs provide palliative or supportive care for terminally ill people, and thus are an alternative to the use of life-sustaining technologies. The first hospice was established in this country in 1973, and there are now about 1,500 hospice programs (142). Hospice is a concept, not a setting, and although most hospice programs provide services to people at home, many also provide inpatient care in a hospital, nursing home, or freestanding unit.

Hospice programs emphasize patient comfort rather than curing or controlling disease. Alleviation of pain is a primary objective, and patients’ emotional and spiritual needs are addressed as well as their physical needs. Care is generally highly individualized, and families are considered part of the unit of care. Care is provided by a multidisciplinary team, including nurses, social workers, home health aides, physicians, and others. Volunteers are often trained to provide counseling, emotional support, and other services (57).

Since 1982, Medicare has included a hospice benefit for enrollees who choose this type of care. The patient’s physician must certify that the pa-

tient is terminally ill—defined in Medicare regulations to mean that the person's life expectancy is 6 months or less. While covered under the hospice benefit, an individual waives some other Medicare benefits, but he or she may revoke the hospice election at any time. Medicare reimbursement to hospice programs is based on the cost of care for each patient, but there is a cap on the average cost of care for all beneficiaries (188).

Many hospice patients are elderly. The National Hospice Study, a study of 13,000 patients cared for in hospices between 1980 and 1982, found that 35 percent were age 65 to 74, and another 30 percent were over age 75 (71). The same study found that 94 percent of the hospice patients had terminal cancer. The large percentage of cancer patients in hospices occurs in part because it is easier to diagnose cancer patients as terminally ill and to predict their life expectancy than to predict the life expectancy of persons with other conditions (170). Anecdotal evidence suggests that people with organic dementias, **such as Alzheimer's disease, are seldom admitted to hospice programs** (221).

Many hospice patients, their families and friends, and hospice staff point out the tremendous value of hospice programs in helping patients and families face terminal illness and cope with the difficult physical and emotional aspects of dying (41, 227). Without questioning the positive effects of hospice for some patients, observers have raised questions about several aspects of the hospice concept and its implementation that are relevant to this report.

First, some observers argue that hospice practices cause some terminally ill people to die sooner than necessary because hospice patients forgo life-sustaining treatments that might extend their lives and because hospice programs use medications

that may shorten patients' lives. In addition, because diagnosis is uncertain, it is suggested that some hospice patients may have curable conditions that are missed because they have decided in favor of palliative care only (67). Advocates of hospice care argue in response that the benefits of this approach for the great majority of patients far outweigh these considerations.

Second, some research suggests that the care received by patients in some hospice programs may not differ significantly from conventional care. In one study, for example, terminally ill cancer patients treated in a hospital-based hospice program were compared with similar patients who received conventional care. The hospice patients reported more satisfaction with their care than the other patients, but there was little difference between the groups in number of invasive and curative treatments and no significant difference in depression, anxiety, or the frequency and intensity of pain reported by the patients (93,94). In contrast, the National Hospice Study found that hospice patients received significantly fewer intensive medical interventions and diagnostic tests than conventional care patients; there were few differences between the two groups in pain and other symptoms accompanying terminal illness or in patient satisfaction with care, however (71).

Many people argue that hospice care is less expensive than conventional care. Some studies support this contention, and others do not. Whether the cost of hospice v. conventional care is an important consideration in deciding whether hospice care should be available as a treatment option is another point of disagreement. In this context, many people argue that it is inappropriate to consider the cost of care and that the important considerations are how to provide appropriate medical care (67) and/or how to minimize patient suffering.

THE COST OF CARE

Total health care expenditures in the United States (including both acute and long-term care expenditures) constitute about 11 percent of the Nation's gross national product (GNP)—among the highest levels in the world. In 1984, these expend-

itures amounted to more than \$380 billion, the equivalent of about \$1,600 per person. Expenditures have increased dramatically in recent decades, whether measured in actual dollars, in spending per capita, or as a proportion of the GNP.

In 1960, for example, total health care expenditures constituted only 5.3 percent of the GNP, \$26.9 billion, and \$146 per capita (192).

This growth in health care expenditures has raised questions about the proportion of national resources allocated to health care and about how health care dollars are allocated among different age groups and different types of care. With regard to the latter question, the following figures are frequently cited:

- Health care expenditures for the Nation's 29 million elderly persons account for about one-third of all health care expenditures, although the elderly constitute only about 11 percent of the population.
- Medicare expenditures (which are primarily for hospital and physician services) are concentrated in a small proportion of users. In 1982, for example, 1 percent of Medicare enrollees over age 65 accounted for 20 percent of all Medicare expenditures, and the top 5 percent of Medicare enrollees over age 65 accounted for more than 50 percent of Medicare expenditures (162).
- Medicare expenditures are concentrated in the end of life. The 5.9 percent of Medicare enrollees who died in 1978, for example, accounted for 27.9 percent of all Medicare expenditures: 30 percent of this was spent for care in the last 30 days of life, 46 percent for care in the last 60 days of life, and 77 percent for care in the last 6 months of life (119).
- Finally, a small proportion of persons who die incur very high Medicare expenses in the last year of life. Three percent of elderly Medicare enrollees who died in 1978 had Medicare expenditures of over \$20,000, and 1 percent had expenditures over \$30,000 (119).

These figures are often cited to suggest that the Nation spends too much on expensive medical care for elderly people, especially in the end of life. This expensive care is assumed to include "heroic measures," such as the life-sustaining technologies discussed in this report, and it is implied, and sometimes stated openly, that such care is wasted on people who are going to die anyway. It is also sometimes suggested that public resources now spent on expensive treatment for elderly people

who are going to die anyway should be spent instead on preventive health care, medical care for younger people, improvements in long-term care for elderly people, or other public programs, such as education.

This section discusses the cost of care in the end of life and provides brief background on several related topics—determining health care costs, how technology affects costs, public programs that pay for health care for elderly people, and the concept of a "right to health care."

Determining Health Care Costs

Determining health care costs is difficult because of the many components that makeup total costs and the ambiguous relationship between costs, charges, and expenditures for health care. Health care costs can include direct, indirect, and intangible costs. Direct costs are the value of products and services related specifically to the diagnosis or treatment of an illness. They include medical costs, such as nursing personnel, equipment, and medical supplies, and nonmedical costs (e.g., travel to a physician's office, special foods, or homemaker services). Indirect costs of health care are the value of lost opportunities, such as lost income, related to mortality or morbidity. Intangible costs include pain, suffering, and other outcomes of illness that are difficult to measure. Information about the costs of medical interventions is often difficult to obtain, and even when costs are reported, they rarely include indirect or intangible costs or even nonmedical direct costs.

Frequently, the only available information about the cost of medical interventions is charges (i.e., billed amounts) or expenditures (i.e., payments). But charges and expenditures may not accurately reflect costs for a variety of reasons not discussed here. Sometimes only Medicare expenditure data are available, but they do not include the Medicare deductible and coinsurance paid by the beneficiary, charges for Medicare-covered products and services that are greater than allowed charges, or the cost of products or services that are not covered by Medicare, including outpatient drugs and most nursing home care. Information in this report about costs, charges, and expenditures should be viewed with these shortcomings in mind.

The Cost of Care at the End of Life

As indicated, a significant percentage of Medicare expenditures is for elderly people at the end of life. Research shows that expenditures for persons who die are significantly greater than expenditures for persons who do not die (128,210,211, 212). One frequently cited study (119) found, for example, that Medicare expenditures in 1978 were six times higher for elderly enrollees who died than for enrollees who did not die in that year,

These figures compare Medicare expenditures for people who died with expenditures for all other elderly Medicare enrollees, some of whom were not sick and some of whom used no Medicare-covered services. In general, people who die have been sick, and health care expenses are higher for people who are sick than for people who are not. This obvious point is sometimes forgotten in discussions about the cost of care at the end of life.

Ninety-two percent of Medicare enrollees who died in 1978 used some Medicare-covered services in their last year of life compared to only 58 percent of Medicare enrollees who did not die (119). When expenditures for these two groups of users are compared, Medicare expenditures are four times higher for those who died than for those who did not die (instead of six times higher as cited above). Thus, *part* of the explanation for higher Medicare expenditures for those who died is the greater likelihood that they used at least some Medicare-covered services in their last year of life.

The relatively high percentage of all health care expenditures for elderly people (29 percent) compared to their proportion of the population (11 percent) is also explained at least in part by the higher prevalence of illness and death among elderly people. In 1984, for example, nearly 70 percent of all decedents were elderly (216). Some people conclude from these arguments that high Medicare expenditures for elderly people who are sick or dying are reasonable and to be expected and that Medicare was enacted precisely to pay for hospital and other acute care for such people.

Although it is true that elderly people who die incur greater Medicare expenditures than those

who do not die, most elderly people who die do not incur high Medicare expenditures. Data presented in table 2-4 show that 69 percent of elderly Medicare enrollees who died in 1978 incurred less than \$5,000 in Medicare expenditures and 45 percent incurred less than \$2,000 in Medicare expenditures. Moreover, average Medicare reimbursement for persons who die decreases with age. In 1978, average reimbursement for persons over 85 who died was only about half the average reimbursement for persons age 67 to 69 who died (119).

No data are available to determine how much is spent on life-sustaining treatments for elderly persons who die, but high health care expenses, especially hospital expenses, are sometimes assumed to indicate the use of life-sustaining treatments. Further inspection of the data in table 2-4 shows that among the approximately 10,000 elderly persons who received more than \$30,000 in Medicare reimbursements in 1978, 5,000 lived, and 5,000 died in that year. Among all those who received \$20,000 to \$29,999 in Medicare reimbursements, 20,000 lived, and 19,000 died. If high Medicare expenditures do indicate the use of life-sustaining treatments, these data suggest that at least half of those who received such treatments lived.

Even so, it could be argued that the expenditures for people who died were wasted. Scitovsky points out, however, that persons who die can only be identified in retrospect:

It is easy enough, of course, to designate a patient as terminal or as dying retrospectively but an entirely different matter to do so prospectively. Despite the enormous advances of modern medicine in the past 50 years or so, medical prognosis is still highly uncertain. In fact, modern medicine, by vastly increasing the armamentarium at the physician's disposal, may well have increased the difficulty and uncertainty of medical prognosis compared to the days when the physician could do little more than give moral support to the sick. Today, predicting imminent death with any degree of certainty is difficult in the case of most patients, and predicting death 12 or 6 or even 3 months in advance well-nigh impossible (170).

When the cost of care for persons “in the last year, 6 months, or 30 days of life is reported in the media, it is sometimes erroneously assumed

Table 2-4.—Medicare Reimbursements for Decedents in Their Last Year of Life and Survivors in 1978

Reimbursement interval	Survival status			
	Decedents		Survivors	
	Number of enrollees in thousands	Amount of reimbursements in millions	Number of enrollees in thousands	Amount of reimbursements in millions
Total	1,142	\$4,969	18,342	\$13,365
No reimbursement	89	0	7,679	0
Less than \$100	86	4	3,597	159
\$100 to \$1,999	336	279	5,111	2,917
\$2,000 to \$4,999	274	919	1,252	3,984
\$5,000 to \$9,999	217	1,546	516	3,540
\$10,000 to \$14,999	84	1,024	124	1,485
\$15,000 to \$19,999	32	552	37	627
\$20,000 to \$29,999	19	439	20	479
\$30,000 and over	5	205	5	173
		Percent distribution		
Total	100	100	100	100
No reimbursement	8		42	0
Less than \$100	8	(^a)	20	1
\$100 to \$1,999	29		28	22
\$2,000 to \$4,999	24	18	7	30
\$5,000 to \$9,999	19	31	3	26
\$10,000 to \$14,999	7	21		11
\$15,000 to \$19,999	3	11	(^a)	5
\$20,000 to \$29,999	2	9	(^a)	4
\$30,000 and over	1	4	(^a)	1

^aLess than 1 percent

SOURCE J Lubitz, and R Prihoda, "The Use and Costs of Medicare Services in the Last 2 Years of Life," *Health Care Financing Review* 5(3)11 7.131, 19S4.

that their deaths were predictable. But accurate predictions are seldom possible.

The findings of one study conducted in an ICU (53) are relevant to this point. When each patient was admitted to the ICU, a physician estimated the probability that the patient would survive to be discharged from the hospital. Results of the study indicate that 9 percent of admissions ended in the death of the patient, and these patients accounted for 17 percent of all charges. Mean charges for patients given less than a 50 percent chance of survival were twice as high as mean charges for patients given a greater than 50 percent chance of survival. However, among survivors, the highest expenditures were for patients given a low probability of survival. Likewise, among nonsurvivors, the highest expenditures were for patients given a high probability of survival. The researchers concluded:

Our study confirms the association between high cost and poor outcome, and documents a similar relation between high cost and a poor prognosis However, these two results do not

follow from each other; the relations between prognosis, expenditure, and outcome are more complex than can be appreciated when a study focuses only on nonsurvivors or on subsets of patients with the poorest prognosis or the highest costs.

Among nonsurvivors, the highest charges were due to caring for patients who were perceived at the time of admission as having the greatest chance of recovery. Among survivors, the highest charges were incurred by those thought to have the least chance of recovery. Patients with unexpected outcomes (death for the patient with a good prognosis or survival for the patient with a poor prognosis) incurred the greatest costs.

Our findings emphasize the importance of clinical uncertainty in determining resource expenditures for the critically ill; when the outcome is least expected, the expenditures are greatest (53).

Many analysts have suggested that better information about the expected outcome of treatment for different types of patients could improve clinical decisionmaking. For this reason, OTA commissioned a paper on "Classification Systems for

Decisionmaking for Critically Ill Elderly Patients” and sponsored a workshop on this topic. The consensus of experts at the workshop was that existing classification systems, while valuable for many administrative and research purposes, are not sufficiently precise to be used for individual **treatment decisions**.⁵

It is frequently said that increased use of expensive life-sustaining treatments for terminally ill patients is responsible, at least in part, for rising health care costs. Scitovsky (170) has argued that the data do not support this contention, and recent analyses of Medicare expenditures for elderly enrollees in 1967, 1975, 1979, and 1982 support her conclusion. The data show that over the past 20 years, average Medicare expenditures for persons who die have increased at about the same rate as Medicare expenditures for persons who survive. According to HCFA analysts, these data indicate that “expensive methods of prolonging the lives of terminally ill patients are not the culprit behind increasing Medicare program expenditures” (162).

The preceding discussion of health care expenses at the end of life is based almost entirely on analysis of Medicare expenditures and therefore only accounts for services that are Medicare reimbursable—primarily hospital and physician services. An important component of the total cost of life-sustaining treatments that is left out of the analysis is the cost of nursing home care. **Medicare pays for only about 2 percent of nursing home care in this country, but many severely debilitated and terminally ill elderly persons spend some time in a nursing home, and some die there.**

The true cost of nursing home care associated with the use of life-sustaining technologies could be said to include the cost of care for people receiving life-sustaining treatments in a nursing home and the cost of care for nursing home residents who are alive because they ever received life-sustaining treatments in any setting. Some in-

formation is available about how many nursing home residents receive each of the treatments OTA studied, but no data are available on the number of nursing home residents who are alive because they have ever received any life-sustaining treatment in any setting.

One retrospective study of medical care expenses in the last year of life for 365 persons cared for by physicians at a California clinic in 1983 and 1984 (171) provides information about the cost of all types of care received by the patients. The study found that the average expense for medical care in the last year of life was \$22,597. Sixty percent of this was spent for hospital care; 20 percent for physician services; 13 percent for nursing home care; and 8 percent for home health care.⁶ Total average expenses decreased with age, from \$27,939 for decedents under age 65, to \$25,418 for decedents age 65 to 79, and \$17,720 for decedents over age 80. Average expenses for hospital care and physician services decreased with age: average expenses for physician services, for example, were \$8,339 for decedents under age 65, \$5,098 for those age 65 to 79, and \$2,177 for those over age 80. Conversely, average expenses for nursing home and home health care increased with age: average expenses for nursing home care were \$326 for decedents under **age 65, \$1,262** for those age 65 to 79, and \$5,407 for those over age 80.

The same study compared medical care expenses in the last year of life for decedents with different levels of functional ability defined in terms of patients’ ability to dress, bathe, and toilet themselves, and to transfer from bed to chair independently. Average medical care expenses were significantly lower for persons who were unable to perform any of the functions independently throughout the 12-month period than for persons who were able to perform all four functions independently throughout the 12 months prior to their death (171). Hospital expenses were sharply lower for persons with impaired functional ability than for persons with unimpaired functional ability. Conversely, nursing home and home health care expenses **were higher for per-**

⁵Some findings of the paper and workshop are incorporated in this report. The reader is also referred to the commissioned paper that is available from the National Technical Information Service (see app. A).

⁶Percent figures do not sum to 100 percent due to rounding.

sons with impaired functional ability. The author concludes:

Data on the relationship between functional status and intensity of care as indicated by expenses for hospital and physician services strongly suggest that the patients who got intensive care in their last year of life were persons who were functioning well during this period, whose prognosis was likely to have been good, and who were not the kind of patients a physician would feel justified in "letting die." **By contrast, persons who were in poor functional condition received largely supportive care but very little intensive hospital and physician services (171).**

When medical expenses for persons of different ages with similar functional abilities are compared, the difference in their use of specific services is striking. Among persons who were able to function independently, for example, those under age 65 had average expenses for hospital care of \$40,227, compared to \$20,864 for those age 65 to 79 and \$12,642 for those over age 80. These figures suggest some implicit rationing by age for hospital care (171).

A 1984-85 study of the last days of life of elderly decedents in Connecticut, sponsored by the National Institute on Aging, will provide further information about the relationship between service utilization and the functional ability of the individual. Results of the study are due to be released in late 1987 (34).

In summary, only a small percentage of elderly people who die incur high Medicare expenditures in their last year of life, and of all Medicare enrollees with high Medicare expenditures, half or fewer die. Thus, what is generally perceived as "the high cost of dying" may be better described as the high cost of medical care for sick people, some of whom live and some die. Over the past 20 years, Medicare expenditures for persons who die have increased at about the same rate as Medicare expenditures for people who survive. Thus, the increase in Medicare expenditures over that time is not due to disproportionate use of expensive life-sustaining treatments for people who die. Finally, the limited available information on all medical expenses in the last year of life indicate that average expenses decrease with age and functional limitations of the patient and that persons

with poor functional ability have significantly lower expenses for hospital care but higher expenses for nursing home and home health care than persons with unimpaired functional ability.

How Technology Affects Health Care Costs

Increases in health care costs can result from increases in the number of persons receiving care; wage and price inflation; and changes in service intensity, which includes changes in technology use. There is a widespread impression that new medical technologies are a major cause of rising health care costs. A 1984 OTA report found that increases in service intensity, including the use of new medical technologies, accounted for about one-fourth of the 93 percent increase in per capita hospital costs from 1977 to 1982 and for a smaller percentage of the increase in nonhospital costs over the same period (199).

Clearly the impact of technology on health care costs should not be evaluated in isolation from its effect on quality of care. There is evidence, however, that some technologies are overused and thus raise health care costs without improving quality of care (199). Overuse is sometimes blamed on what is called the "technological imperative" that is, the belief that if a technology exists, it should be used. Other reasons for overuse of medical technologies are: 1) physicians' desire to do as much as possible for their patients; 2) uncertainties about what constitutes appropriate use; 3) increasing specialization within **medicine**; 4) **public demand** for sophisticated technologies; 5) competition among hospitals to attract patients and physicians; 6) incentives created by reimbursement policies; and 7) the practice of "defensive medicine"—i.e., overuse of medical tests and procedures to defend against malpractice suits (198).

As discussed earlier, the development and diffusion of medical technologies is strongly influenced by Federal funding for research and by the coverage and reimbursement policies of Federal programs that pay for medical care. Some observers have noted that one way to limit rising health care costs would be to limit the development and/or diffusion of new medical technologies. Yet few

people advocate this approach because of its long-range impact on the quality of health care (75,85). Moreover, although many technologies raise health care costs, some reduce costs, particularly those that decrease the need for hospital care (192). At least one expert believes, however, that limiting the development and diffusion of new medical technology may be the only way to control rising health care costs over the long term (169).

Public Programs That Pay for Medical Care for Elderly People

Public programs pay for a substantial proportion of health care expenses of elderly people. In 1981, they accounted for 64 percent of all such expenses, Private insurance and out-of-pocket payments accounted for the remaining 36 percent (205).

Medicare is the Federal program that pays for medical services for most persons over 65, some disabled persons under 65, and persons with end-stage renal disease. In 1981, Medicare paid about 45 percent of all health care expenses of elderly people, including about 75 percent of hospital care, 55 percent of physicians' services, and about 2 percent of nursing home care (205).

Medicare has two parts: hospital insurance, Part A; and supplementary medical insurance, Part B. Medicare Part A covers the first 60 days of hospital care after the patient has paid an initial deductible (\$520 in 1987) and the 61st to 90th day of hospital care after the patient has paid a daily coinsurance (\$130 per day in 1987). Medicare enrollees also have a lifetime reserve of 60 days of covered hospital care, but they must pay a daily coinsurance of one-half the initial deductible (\$260 in 1987).

Medicare Part A also pays for up to 100 days of post-hospital nursing home care if the Medicare intermediary determines that the beneficiary meets Medicare's eligibility criteria for nursing home care. After the 20th day, the patient must pay a daily coinsurance (\$65 in 1987). In 1984, Medicare paid for an average of 27 days of nursing home care for eligible beneficiaries (189). Home health care, including visits of a nurse, home health aide, speech or physical therapist, or med-

ical social worker, is also covered within strict guidelines. There is no deductible or copayment for home health care. In 1984, Medicare paid for an average of 27 home health care visits for eligible beneficiaries (189).

Medicare Part B benefits include physician services, supplies ordered by physicians, outpatient hospital visits, and durable medical equipment, prosthetic devices, and other medical services and equipment provided outside the hospital. Part B reimburses 80 percent of "reasonable charges" for covered services, and the beneficiary is responsible for the remaining 20 percent, plus an annual deductible (\$75 in 1987) and a monthly premium (\$17.90 in 1987).

Medicaid is the joint Federal/State program that pays for medical services for low-income individuals of all ages. In 1981, Medicaid paid about 14 percent of all health care expenses of elderly people, including about 4 percent of hospital care, 3 percent of physicians' services, and 45 percent of nursing home care (205).

Medicaid regulations are established by each State within Federal guidelines, and eligibility requirements and covered services vary significantly among the States. In general, however, Medicaid pays for hospital care for the small proportion of elderly people who lack Medicare coverage, private insurance, or sufficient income and assets to pay for their own care. In addition to physician services and nursing home care mentioned earlier, Medicaid also pays for outpatient hospital care, laboratory services, home health care, medical supplies, drugs, and the inpatient hospital deductible for eligible individuals.

There are no deductibles or copayments in Medicaid, but limitations on allowable income and assets restrict eligibility to persons with low income in all States and very low income in some States.

The Veterans' Administration provides hospital care in VA facilities and nursing home care in VA and non-VA facilities for eligible veterans. Home care is provided through some VA medical centers. Veterans with service-connected disabilities can receive medical care through the VA. Veterans without service-connected disabilities who have income below specified levels or who con-

tribute a specified amount toward the cost of their care can also receive medical care through the VA.

Other public programs also pay for some health care expenses of elderly people but are not discussed here because they seldom pay for services related to the use of life-sustaining treatments. As of 1981, public programs other than Medicare and Medicaid but including the VA paid for about 5 percent of all health care expenses of elderly people, including 8 percent of hospital expenses, less than 1 percent of physician services, and about 4 percent of nursing home care (205).

Public Programs and the Concept of a Right to Health Care

Although health care is regarded by many people as a basic necessity and a basic human right, neither the U.S. Supreme Court nor any appellate court has ruled that there is a constitutional right to health care (154). Federal and State statutes that authorize programs to fund health care—e.g., the Medicare, Medicaid, and VA programs just discussed—thereby create entitlement rights to some health care services; that is, the intended beneficiaries of a program are considered to have a legal right to reimbursement for the health care services designated by the statute or by regulations that implement the statute. But this right does not extend to health care services not covered by the statute or regulations that implement it. Thus, for example, elderly persons enrolled in Medicare have a legal right to reimbursement for Medicare-covered services but no legal right to reimbursement for services, such as outpatient prescription drugs, that are not currently covered by Medicare. Likewise, elderly veterans have a legal right only to specific health care services designated by statute and VA regulations.

Individuals who believe they have been denied services that they have a legal right to receive under Federal or State statutes and regulations can appeal through administrative and judicial channels, but such appeals must be formulated within the limits of the statutes and regulations. The fact that an individual believes he or she needs a given health care service or that a physician says the

individual needs the service, or even that the service has already been provided is generally not considered to create a legal obligation for a public program to pay for the service unless the individual is eligible and the service is covered under the program's regulations.

In its 1983 report, ***Securing Access to Health Care***, the President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research concluded that:

Society has a moral obligation to ensure that everyone has access to adequate health care without being subject to excessive burden (154).

The Commission determined that this moral obligation does not create a corresponding moral right to health care for the individual. Furthermore, the Commission determined that the societal obligation to ensure access to adequate health care is not solely or even primarily the obligation of government. Rather it is an obligation of society in general—including individuals; public and private groups; local, State, regional, and national organizations; professional and workplace organizations; and family, kinship, and ethnic groups (154). Nevertheless, the Commission stated that:

When the (private health care) market and charity do not enable individuals to obtain adequate care or cause them to endure excessive burdens in doing so, then the responsibility to ensure that these people have equitable access to health care resides with local, State, and Federal Governments.

Although it is appropriate that all levels of government be involved in seeing that equitable access to health care is achieved, the ultimate responsibility for ensuring that this obligation is met rests with the Federal Government (154).

Some commentators have criticized the President Commission for its failure to assert a moral right to health care for the individual and for its failure to advocate a legal right to health care (see, for example, Arras, 1984 [20]). These competing positions have been the topic of extensive legal, ethical, and philosophical debate in recent decades. This debate is relevant to many of the issues discussed in this report, including the issue of how to distribute limited health care resources (see ch. 4).

CONTAINING HEALTH CARE COSTS

Concern about high health care costs in general and about public expenditures in particular have resulted in cost-containment measures in all public programs that pay for health care. This section focuses on Medicare's Part A prospective payment system (PPS) because the technologies OTA studied are provided primarily in hospitals. PPS has created increased demand for out-of-hospital care, however, and cost-containment measures in public programs that pay for nursing home and home care are also discussed briefly.

Medicare's Prospective Payment System for Hospital Care

From its inception in 1965 until 1983, Medicare reimbursed hospitals for inpatient care of Medicare enrollees on the basis of the cost of enrollees' care, subject to certain limitations. The Social Security Amendments of 1983 mandated a new hospital reimbursement system, the prospective payment system. PPS uses diagnosis-related groups (DRGs) to classify patient groups by particular diagnoses. Each DRG category has a predetermined payment that was set in the beginning to reflect the average charges per patient per hospital stay for treatment of the disease(s) subsumed under it.

The 470 DRGs are based primarily on diagnosis, but surgical procedures, patient age (i.e., under or over age 70), comorbidities, complications, and discharge status are also used to define some DRGs. Comorbidities are defined as preexisting conditions that, combined with a specific diagnosis, prolong length of stay by 1 day or more in at least 75 percent of cases. **Complications** are conditions that arise during the hospital stay and prolong length of stay by 1 day or more in at least 75 percent of cases. Comorbidities and complications exist in a particular case if a patient with a given primary diagnosis also has specified secondary diagnoses.

In some cases, patients with identical diagnoses are covered by two DRGs; one includes patients who are over age 70 or have comorbidities or complications, while the other includes patients who are under age 70 and have no comorbidities or complications. Reimbursement for the former

DRG is higher than for the latter, and patients who are over age 70 are in the former DRG automatically. There is no additional reimbursement for comorbidities or complications for them.

Patients are assigned to a DRG when they are admitted to a hospital. Those who remain in the hospital much longer than the average length of stay or have much higher than average costs for their DRG category are called "outliers." Medicare reimbursement for outliers is based on the marginal cost of care. Reimbursement for length-of-stay outliers, for example, is 60 percent of the appropriate per diem amount. Outlier payment policy has been a controversial aspect of PPS since its inception. Although outlier payments help to defray losses incurred by hospitals in the care of unusually expensive cases, they do not cover the full cost of these cases, nor are they intended to (158).

The purpose of PPS is to reduce Medicare expenditures while maintaining an acceptable level of quality of care and access for beneficiaries. Since hospitals make money on patients whose care costs less than the fixed payment for their DRG and lose money on patients whose care costs more than the fixed payment, PPS creates a financial incentive for hospitals to decrease the cost of treating a patient in a single hospital stay. Strategies hospitals can use to do this include reducing a patient's length of stay, reducing the intensity of services (i.e., number of services provided), and reducing staffing levels (202).

PPS is based on the assumption that some of the services provided by hospitals in the past were unnecessary or were produced inefficiently, and that cost containment can be achieved by eliminating such services without sacrificing quality of care or restricting access to necessary care. It is recognized, however, that the system will have both positive and negative impacts. The potential positive impacts of reduced length of stay and reduced intensity of services include psychological benefits for some patients, reduced use of **unnecessary services, and lessened chance of iatrogenic events (infections, drug reactions, or other problems that result from medical treatment)**. Potent-

tial negative impacts include decreased access to and use of necessary services and premature discharge of hospitalized patients (202).

PPS is expected to affect the care of different kinds of patients in different ways, and analysts have identified several groups of elderly patients who may be at risk of reduced quality of care, reduced access to necessary care, or both. They include:

- the oldest elderly (74,202, 215),
- patients with multiple conditions (28)84)131, 156)202))
- severely or critically ill patients (28,176),
- patients with end-stage renal disease (215),
- patients who require nursing home or home health care following hospital discharge (131), and
- the poor elderly (215).

These groups overlap. Common factors among them are the likelihood that patients in each group will remain in the hospital longer or incur higher costs than other patients in the same DRG. Patients in these groups have been called “DRG losers.” Since they are relatively easy to identify, some observers fear that some hospitals will refuse to admit them or transfer them to public hospitals, a phenomenon called “dumping”; that they may not receive all the services they need; and that they may be discharged too soon (28)56)176). Other observers argue that professional ethics and fear of malpractice suits will outweigh financial incentives to reduce services for these patients and that high quality care will be maintained (215).

Average length of hospital stay, number of hospital admissions per 1000 population, and hospital occupancy were all dropping before PPS began and have continued to drop since then, although average length of stay for adults increased slightly in 1986. Hospital staffing levels have dropped since PPS began, and the incidence of patients being transferred to other hospitals has increased (86)158,215). These objective findings have no clear implications for either quality of care or access to care, however. A growing volume of anecdotal evidence and research findings indicate, in addition, that some patients are being discharged “quicker and sicker” (58,121,167,193, 195)206)207).

There are also reports that some hospitals are using the **average** length of stay and **average** cost of care for DRGs as **maximum** lengths of stay and costs (157). Statistical analysis of length of stay data for fiscal year 1986 indicate that this practice, if it exists, is not widespread (40). Nevertheless, since PPS began, an unknown number of patients have been told, improperly, that they had to leave the hospital because their Medicare coverage had run out (157,191,223).

In response to recent polls sponsored by HCFA, the American Society of Internal Medicine, the American Medical Association, and the National Opinion Research Center, one-half to three-quarters or more of the physicians surveyed reported being asked by hospital administrators to reduce lengths of stay, diagnostic testing, and medical procedures in general (130). According to polls and anecdotal reports, many physicians believe that such reductions in length of stay and service intensity are reducing quality of care and access to care (14)86,138,233).

Before PPS and on a continuing basis, experts have identified problems in quality of care and access to care that could occur in response to the system (28,174,202). ProPAC, other public and private agencies, and professional associations are monitoring its impact. HCFA is conducting numerous studies to identify and evaluate the effects of PPS (215), **but the adequacy** of this research has been questioned by OTA, the General Accounting office, and some congressional committees (193,202,207).

A major problem in evaluating the effects of PPS is the difficulty of defining and measuring quality of care. Ideally, quality of care could be evaluated in terms of patient outcomes, but there are many problems with this approach (202). As one observer has noted:

Negative outcomes (e.g., death, disability) are inevitable given the current state of the medical art—despite tremendous technologic advances, many diseases still elude a cure. **This problem is especially pertinent to those elderly with multiple comorbidities. Therefore, the key to outcome studies is to try to disentangle inappropriate outcomes from those which were unavoidable. Once this task is complete, the negative outcome must be linked with some step or misstep in the proc-**

ess of care. Even in settings of clinical trials, establishing this causality may prove a complex task fraught with pitfalls (84).

The Institute of Medicine, OTA, and other public and private agencies are currently studying aspects of the problem of measuring quality of care.

Under PPS, hospitals are required to contract with a peer review organization (PRO) to monitor quality of care and evaluate the medical necessity and appropriateness of admissions, inpatient procedures, discharges, and readmission (202, 215). PRO reviews can result in reclassification of a case from one DRG to another or in total payment denial. In addition, if PRO reviews indicate a pattern of prohibited actions, the Inspector General can terminate the Medicare provider agreement with the responsible hospital, thus prohibiting any Medicare payments to the hospital (215).

Many questions have been raised about the adequacy of the PRO review process in monitoring quality of care (156). Some observers say that PROS have focused more on cost-containment objectives, such as limiting unnecessary admissions and medical and surgical procedures, than on maintaining quality of care (114,125,202). This focus is changing, however, in response to public, congressional, and administration concern about quality of care.

A variety of other measures to ensure quality of care and access to care have been implemented or are being studied. In response to complaints that some patients were being discharged too soon or told that Medicare would not cover their hospitalization, DHHS mailed a notice to each Medicare beneficiary explaining Medicare discharge regulations and how to appeal a premature discharge (214). In addition, ProPAC and other agencies are studying methods of improving the case-mix formulas on which DRGs are based in order to reduce financial incentives for hospitals to deny or limit care for "DRG losers." Under the current system, patients in the same DRG vary greatly in terms of severity of illness, resource use, and the cost of their care. Yet the hospital receives the same payment for all patients in the same group. Addition of a severity of ill-

ness measure to the DRG system has been proposed (28,82,176) and is being studied by ProPAC. DHHS recently proposed dropping age as a patient classification variable in PPS because age is not a good predictor of resource use once patient comorbidities and complications are taken into account (183).

None of the preceding discussion addresses the impact of PPS on life-sustaining technologies directly. Clearly the system is not intended to reduce access to or the quality of such treatments. Available evidence as to its impact is discussed in other chapters.

Analysis of the impact of PPS in general or on specific technologies is complicated by the fact that PPS is only one of the factors changing the health care system. These factors include the supply of physicians, enrollment in HMOs and other health care delivery systems that limit hospital use, the emphasis on price competition in medical care in general, and changes in coverage and reimbursement policies in other public programs that pay for medical care. Separating the impact of PPS from the effects of these other factors is difficult, if not impossible, at present (84,86,202).

Cost-Containment Measures in Public Programs That Pay for Nursing Home and Home Health Care

Earlier discharge from hospitals of sicker patients has increased the demand for post-hospital nursing home and home health care (121,144, 156,167,194,195,215). Yet cost-obtainment measures in the public programs that pay for these services may be limiting access to them, at least in some parts of the country.

As a result of very restrictive eligibility and coverage policies, Medicare pays for only about 2 percent of all nursing home expenses in this country. Recently, there have been reports of increased denials of Medicare reimbursement for nursing home care due to tighter interpretation of existing regulations by some Medicare intermediaries (143,145).

Prior to PPS, patients who could not be placed in nursing homes remained in hospitals, paid for under the Administrative Days Program. PPS cre-

ates strong financial incentives for discharging such patients from hospitals now.

A 1986 survey by the General Accounting Office found that 97 percent of hospital discharge planners reported having problems placing Medicare patients in skilled nursing facilities. More than half of those surveyed reported that the percentage of patients waiting in the hospital for placement in post-hospital care was greater in 1985 than in 1982 (195).

Medicaid pays for about 45 percent of all nursing home care, but because Medicaid patients must contribute their own resources toward the cost of their care, Medicaid actually covers a much higher proportion of nursing home residents—65 to 75 percent nationally (220) and 85 to 90 percent in some States (64). Thus Medicaid policies have a strong impact on access to nursing home care.

In recent years, most States have instituted programs to limit Medicaid nursing home expenditures. These include preadmission screening programs, limitations on reimbursement per case, and certificate-of-need programs that restrict the supply of nursing home beds. As a result of differences between States in these cost-containment

measures and other factors not discussed here, access to nursing home care for Medicaid patients varies greatly among States. Nursing home bed supply, that affects access for all patients, varies greatly, from a high of 94 beds per 1,000 elderly persons in Wisconsin to a low of 22 beds per 1,000 elderly persons in Florida (190).

Medicare-covered home health care is limited to patients who are confined to their homes and are in need of skilled nursing care or physical or speech therapy for acute conditions. Long-term home health care needed to maintain patient functioning is not covered. Effective July 1985, new Medicare regulations, intended to decrease expenditures, have been put into effect. National and State surveys and anecdotal evidence indicate a recent increase in denials of home health care claims by Medicare (143,196,208). In 1987, 14 Congressmen, 3 home health care agencies, 17 Medicare beneficiaries, and the National Association of Home Care filed suit in the U.S. District Court against DHHS for “irrational and unexplained coverage determinations which fail to take into account and consideration individual patient needs, the attending physician’s opinion, and community medical practice” (182).

WHY FOCUS ON THE ELDERLY?

Concern about the use of life-sustaining technologies for elderly people arises in part from awareness of the increasing size of the elderly population and the possibility that many elderly people may be candidates for life-sustaining treatments. This section discusses the growth of the elderly population and patterns of disease and mortality that make many elderly people candidates for life-sustaining treatments. In addition, some reasons to suspect that decisions about the use of life-sustaining treatments and the outcome of treatment may differ for elderly and younger people are discussed.

Growth of the Older Population

The number of elderly people in this country has increased dramatically in this century and will continue to increase well into the next century,

as illustrated in table 2-5. In 1900, there were 3 million people over 65. Now there are about 29 million. By 2010, there will be about 39 million. The elderly population is growing at a faster rate than younger age groups. Thus the percentage of elderly people in the population has also increased—from 4 percent in 1900 to 11 percent now—and is projected to reach 14 percent by 2010 and 22 percent by 2050 (209).

Among those over 65, the older groups (age 75 to 84 and 85+) are growing at a faster rate than the younger group (age 65 to 74). The group age 75 to 84 is expected to increase from about 7.7 million people now (3 percent of the population) to 12 million in 2010 (4 percent of the population) and 21 million in 2050 (almost 7 percent of the population). The age group 85 +, which is the fastest growing age group in the population, is

Table 2-5.—Growth of the Older Population: 1900 to 2050 (numbers in thousands)

Year	Total population all ages	65 to 74 years		75 to 84 years		85 years and over		65 years and over	
		Number	Percent	Number	Percent	Number	Percent	Number	Percent
1900	76,303	2,189	29	772	10	123	02	3,084	40
1910	91,972	2,793	30	989	11	167	02	3,950	43
1920	105,711	3,464	33	1,259	12	210	02	4,933	47
1930	122,775	4,721	38	1,641	13	272	02	6,634	54
1940	131,669	6,375	48	2,278	17	365	03	9,019	68
1950	150,697	8,415	5.6	3,278	2.2	577	04	12,270	81
1960	179,323	10,997	6.1	4,633	2.6	929	05	16,560	92
1970	203,302	12,447	6.1	6,124	3.0	1,409	07	19,980	98
1980	226,505	15,578	6.9	7,727	3.4	2,240	10	25,544	11.3
1990	249,731	18,054	7.2	10,284	4.1	3,461	14	31,799	12.7
2000	267,990	17,693	6.6	12,207	4.6	5,136	19	35,036	13.1
2010	283,141	20,279	7.2	12,172	4.3	6,818	24	39,269	13.9
2020	296,339	29,769	10.0	14,280	4.8	7,337	25	51,386	17.3
2030	304,330	34,416	11.3	21,128	6.9	8801	29	64,345	21.1
2040	307,952	29,168	9.5	24,529	8.0	12,946	4.2	66,643	21.6
2050	308,856	30,022	9.7	20,976	6.8	16,063	5.2	67,061	21.7

SOURCE: U.S. Department of Commerce, Bureau of the Census, *America's Transition: An Aging Society*, Series P-23, No. 128, Washington, DC: U.S. Government Printing Office, September 1983.

projected to increase from about 2 million now (1 percent of the population) to almost 7 million in 2010 and 16 million in 2050 (5 percent of the population) (209).

Life expectancy at birth has increased dramatically from 49 years in 1900 to 74 years in 1981 (209). Most of this gain has been due to increased survival past the high risk period of infancy and early childhood. In 1900, for example, only two-fifths of all babies born alive could expect to live to age 65. Today, more than three-fourths of all babies born alive are expected to reach age 65 (163).

Advances in life expectancy after age 65 have been minimal by comparison. A person who reached 65 at the turn of the century could expect to live another 12 years. Today a 65 year-old can expect to live another 17 years. Of the total gain in life expectancy of 5 years, one-half was achieved between 1900 and 1960, and the other half between 1960 and 1983. Hence it appears that life expectancy at older ages has been increasing at a faster rate in the past two decades than previously.

Patterns of Disease and Mortality

Most older people do not suffer from serious illness and are able to function quite well, but the likelihood that persons will suffer from chronic

and acute illnesses increases with age, especially after age 75 or 85. The older population has the highest prevalence of chronic conditions such as heart disease, chronic obstructive pulmonary disease, atherosclerosis (deposits of fatty substances within the arteries, or "hardening of the arteries"), and hypertension (persistently high arterial blood pressure). In turn, these chronic conditions increase the risk of acute medical episodes including heart attacks, respiratory arrests, strokes, and pneumonia (216).

Trends in mortality among all age groups since the turn of the century have shown substantial declines in deaths due to infectious diseases, and in age-specific death rates from heart disease, some types of cancer (malignant neoplasm), and cerebrovascular diseases (strokes). These three diseases are the major causes of death in the elderly (see table 2-6).

In general death occurs at older ages than in the past. In 1984, 70 percent of all deaths occurred in the age group over 65; 24 percent among people age 65 to 74; 27 percent among those age 75 to 84; and 19 percent among people over 85. Since elderly people are at greater risk than younger people of chronic and acute illnesses and death, they are also more likely candidates for life-sustaining treatments.

**Table 2-6.—Top Ten Causes of Death, Population Aged 65 and Over,
United States: 1980**

Rank	Cause of death	Number per 100,000 65+	Percent of all deaths
1	Heart disease	2,330	44.4
2	Malignant neoplasms	1,011	19.2
3	Cerebrovascular diseases	573	10.9
4	Pneumonia and influenza	178	3.4
5	Chronic obstructive pulmonary diseases	171	3.2
6	Atherosclerosis	110	2.1
7	Diabetes mellitus	99	1.9
8	Accidents and trauma	97	1.8
9	Nephritis and related conditions	51	1.0
10	Chronic liver disease and cirrhosis	37	0.7
All causes		5,252	100.0

SOURCE: National Center for Health Statistics, Division of Vital Statistics, *Vital Statistics of the United States Vol // Mortality* published and unpublished data

Reasons Why Decisions About Life-Sustaining Treatments or Their Outcome May Differ for Elderly People

In addition to the size of the elderly population and the likelihood that large numbers of elderly people may be candidates for these treatments, concern about life-sustaining treatments for them arises from the expectation that use of these treatments and their outcome may differ for elderly and younger people. Reasons for this expectation, that could be considered some of the hypotheses for this OTA assessment, are discussed briefly below. They are hypotheses, not conclusions, and findings relevant to them are presented in later chapters.

Since, in general, elderly people have a higher prevalence of chronic disease and decreased physiological reserve, there is reason to expect that life sustaining treatments will have poorer outcome for them than for younger people.

The greater prevalence of chronic disease among elderly people means that elderly people with life-threatening conditions are likely to have one or more coexisting chronic conditions that tend to complicate their treatment and lead to poorer outcome. In addition, longitudinal investigations such as the Framingham Heart Study, the Duke Longitudinal Studies of Normal Aging, and the Baltimore Longitudinal Study on Aging have established that chronological age generally is accompanied by progressive reductions in

“physiological reserve,” i.e., the functioning and efficiency of major organs.

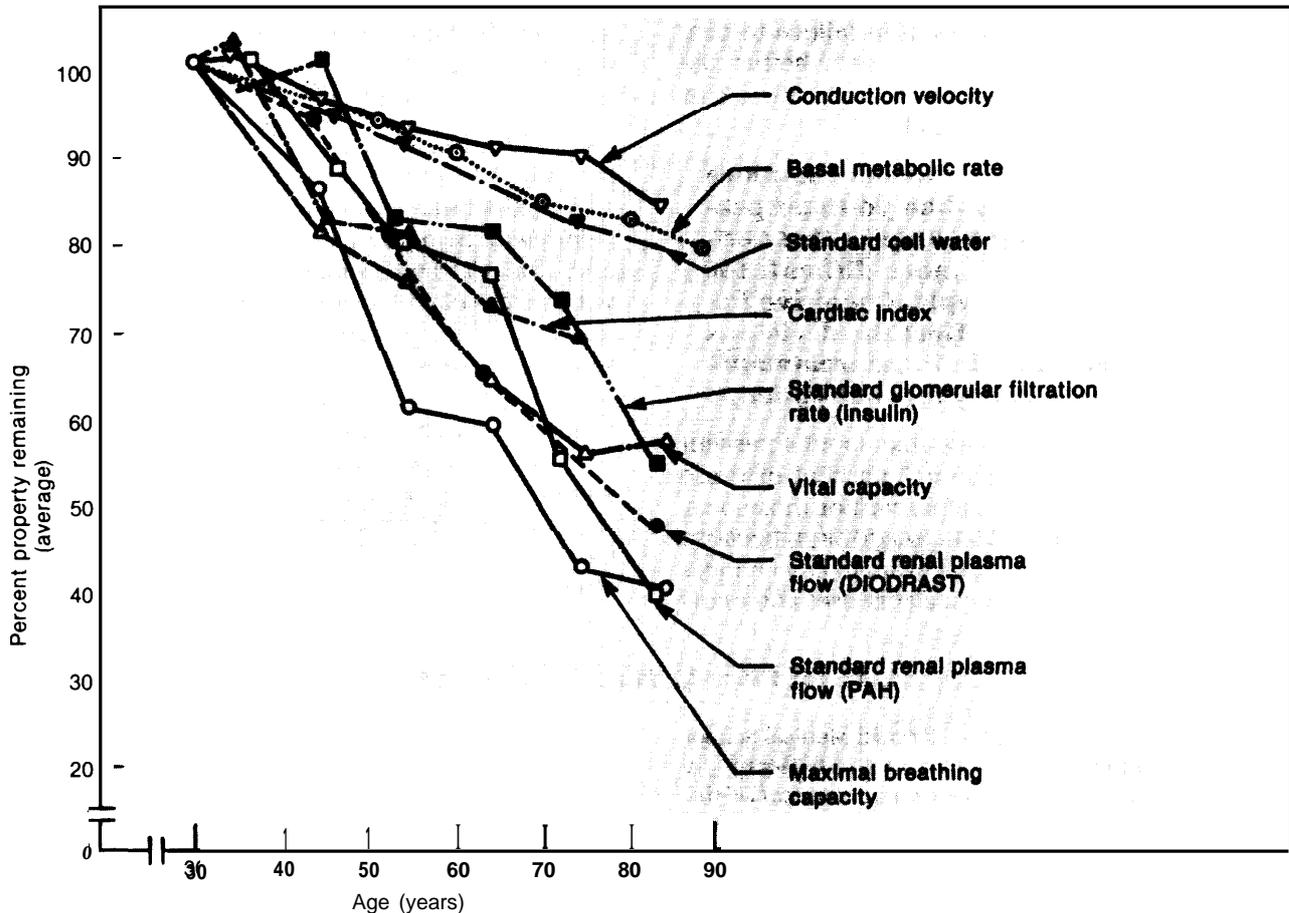
Decreased physiological reserve is different from disease and may not affect an individual’s normal functioning. However, it reduces the body’s ability to cope with physiological stress, such as acute illness or trauma and, therefore, complicates the treatment of disease and places the individual at greater risk of poor outcome (165). Some changes in average physiological functioning with age are illustrated in figure 2-2.

The rate of reduction in physiological reserve associated with aging varies greatly from one individual to another. In fact, although the physiological status of the older population is certainly poorer as a whole, variation in physiological functioning among individual older persons is greater than in any other age group.

Since elderly people have lived many years and at best have only a limited number of years left, and since they have higher prevalence of chronic conditions and may have lost family and friends, there is reason to expect that their quality of life may be poor and that they may be less willing to accept the burdens of life-sustaining treatment, and more ready to die than younger people.

This hypothesis is seldom stated in full but often appears to underlie some people’s attitudes about life-sustaining treatment and elderly people. The elements of the hypothesis—that, on average,

Figure 2-2.—Changes in Physiological Functioning, by Age



SOURCE: N. W. Shock, "The Physiological Basis of Aging," *Frontiers in Medicine: Implications for the Future*, R.J. Morin and R.J. Bing (eds.) (New York, NY: Human Sciences Press, 1985).

elderly people have fewer years left to live than younger people, that they have higher prevalence of chronic conditions, and that many of their relatives and friends may have died—are demonstrably true. The conclusion, however, is not obvious, and OTA is not aware of any data to support it. Anecdotal evidence is contradictory. One observer has commented that older people are more resigned to death than their caregivers (186). Others have commented, however, that elderly people may be more willing to accept a relatively poor quality of life than younger people (77). Generalizations in this area are fraught with difficulties. Nevertheless, the chapters present what is known about differences between elderly and younger people in their attitudes toward maintaining their own lives with the technologies OTA studied.

Because people believe that life-sustaining treatments will have poorer outcome in elderly than younger people, that elderly people have poorer quality of life, and that they maybe more ready to die than younger people, and because of a pervasive ageism in our society, there is reason to expect that life sustaining treatments may be provided less often for elderly than younger people and that, as a result, some elderly people who might benefit from treatment do not receive it.

Negative stereotypes about aging and elderly people among health care providers and the public in general have been well documented (26)39, 120)129,230). When compounded by doubts

about the outcome of treatment and doubts about whether elderly people want to live longer, these negative attitudes could result in failure to provide treatment. The report discusses whether age in itself is a factor in decisions about the use of the technologies OTA studied,

Since cognitive impairment is more prevalent in elderly than younger people, there is reason to suspect that decisionmaking may be more difficult for and with elderly people. Cognitive impairment may also affect the decisions that are made and limit the treatments that can be used safely for such patients.

Current estimates indicate that about 1 percent of those age 65 to 74, about 7 percent of those age 75 to 84, and about 25 percent of those over age 85 have dementia (204). In addition, because of the sensitivity of the aging brain to any changes in physical condition, almost all diseases and many

medications can reduce cognitive functioning in elderly people (179). As a result, there is reason to expect that more elderly than younger people who are candidates for life-sustaining treatments are cognitively impaired.

Cognitive impairment limits the capacity of the individual to participate in treatment decisions and necessitates involvement of a surrogate decisionmaker in many cases. Families, physicians, and other caregivers may conclude that persons with severe cognitive impairment have very poor quality of life, and they may decide on this basis that some life-sustaining treatments should be withheld or withdrawn. Finally, treatments that require the cooperation of the patient may not be usable for patients who are cognitively impaired. The report discusses what is known about the relationship between a patient cognitive status and the life-sustaining technologies OTA studied.

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