

chapter 4

Ethical Issues

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Ethical Issues

INTRODUCTION

Modern science has brought about dramatic changes in medical care, particularly since the early 1950s, and technology now gives people considerable power to alter both the quality and length of human life. However, the use of life-sustaining technologies such as the five examined in this assessment—resuscitation, mechanical ventilation, dialysis, nutritional support, and life-sustaining antibiotics—raises many important ethical questions. Society thus finds itself asking difficult questions about individual rights, the processes of living and dying, and the proper distribution of technological resources. The use of life-sustaining technologies necessitates the development of an ethical vision that is acute enough to discern the needs and wants of particular individuals and yet wide-ranging enough to guide contemporary public policy. This chapter explains some of the major ethical debates that have occurred in the public, academic, and clinical domains about these issues.

Ethical analysis can help clarify ethical dilemmas. Such dilemmas occur where any possible solution to a problem seems to involve some type of harm or where it only seems possible to achieve a good outcome through the use of unethical means. In these difficult cases, ethical analysis may not point definitively to one and only one “right” answer, but it can clarify competing systems of justification for certain courses of action. It can also show where different principles or methodologies for decisionmaking are needed. (For an international list of organizations specializing in ethical analysis, see app. D.)

The Relationship Between Ethics and Law

It is a fact of life in our society that an emerging moral or ethical consensus may not be embodied in existing statutes and that the legal system may actually pose barriers to the resolution of ethical

dilemmas. Nonetheless, legal cases in which the rights and interests of competing parties are adjudicated provide public access to the analysis of competing points of view. These points of view often consist of important ethical arguments.

The growth of newer types of deliberative bodies such as institutional ethics committees provides an important alternative or adjunct to the legal system. A terminally ill elderly person, for example, cannot wait for the results of a protracted legal battle to evaluate his or her claims and preferences for or against life-sustaining treatment. In addition, the establishment of a legal precedent concerning one use of a particular life-sustaining technology may not be relevant or meaningful in other cases. Certain features of the legal system may make it difficult to resolve the ethical dilemmas associated with the use of life-sustaining technologies.

Ethics in Clinical Practice

The growing role of ethicists and ethics committees in health care settings is an important development. Several State courts have specified a role for institutional ethics committees in all decisions to withdraw or withhold life-sustaining



Photo credit: Hennepin County Medical Center, Minneapolis, MN

Biomedical ethics committee at work.

treatment (see ch. 3). Ethics committees can provide an opportunity for multidisciplinary input regarding problems that require several types of expertise and their membership can represent the plurality of values present in American society. Committee deliberations can build consensus that may also be helpful to patients and their families

at times of crisis. Reservations about the utility of ethicists and ethics committees usually center on the way in which their input will be used and the amount of authority that will be given to their recommendations. Guidelines about the roles of ethicists and ethics committees are still in an early phase of development (17).

ETHICAL ISSUES IN THE CARE AND TREATMENT OF INDIVIDUAL PATIENTS¹

Four ethical principles are of great use in analyzing dilemmas concerning the use of life-sustaining technologies:

1. Beneficence = being of benefit to others;
2. Nonmaleficence = not harming—including not killing others (sometimes viewed as a subset of the principle of beneficence) (26);
3. Respect for persons = treating others as ends in themselves and showing regard for their autonomy (sometimes called the principle of respect for persons or the principle of autonomy); and
4. Justice = treating others fairly according to principles of equity in the distribution of benefits and burdens.

Other independent or derivative principles have been recognized, including privacy, truthfulness, and fidelity in keeping promises and contracts (6,42).

Because of the strong prohibitions that are derived from the second principle, which in the Hippocratic tradition of medicine is interpreted as "first or at least do no harm," both suicide and mercy killing are generally prohibited in our society. Death is viewed as a major—often the major—harm, and thus deliberately engaging in actions that bring about, hasten, or cause death is an obvious wrong as a violation of the principle of nonmaleficence. This principle is so important that most traditions tend to justify killing persons only in self defense, war, and capital punishment. Most traditions tend to view acts that cause the deaths of innocent persons, even those who are suffering greatly, as justifiable only if they do not involve the direct *killing* of those persons.

¹This section is based in part on a paper prepared for OTA by James F. Childress, 1985 (14).

In decisionmaking about life-sustaining technologies, distinctions are sometimes made between *withholding v. withdrawing treatment*, *direct v. indirect effects* of actions, *letting die and killing*, and *ordinary and extraordinary* means of treatment. These distinctions are analyzed below.

Withholding v. Withdrawing

Physicians, nurses and other health care providers often feel that the distinction between *withholding* (not starting) and *withdrawing* (stopping) life-sustaining technologies is very important, even though it is hard to defend in terms of various ethical traditions. The following case illustrates the appeal of this distinction:

Case 1: An elderly man was suffering from several major medical problems, including terminal cancer, with no reasonable chance of recovery. The patient was clearly incompetent and could not communicate with others; he had no family to serve as surrogate decisionmakers. The members of the staff caring for the patient had easily and quickly agreed on a "no code" or "do not resuscitate" (DNR) order. They felt comfortable with this decision because of the patient's overall condition and prognosis and because not resuscitating the patient in the event of cardiac arrest could be viewed as withholding rather than withdrawing treatment.

The patient was being maintained by intravenous nutrition and hydration and was receiving antibiotics to fight infection. Several members of the team thought that all medical treatment, including artificial nutrition, hydration, and antibiotics, should be stopped, but others thought that it would not be right to stop these treatments. However, when an intravenous line slipped out of place, some of the latter group concurred that

it was not obligatory to start the line again, especially if it involved a more invasive insertion procedure, because this could be viewed as *starting* rather than *continuing* a treatment. Others sharply criticized this use of the distinction between withholding and withdrawing treatments on the grounds that it was a self-deceptive rationalization (14).

Perhaps the clearest rationale for the distinction between withholding and withdrawing treatments is that in initiating a life-sustaining treatment, a physician or other health professional makes a promise, or engenders expectations, which, on grounds of fidelity or loyalty to the patient, require that the treatment not be stopped. An opposing view, however, is that a physician's fundamental promise is to act in accord with the patient's wishes and interests (the principles of beneficence and respect for persons), and this can override the original or implied promise to the patient.

Some professionals reportedly have been reluctant to start treatments in some circumstances for fear of being locked into their continuation. Yet, it is often necessary to start life-sustaining treatments to gain time and information for better diagnosis, prognosis, and decisionmaking. The President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research argued in 1983 that the burden of proof should be higher for withholding than for withdrawing treatment since a judgment about the latter could presumably be reached on more solid grounds (30). The Commission states "whatever considerations justify not starting should justify stopping as well." The Commission concludes that neither law nor public policy should mark a difference in moral seriousness between stopping and not starting treatment (30).

Direct v. Indirect Effects

The application of the distinction between *direct* (intended) and *indirect* (unintended but foreseen) effects of actions has often been used in the Roman Catholic tradition and in others to distinguish morally acceptable actions that have indirect, unintended, or merely foreseen effects such as death from morally prohibited actions of

suicide or murder. Traditionally the distinction between direct and indirect effects has involved four conditions: 1) the action in itself must be good or at least ethically neutral; 2) the agent must intend only the good effect and not the evil effect; 3) the evil effect cannot be a *means* to the good effect; 4) there must be proportionality between the good and evil effects of the action, that is, a proportionately strong reason for allowing the evil effect to occur. The evil effect is allowed, but not sought; it is foreseen, but not intended. This is called the rule of double effect (6,8,23).

Most often, the distinction between direct and indirect effects is invoked when there is a conflict between obligations or values and it is not possible to meet or realize all of them simultaneously. For example, a conflict may arise when, in the care of a terminally ill patient, the principle of nonmaleficence establishes a duty not to harm or kill the patient, while the principles of beneficence and respect for persons establish a duty to make the patient comfortable by relieving pain or inducing sleep. In some situations, it may be possible to make the patient comfortable only by engaging in actions that hasten the patient's death. According to the Ethical and Religious Directives for Catholic Health Facilities, "it is not euthanasia to give a dying person sedatives and such a measure is judged necessary, even though it may deprive the patient of the use of reason, or shorten his life" (37).

The rule of double effect thus distinguishes between relieving pain at the risk of bringing about death and relieving pain by bringing about death. According to some critics of the distinction, the question is not whether death is *intended* as an end or as a means, but *how* death is brought about. These critics assert that society has moral reasons for excluding some means of bringing about death, even if there is agreement among all the parties, including the patient, that he or she would be better off dead.

Letting Die and Killing

Case 2: A 62-year-old patient was hospitalized for metastatic cancer of the colon. When it became clear that he would not likely benefit from

either chemotherapy or radiation, the patient refused further laboratory tests, antibiotics, transfusions, and dialysis, while accepting pain medication, nasogastric suction, and intravenous fluids. Four days later he asked doctors to "speed up" his death, less because of his pain and discomfort and more because he could not endure the dying process any longer and did not want to jeopardize his family's limited financial resources. The staff gave substantial doses of morphine and diazepam, with the agreement of the patient and family (20).

This case cannot be brought under the rule of double effect for "allowed deaths"; the medication was not given to relieve pain at the risk of hastening death. It was not a case of letting the patient die but rather one of directly and actively killing the patient at his request by the administration of toxic drugs.

Sometimes the distinction between killing and letting die is discussed under other headings, such as omission and commission or passive and active, because it is argued that more descriptive terms are needed to replace "killing," which most people tend to view as wrong, and "letting die," which most tend to view as right. Thus, the President's Commission (30) used the descriptive phrases: *actions that lead to death* and *omissions that lead to death*. Whatever terms are employed, the issues are the same.

Most ethical traditions have a rule prohibiting the direct, active killing of patients, even though they disagree about the foundations of that rule. Some traditions hold that it is intrinsically wrong to kill innocent persons; others hold that it is not intrinsically and absolutely wrong to do so, for example, when the suffering patient requests "mercy killing," but that a rule prohibiting mercy killing is necessary to prevent bad consequences for future patients and ultimately for the society. Thus, many people who deny that acts of killing innocent persons are always wrong still support a rule of practice that prohibits such acts because of the dangers of abuse, loss of trust between professionals and patients, and subversion of the societal commitment to the protection of human life.

Some critics hold that there is no intrinsic ethical difference between killing and letting die and that "letting nature take its course" is not appropriate when interventions are available. These critics argue that whether there is an ethical difference between killing and letting die will depend on the circumstances of the case. Thus, in a widely discussed article, one philosopher contends that the "bare difference" between acts of killing and acts (omissions) of letting die is not in itself an ethically relevant difference. He argues his point by sketching two cases that differ only in that one involves killing, while the other involves allowing to die, and asks whether we would make different ethical judgments about the cases (31). In those cases—killing a 6-year-old cousin or letting him die to gain a large inheritance—both acts are equally reprehensible because of the agent's motives, ends, and actions or inactions.

But reprehensible illustrations may obscure the significance of the distinction in other cases where agents are trying to benefit (rather than harm) patients and where they are also concerned about broader social consequences and protecting society's commitment not to let innocent people be killed. Although the distinction between killing and letting die may not be important in some contexts, this distinction may be important in other cases, because of other moral principles and rules.

The prohibition against direct, active killing of innocent persons is built into the legal system as well as into professional codes and religious and humanistic traditions. Arguments to change this rule often appeal to cases of extreme, intractable pain and suffering, usually related to a slow death from cancer. According to critics of the rule, a failure to kill a patient in circumstances where the patient pleads for "(mercy)" is cruel and inhumane.

Several counterarguments have been offered, however. First, it is not clear that there are many cases of uncontrollable pain and suffering; in the medical setting (perhaps in contrast to the battlefield or an accident) pain can usually be controlled, although its relief may hasten death (which is acceptable according to the rule of double effect). A second argument is that permitting mercy kill-

ing will divert attention from finding methods short of killing, for example, institutional and social options such as hospices that can reduce the pain and suffering to tolerable levels and permit compassionate social and personal attention from the community.

Since the need to change society's standard in order to allow mercy killing to relieve pain and suffering is uncertain, and since such a change presents potential dangers to society through abuse, decline of trust within medical relationships, and the threat to the principle of nonmaleficence that prohibits killing, there do not appear to be sufficient reasons to change the prohibition against killing. Some people argue that the burden of proof should be on those who would maintain a rule that infringes on the principle of autonomy. However, it is plausible to argue that the policy and practice of prohibiting killing (while accepting some cases of allowed deaths) has served society well, though not perfectly, and that the burden of proof should rest on those who argue for changing it. Many commentators contend that this burden has not been met (6).

In addition, there are ways to "accept" some exceptional cases of mercy killing without changing the current legal and social prohibition—e.g., prosecutorial discretion, jury findings of not guilty by reason of temporary insanity, and recognition of "mercy" as a factor that mitigates punishment even though it may not exculpate the agent. Even with these informal exceptions, the rule may serve as a valuable reminder of the principle of non-maleficence (first of all do no harm). Although some people argue that a regulatory scheme to assure that the patient really wants to die would prevent abuses, the formalization of such a process would have its own costs because it would involve society prospectively and directly in choosing and implementing mercy killing.

Even if the distinction between killing and letting die is accepted as a social and legal rule, debates will continue about where the line should be drawn between the two concepts. It is not sufficient to point to the categories of active and passive or acts and omissions. Nor is it simply a matter of identifying the cause of death because identifying "the cause" in ethical and legal settings is in part a moral as well as an empirical matter.

Some ambiguity and uncertainty about the line between killing and letting die will always exist and different health care professionals and others will draw it in different places, as was shown in Case 1. However, there are some clear cases of direct, active killing, such as Case 2, and it is not unreasonable to continue to prohibit them even as society continues to assess where the line should be drawn.

Ordinary and Extraordinary Means of Treatment

Originally formulated in Roman Catholic moral theology, the distinction between ordinary and extraordinary means of treatment has been widely adopted in other ethical traditions and in legal decisions and professional codes. For example, after rejecting mercy killing or the "intentional termination of the life of one human being by another," the American Medical Association House of Delegates in 1973 held that the patient and/or his immediate family can decide about the "cessation of extraordinary *means* to prolong the life of the body when there is irrefutable evidence that biological death is imminent" (1).

The distinction was originally used to determine whether a patient's refusal of treatment should be classified as a suicide. Refusal of "ordinary" means of treatment was viewed as suicide, whereas refusal of "extraordinary" means was not viewed as suicide; withholding or withdrawing "ordinary" means from a patient was homicide, whereas withholding or withdrawing "extraordinary" means was not considered homicide.

According to one interpreter of the distinction, ordinary means are all medicines, treatments, and operations that offer a reasonable hope of benefit for the patient and that can be obtained and used without excessive expense, pain, or other inconvenience (19). ***Extraordinary*** means are all medicines, treatments, and operations that cannot be obtained or used without excessive expense, pain, or other inconvenience, or that, if used, would not offer a reasonable hope of benefit. The distinction does not refer to properties of medical practice or of the technologies themselves. Rather it hinges on two criteria: whether any particular medical treatment offers a reasonable

chance of benefit and whether its probable benefits outweigh its probable burdens, including expense and pain.

The language of ordinary and extraordinary means is subject to criticism because it focuses attention on customary medical practice and technologies rather than on underlying principles and values. Hence technologies are sometimes viewed as ordinary if it is usual or customary for physicians to use them for certain diseases or problems and extraordinary or heroic if use is not customary. The patient as a person often disappears from view. Several other criteria have been invoked to distinguish ordinary from extraordinary means of treatment: their simplicity (simple/complex), their naturalness (natural/artificial), their expense (inexpensive/costly), their invasiveness (noninvasive/invasive), their chance of success (probable/improbable), and their balance of benefits and burdens (proportionate/disproportionate). It is alleged that a technology that meets the first of the paired terms is closer to ordinary, while one that meets the second of the paired terms is closer to extraordinary.

Some ethicists propose to replace the terms ordinary and extraordinary with other terms that are less misleading (33,40). "Ordinary" could be redefined to mean morally obligatory, mandatory, required, or imperative, while "extraordinary" could be used to mean morally optional, elective, or expendable. These terms seem to reflect the practical point of the distinction more clearly. But if the new meanings are accepted, there is still the question about which criteria can adequately distinguish obligatory from optional treatments in particular circumstances.

If the criteria that distinguish ordinary from extraordinary appear to be relevant in a given case, it may be because they express other principles and values, such as acting in accord with a patient's wishes (the principle of autonomy) and in accord with a patient's interests (the principles of beneficence and nonmaleficence). For example, if an available treatment is simple and natural but not in accord with a patient's wishes and interests, it is hard from the patient's perspective to see why it should be handled differently than another treatment that is complex and artificial.

Furthermore, many of the criteria are unclear. According to one study conducted after the Natural Death Act was implemented in California, physicians in that State generally viewed mechanical ventilation, dialysis, and resuscitation as "artificial," but split evenly on intravenous feeding. Two-thirds viewed insulin, antibiotics, and chemotherapy as "natural" (35). Other criteria, such as the degree of invasiveness (noninvasive/invasive) and cost (expensive/costly), may be ethically relevant in view of the patient's overall condition, interests, and preferences.

The main consideration for many ethical traditions is consistent with what has been called the criterion of "proportionality":

Is it necessary in all circumstances to have recourse to all possible remedies? In the past, moralists replied that one is never obliged to use "extraordinary" means. This reply, which as a principle still holds good, is perhaps less clear today, by reason of the imprecision of the term and the rapid progress made in the treatment of sickness. Thus some people prefer to speak of "proportionate" and "disproportionate" means. In any case, it will be possible to make a correct judgment as to the means by studying the type of treatment to be used, its degree of complexity or risk, its cost and the possibilities of using it, and comparing these elements with the result that can be expected, taking into account the state of the sick person and his or her physical and moral resources (37).

In general, the distinctions between withholding and withdrawing, direct and indirect effects, killing and letting die, and ordinary and extraordinary means do not provide ethical answers, although they may reflect important ethical considerations. Whether these distinctions are valuable will depend then on whether they illuminate or distort the relevant ethical considerations that have been identified as part of a widespread consensus in a pluralistic society. According to several ethical traditions, the relevant considerations are the patient's wishes and interests, in light of his or her condition and in view of the overall societal allocation of resources and the necessity of some societal rules, such as the prohibition of killing.

Levels and Kinds of Care

Some commentators suggest that distinctions between levels and kinds of technologies have ethical implications. In an article on the physician's responsibility to "hopelessly ill" patients, the authors distinguished the following levels of care:

1. emergency resuscitation;
2. intensive care and advanced life support, including mechanical ventilation;
3. general medical care, including antibiotics, dialysis, and artificial hydration and nutrition; and
4. general nursing care, including pain relief, hydration, and nutrition for patient comfort (43).

The five technologies that are the subject of this report—resuscitation, mechanical ventilation, dialysis, nutritional support, and life-sustaining antibiotics—are at different levels in this hierarchy.

The application of distinctions between levels of care in withholding or withdrawing treatment is illustrated in the following cases, each involving a severely ill elderly patient.

Case 3: Mrs. X, a 79-year-old widow, had been a resident of a nursing home for several years. In the past she had experienced repeated transient ischemic attacks (brief neurological disturbance due to decreased cerebral blood flow). Because of progressive organic brain syndrome, she had lost most of her mental abilities and had become disoriented. She also had episodes of thrombophlebitis as well as congestive heart failure. Her daughter and grandchildren visited her frequently and obviously loved her deeply.

One day she was found unconscious on the bathroom floor. She was hospitalized, and the diagnosis was a massive stroke. She made no recovery, remaining nonverbal, but continuing to manifest a withdrawal reaction to painful stimuli and some purposeful behaviors. Mrs. X refused to allow a nasogastric tube to be inserted. At each attempt she thrashed about violently and pushed the tube away. After the tube was finally placed, Mrs. X pulled off her restraints and managed to remove it. After several days, her sites for intravenous infusions (IVs) were exhausted.

The question for the staff was whether to do further "extraordinary" or "heroic" measures to

maintain fluid and nutritional intake for this elderly patient who had made no recovery from a massive stroke and who was largely unaware and unresponsive. After much mental anguish and discussion with the nurses on the floor and with the patient's family, the physicians in charge decided not to provide further IVs or a feeding tube, and to allow Mrs. X to die. She had minimal oral intake and died quietly the following week.

In Case 3, the family and staff decided to let Mrs. X die even though they could have prolonged her life for some time through artificial nutrition and hydration. One major issue in drawing lines is whether all medical treatments can be construed as "heroic" or "extraordinary" if they are out of proportion with the patient's wishes and interests. This question has been examined in several major court decisions and widely discussed (10, 11, 12)22) in efforts to determine:

- whether nutrition and hydration by peripheral or central intravenous lines, nasogastric tubes, or gastrostomy tubes are more similar to other medical treatments, such as mechanical ventilation, or more similar to the provision of food and water by mouth;
- whether they are needed for comfort and dignity even when they are morally optional for the prolongation of life; and
- whether they so symbolize care and compassion that to withhold or withdraw them would threaten the foundation of humane and respectful medical care and, ultimately, social interaction.

If nutrition and hydration through medical means are similar to other medical treatments, then their use can be decided according to the criteria used for these other treatments. Critics of this position make several arguments. One argument is that medical nutrition and hydration are significantly different from other medical treatments because they are essential for comfort and dignity. However, some methods, such as central intravenous lines involve risks, and some may require that the patient be physically restrained. Another argument is that in withdrawing medical nutrition and hydration, the agent intends or aims at the patient's death (25). However, this intention may be present in other cases, such as

removing the mechanical ventilator, and may not be inappropriate in all cases.

Probably the major criticism of failing to distinguish medical nutrition and hydration from other medical treatments stresses the symbolic significance of these activities, contending that the similarities among all acts of providing nutrition and hydration are so great that it is impossible to distinguish their methods (e.g., a gastrostomy from normal feeding). These acts are not only means to the ends of sustaining life and providing comfort; they also express the values of care and compassion.

Finally, concern about symbolic actions also leads several critics to believe that to accept the withholding or withdrawing of nutritional support and hydration, in any case, could lead to undesirable consequences for society as a whole. First, they believe even compassionate calls for withdrawing fluids in a few selected cases bear the seeds of great potential abuse. This fear arises if the act of withholding fluids is seen as a first step along a “slippery slope”) where the standard of care shifts from actions in accord with the patient’s interests to actions in accord with the society’s interests, from the patient’s quality of life to the patient’s value for society, from dying patients to nondying patients, from letting die to killing, from cessation of artificial feeding to cessation of natural feeding, etc.

While these fears may be exaggerated, they have to be taken seriously, especially because of possible new threats of *undertreatment* as a result of cost-containment measures. This is a stark contrast to earlier threats of *overtreatment*. Simply stated, there is a danger that the “right to die” may become the “duty to die”) even against the patient’s wishes and interests (10). Although it is not clear that this danger can be avoided by mandating artificial nutrition and hydration in all cases, continuing fluids, even to dying patients, provides an important clinical, psychological, and social limit to acceptable withdrawals that some people believe should be retained (38).

Policies regarding cardiopulmonary resuscitation (CPR) have emerged separately and in some independence from policies about other life-sustaining technologies, such as mechanical ventila-

tion. Decisions to provide—and decisions not to provide—CPR are often made without consultation in advance with patients or their families (2, 7, 16, 21). No one has adequately justified why decisions about CPR in hospitals are viewed as different from decisions about other life-sustaining technologies. Furthermore, it is often unclear to hospital personnel, as well as to patients and their families, what an order not to resuscitate means, if anything, about other levels of care and other technologies. For example, some patients with DNR orders still receive chemotherapy, surgery, and admission to the intensive care unit (ICU), while others do not receive even supportive care (16). It may be appropriate to indicate very concretely what will be provided in case of cardiac arrest and which medical and supportive efforts will be continued and which will not after a DNR order has been given.

The following case illustrates some of the moral and practical difficulties in respecting patients’ wishes and meeting their needs:

Case 4: A 79-year-old widow experienced recurrent congestive heart failure and chronic obstructive lung disease. During one hospital admission, she had “absolutely refused” to be intubated (have a breathing tube inserted into her windpipe) ever again. She was readmitted to the hospital for 5 days after another period of crisis. Only 2 days after being discharged, she was again readmitted to the hospital. She repeated her wish not to be intubated, although she was willing to receive basic CPR if necessary. Serious problems of pneumonia, absence of urination and episodes of irregular heartbeat developed. On the 21st hospital day, she said that intubation “might be considered.” When lucid, she sometimes “wasn’t sure” about intubation, and, at other times, the patient did not want intubation. On day 25, shock, lack of oxygen, and abdominal swelling developed. Because there were potentially reversible causes for the deterioration of her condition, the physicians intubated her, administered vasopressor medications to lower her blood pressure, and transferred her to the intensive care unit. On the 31st day, she responded unambiguously and consistently with head nodding that she wanted mechanical ventilation and maximal care. Her condition worsened. On day 40, she was comatose and still required mechanical ventilation and

vasopressor therapy. The physicians judged that no reversible disease was present. With the concurrence of her son, treatment with vasopressor agents was discontinued, a DNR order was written, and she was allowed to die (21).

When a patient's wishes and interests are considered, important distinctions can be drawn regarding levels and types of care, pertaining both to the range of CPR procedures and to other treatments. However, these distinctions cannot be assumed to hold in all cases because, as Case 4 indicates, medical treatments as such are not always obligatory. Whether they are obligatory or optional in a particular case is a judgment call based on the patient's wishes and interests in the context of a just allocation of societal and hospital resources and social rules to prevent unacceptable consequences.

Major Considerations in a Typology of Withdrawing and Withholding Life-Sustaining Medical Treatment

In proposed topologies of withholding and withdrawing life-sustaining medical treatment, the following issues are among the most important (14):

- How is death brought about?
- Who brings it about?
- Who decides?
- Why is death brought about?

The major distinctions discussed so far have focused primarily on how death is brought about. Although "euthanasia" is sometimes defined by its etymological roots (from the Greek, eu +thantos =good or easy death), its more common, contemporary usage denotes "mercy killing." The terms "active euthanasia" and "passive euthanasia" are sometimes used. The distinctions between direct and indirect effects and ordinary and extraordinary means are also relevant to possible topologies of withholding or withdrawing life-sustaining technologies.

Despite some overlap, there is an important distinction between who acts and who decides. Some analysts ignore the distinction between agents who act and concentrate on agents who decide; thus, Mayo (24) insists that "voluntary active eu-

thanasia is assisted suicide," and Tonne (39) suggests that the term "suicide" should be replaced by the term "autoeuthanasia." However, it is as important to preserve the distinction regarding who acts as it is to preserve the distinction in decisionmaking; who acts is important in distinguishing suicide from other actions. The line between "assisted suicide" and "(voluntary, active euthanasia," which both involve killing, is determined by who is the final actor, the patient or someone else. However, the question of who decides remains important in cases of "euthanasia" or "mercy killing," which may be voluntary or involuntary from the standpoint of the patient.

Finally, it is also important to consider the grounds of the decision—the why of the decision—regardless of who makes it and carries it out. The major distinction is between reasons based on the patient's interests and reasons based on the interests of others, such as the family or society. These reasons are not always incompatible, but possible tensions should be noted, particularly when a decision is made by someone other than the patient for the interests of parties other than the patient. Thus, it may be necessary to develop procedures to protect patient decision-making and patient wishes and interests (as discussed in several places in this report).

Too many variables are involved in decisions about withholding or withdrawing life-sustaining treatments to permit tight and illuminating typologies. But important themes can be used to describe and evaluate various acts, some of which will also appear in the discussion of suicide and its relation to the refusal of life-sustaining treatments.

Defining Suicide and Its Application to Cases of Elderly People Receiving Life-Sustaining Technologies

Growing attention is being paid to the idea that individuals may want to exert direct control over the timing of their deaths by withdrawing life-sustaining technologies or by taking specific medications in lethal amounts (13). The empirical relationship between the use of the life-sustaining technologies and deliberate deaths cannot be quantitatively described because no data are avail-

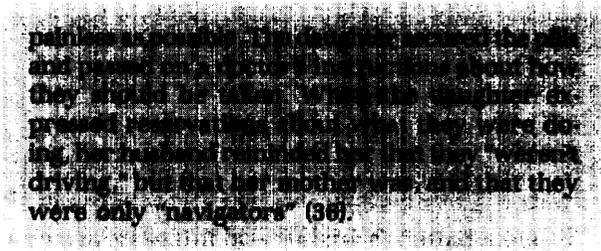
able. In addition, important conceptual problems need to be considered in order to talk about suicide and assisted death in meaningful ways.

There is no clear, neutral, widely accepted definition of "suicide." Suicide is always defined within traditions that make normative as well as conceptual points—the definitions are intended to guide behavior. For example, some traditions hold that suicide is always wrong and then sharply distinguish acts of suicide from other acts that lead to one's own death. Other traditions hold that suicide can be justified under some circumstances and thus do not worry as much about the line between suicide and other acts that cause one's own death. Justified exceptions to a rule prohibiting suicide within one tradition may be built into the definition of the rule in another tradition. For example, one tradition might justify acts of suicide to save others, while another tradition might hold that acts that are intended to help others rather than to bring about one's own death (such as falling on a grenade to save one's comrades) are not really acts of suicide and thus do not violate the rule against suicide.

At the very least, the concept of suicide involves: 1) a person's death, and 2) that person's involvement in his/her death. For an act to be considered a suicide it is necessary for a person to have intentionally brought about his or her own death, but these criteria are not sufficient to define suicide.

The questions and distinctions developed in the previous section suggest some key points: who *decides*? In suicide, the one whose death is brought about makes the decision for death. Who *acts*? In suicide, the final actor, however much assistance is involved, is the one whose death is brought about.

Case 5: A 75-year-old woman, suffered from ovarian cancer. Her physicians indicated that she had only a few months to live, that chemotherapy would not arrest the cancer, and that her dying would be very painful. The chemotherapy made her bald and resulted in constant nausea and vomiting. She indicated to her daughter that she wanted to commit suicide and asked for her daughter's assistance in making it as efficient and



As these metaphors suggest, in suicide the person whose death is brought about both decides *and* acts. If the agent did not decide and act voluntarily, that is, apart from coercion by others, the act of killing oneself would not be an act of suicide (5). Nevertheless, disputes arise, particularly about determining the intentionality of the act. At the very least, knowledge that an action will probably bring about one's own death is usually sufficient for suicide.

How is death brought about? In some religious traditions, when death is brought about by letting nature take its course rather than by killing, by indirect rather than by direct means, and by forgoing extraordinary rather than ordinary procedures, the act is not considered suicide, especially if death from disease is inevitable and imminent whatever is done. In general, the more active the means of bringing about death and the closer the temporal association between the action and the death, the more likely the death is to be considered a suicide. Thus, several factors distinguish refusals of treatment from acts of suicide. These factors are:

- . whether the person is already terminally ill so that death is imminent regardless of what is done;
- whether the means of death is active rather than passive and involves action rather than omission; and
- . whether the death results fairly quickly after the action or omission.

Judgments about the role of these factors affect whether an act is considered negative (suicide) or neutral (refusal of life-sustaining treatment). For example, one commentator notes, "to the extent that we have unmistakable cases of actions by an agent that involve an intentionally caused death using an active means where there is a non-fatal condition, the more inclined we are to clas-

sify such acts as suicides; whereas to the extent such conditions are absent, the less inclined we are to call the acts suicides” (5).

Case 6: When Barney Clark at age 62 became the first human to receive a permanent artificial heart on December 2, 1982; he also was given a key that he could use to turn off the compressor if he wanted to die. As Dr. Willem Kolff noted, “If the man suffers and feels it isn’t worth it anymore, he has a key that he can apply ...I think it is entirely legitimate that this man whose life has been extended should have the right to at it off if he doesn’t want it, if life ceases to be enjoyable . . .” (32).

Although Clark’s actions would have been vigorously debated if he had used the key to end his life, according to most of the criteria identified it appears that his act should have been characterized as a suicide without necessarily prejudging its morality. In some traditions, however, it is not possible to call an act suicide without simultaneously judging it negatively. Within such traditions, those who viewed the action as morally acceptable probably would take the position that the artificial heart was experimental and extraordinary and that Clark simply acted to end an experiment or to terminate an extraordinary treatment.

Why is *death brought about*? It is useful to distinguish two types of suicide or attempted suicide (a similar distinction would apply to refusals of treatment). In goal-oriented conduct, an agent attempts to realize some goal and bring about some effect or consequence. In suicides of this type, the language of cause and effect is very important; for example, an agent may attempt or

commit suicide because of a belief that death is better than a life of pain and suffering or disability. In expressive acts of suicide—often attempted rather than actual—an agent conveys a meaning or makes a statement, such as a lack of hope or contempt for life or an appeal for help or attention. Some acts of attempted or successful suicide may be both instrumental and expressive.

Case 7: A 62-year-old artist committed suicide on June 9, 1979. Having learned in March 1978 that she had breast cancer which had spread to her lymph nodes, she underwent 10 months of chemotherapy before deciding to commit suicide. With the help of her family and friends, she fashioned her “life sculpture”—a pine coffin-like box filled with personal mementos, and then she wrote a farewell letter to 60 friends, said goodbye to her family and swallowed 35 sleeping pills, washed down with champagne. Her family and friends cooperated.

This suicide illustrates both instrumental reasons (she believed that death was better than suffering from cancer and chemotherapy) and expressive reasons (she wanted to express her beliefs about “self-termination” and her conviction that “life can be transformed into art”). An autopsy indicated that her cancer had not spread beyond the lymph nodes to any vital organ (27).

Some traditions tend not to characterize sacrificial acts as suicide. However, there are limits; in Case 2, even if the patient had been able to secure and take the lethal medication himself, rather than having it administered by his physicians, his act would have been a suicide despite his other reason of not wanting to deplete his family’s resources. Motives may be and usually are mixed.

ETHICAL IMPLICATIONS OF DISTRIBUTING LIFE-SUSTAINING TECHNOLOGIES

In addition to the ethical distinctions involved in treating individual patients, there are significant ethical issues associated with the way in which life-sustaining technologies are allocated,

²This section is based in part on a paper prepared for OTA by Robert M. L'Abate, 1985 (41).

shared, or distributed. The distribution of life-sustaining technologies is important because 1) such technologies may be scarce or expensive; and 2) the use of age as a criterion in allocation decisions has important implications for the heterogeneous group of people called the “elderly”.

The problem of how to allocate resources ethically is usually referred to as a problem of justice. Justice is, however, a deceptively ambiguous term. In a general sense, justice means “the right.” Thus, one might say that it is unjust to tell a lie. Justice in a narrower sense refers to fair distribution. It is in this second, narrower sense that justice can be examined in terms of the distribution of scarce life-sustaining technologies. Two important questions arise:

1. What are the major theories of a just distribution?
2. What are their implications for the use of age as a basis for allocating life-sustaining technologies?

The Interface Between the Ethics and Economics of Distributive Justice

The ethical issues raised by the use of life-sustaining technologies for elderly persons are closely related to the economics of their use. Economics, however, often only provides data about dollar costs per unit of benefit. It can, by extension, provide data about some other costs such as, social, psychological, and cultural costs. But economic analysis generally does not indicate how cost data ought to be assessed.

Theories of distributive justice are based on underlying sets of ethical suppositions. One might emphasize liberty and the rights that accrue with ownership of private property; another might emphasize the goal of maximizing aggregate net benefit, maximizing the position of the least well off groups, or striving for greater equality. Thus, even if there were complete agreement on the relative costs and benefits of alternative policy options, it would not necessarily be clear which policy should be adopted.

Increasingly, however, the critical ethical problems in health care will be distributive justice problems. Under most economic systems, persons ought to be permitted to refuse care that they do not find beneficial, provided that the refusal does not generate extra costs for society (and normally, it would not). The life-sustaining technologies that are the focus of this study sometimes offer only marginal benefit, but at great costs to third par-

ties (insurers, hospitals, and governments). In these cases, the societal costs of care become a critical, **ethical problem**. Only by choosing a theory of distributive justice and integrating that theory into the calculations and analyses done to compare policy alternatives is it possible to decide how to respond to cases in which care is marginally beneficial and very expensive to third-party payers. How can goods be fairly distributed? Four major positions are responsive to this question: the libertarian, utilitarian, maximin, and egalitarian positions.

Major Theories of Distributive Justice

Libertarianism is one of a group of theories that spells out what persons are entitled to possess. These are sometimes referred to as entitlement theories. Libertarianism holds that persons are entitled to what they possess provided that they acquired it fairly (29). Fair acquisition includes gifts, exchange (including purchase), or original appropriation of previously unowned property. Heavily influenced by John Locke and the image of original appropriation from a state of nature, the libertarian position places great emphasis on individual liberty. Persons are permitted to do whatever they want with what they possess provided that they do not violate the holdings of others.

Utilitarianism, a second major position, holds beneficence or the maximizing of utility as dominant. The ‘(right)’ pattern of distribution is one that produces the most good. That is the moral logic behind many policy analyses such as those using cost-benefit and cost-effectiveness analyses. These are economic methods for calculating the benefits and harms of alternative policies to determine which one will produce the greatest good **overall**. Thus, when a straightforward cost-benefit analysis is conducted it shows an implicit commitment to utilitarianism.

The libertarian and utilitarian patterns of distribution are obviously very different. What is striking, however, is that neither necessarily involves any redistribution to meet the needs of the poor, the sick, or the least well off, including the elderly (who may be poor, sick, and/or least well off). Libertarianism would permit such redistri-

bution as a matter of charity. Utilitarianism would be open to redistributions to the poor if, and only if, redistributing resources increased the total amount of good in society. Such redistributions often increase the total amount of good because the harm that is likely to be done to the wealthy person is less than the good that could be done for poor persons. But there is no inherent moral principle that favors equality or redistribution on the basis of need.

Maximin theorists are concerned about those special cases where distributing things more equally or distributing in proportion to need will benefit the least well off. The most important maximin theorist is John Rawls, whose book, *A Theory of Justice* (34) has reoriented 20th century philosophical and public policy analysis of the problems of distribution. Rawls states that a group of rational, disinterested people would agree on two basic principles to guide the allocation of resources in a just society. These principles are:

- 1) Each person is to have an equal right to the most extensive basic liberty compatible with a similar system of liberty for others.
- 2) Social and economic inequalities are to be arranged so that they are both:
 - a) to the greatest benefit of the least advantaged, consistent with the just savings principle, and
 - b) attached to offices and positions open to all under conditions of fair equality of opportunity (34).

Since Rawls' second principle is designed to maximize the position of the least well off group, this theory of distribution is often referred to as the "maximin" theory. It holds that there is something ethically compelling about arranging resources so that the group on the bottom is as well off as possible, even if the result is that the amount of good per person is not as great as it could have been with some other distribution. The maximin position provides a powerful intellectual framework that overcomes some of the most severe problems with utilitarianism. Maximin theory, for example, squares with many people's moral intuition that slavery is wrong regardless of whether it may do more good than harm.

Egalitarianism is a coherent theory of justice as well as a theme within maximin theory. Maxi-

min theory is one example of a theory of justice that places special emphasis on equality as a check against individual liberty and aggregate social welfare. It seems to be consistent with important religious and secular strands of Western thought. Some observers, however, have pointed out that maximizing the position of the least well off group does not necessarily require moving toward greater equality. In fact, maximin theory provides a framework for deciding precisely when inequalities are morally appropriate.

Several commentators distinguish between Rawls and other maximin theorists, on the one hand, and "true" or "radical" egalitarians on the other (3,4,28). True or radical egalitarians are committed in a straightforward manner to the goal of equality per se.

The important test case for separating maximin theorists and egalitarians is how they handle situations where the best way to improve the lot of the least well off is to devote substantial resources to talented elites to give them an incentive to use their skills to benefit those on the bottom (trickle down theory). Maximin theorists hold that in these circumstances, justice requires that the resources be given to the well off elites even though inequalities will actually increase. True egalitarians are distressed at the increases of inequality because they see great moral importance attached to equality as well as to increasing welfare.

Implications of Theories of Justice For the Use of Life-Sustaining Technologies With the III Elderly

The concept of "terminal illness" was defined in chapter 1 as an illness that has a **predictably** fatal progression that cannot be stopped by any known treatment. Terminal illness is distinguished from "critical illness" by the certainty of outcome. Many of the ethical dilemmas surrounding the use of life-sustaining technologies with elderly individuals arise from situations in which the patient is seriously ill and death is a possible **outcome**. The great uncertainty attached to the course of critical illness creates a crisis situation where decisionmaking is difficult and complex.

The **libertarian** perspective asks who would want and be able to receive life-sustaining treatment if free market forces and charity were the principal bases of access. Most life-sustaining technologies are sufficiently expensive that few people would have access to them, under a libertarian distribution scheme, unless they had personal financial resources or insurance coverage. Thus, a line would be drawn between elderly persons who either set aside money or purchased health insurance (presumably to supplement Medicare) to guarantee their access to treatment. Additional divisions could be seen among those elderly persons who buy health insurance, according to the level and type of coverage they choose. For example, some persons would choose a health insurance policy that provides coverage during terminal illness, while others would not want such coverage. Some would choose coverage for long-term care, while others would view as sufficient coverage for hospital care. Some would consider their benefits under Medicare sufficient.

There are problems with this position, however. Most people would at least want life-sustaining technologies if they relieved pain and suffering and relieved it at a relatively low cost. Some might also desire more aggressive treatment, but the libertarian approach would require them to compare the benefits of having the insurance coverage with the benefits of having the money needed to buy that coverage to spend on something else. It is likely that a great many people would forgo the coverage, especially coverage beyond that necessary to provide comfort. They would probably be more willing to buy coverage for life-sustaining technologies that were relatively inexpensive. In addition, while failure to purchase health insurance is sometimes a fair statement of an individual's evaluation of the benefits, it frequently is not. Many people who would opt for life-sustaining treatment may end up without it because they do not understand the details of their Medicare benefits and lack the information needed to supplement those benefits.

Utilitarianism would provide a very different analysis of the use of life-sustaining technologies during terminal illness. It would ask what the benefits are in comparison to the costs (economic and social) and compare the net benefits from the use

of these technologies with the net benefits of other uses of the resources.

Given that some people consider some uses of life-sustaining technologies during terminal illness a net loss, the case for their use will be a difficult one to make. The calculation will have to involve benefits to the patient as well as benefits to society. In both cases the benefits are problematic. Surely in some cases the patient benefits, either because the treatments relieve pain and suffering or because continued living is desired by the patient and/or others. Even in those cases, however, the benefits are likely to be small in comparison to the use of the resources in other ways.

In previous paragraphs, a distinction was made between persons who are inevitably dying and those who will die if they are not treated with a life-sustaining technology, but could probably live if treated. A distinction was also made between life-sustaining technologies that are used once to meet acute needs and those that must be used on a continuing basis. For the utilitarian, who is especially concerned about anticipated benefit, whether the illness is reversible or irreversible and whether use of the technology is acute or chronic will be very important.

Utilitarian analysis would also require taking into account the net benefits to society of the use of these technologies as well as alternative uses of the funds. Their use might be supported on grounds of societal benefits in rare cases where the terminally ill elderly person could still make a substantial social contribution, but that is likely to be uncommon. When compared with the use of the resources in other ways, the societal benefits are likely to be small.

The societal benefit that a more sophisticated utilitarian is likely to identify is the benefit for family members who will get positive value out of having a loved one remain alive even a short time longer. In some cases, these benefits could be significant such as when a relative is traveling from out of town and desires to see the dying person one last time. A strict utilitarian would insist that these benefits be included in the calculation. These social benefits, however, are extremely subjective and hard to quantify. Moreover, their inclusion has some unsettling implications. An ill elderly person with no relatives or friends would

have no claim based on these benefits. This could lead to policies of using life-sustaining technologies for the terminally ill only in cases where there are relatives. Extending the argument one step further, their use might be reserved for those cases where relatives will be made happy by the dying person's continued existence.

There is one final issue raised by a utilitarian calculation. Different life-sustaining technologies may have different subjective impacts on the population. In some cases the decision to prohibit their use is likely to be very distressing to the sensibilities of some of the population. In other cases, the decision not to use the technology may produce little distress at all. For example, the level of psychological distress at the decision not to provide basic nutrition and hydration is probably much greater than that of deciding not to implant an artificial heart in a person who will inevitably die without one.

How should a utilitarian respond to these different subjective feelings on the part of members of the society? Should they be considered as benefits and harms of the treatment decision? It seems odd to decide whether to provide nasogastric tube feeding on the basis of whether it makes other people uncomfortable if such feeding is not provided. Decisions about what treatments should be provided are not normally made by determining whether citizens would be upset by their lack of provision. A utilitarian approach to allocating life-sustaining technologies will have to determine whether these subjective benefits and harms of providing life-sustaining technologies are relevant or whether a more objective measure such as years of life added should be used instead.

Maximin theorists and egalitarians would be much less concerned about whether the patient is terminally or critically ill and the frequency of treatment because aggregate benefit is not considered critical. Their major question is whether terminally ill elderly people constitute a least well off group or have the greatest needs and, if so, whether the technologies provide any benefit. Terminally ill elderly persons might well be considered a least well off group. From the slice-of-time perspective, they are in very bad shape. Yet from the over-a-lifetime perspective they are plausibly

better off than persons who are terminally ill and young.

If terminally ill elderly people are viewed as a least well off group, they have claims to the resources that would benefit them. In the case where life-sustaining treatment is perceived as beneficial, maximin and egalitarian theorists who conclude that the terminally ill elderly are a least well off group would support treatment even if the benefits were minor.

There is room for dispute among these theorists when there is good reason to believe that the treatment would not be beneficial. What should happen, for example, when a dying elderly patient insists that an antibiotic be used for an infection and the consensus of medical opinion is that the antibiotic is extremely unlikely to overcome the infection and is very likely to produce undesirable side effects? Withholding the antibiotic is likely to produce distress for the patient, but supplying it is likely to produce harmful side effects. Maximin and egalitarian analysts will need to decide whether their theories require providing subjective benefit from the patient perspective or only benefits measured in some more objective manner.

If terminally ill elderly people are viewed as a group that is not least well off, a different set of issues arises. Presumably maximin theorists and egalitarians would reach the conclusion that the life-sustaining technologies should be withheld on grounds of justice. Consider a dialysis patient who has a few days to live and those days will be lived in a state of semi-conscious stupor. It may be tragic to have to withhold dialysis or CPR from such a patient on resource allocation grounds, but if, by hypothesis, others are in greater need, then that is the decision a maximin theorist or egalitarian would support.

For life-sustaining technologies that also provide comfort and do so relatively inexpensively, the problem is more complex if terminally ill elderly people are not considered a least well off group. Consider a terminally ill elderly patient whose life will be sustained through hydration and nasogastric tube feeding. What should happen if withdrawing those treatments produces discomfort for the patient?

The egalitarian or maximin approach is that, if these are not least well off patients, they have no claim to the resource even if the suffering prevented is quite great and the cost of the treatment is quite small. For a terminally ill elderly person who has previously had a good life, the burden would probably have to be severe to outweigh the lifetime of wellbeing. And finally, for another terminally ill patient who needs nutritional support for comfort, but who has had a miserable existence throughout his life, his claim for benefit would be much greater. For these reasons, some egalitarians argue that for providing the basics of comfort care, the slice-of-time perspective must be used but decisions pertaining to research, development, and experimental and high-technology treatment require an over-a-lifetime perspective.

Consideration of Age as a Criterion in the Allocation of Technological Resources

Many criteria are relevant to decisions about the allocation of technological resources. First, it is possible to distribute resources according to each theory of justice or some combination thereof. The health care delivery system in the United States, for instance, is based on an amalgam of competing points of view about what is fair and equitable. Second, it is possible to distribute resources in a discriminating way in terms of kinds of care (e.g., prevention, diagnosis, treatment, and rehabilitation), relative costs, merit, need, or age group. Because this report focuses on the use of life-sustaining technologies and elderly people, a discussion of the ethical implications of the use of age as a criterion for the distribution of resources is particularly relevant.

Age as a Direct and Indirect Measure

It is important to distinguish between two possible ways of using chronological age as a criterion in the allocation of technological resources. Age can be used in a direct way as the basis for allocating resources or, more commonly and probably more plausibly, age can be used as an indirect measure of some other variable that is thought to be the legitimate basis for allocating resources. Age can be an indirect measure of many differ-

ent variables but the most obvious is as a predictor of medical benefit.

It has been common to use age as a basis for excluding patients from some procedures such as heart transplants. Both very old and very young patients were believed to be poor medical risks. Exclusion from dialysis on the basis of age was largely due to the belief that dialysis would not work well for older patients. This is of course an empirical argument that needs to be based on evidence about whether age really correlates with expected outcomes. (Note that exclusion from dialysis based on chronological age is not a practice under the current Medicare End Stage Renal Disease Program.)

The medical benefit criterion is attractive because it appears to be objective but in reality, it often is not. The reasoning is that, if two people are candidates for an organ transplant and one will live more years than the other, then the person who will live longer becomes the correct recipient of care. That may well be the case, but if it is, it is not without evaluative judgment. The notion of medical benefit often includes not only years of survival but the likelihood of complications, the amount of effort necessary to make the procedure successful, the likelihood of success, and many other factors. The complex combination of these that leads to the conclusion that one patient can benefit more than another is highly subjective.

Age can be an indirect measure not only of expected medical benefit, but of a number of other factors that are significant in various theories of justice. The most obvious is that age is an imperfect predictor of years of life potentially added by a life-sustaining intervention. This is true especially for acute interventions such as antibiotics. ***Other things being equal***, a 70-year-old person can be expected to gain more years of life from an antibiotic for pneumonia than an 80-year-old person. If the policy were to allocate to the person who would get the most life-years from the treatment, then age would be an important factor in deciding who gets treatment.

In addition, age is an inadequate measure of the amount of well-being or quality of life one has had over a lifetime. For those who work with an

over-a-lifetime concept of equality, age is an important predictor of how much well-being has been accumulated, other things being equal. The problem, of course, is that other things are not usually equal. Age is a predictor of medical success, years of life potentially added, or cumulated well being, but it is an imperfect predictor. So even if one accepts age as a legitimate basis for allocating technologies, it does not follow that chronological age can be used as the sole basis for allocation,

Arguments in Support of the Use of Age as a Criterion

At least four ethical arguments can be employed to defend the use of age as a criterion in allocating health care resources. They are: 1) the “age demands respect” argument; 2) the “age as a predictor of accrued benefit” argument; 3) the “over-a-lifetime well-being” argument; and 4) the argument from contract.

The “Age Demands Respect” Argument.—It is striking that in traditional societies age was without question a legitimate basis for allocating certain resources. The elderly commanded a special place as people deserving respect. Some vestiges of this remain in our society. Older persons are still occasionally given courtesies of title. They still sometimes expect higher salaries for work similar to that done by a younger person. These practices reflect the conviction that age brings wisdom. Even in an era of orientation to youth, it is important to realize that using age as a criterion of allocation does not necessarily mean that elderly people will be less likely to receive life-sustaining technologies. For instance, if there were a choice between a 65-year-old and a newborn infant, some people might opt for the elderly person on the grounds that a person whose character is fully developed demands respect over an infant.

The “Age as a Predictor of Accrued Benefit” Argument.—A second argument for the use of age as a criterion is more likely to lead to decisions limiting access to life-sustaining technologies. This argument uses age as a predictor of the benefit that will accrue from intervention. The benefit includes the medical factors considered above, but also, especially for one-time interventions, the

years of life added, the useful contribution of the individual to the society in the future, and other factors.

Utilitarians would defend the use of age even if it is only an imperfect predictor of utility. The utilitarian, driven to maximize net benefit, would concede that it would be best to use life-sustaining resources in the way that maximizes their benefit. They would concede that occasionally older people get great benefit out of life-sustaining technologies and that they might continue to live and contribute to society if such technologies were used. They also concede that some younger people ought to be disqualified if usefulness to the patient and to society were the criteria. They might argue, however, that there would be great disutility in setting up complex procedures for determining which elderly persons of a particular age were the exceptions that justified special consideration. The labor and psychological stresses involved might make it such that the most efficient way to maximize utility is simply to include or exclude all persons of a particular age, ignoring the fact that some persons would thereby be wrongly classified.

The Argument for Over-a-Lifetime Well-Being.—A third argument for the use of age as a criterion leads to a similar conclusion—limiting access to life-sustaining technologies—but on very different grounds. This argument works from the maximin or egalitarian theory of justice and uses the over-a-lifetime perspective for determining who is least well off. However, attempting to assess individual variations in lifetime well-being for two persons of similar age would be an overwhelmingly complicated task. For policy purposes, so the defenders of this argument would claim, it is better to have a crude, simple basis for decisionmaking that will provide at least an approximation of cumulated well-being.

If this position is adopted, the older a person is, the less claim he or she has to resources. Diseases of infancy would appear to get very high priority, then diseases of children, etc. Those who have lived to old age would perhaps have a claim to the basics of care—safe, simple treatments of basic problems, comfort care, and standard medicine, but not expensive, high technology or ex-

perimental treatments. Instead of delivering these complex, expensive treatments to the elderly, more work should be done for those who otherwise will never have the opportunity to see old age.

The Argument From Contract.—A final argument can be offered that may lead to the conclusion that age can legitimately be a criterion for allocating health care (15). It draws on certain egalitarian premises, but also incorporates many of the ideas of those committed to individual liberty. This approach struggles with the problem of what constitutes a fair transfer of resources for health care from the younger generation, who have the ability to pay for care, to the older generation, who have great need for care. It helps to think of the problem as more of an intrapersonal problem rather than an interpersonal one. Then the issue becomes one of how much of the resources available to the younger generation would prudently be saved for health care in old age.

This view argues that rational persons would allocate funds in a manner that does not necessarily provide the same health care services at all ages during their lives. Individuals in the population have a range of opportunities that vary from one age to another. What is normal functioning for one age is not for another. Prudence would dictate that persons would allocate their health care dollars with an eye to those “age relativized opportunity ranges” (15). The result would be different patterns of health care for different age groups, but comparable levels of satisfaction for individuals. “Justice requires that we allocate health care in a manner that assures individuals a fair chance at enjoying the normal opportunity range, and prudence suggests that it is equally important to protect an individual’s opportunity range for each stage of life” (15).

The over-a-lifetime perspective seems to imply that the younger a person is, the greater the claim to societal resources. As a practical policy matter this perspective could create some serious problems—say of choosing between a 33- and a 34-year-old person on the basis of age. Since the primary area of controversy is over the use of expensive, marginally beneficial resources for those who have met many of their life goals, it is possi-

ble that some cut off point would be adopted in using age as a criterion. Here use might be made of the newer distinctions among subgroups of elderly people. It is possible that an age criterion could be used for limiting certain life-sustaining technologies only for the older subgroups. It is also possible that if age criteria are generally adopted, different age ranges would be adopted for different subgroups of elderly people.

Arguments Against the Use of **Age** as a Criterion

The arguments favoring the use of age as a criterion for allocating health care resources clearly depend on which theory of justice one adopts. The counterarguments will also follow the patterns established in the theories of justice debate. Any argument against the premises of the particular theory of justice will turn out to be a reason to oppose the use of age as a criterion. For example, anyone who rejects utilitarianism will likewise reject the utilitarian reasons why age might be used as a criterion.

Egalitarianism With the Slice-of-Time Perspective.—Perhaps the most common argument on both sides of the debate over the use of age as a criterion in allocating resources is the argument that people should be treated equally and that that means equal needs should have an equal chance of being met regardless of age. In other words, people equally sick at a given point in time have an equal claim.

Libertarianism.—An argument against the use of age as a criterion for allocating life-sustaining technologies is rooted in the libertarian theory of distribution. It emphasizes that life-sustaining technologies, like other goods and services, should be available to those who want to purchase them or to those who are the recipients of gifts or exchanges from others who control these services. Under this view, anyone who has the resources (either direct funds or insurance coverage) should have access regardless of age.

Age might enter into individual choices about whether to make use of life-sustaining technologies for instance, some elderly people might reason that they would rather have their resources

used for other purposes. Age might also influence the distribution of resources, thereby determining who has the funds to purchase life-sustaining technologies. But age per se would not, according to the libertarian perspective, determine who should have access to any resource including life-sustaining technologies. If some people are unable to gain access because of lack of resources that is unfortunate, but not unfair.

The Utility Arguments About Using Age as a Criterion.—Utilitarians would argue that since age is an indirect indicator of other factors that correlate highly with the amount of benefit produced by life-sustaining technologies—factors such as predicted medical success, years of life added, and social usefulness of the life saved—it is most efficient to operate under some general rules that allocate life-sustaining technologies strictly on the basis of age.

Other utilitarians might push this reasoning one step further. They might be concerned about the disutilities of having some persons in the society receive life-sustaining technologies while others—equally sick and equally at risk—do not. They might argue that to minimize the social friction created by age cutoffs, everyone, regardless of age, should have the same access to life-sustaining technologies. That rule, even with the inefficiencies that result from delivering care to elderly persons who are likely to gain very little benefit and add very little to society, may end up producing more good than trying to institutionalize age-based discrimination.

The Life-is-Sacred Argument.—Still another argument against the use of age as a criterion is specific to life-sustaining technologies. Some people in certain religious and cultural traditions believe that life in all of its moments is sacred. They hold that life should never be shortened by the withdrawal or withholding of medical technologies under any circumstances. They consistently oppose withholding mechanical ventilators, the writing of DNR orders, and the refusal of any other life-sustaining treatments such as nutritional support and antibiotics. Anyone taking this position would necessarily oppose the use of age as a criterion for determining who should get life-sustaining technologies.

The Use-of-Sociological Categories Argument.—A final argument against the use of age as a criterion draws on parallel debates from the civil rights and women's rights movements. In the early phases of these debates, some who would defend discrimination on the basis of age or sex did so using the argument that sociological categories (e.g., race or sex) can be used to predict performance or success in the workplace and other settings. This generated substantial argument. Members of minority groups took strong exception. They argued that it was unfair to assume that they, as individuals, would perform poorly, that they would follow the stereotypes of a particular sociological group.

The critics of the use of ascribed sociological categories have now largely won the debates regarding sex and race. These factors now can legally be used as selection criteria only in very special circumstances where sex or race are inherently linked to a job.

The implications for the use of age as a selection criterion are apparent. Age, as has been indicated, is almost always used as an indirect, imperfect indicator for some other factor thought to be relevant in selection. Furthermore, chronological age is an ascribed category. There is nothing anyone can do by hard work to change it any more than one can (with very special exceptions) change race or sex. If race and sex cannot be used for allocation without being unfair, does it not follow, so these critics argue, that age likewise cannot be used? This leads to the conclusion that anyone who wants to exclude a particular patient on the basis of medical benefit, utility calculations, or accumulated well being over a lifetime would need to find direct evidence that these factors justify exclusion in the particular patient. Age per se could not be used as a sociological short cut to these factors.

Mixed Arguments Regarding Age as a Criterion

It is possible to accept the use of age as a criterion in certain circumstances and reject it in others. Some egalitarians are experimenting with a differentiated approach whereby age is legitimately used in allocating research and develop-

ment funds, experimental treatments, expensive treatments, and those with low likelihood of success while everyone would have equal access on the basis of need to inexpensive, safe, and effective treatments and to comfort care regardless of age. Other formulas for mixed policies where age is sometimes used as a criterion and other times is not are likely to emerge in the future.

Intergenerational Responsibilities and Conflicts

Considering the use of age as a criterion for allocating life-sustaining technologies poses the problem of intergenerational responsibility and conflict among generations. Thinking of the use of life-sustaining technologies for the terminally ill elderly, many elderly individuals have come to the conclusion that such uses, even if they are desired, consume large amounts of personal resources that could better be used by one's children and grandchildren. On that basis, some individuals wish to forgo the use of life-sustaining technologies during life-threatening illness. If individuals make such decisions with their own resources, the question arises whether at the public policy level decisions should be made such that society's resources are not used excessively for the older generation.

If many people consider the benefits of using their resources for life-sustaining technologies small or even nonexistent, the utilitarian perspective would reasonably support preservation of the resources for future generations. In fact, it is not clear that this preservation of resources would be limited to existing generations. The calculation of benefits and harms could include all future persons, whether presently living or not. However, some people have argued that those more than two or three generations in the future will be so different from us that it will be virtually impossible to predict their interests and that, therefore, they do not need to be taken into account (18). Others are not as convinced of the radical discontinuity between our generation and future ones (9). At least when it comes to the desire of future generations to avoid end-stage kidney disease, infections, dehydration, nutritional deficit, and sudden cardiac or respiratory arrest, it seems rea-

sonable that those in the future are likely to want these problems solved.

Similar problems of intergenerational responsibility arise for maximin theorists and egalitarians. They must determine whether the present terminally ill elderly are among the worst off groups, taking into account the existing younger generation and possibly future generations as well. In fact, some ethicists and economists have worried a great deal about justice between generations (34). Because no one knows into which generation he will be born, the result will be what is called the "just savings principle" where there is "an understanding between generations to carry their fair share of the burden of realizing and preserving a just society" (34).

The intergenerational responsibility problem is critical for what is called the prudent saver model of resource allocation (15). Health coverage for the elderly is essentially a scheme whereby each older generation is the beneficiary of the resources of the younger generation. If a plan providing age-relativized opportunities for health care is once in place, even if elderly persons did not get the same levels of coverage for life-sustaining technologies, everyone would be treated fairly—at least if every generation were of the same size and contributed equally. The intergenerational transfers would theoretically cancel out with each younger generation contributing to the support of the older generation.

However, all generations may not be equally equipped to pay for care of the elderly. Some paying generations may be quite small yet have to pay for care for an elderly generation that is large. Other generations may face the opposite demographics. Some generations may face long periods where economic conditions make it difficult to pay for care for the older generation. From the point of view of a distribution system emphasizing equality, adjustments would need to be made to even out the ratio of burdens to benefits. In any case, if a plan using age as a criterion for allocating life-sustaining technologies were suddenly institutionalized, adjustments would have to be made to deal with intergenerational responsibilities during the transition generations and between generations that had unequal abilities to support health care.

One of the key problems of intergenerational responsibility is the extent to which children bear responsibility for their parents in a direct way. Both recognize that the parental generation transfers resources to the younger generation during early years and that some reciprocal responsibility is borne by children for their parents during their old age. At the same time, both place substantial limits on the obligation of the younger generation for the older. Some thinkers express this in terms of the obligation of each generation to save for its immediate descendants (34). Others look at it in terms of the way a prudent saver would allocate a life's resources (15). In both cases, it is clear that limits exist on what would be transferred from the younger generation to the older. Taking a somewhat different perspective, government programs to meet the needs of the elderly can be seen as a way of easing tensions between generations: the younger generation would not bear a responsibility for providing care for the older, but would nevertheless remain in contact with them through family ties.



Photo credit. Foster Medical Corp.

Intergenerational needs and life-sustaining technology.

FINDINGS AND IMPLICATIONS

The ethical issues associated with the use of the five identified life-sustaining technologies on behalf of life-threatened elderly individuals are many and varied. This chapter is just a sampling of significant ethical arguments and does not treat all of the relevant ethical issues. Nonetheless, important findings emerge:

- Categorical distinctions can be helpful in clarifying the specific points at which ethical dilemmas exist but do not lend themselves readily to clear criteria for decisionmaking.
- According to several ethical traditions, the relevant considerations in decisionmaking are the patient's wishes and interests, in light of his or her condition; societal allocation of resources; and the necessity for some societal rules, such as the prohibition of killing.
- Each of the life-sustaining technologies discussed in this assessment raises a heterogeneous, though not necessarily a unique, combination of ethical issues and questions.
- There is insufficient data from which to draw any conclusions about a possible relationship between suicide among the elderly and the use of life-sustaining technologies.
- Whether or not an individual act of withdrawing a life-sustaining technology constitutes suicide or assisted death depends directly on how these terms are defined.
- The way in which health care services should be distributed to elderly persons depends directly on the theory (or theories) of justice that one holds and that can be effectively translated into public policies.
- The way in which life-sustaining technologies should be distributed to terminally ill elderly persons will depend in part on whether age is adopted as an appropriate criterion for allocation and on the availability of a particular technology.
- There are important arguments, both pro and con, for using chronological age as a criterion in the allocation of technological resources.
- An important factor in the alternative arguments about the use of chronological age in the allocation of resources is whether one adopts an "over-a-lifetime" or "slice-of-time" perspective concerning individual quality of life and human welfare.

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