

# 7. ISSUES IN DEATH AND DYING

## 1. EUTHANASIA

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If human beings have a right to autonomy and self-determination in the conduct of their lives, do they also have the right to control the circumstances of their deaths insofar as possible? If people have a "right to life," do they have a "right to die" as well, or a right to "death with dignity"? As in the issues of abortion and genetic responsibility, questions arise about who is entitled to assess the quality and value of an individual life. Should it be the state, medical professionals, the family, the individual, or some combination of these? Just as abortion raises the question of when human life begins, euthanasia calls up questions about when it ends.

11 The term *euthanasia* comes from Greek words meaning "good death." In our society, a good death is usually thought to be one that is painless and quick. Most people hope that dying will spare them and their loved ones prolonged suffering and the crushing expenses and loss of dignity of lengthy hospitalization. Advances in medical technology make it possible—even likely—for biological life to be sustained in persons who in earlier times would have died. A person in an irreversible coma, one who has a completely deteriorated personality, or one whose consciousness alternates between excruciating pain and drug-induced stupor has lost the capacity for meaningful or satisfying experiences of life. Many argue that such persons are "better off dead," that mercy would be on the side of

death. One might feel tempted to hasten the arrival of death for such persons, or for oneself in a similar situation. However, the ethical implications of an action to assist death are profound. Is providing an easy death for oneself the same as suicide? If we aid in the death of another—whatever the motive may be—are our actions a form of murder? Can such acts ever be justified?

Utilitarians argue that expending health care resources on persons who lack the capacity for meaningful life is unjustified. Deontological support for euthanasia arises from an ethic of respect for individual human dignity. Patients who request an end to their suffering should have their choices respected. Others, who cannot express their choices (such as those in a persistent vegetative state), should be allowed to die on grounds that distinctively human life involves certain minimum standards of quality.

Philosophers distinguish between killing and letting die, or *active* versus *passive* euthanasia. The former involves performing an act to help bring about death (for example, giving a lethal injection), whereas the latter refrains from actions prolonging life (such as administering an antibiotic). The code of ethics of the American Medical Association recognizes the distinction and officially endorses the "standard view" regarding the morality of euthanasia. The view holds that passive euthanasia is morally acceptable (under specified conditions), but



that active euthanasia is never acceptable. Others construe the active versus passive distinction in a different way. They reserve the term euthanasia for acts that aid the death of a person (also called *mercy killing*); allowing someone to die does not count as euthanasia.

Further controversy revolves around the distinction between *ordinary* and *extraordinary* means of sustaining life. Some believe that it is morally justifiable to withhold or withdraw extraordinary means of life support (such as a respirator), but that to refrain from ordinary treatment is not justifiable. Attempting to apply the distinction can be problematic, given the difficulty of saying what counts as extraordinary means.

Such treatments as hemodialysis or coronary bypass surgery were once rare but are now routine. If a physician fails to perform surgery to correct intestinal obstruction in a severely defective newborn who is likely to die from other causes, should the surgery be considered ordinary (since it is a routine medical procedure) or extraordinary treatment? Has the physician engaged in euthanasia by refraining from operating?

Still others argue that a moral distinction exists between withdrawing extraordinary means of life support ("pulling the plug") and withholding such treatment in the first place. They consider the former, but not the latter, active euthanasia or killing. A less controversial distinction involves the difference between *voluntary* and *involuntary* euthanasia. Involuntary euthanasia occurs when a person is incapable of giving informed consent, whereas voluntary euthanasia has been previously consented to by the person. Cases of involuntary euthanasia arise with adults who are incompetent or comatose (the well-known case of Karen Ann Quinlan is an example). Involuntary euthanasia also arises with severely defective neonates. The special problems involving defective newborns are addressed in a separate section of the chapter.

Another problem has evolved with the development of medical technologies capa-

ble of sustaining biological functions in severely damaged patients. Patients may have brains that have irreversibly ceased to function ("brain dead"), but their heartbeat and respiration can be maintained mechanically. Others may have damage to the cerebral cortex, or "higher brain," but retain enough brainstem function to sustain heartbeat and respiration. The second group is in a "persistent vegetative state." A person in either group suffers irreversible loss of consciousness and cognitive ability. Should that person be regarded as alive or dead, and what medical treatment is ethically indicated?

Some call for a redefinition of the standard of death. Traditionally death occurs with the permanent cessation of cardiopulmonary function (heartbeat and respiration). By this standard, the "brain dead" patient on a life-support system is alive. An ad hoc committee of the Harvard Medical School addressed this issue in a report published in the *Journal of the American Medical Association* in 1968. The committee outlined tests for diagnosing the condition of "brain death" or permanent nonfunctioning of the whole brain. The committee recommended that, once such a condition is identified, the person be declared dead and life-support systems be turned off. In other words, death occurs despite continuing heartbeat and respiration.

A redefinition of death has a substantial effect on our views about euthanasia. If a person is "dead" before the removal of life-support systems, the act does not constitute euthanasia in its active or passive form. However, if the "brain-dead" patient is alive, withdrawing life-support systems represents active or passive euthanasia, depending on how the terms are construed. Additionally, the way death is defined affects the practice of harvesting organs for transplantation. If a "brain-dead" patient is alive, removal of vital organs is a partial cause of death and is ethically problematic. On the other hand, if the patient is already dead (and appropriate consent has been obtained), no such problem arises.



To avoid the possibility of being kept alive by artificial means or so-called "heroic measures," some advise competent adults to make a *living will* to express their wishes should they ever become incompetent. While not legally binding in most states, the living will serves as a guideline for medical professionals as well as family members. It relieves them of the painful responsibility of making euthanasia decisions on another's behalf.

Legislation concerning euthanasia has been actively debated in several states in recent years. Most proposals have sought to establish an individual's right to be "allowed to die," without advocating voluntary or involuntary euthanasia (which is illegal in all fifty states). Critics warn that legalizing passive euthanasia could lead to legalization of active euthanasia. Some who oppose legalization of (voluntary) active euthanasia feel that it is inherently immoral. Others believe that it is morally acceptable in individual cases but oppose making it a social policy because of the dangers of abuse. They suggest that such a policy could undermine respect for the sanctity of human life and lead to the legalization of involuntary active euthanasia practiced not only on the comatose but also on persons deemed socially undesirable.

The issue of euthanasia presents severe ethical dilemmas for health care providers. Traditionally, one of the primary tenets of the medical profession is the injunction, "Do no harm." The Hippocratic Oath specifies that a physician "will neither give a deadly drug to anybody . . . nor . . . make a suggestion to this effect."<sup>1</sup> In the same oath, the physician promises to "keep them [the sick] from harm and injustice." The first principle affirmed by the ethical code of

the AMA states that "A physician shall be dedicated to providing competent medical service with compassion and respect for human dignity" (see Appendix). The requirements to protect patients from injustice and to care for them with compassion and respect for dignity provide the moral groundwork for euthanasia. If a patient's condition is deteriorated to the extent that life becomes meaningless or unbearable, should the professional's duty to preserve life be overridden by the demands of compassion, respect, and justice? In such a case, helping the patient to die seems not only ethically permissible but, on grounds of humane treatment, obligatory.

In the following article James Rachels examines the conventional view condoning passive euthanasia while condemning active euthanasia. He argues that active euthanasia is often more humane than passive euthanasia. This is an important consideration since compassion is the primary justification for euthanasia. Rachels also suggests three other grounds for challenging the acceptability of the conventional view and urges physicians to reconsider its moral validity.

In the second article, physician David Hellerstein argues against the excessive use of medical technologies for "very ill people whose physical existence can be prolonged almost indefinitely but whose quality of life will be intolerable." Hellerstein suggests that, in order to combat overreliance on technological solutions, medical students should be trained in listening to patient concerns and communicating with patients, especially the terminally ill and their families. Practicing physicians should also be counseled (via hospital- and medical association-sponsored conferences) in avoiding "technological overkill." The author's third proposal is to institute "technology evaluation teams" to help physicians and patients set treatment goals and evaluate uses of technology.

<sup>1</sup>*Ancient Medicine: Selected Papers of Ludwig Edelstein*, ed. Owsei Temkin and C. Lillian Temkin (Baltimore: Johns Hopkins University Press, 1967), p. 6.



JAMES RACHELS

***Active and Passive Euthanasia***

The distinction between active and passive euthanasia is thought to be crucial for medical ethics. The idea is that it is permissible, at least in some cases, to withhold treatment and allow a patient to die, but it is never permissible to take any direct action designed to kill the patient. This doctrine seems to be accepted by most doctors, and it is endorsed in a statement adopted by the House of Delegates of the American Medical Association on December 4, 1973:

The intentional termination of the life of one human (being by another—mercy killing)—is contrary to that for which the medical profession stands and is contrary to the policy of the American Medical Association.

The cessation of the employment of extraordinary means to prolong the life of the body when there is irrefutable evidence that biological death is imminent is the decision of the patient and/or his immediate family. The advice and judgment of the physician should be freely available to the patient and/or his immediate family.

However, a strong case can be made against this doctrine. In what follows I will set out some of the relevant arguments and urge doctors to reconsider their views on this matter.

To begin with a familiar type of situation, a patient who is dying of incurable cancer of the throat is in terrible pain, which can no longer be satisfactorily alleviated. He is certain to die within a few days, even if present treatment is continued, but he does not want to go on living for those days since the pain is unbearable. So he asks the doctor for an end to it, and his family joins in the request.

Suppose the doctor agrees to withhold treatment, as the conventional doctrine says he may. The justification for his doing so is

that the patient is in terrible agony, and since he is going to die anyway, it would be wrong to prolong his suffering needlessly. But now notice this. If one simply withholds treatment, it may take the patient longer to die, and so he may suffer more than he would if more direct action were taken and a lethal injection given. This fact provides strong reason for thinking that, once the initial decision not to prolong his agony has been made, active euthanasia is actually preferable to passive euthanasia, rather than the reverse. To say otherwise is to endorse the option that leads to more suffering rather than less, and is contrary to the humanitarian impulse that prompts the decision not to prolong his life in the first place.

Part of my point is that the process of being "allowed to die" can be relatively slow and painful, whereas being given a lethal injection is relatively quick and painless. Let me give a different sort of example. In the United States about one in 600 babies is born with Down's syndrome. Most of these babies are otherwise healthy—that is, with only the usual pediatric care, they will proceed to an otherwise normal infancy. Some, however, are born with congenital defects such as intestinal obstructions that require operations if they are to live. Sometimes, the parents and the doctor will decide not to operate, and let the infant die. Anthony Shaw describes what happens then:

... When surgery is denied [the doctor] must try to keep the infant from suffering while natural forces sap the baby's life away. As a surgeon whose natural inclination is to use the scalpel to fight off death, standing by and watching a salvageable baby die is the most emotionally exhausting experience I know. It is easy at a conference, in a theoretical discussion, to decide that such infants should be allowed to die. It is altogether different to stand by in the nur-



sery and watch as dehydration and infection wither a tiny being over hours and days. This is a terrible ordeal for me and the hospital staff—much more so than for the parents who never set foot in the nursery.<sup>1</sup>

I can understand why some people are opposed to all euthanasia and insist that such infants must be allowed to live. I think I can also understand why other people favor destroying these babies quickly and painlessly. But why should anyone favor letting "dehydration and infection wither a tiny being over hours and days"? The doctrine that says that a baby may be allowed to dehydrate and wither, but may not be given an injection that would end its life without suffering, seems so patently cruel as to require no further refutation. The strong language is not intended to offend, but only to put the point in the clearest possible way.

My second argument is that the conventional doctrine leads to decisions concerning life and death made on irrelevant grounds.

Consider again the case of the infants with Down's syndrome who need operations for congenital defects unrelated to the syndrome to live. Sometimes, there is no operation, and the baby dies, but when there is no such defect, the baby lives on. Now, an operation such as that to remove an intestinal obstruction is not prohibitively difficult. The reason why such operations are not performed in these cases is, clearly, that the child has Down's syndrome and the parents and doctor judge that because of that fact it is better for the child to die.

But notice that this situation is absurd, no matter what view one takes of the lives and potentials of such babies. If the life of such an infant is worth preserving, what does it matter if it needs a simple operation? Or, if one thinks it better that such a baby should not live on, what difference does it make that it happens to have an unobstructed intestinal tract? In either case, the matter of life and death is being decided on irrelevant grounds. It is the Down's syndrome, and not the intestines, that is the issue. The matter should be decided, if

at all, on that basis, and not be allowed to depend on the essentially irrelevant question of whether the intestinal tract is blocked.

What makes this situation possible, of course, is the idea that when there is an intestinal blockage, one can "let the baby die," but when there is no such defect there is nothing that can be done, for one must not "kill" it. The fact that this idea leads to such results as deciding life or death on irrelevant grounds is another good reason why the doctrine should be rejected.

One reason why so many people think that there is an important moral difference between active and passive euthanasia is that they think killing someone is morally worse than letting someone die. But is it? Is killing, in itself, worse than letting die? To investigate this issue, two cases may be considered that are exactly alike except that one involves killing whereas the other involves letting someone die. Then, it can be asked whether this difference makes any difference to the moral assessments. It is important that the cases be exactly alike, except for this one difference, since otherwise one cannot be confident that it is this difference and not some other that accounts for any variation in the assessments of the two cases. So, let us consider this pair of cases:

In the first, Smith stands to gain a large inheritance if anything should happen to his six-year-old cousin. One evening while the child is taking his bath, Smith sneaks into the bathroom and drowns the child, and then arranges things so that it will look like an accident.

In the second, Jones also stands to gain if anything should happen to his six-year-old cousin. Like Smith, Jones sneaks in planning to drown the child in his bath. However, just as he enters the bathroom Jones sees the child slip and hit his head, and fall face down in the water. Jones is delighted; he stands by, ready to push the child's head back under if it is necessary, but it is not necessary. With only a little thrashing about, the child drowns all by himself, "accidentally," as Jones watches and does nothing.



Now Smith killed the child, whereas Jones "merely" let the child die. That is the only difference between them. Did either man behave better, from a moral point of view? If the difference between killing and letting die were in itself a morally important matter, one should say that Jones's behavior was less reprehensible than Smith's. But does one really want to say that? I think not. In the first place, both men acted from the same motive, personal gain, and both had exactly the same end in view when they acted. It may be inferred from Smith's conduct that he is a bad man, although that judgment may be withdrawn or modified if certain further facts are learned about him—for example, that he is mentally deranged. But would not the very same thing be inferred about Jones from his conduct? And would not the same further considerations also be relevant to any modification of this judgment? Moreover, suppose Jones pleaded, in his own defense, "After all, I didn't do anything except just stand there and watch the child drown. I didn't kill him; I only let him die." Again, if letting die were in itself less bad than killing, this defense should have at least some weight. But it does not. Such a "defense" can only be regarded as a grotesque perversion of moral reasoning. Morally speaking, it is no defense at all.

Now, it may be pointed out, quite properly, that the cases of euthanasia with which doctors are concerned are not like this at all. They do not involve personal gain or the destruction of normal, healthy children. Doctors are concerned only with cases in which the patient's life is of no further use to him, or in which the patient's life has become or will soon become a terrible burden. However, the point is the same in these cases: the bare difference between killing and letting die does not, in itself, make a moral difference. If a doctor lets a patient die for humane reasons, he is in the same moral position as if he had given the patient a lethal injection for humane reasons. If his decision was wrong—if, for example, the patient's illness was in fact curable—the decision would be equally regrettable no matter which method was used to

carry it out. And if the doctor's decision was the right one, the method used is not in itself important.

The AMA policy statement isolates the crucial issue very well; the crucial issue is "the intentional termination of the life of one human being by another." But after identifying this issue, and forbidding "mercy killing," the statement goes on to deny that the cessation of treatment is the intentional termination of life. This is where the mistake comes in, for what is the cessation of treatment, in these circumstances, if it is not "the intentional termination of the life of one human being by another"? Of course it is exactly that, and if it were not, there would be no point to it.

Many people will find this judgment hard to accept. One reason, I think, is that it is very easy to conflate the question of whether killing is, in itself, worse than letting die, with the very different question of whether most actual cases of killing are more reprehensible than most actual cases of letting die. Most actual cases of killing are clearly terrible (think, for example, of all the murders reported in the newspapers); and one hears of such cases every day. On the other hand, one hardly ever hears of a case of letting die, except for the actions of doctors who are motivated by humanitarian reasons. So one learns to think of killing in a much worse light than of letting die. But this does not mean that there is something about killing that makes it in itself worse than letting die, for it is not the bare difference between killing and letting die that makes the difference in these cases. Rather, the other factors—the murderer's motive of personal gain, for example, contrasted with the doctor's humanitarian motivation—account for different reactions to the different cases.

I have argued that killing is not in itself any worse than letting die; if my contention is right, it follows that active euthanasia is not any worse than passive euthanasia. What arguments can be given on the other side? The most common, I believe, is the following:

"The important difference between active and passive euthanasia is that, in passive euthanasia, the doctor does not do anything to



bring about the patient's death. The doctor does nothing, and the patient dies of whatever ills already afflict him. In active euthanasia, however, the doctor does something to bring about the patient's death: he kills him. The doctor who gives the patient with cancer a lethal injection has himself caused his patient's death; whereas if he merely ceases treatment, the cancer is the cause of the death."

A number of points need to be made here. The first is that it is not exactly correct to say that in passive euthanasia the doctor does nothing, for he does do one thing that is very important: he lets the patient die. "Letting someone die" is certainly different, in some respects, from other types of action—mainly in that it is a kind of action that one may perform by way of not performing certain other actions. For example, one may let a patient die by way of not giving medication, just as one may insult someone by way of not shaking his hand. But for any purpose of moral assessment, it is a type of action nonetheless. The decision to let a patient die is subject to moral appraisal in the same way that a decision to kill him would be subject to moral appraisal: it may be assessed as wise or unwise, compassionate or sadistic, right or wrong. If a doctor deliberately let a patient die who was suffering from a routinely curable illness, the doctor would certainly be to blame for what he had done, just as he would be to blame if he had needlessly killed the patient. Charges against him would then be appropriate. If so, it would be no defense at all for him to insist that he didn't "do anything." He would have done something very serious indeed, for he let his patient die.

Fixing the cause of death may be very important from a legal point of view, for it may determine whether criminal charges are brought against the doctor. But I do not think that this notion can be used to show a moral difference between active and passive euthanasia. The reason why it is considered bad to be the cause of someone's death is that death is regarded as a great evil—and so it is. However, if it has been decided that euthanasia—even passive euthanasia—is desirable in a

given case, it has also been decided that in this instance death is no greater an evil than the patient's continued existence. And if this is true, the usual reason for not wanting to be the cause of someone's death simply does not apply.

Finally, doctors may think that all of this is only of academic interest—the sort of thing that philosophers may worry about but that has no practical bearing on their own work. After all, doctors must be concerned about the legal consequences of what they do, and active euthanasia is clearly forbidden by the law. But even so, doctors should also be concerned with the fact that the law is forcing upon them a moral doctrine that may well be indefensible, and has a considerable effect on their practices. Of course, most doctors are not now in the position of being coerced in this matter, for they do not regard themselves as merely going along with what the law requires. Rather, in statements such as the AMA policy statement that I have quoted, they are endorsing this doctrine as a central point of medical ethics. In that statement, active euthanasia is condemned not merely as illegal but as "contrary to that for which the medical profession stands," whereas passive euthanasia is approved. However, the preceding considerations suggest that there is really no moral difference between the two, considered in themselves (there may be important moral differences in some cases in their consequences, but, as I pointed out, these differences may make active euthanasia, and not passive euthanasia, the morally preferable option). So, whereas doctors may have to discriminate between active and passive euthanasia to satisfy the law, they should not do any more than that. In particular, they should not give the distinction any added authority and weight by writing it into official statements of medical ethics.

#### Note

1. Shaw A.: "Doctor, Do We Have a Choice?" *The New York Times Magazine*, January 30, 1972, p. 54.



DAVID HELLERSTEIN

## *Overdosing on Medical Technology*

A few years ago, when I was in medical school, I spent a long Sunday afternoon squeezing bags of blood. I was on Surgery service then, and had half a mind of becoming a surgeon—I loved the cutting and sewing, the urgent rush to the operating room, and the feeling of omnipotence that came from excising disease and suturing together what was left.

This particular Sunday, an old alcoholic was brought into the emergency room, nearly dead. His name was Kalicki (all the names in this article have been changed), and his bloated belly was rigid. His body had all the stigmata of the end-stage boozier—beef-red palms, dilated webs of veins across his stomach, spidery bursts of broken blood vessels on his face and chest. There seemed to be no question of what to do. The excited voices of residents and nurses filled the emergency room, as intravenous lines were started, blood was drawn, and catheters passed into stomach and bladder. Soon old Kalicki was in the operating room. His belly was shaved and prepped, and in a few minutes the surgeon had made an incision along the line of his ribs.

Kalicki's insides were a confusion of old scars and adhesions. With each slice of the surgeon's scalpel, each movement of a blunt probe, new blood bubbled up black from within. The electric bovie, which usually stops bleeding with its cauterizing jolt, only brought forth new oozing. Kalicki's pressure began to drop; the intravenous lines were opened wide. His pressure kept falling. The blood bank was notified of the state of emergency, and soon soft plastic bags of blood began to arrive. Plastic tubing was uncoiled, new lines were started in the arms and neck, and in a few minutes what seemed like a forest of weird maroon fruit with long purple stems

hung over the table. Yet Kalicki's blood pressure stayed low.

That was when they told me to drop the retractor I had been holding and grab a bag of blood in my gloved hands. And to squeeze. I squeezed. I squeezed like hell. I must have squeezed a dozen bags until my hands went limp. Then somebody else took over, pushing hands together to force blood through the limp plastic tubing, frantically fighting to replace the deluge on the table. Of course it didn't work. Every suture put inside Kalicki's belly to stop the bleeding only brought new blood softly pumping to the surface. Finally, after 30-odd units of precious blood had traveled through Kalicki's leaky system, the chief surgeon said to stop. And everyone stood there in that stainless steel and tile room, gowned and gloved, as the pressure fell and Kalicki died. By the time somebody went to tell Kalicki's son, it was 7:30 at night; the day was gone. The son was not much surprised. Really, he said, it was for the best. The family had been expecting this for years.

That was it. Or almost it. A few weeks later, in the monthly morbidity and mortality conference, somebody brought up Kalicki's case, and mentioned a paper about the regrettably high incidence of uncontrollable bleeding in end-stage cirrhosis of the liver. Our chief commented that as soon as he made the first cut, he knew he wouldn't be able to stop the bleeding. But once he'd started, what choice did he have?

### *Pointless Displays of Technique*

The events of that afternoon have stuck with me. Even without them I doubt I'd have been a surgeon, but they did cast a pall on the whole endeavor. What had looked so heroic



now seemed bullheaded and pointless, a display of technique for its own sake.

At first such displays seemed peculiar to surgery, but as I finished medical school and began my internship and residency I began to see the same sequence of events played out over and over in different settings—in internal medicine, pediatrics, neurology, and oncology. Time after time we'd be there, in situations with no hope of survival. What I was seeing, I realized finally, was not an isolated phenomenon but something pervading the contemporary practice of medicine in America.

Certainly there are some situations where the motives for continuing aggressive treatment are more or less rational. If there is a slight hope of recovery, it's always difficult to stop treatment. And in an emergency, it's often better to act first and question later. Sometimes there are educational reasons for making a vigorous push—so interns and residents can learn to deal with the failure of multiple systems. Other times there's a need to experiment with a new drug or technique. Still other times I think there's a vague fear that lawyers might be sniffing around for malpractice possibilities or that an outraged family member might turn up after the fact. And in still other situations, unethical practitioners may perform extra tests for their own financial gain. But in many terminal situations, the barage of testing and treatment continues without any apparent reason. The machinery of the hospital, once set in motion, just continues rolling.

These are the most baffling situations. For some reason we doctors don't seem to know how *not* to treat, how not to make the first cut, how to stand back and let nature have its way. To decide not to treat the pneumococcal pneumonia in a dying patient seems like negligence—even if it may be mercy. To leave a cancer drug on the shelf seems like a crime.

To some degree, this obsession with technology reflects a bias of our culture. But to blame this situation solely on our culture would be futile. It would also be a mistake, because the problem has as much to do with

the habits of the medical profession as anything else. Over the past century, medicine has grown from being a relatively passive clinical discipline with an emphasis on the observation of disease into a scientifically based profession dedicated to the collection of data, the close monitoring of organ function, and above all the aggressive treatment of disease. The medical profession embraces—indeed, endorses—technology with little critical examination. It rewards overtesting and overtreatment. And worst of all, it has trained an entire generation of doctors—mine—in certain attitudes and thought patterns that are often detrimental to patient care.

My own experience was a textbook example. I received my training in a medical center that prides itself on delivering highly specialized, state-of-the-art care. But along with my excellent formal education in high-tech medicine came a number of informal lessons that often led to bad treatment.

### **Technology Pays**

One was the lesson of our patients' lab sheets. Every day, a new computerized record of all lab tests would be put into all the patient's charts; it was a record of all tests done since the person entered the hospital. By the time someone had been in the hospital for a few weeks, this record could amount to 30 or 40 pages. The sense one got from this was that it would be a good idea to order a whole new set of tests every day—to check against the day before.

A second lesson—which I occasionally wish I had learned better—was that technology pays. Technology gets people grants, promotions, tenure. The surest way to power in a medical center is to ally oneself with technology. I can think of one resident in my psychiatry program who has learned this lesson particularly well. When he heard that our medical center was about to get an NMR scanner, an experimental diagnostic device, he learned as much as he could about the new machine and its possible relevance to psychiatry. He became instrumental in writing



up protocol for research on the new machine and in supervising the research. This affiliation has given him power—the power to control access to this device—and will eventually enable him to publish a stream of research papers that can only increase his standing among other psychiatrists.

In addition, technology reimburses its followers well. The anesthesiologist makes more than the pediatrician, and the internist who performs more procedures to make a diagnosis makes more money than the internist who does only a few.

A third lesson, not explicitly stated but obviously followed in practice, was that virtually everyone should be treated. Instead of acknowledging that one patient might stand a chance of being cured while another might only have his or her terminal pain relieved, our approach was that we should try to do everything for everybody. It was extremely difficult for us to step back and ask what our overall goals should be or even more important, to find out what the patient might want.

The same lessons, apparently, are still being taught today. In the first major review since 1932 of what doctors study for their M.D. diploma, a panel of the Association of the American Medical Colleges (AAMC) found that medical students are being swamped by science and technology at the expense of basic healing skills. "Specialization and the rapid rate of advancement of knowledge and technology may tend to preempt the attention of both teachers and students from the central purpose of medicine, which is to heal the sick and relieve the suffering," was how the AAMC panel phrased it.

Aside from doctors' attitudes, another reason for the excessive use of technology has to do with its consumers—patients and their families. Technology often serves the purposes that religious ritual once did. Better than prayers or candles or offerings, technology conveys hope. For the dying patient, the lab test and the CAT scan are symbols of recovery, and the administration of drugs or futile emergency operations brings a certain degree of relief. For the family, there is also some

consolation in the thought that everything that can be done is being done. "Intensive care" sounds like love, so the dying patient is surrounded by monitors and catheters and respirators.

### ***Hiding Behind Machines***

Technology is often used as a distraction as well—to avoid painful and difficult issues. During my internship, this happened with an old man dying of stomach cancer. Mr. Johnson came to my hospital floor in a terminal state. But before we'd let him die, we did an enormous workup: CAT scans of body and head, X-rays of soft and hard tissues, collections of all available body fluids. He spent days in radiology waiting for these tests. He was sure we'd cure him; he had great faith in medicine. He'd already gone through one regimen of anticancer drugs with no effect; we gave him a second, experimental regimen. When that failed, a third course was begun. The most difficult thing to recall in retrospect is his suffering, not only the pain of his disease but the long waits for tests and his extreme pain from the corrosive chemotherapy. He'd cry when the futile medication went through his IV. Only in the last day or so did he realize that it was having no effect, and then he began screaming that we were killing him. There was no way to console him.

He was wrong, of course—we weren't killing him, but we weren't doing him any favor either. We were just adding to his expense and suffering, misleading him with technology. Probably we, his doctors, were misleading ourselves too; the oncologists I was working with knew full well they couldn't save Mr. Johnson, but nobody could admit it. And that's the problem. Despite all the promise of medical technology, in the crucial moments, many of us are ashamed to admit how woefully inadequate it remains.

Technology serves still another function: that of communication. There is no language anymore for sitting by the bedside; the doctor has no time for waiting and consoling. More and more, the monitor's beep and squeal re-



places the doctor's voice. The sounds of communication in the hospital are not English words but the respirator and the CAT scan. Many patients, like Mr. Johnson, are falsely reassured by these sounds, only to learn too late that they mean nothing.

Whether serving as communication, ritual, habit, or evasion, medical technology fulfills often fundamentally dishonest purposes. It is expensive, wasteful, and not infrequently inhumane to communicate through machines. And it may not even improve doctors' ability to diagnose disease, according to a recent study by physicians at Boston's Brigham and Women's Hospital. The study was conducted to determine whether the new diagnostic hardware was making autopsies obsolete as a way of helping doctors learn from their mistakes. The investigators studied the results of 100 post-mortem examinations performed at their hospital in 1960, 1970, and 1980, and they found that the percentage of diagnostic error was about the same in each of the three time periods. So much for the infallibility of technology.

### ***Learning How to Listen***

What, then, can be done to remedy this addition to machines, this technological fix? Ironically, sheer cost is forcing policymakers on the state and federal level to act. Already, five states have devised their own hospital-reimbursement plans based, for the most part, upon fixed fees for services. The Reagan administration is proposing a similar package that would replace the traditional Medicaid reimbursement system with one that establishes, in advance, prices for 467 specific diagnoses. If a hospital spends less than the set Medicaid price, it gets to pocket the difference, creating an incentive to hold costs down. However, under this system, hospitals may end up denying patients care beyond a certain arbitrary limit. Particularly needy patients may suffer, and I don't believe this approach will make doctors more selective in their use of technology.

Any truly effective changes must come

from the medical profession itself. And the place to start is at the beginning—by changing the values taught in medical school. The AAMC panel has wisely concluded that students must be taught to pay attention to treating minor problems, compiling patient histories, and using fundamental instruments such as the stethoscope. I would also suggest instruction in how to deal with terminally ill patients and their families, how to rely less on tests and more on diagnostic judgment, how to listen to patients' concerns. Such courses should be required, beginning in medical school and continuing through the clinical years of training.

Furthermore, we should attempt to change the attitudes of doctors already out of school. Many practitioners, in an effort to keep up with the bewildering pace of clinical research, regularly attend conferences and read two or three professional journals a week. Why not hold conferences, sponsored by individual hospitals or medical associations, in which the questions of technological overkill are discussed regarding specific cases? Answers to questions such as what tests are unnecessary and at what point treatment should be abandoned become increasingly important as newer technologies emerge, as we implant artificial hearts as well as kidneys, as the prospect of artificial livers becomes less fantastic. We may soon face a day when all our hospitals will be filled with very ill people whose physical existence can be prolonged almost indefinitely but whose quality of life will be intolerable.

### ***The Team Approach***

I also think it essential that we get directly into the medical arena to affect decisions as they are being made. Most hospitals have professional groups that evaluate patient care, but these "utilization review" committees are not very effective in dealing with the problem of overtreatment. They basically want to make sure that some kind of active treatment—or testing—is under way; they don't look too closely at whether it's really necessary. In fact,



these committees may sometimes encourage a frenzy of overactivity among doctors who don't even know whether a particular patient should be hospitalized.

What I propose instead is the team approach—a group of medical professionals who would go on regular hospital rounds to evaluate the use of technology in patient care. Such a team could be similar to the “pain team” I know of at one hospital that evaluates the best approach to relieving the pain of terminal cancer patients. The team includes an internist, a neurologist, a psychiatrist, a social worker, and a nurse. Similarly, a “technology evaluation team” could be composed of an internist, an intensive-care specialist, a psychiatrist, a nurse, and a few patient advocates. Team members would work with doctors and patients to help them decide on reasonable treatment goals and on the best use of medical technology. Such teams could help restore medical technologies to their proper role as useful, but fallible, tools. Some doctors may perceive this kind of team as a threat to their own authority or as a potential source of embarrassment. But I think many would welcome the support in making difficult clinical decisions.

One final example. At the end of my internship, an elderly man, a Mr. Stone, came to my floor with severe heart failure. Despite high doses of all the right medications, his body filled up with excess fluid. He was almost unable to breathe; only by giving him intravenous Lasix, which increases the flow of urine, could his lungs be kept clear. I was shocked when his cardiologist, Dr. Evans, took me aside one afternoon to recommend that I stop giving Lasix. Dr. Evans said that Mr. Stone was not enjoying life anymore, that he was very unlikely to make it out of the hospital, that he, Dr. Evans, had discussed intensive care and dialysis with the Stones and they had decided

against that kind of intervention, and that Mrs. Stone was suffering because of her husband's protracted illness.

I can't see it, I said—it's just a few squirts of Lasix every day. So I continued. Mr. Stone kept getting heavier and had more trouble breathing. Mrs. Stone was sitting at his bedside every day, suffering. So one day I decided that I was being ridiculous and did what Dr. Evans suggested. Mr. Stone died. Mrs. Stone cried and thanked me and went home.

I knew I'd done the right thing yet I felt strange, because I knew that if I wanted to I could have kept his heart going for quite a long time. It was very unsettling, after the kind of training I'd received, to just stand aside and let nature have its way.

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### Suggested Further Reading

- Engelhardt, H. Tristram, “Defining Death: A Philosophical Problem for Medicine and Law,” *American Review of Respiratory Disease*, 112 (1975), 587–90.
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- Imbus, Sharon, and Bruce E. Zawacki, “Autonomy for Burned Patients when Survival Is Unprecedented,” *The New England Journal of Medicine*, 297, no. 6 (August 11, 1977), 309–11.
- Kamisar, Yale, “Euthanasia Legislation: Some Nonreligious Objections,” *Minnesota Law Review*, 42, no. 6 (1958), 969–1042.
- Sullivan, Thomas D., “Active and Passive Euthanasia: An Impertinent Distinction?” *Human Life Review*, 111, no. 3 (Summer 1977), 40–46.
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## DECISION SCENARIO 3

### Euthanasia

Woody watched his brother, R.C., become more and more incapacitated with amyotrophic lateral sclerosis (Lou Gehrig's disease). Woody and R.C. had had an extremely close relationship. For years they had worked the family farm together. When R.C. was admitted to a nursing home, Woody's pain increased even more. Woody came to visit every day.

R.C. then had a series of strokes unrelated to the disease. They left his body contorted, with his left side partially paralyzed. R.C.'s breathing was labored, and the medical team had decided to place him on a ventilator after the weekend.

The latest series of events gave Woody no rest. He went to R.C.'s wife, begging her to do something to allow R.C. to die with dignity. The wife agreed that it was important but did not want to bring the matter up with the physician. R.C. had had a good life and now she wanted to let nature take its course. Woody himself felt there was no help from the doctors at the nursing home.

With that, Woody had his mind made up. On Sunday he visited his brother one last

time. "God forgive me," he said, "but I know you don't want to end up a vegetable." He pulled out a handgun and fired one shot at point-blank range into R.C.'s left temple. He laid the gun on R.C.'s chest and gave himself up to the supervising nurse.

### Questions

1. Is Woody's act an example of euthanasia?
2. Did he do the morally right thing? Ought he to have considered alternative courses of action? Should he be punished by law?
3. Suppose Woody argues that he knew what his brother wanted and that he was carrying out his wishes. Does this fact make his choice of a quick and painless means of death right?
4. If the doctors had the legal right to dispense lethal drugs to induce death, Woody would have felt differently. Should the means of active euthanasia be legislated?
5. How do you compare the motives of Woody, R.C.'s wife, and the nursing home medical staff? Does the duty to respect a patient imply respecting the patient's right not to have death postponed?

## 2. TREATMENT OF DEFECTIVE NEONATES

The moral problems associated with treating infants born with severe defects and deformities are especially painful for health care professionals and for the infants' families. The atmosphere of joyous expectation is transformed into an occasion of sorrow and anxiety when the newborn is found to be defective. The central moral question regarding treatment of severely defective neonates is whether (and under what circum-

stances) they ought to be allowed to die. A related question is the level of care appropriate for such infants. Since not all defects are equally severe, morally acceptable treatment varies considerably from case to case. Should the infant be given extraordinary care, ordinary care, or no care at all and simply permitted to die? The question relates primarily to passive euthanasia, but active euthanasia may also come under consider-



ation. If compassion is on the side of death, does acting in the infant's best interest require that he or she be mercifully killed?

Underlying these questions are two, more basic ethical issues. The first involves assigning a moral status to the newborn. This issue is related to the question of the moral status of fetuses, outlined in the section on abortion. Should the severely defective infant be regarded as a person? If the answer is yes, an obligation exists to provide the same treatment we would extend to other persons. As in the discussion of euthanasia, opinions vary widely as to what treatment should be. If the defective newborn does not have the status of personhood, then different criteria for treatment need to be developed. Some utilitarian arguments stress the social, emotional, and economic costs of saving the life of a severely defective infant. On these grounds, the infant ought not to be permitted to live, and no extraordinary steps should be taken to preserve its life. Arguments from a deontological standpoint, while recognizing the inherent value of a human life, find justification for withholding treatment by appealing to the duty to further the well-being of others. In such a case, extending life is a greater harm to the individual than allowing death. Such harm is an "injury of continued existence"

The second underlying issue concerns the fact that newborn infants are inherently incapable of making decisions for themselves. Who has the right or obligation to make choices on behalf of the newborn? Some argue that the decisions are medical in nature and ought to be made by health care professionals. Others believe that primary responsibility lies with the parents because they have the greatest interest in the welfare of

their offspring. Some hospitals have ethics committees charged with the responsibility of reviewing all decisions regarding the treatment of defective newborns. Conflicts sometimes develop between family members and the medical professionals about choices of treatment, and the final decision is made by the courts. On occasion, when physicians and parents decide to allow a newborn to die without treatment, an outside party institutes legal procedures aimed at forcing them to provide additional care.

Arguments about the moral acceptability of allowing a severely defective neonate to die range from the strictly conservative position, which holds that no decision of the kind is ever permissible, to more liberal views, which develop various ethical criteria to be satisfied. Conservatives often argue that quality-of-life judgments and cost considerations are not valid reasons to withhold treatment. They assert that defective newborns are entitled to any and all care which we would provide for a normal infant, on the assumption that both have the same basic right to live.

In the following article Richard A. McCormick argues that life is a relative good and not an absolute one. It has a value, he maintains, as a condition which allows for other, "higher" goods, particularly the good of human relationships. If a life severely compromises the potential for human relationship by the struggle to survive, extraordinary efforts to preserve that life are no longer morally required. McCormick stresses the need to make decisions strictly on the basis of the infant's interest, without consideration of the emotional or financial burdens which others may incur in saving a defective newborn's life.



RICHARD A. McCORMICK

*To Save or Let Die: The Dilemma of Modern Medicine*

On February 24, the son of Mr. and Mrs. Robert H. T. Houle died following court-ordered emergency surgery at Maine Medical Center. The child was born February 9, horribly deformed. His entire left side was malformed; he had no left eye, was practically without a left ear, had a deformed left hand; some of his vertebrae were not fused. Furthermore, he was afflicted with a tracheal esophageal fistula and could not be fed by mouth. Air leaked into his stomach instead of going to the lungs, and fluid from the stomach pushed up into the lungs. As Dr. André Hellegers recently noted, "It takes little imagination to think there were further internal deformities" (*Obstetrical and Gynecological News*, April 1974).

As the days passed, the condition of the child deteriorated. Pneumonia set in. His reflexes became impaired and because of poor circulation, severe brain damage was suspected. The tracheal esophageal fistula, the immediate threat to his survival, can be corrected with relative ease by surgery. But in view of the associated complications and deformities, the parents refused their consent to surgery on "Baby Boy Houle." Several doctors in the Maine Medical Center felt differently and took the case to court. Maine Superior Court Judge David G. Roberts ordered the surgery to be performed. He ruled: "At the moment of live birth there does exist a human being entitled to the fullest protection of the law. The most basic right enjoyed by every human being is the right to life itself."

*"Meaningful Life"*

Instances like this happen frequently. In a recent issue of the *New England Journal of Medicine*, Drs. Raymond S. Duff and A. G. M. Campbell<sup>1</sup> reported on 299 deaths in the

special-care nursery of the Yale-New Haven Hospital between 1970 and 1972. Of these, 43 (14%) were associated with discontinuance of treatment for children with multiple anomalies, trisomy, cardiopulmonary crippling, meningomyelocele, and other central nervous system defects. After careful consideration of each of these 43 infants, parents and physicians in a group decision concluded that the prognosis for "meaningful life" was extremely poor or hopeless, and therefore rejected further treatment. The abstract of the Duff-Campbell report states: "The awesome finality of these decisions, combined with a potential for error in prognosis, made the choice agonizing for families and health professionals. Nevertheless, the issue has to be faced, for not to decide is an arbitrary and potentially devastating decision of default."

In commenting on this study in the *Washington Post* (October 28, 1973), Dr. Lawrence K. Pickett, chief-of-staff at the Yale-New Haven Hospital, admitted that allowing hopelessly ill patients to die "is accepted medical practice." He continued: "This is nothing new. It's just being talked about now."

It has been talked about, it is safe to say, at least since the publicity associated with the famous "Johns Hopkins Case"<sup>2</sup> some three years ago. In this instance, an infant was born with Down's syndrome and duodenal atresia. The blockage is reparable by relatively easy surgery. However, after consultation with spiritual advisors, the parents refused permission for this corrective surgery, and the child died by starvation in the hospital after 15 days. To feed him by mouth in this condition would have killed him. Nearly everyone who has commented on this case has disagreed with the decision.

It must be obvious that these instances—



and they are frequent—raise the most agonizing and delicate moral problems. The problem is best seen in the ambiguity of the term “hopelessly ill.” This used to and still may refer to lives that cannot be saved, that are irretrievably in the dying process. It may also refer to lives that can be saved and sustained, but in a wretched, painful, or deformed condition. With regard to infants, the problem is, which infants, if any, should be allowed to die? On what grounds or according to what criteria, as determined by whom? Or again, is there a point at which a life that can be saved is not “meaningful life,” as the medical community so often phrases the question? . . .

Thus far, the ethical discussion of these truly terrifying decisions has been less than fully satisfactory. Perhaps this is to be expected since the problems have only recently come to public attention. In a companion article to the Duff-Campbell report,<sup>1</sup> Dr. Anthony Shaw<sup>3</sup> of the Pediatric Division of the Department of Surgery, University of Virginia Medical Center, Charlottesville, speaks of solutions “based on the circumstances of each case rather than by means of a dogmatic formula approach.” Are these really the only options available to us? Shaw’s statement makes it appear that the ethical alternatives are narrowed to dogmatism (which imposes a formula that prescind from circumstances) and pure concretism (which denies the possibility of usefulness of any guidelines).

### ***Are Guidelines Possible?***

Such either-or extremism is understandable. It is easy for the medical profession, in its fully justified concern with the terrible concreteness of these problems and with the issue of who makes these decisions, to trend away from any substantive guidelines. As *Time* remarked in reporting these instances: “Few, if any, doctors are willing to establish guidelines for determining which babies should receive lifesaving surgery or treatment and which should not” (*Time*, March 25, 1974). On the other hand, moral theologians, in their fully justified concern to avoid total normlessness

and arbitrariness wherein the right is “discovered,” or really “created,” only in and by brute decision, can easily be insensitive to the moral relevance of the raw experience, of the conflicting tensions and concerns provoked through direct cradle-side contact with human events and persons.

But is there no middle course between sheer concretism and dogmatism? I believe there is. Dr. Franz J. Ingelfinger,<sup>4</sup> editor of the *New England Journal of Medicine*, in an editorial on the Duff-Campbell-Shaw articles, concluded, even if somewhat reluctantly: “Society, ethics, institutional attitudes and committees can provide the broad guidelines, but the onus of decision making ultimately falls on the doctor in whose care the child has been put.” Similarly, Frederick Carney of Southern Methodist University, Dallas, and the Kennedy Institute . . . stated of these cases: “What is obviously needed is the development of substantive standards to inform parents and physicians who must make such decisions” (*Washington Post*, March 20, 1974).

“Broad guidelines,” “substantive standards.” There is the middle course, and it is the task of a community broader than the medical community. A guideline is not a slide rule that makes the decision. It is far less than that. But it is far more than the concrete decision of the parents and the physician, however seriously and conscientiously this is made. It is more like a light in a room, a light that allows the individual objects to be seen in the fullness of their context. Concretely, if there are certain infants that we agree ought to be saved in spite of illness or deformity, and if there are certain infants that we agree should be allowed to die, then there is a line to be drawn. And if there is a line to be drawn, there ought to be some criteria, even if very general, for doing this. Thus, if nearly every commentator has disagreed with the Hopkins decision, should we not be able to distill from such consensus some general wisdom that will inform and guide future decisions? I think so.

The task is not easy. Indeed, it is so harrow-



ing that the really tempting thing is to run from it. The most sensitive, balanced, and penetrating study of the Hopkins case that I have seen is that of the University of Chicago's James Gustafson.<sup>2</sup> Gustafson disagreed with the decision of the Hopkins physicians to deny surgery to the mongoloid infant. In summarizing his dissent, he notes: "Why would I draw the line on a different side of mongolism than the physician did? While reasons can be given, one must recognize that there are intuitive elements, grounded in beliefs and profound feelings, that enter into particular judgments of this sort." He goes on to criticize the assessment made of the child's intelligence as too simplistic, and he proposes a much broader perspective on the meaning of suffering than seemed to have operated in the Hopkins decision. I am in full agreement with Gustafson's reflections and conclusions. But ultimately, he does not tell us where he would draw the line or why, only where he would *not*, and why.

This is very helpful already, and perhaps it is all that can be done. Dare we take the next step, the combination and analysis of such negative judgments to extract from them the positive criterion or criteria inescapably operative in them? Or more startlingly, dare we *not* if these decisions are already being made? Gustafson is certainly right in saying that we cannot always establish perfectly rational accounts and norms for our decisions. But I believe we must never cease trying, in fear and trembling to be sure. Otherwise, we have exempted these decisions in principle from the one critique and control that protects against abuse. Exemption of this sort is the root of all exploitation whether personal or political. Briefly, if we must face the frightening task of making quality-of-life judgments—and we must—then we must face the difficult task of building criteria for these judgments.

### ***Facing Responsibility***

What has brought us to this position of awesome responsibility? Very simply, the sophistication of modern medicine. Contemporary resuscitation and life-sustaining devices have

brought a remarkable change in the state of the question. Our duties toward the care and preservation of life have been traditionally stated in terms of the use of ordinary and extraordinary means. For the moment and for purposes of brevity, we may say that, morally speaking, ordinary means are those whose use does not entail grave hardships to the patient. Those that would involve such hardship are extraordinary. Granted the relativity of these terms and the frequent difficulty of their application, still the distinction has had an honored place in medical ethics and medical practice. Indeed, the distinction was recently reiterated by the House of Delegates of the American Medical Association in a policy statement. After disowning intentional killing (mercy killing), the AMA statement continues: "The cessation of the employment of extraordinary means to prolong the life of the body when there is irrefutable evidence that biological death is imminent is the decision of the patient and/or his immediate family. The advice and judgment of the physician should be freely available to the patient and/or his immediate family" (JAMA 227:728, 1974).

This distinction can take us just so far—and thus the change in the state of the question. The contemporary problem is precisely that the question no longer concerns only those for whom "biological death is imminent" in the sense of the AMA statement. Many infants who would have died a decade ago, whose "biological death was imminent," can be saved. Yesterday's failures are today's successes. Contemporary medicine with its team approaches, staged surgical techniques, monitoring capabilities, ventilatory support systems, and other methods, can keep almost anyone alive. This has tended gradually to shift the problem from the means to reverse the dying process to the quality of the life sustained and preserved. The questions, "Is this means too hazardous or difficult to use" and "Does this measure only prolong the patient's dying," while still useful and valid, now often become "Granted that we can easily save the life, what kind of life are we saving?" This is a quality-of-life judgment. And we fear it. And



certainly we should. But with increased power goes increased responsibility. Since we have the power, we must face the responsibility.

### ***A Relative Good***

In the past, the Judeo-Christian tradition has attempted to walk a balanced middle path between medical vitalism (that preserves life at any cost) and medical pessimism (that kills when life seems frustrating, burdensome, "useless"). Both of these extremes root in an identical idolatry of life—an attitude that, at least by inference, views death as an unmitigated, absolute evil, and life as the absolute good. The middle course that has structured Judeo-Christian attitudes is that life is indeed a basic and precious good, but a good to be preserved precisely as the condition of other values. It is these other values and possibilities that found the duty to preserve physical life and also dictate the limits of this duty. In other words, life is a relative good, and the duty to preserve it a limited one. These limits have always been stated in terms of the *means* required to sustain life. But if the implications of this middle position are unpacked a bit, they will allow us, perhaps, to adapt to the type of quality-of-life judgment we are now called on to make without tumbling into vitalism or a utilitarian pessimism.

A beginning can be made with a statement of Pope Pius XII<sup>5</sup> in an allocution to physicians delivered November 24, 1957. After noting that we are normally obliged to use only ordinary means to preserve life, the Pontiff stated: "A more strict obligation would be too burdensome for most men and would render the attainment of the higher, more important good too difficult. Life, death, all temporal activities are in fact subordinated to spiritual ends." Here it would be helpful to ask two questions. First, what are these spiritual ends, this "higher, more important good"? Second, how is its attainment rendered too difficult by insisting on the use of extraordinary means to preserve life?

The first question must be answered in

terms of love of God and neighbor. This sums up briefly the meaning, substance and consummation of life from a Judeo-Christian perspective. What is or can easily be missed is that these two loves are not separable. St. John wrote: "If any man says 'I love God' and hates his brother, he is a liar. For he who loves not his brother, whom he sees, how can he love God whom he does not see?" (1 John 4:20-21). This means that our love of neighbor is in some very real sense our love of God. The good our love wants to do Him and to which He enables us, can be done only for the neighbor, as Karl Rahner has so forcefully argued. It is in others that God demands to be recognized and loved. If this is true, it means that, in Judeo-Christian perspective, the meaning, substance, and consummation of life is found in human relationships, and the qualities of justice, respect, concern, compassion, and support that surround them.

Second, how is the attainment of this "higher, more important (than life) good" rendered "too difficult" by life-supports that are gravely burdensome? One who must support his life with disproportionate effort focuses the time, attention, energy, and resources of himself and others not precisely on relationships, but on maintaining the condition of relationships. Such concentration easily becomes overconcentration and distorts one's view of and weakens one's pursuit of the very relational goods that define our growth and flourishing. The importance of relationships gets lost in the struggle for survival. The very Judeo-Christian meaning of life is seriously jeopardized when undue and unending effort must go into its maintenance. . . .

### ***The Quality of Life***

. . . Life's potentiality for other values is dependent on two factors, those external to the individual, and the very condition of the individual. The former we can and must change to maximize individual potential. That is what social justice is all about. The latter we sometimes cannot alter. It is neither inhuman nor unchristian to say that there comes a point



where an individual's condition itself represents the negation of any truly human—i.e., relational—potential. When that point is reached, is not the best treatment no treatment? I believe that the *implications* of the traditional distinction between ordinary and extraordinary means point in this direction.

In this tradition, life is not a value to be preserved in and for itself. To maintain that would commit us to a form of medical vitalism that makes no human or Judeo-Christian sense. It is a value to be preserved precisely as a condition for other values, and therefore insofar as these other values remain attainable. Since these other values cluster around and are rooted in human relationships, it seems to follow that life is a value to be preserved only insofar as it contains some potentiality for human relationships. When in human judgment this potentiality is totally absent or would be, because of the condition of the individual, totally subordinated to the mere effort for survival, that life can be said to have achieved its potential.

### **Human Relationships**

If these reflections are valid, they point in the direction of a guideline that may help in decisions about sustaining the lives of grossly deformed and deprived infants. That guideline is the potential for human relationships associated with the infant's condition. If that potential is simply nonexistent or would be utterly submerged and undeveloped in the mere struggle to survive, that life has achieved its potential. There are those who will want to continue to say that some terribly deformed infants may be allowed to die *because* no extraordinary means need be used. Fair enough. But they should realize that the term "extraordinary" has been so relativized to the condition of the patient that it is this condition that is decisive. The means are extraordinary because the infant's condition is extraordinary. And if that is so, we must face this fact head-on—and discover the substantive standard that allows us to say this of some infants, but not of others.

Here several caveats are in order. First, this guideline is not a detailed rule that preempts decisions; for relational capacity is not subject to mathematical analysis but to human judgment. However, it is the task of physicians to provide some more concrete categories or presumptive biological symptoms for this human judgment. For instance, nearly all would very likely agree that the anencephalic infant is without relational potential. On the other hand, the same cannot be said of the mongoloid infant. The task ahead is to attach relational potential to presumptive biological symptoms for the gray area between such extremes. In other words, individual decisions will remain the anguishing onus of parents in consultation with physicians.

Second, because this guideline is precisely that, mistakes will be made. Some infants will be judged in all sincerity to be devoid of any meaningful relational potential when that is actually not quite the case. This risk of error should not lead to abandonment of decisions; for that is to walk away from the human scene. Risk of error means only that we must proceed with great humility, caution, and tentativeness. Concretely, it means that if err we must at times, it is better to err on the side of life—and therefore to tilt in that direction.

Third, it must be emphasized that allowing some infants to die does not imply that "some lives are valuable, others not" or that "there is such a thing as a life not worth living." Every human being, regardless of age or condition, is of incalculable worth. The point is not, therefore, whether this or that individual has value. Of course he has, or rather *is* a value. The only point is whether this undoubted value has any potential at all, in continuing physical survival, for attaining a share, even if reduced, in the "higher, more important good." This is not a question about the inherent value of the individual. It is a question about whether this worldly existence will offer such a valued individual any hope of sharing those values for which physical life is the fundamental condition. Is not the only alternative an attitude that supports mere physical life as long as possible with every means?