

ETHICAL PROBLEMS OF DEATH AND DYING

7. Mrs. Rousseau, RN, CFNP, MSN, has been assigned to train unlicensed personnel to assist RNs in drawing blood, inserting catheters, and taking vital signs. She has 5 hours of lecture and 15 hours of on-the-job training. Her pupils, most of them from a government poverty program, are a mixed group. Some are bright, dexterous, and quick to learn. Others are slow and awkward. Others, since they cannot multiply, cannot take a pulse for 15 seconds and multiply by 4, but must count through an entire minute. They often get confused about how many beats they have counted. About half the group has trouble hearing even a severe irregularity. One or two do not even notice when a patient is turning blue. This appears to be a matter of attention span, since when not busy they appear to be off in space.

Because by passing them, Rousseau will put them on the floor, she is torn apart. "Some of them just do not have it," she muses to herself.

Should Rousseau approve all of them despite her serious doubts? Which candidates should be rejected out of hand? Should she go with the principle of "Don't rock the boat," and merely suggest a better screening method for future candidates?

Note

1. The obligation to police, which includes the obligation to blow the whistle, is recognized in varying ways by the following excerpts from the codes of health care providers.

The American Nurses Association (3.5, 2010) directs nurses to be aware of any occurrence which might harm a patient, including actions reflecting incompetence, illegality, or impaired practices.

The American Physical Therapy Association (1994):

- 7.1 Physical therapists are to report any conduct which appears to be unethical, incompetent, or illegal.

The American Medical Association (1980 version):

A physician shall deal honestly with patients and colleagues and shall strive to expose those physicians deficient in character and competence, or who engage in fraud or deceptions.

The American Medical Association (1989) is more explicit:

- 9.04 DISCIPLINE AND MEDICINE. A physician should expose, without fear or favor, incompetent or corrupt, dishonest or unethical conduct on the part of members of the profession. Questions of such conduct should be considered, first, before proper medical tribunals in executive sessions or by special or duly appointed committees on ethical relations, provided that such a course is possible and provided, also, that the law is not hampered thereby. If doubt should arise as to the legality of the physician's conduct, the situation under investigation may be placed before officers of the law, and the physician-investigators may take the necessary steps to enlist the interest of the proper authority.

INTRODUCTION

Few areas in medical ethics are as difficult as those concerning death and dying. These topics raise questions about the meaning of life, the purpose of medical treatment, and a person's right to determine when medical treatment, and even life, should end.

The first part of this chapter takes up the *ethics of the patient*, and the second is concerned with the *ethics of the care giver in the face of death and dying*. The third and final part is devoted to issues involving surrogates. The ethics of the patient involve the refusal of treatment or the request to discontinue treatment when such acts will lead to, or at least hasten, death. Of necessity, this involves a discussion of the ethics of both passive and active suicide. Once we have discussed the ethics of suicide, we proceed to a consideration of the health care provider's ethical problems in cooperating with the patient's refusal of treatment or even physician-assisted suicide, as well as related questions involving living wills, the patient in a permanent vegetative state, and the quality of life for the individual person.

ETHICS OF THE PATIENT

First, we shall attempt to answer two basic questions: (1) Is refusing treatment suicide? (2) Is suicide always unethical?

Suicide: is the intentional termination of one's own life. This definition will include all those cases in which a person wants to kill himself or herself, whether the person does this by omitting something (passive suicide) or by doing something (active suicide).

FOCUS QUESTION: Mr. Jones has an implanted defibrillator that has worked twice to shock him out of a life-threatening heart rhythm problem. He has just learned that he now has an untreatable form of cancer. Can his heart doctor agree to Mr. Jones's request to turn off the defibrillator?

Refusal of Treatment and Passive Suicide

In chapter 2, we argued that a patient has a right to refuse treatment. In chapter 3, we developed the idea that the patient needs a proportionate reason for refusing to begin or continue treatment. In short, using the approach of practical wisdom, we argue that it is ethical for the patient to refuse treatment for a proportional reason, *all things considered*. Unfortunately, many people, including many health care providers, want to challenge the right of the patient to refuse treatment when the refusal leads to death or at least a speeding up of the death process. Emotionally, if not intellectually, those who object to the patient's decision argue that such a refusal is suicide and unethical, because all suicide is unethical. The issue becomes more disputed when it is necessary for surrogates to make the decision.

Let us start with a commonsense definition of suicide as *the intentional termination of one's own life*. This definition will include all those cases in which a person wants to kill himself or herself, whether the person does this by omitting something (passive suicide) or by doing something (active suicide).¹ It does not include cases in which the person does not intend to terminate her or his life, but omits an action or performs an action that the person foresees as possibly leading to death. A person who gives up food so that others may live is often not considered to be committing suicide, even though this person may starve to death. Even if one calls this altruistic act suicide, it is still ethical in a consequentialist view, since there is a proportionate reason for risking or permitting death. Similarly, the person who dies because he or she has refused treatment in order to avoid a degrading and painful existence may be said to commit suicide, but this would be a passive suicide. In line with what was said in chapter 3 about the proportional nature of the patient's obligation to care for himself or herself, arguably this is an ethical action. A serious difficulty is identifying when such refusal is not truly a passive acquiescence to the inevitability of a disease, and instead is a disproportionate seeking out of death.

Part of the difficulty is in the meaning of the word *intend*. One can know that death will result from one's actions without *intending* to die (consider the discussion of the principle of double effect in chapter 3 and O'Rourke, 1996). Altruistic acts leading to death are rarely considered suicide because of this distinction. However, particularly in medical ethics, we can be faced with situations in which a patient or the patient's surrogate may intend the patient's death, not because he or she wants to die, but because a medical condition or the treatment for it is intolerable. They intend their deaths only because of the inhumaneness of their circumstances. The real issue (what is intended) is the elimination of suffering, and the means is perhaps discontinuing ventilation. A test for this would be that given a life without this suffering, the patient would prefer to be alive. It is in this sense that we refer to a proportionate reason for refusing treatment and ultimately conclude that not

all suicide defined as the intentional killing of oneself is unethical by common sense or practical wisdom standards.

Why Is Suicide Thought to Be Unethical?

The difficulty of this question centers on the question of what constitutes a proportionate reason. To answer this question, we must first look at the reasons given for condemning active suicide. These arguments make a *prima facie*, or presumptive, case against active suicide, but do not in our opinion prove philosophically that suicide is always and in all circumstances an ethical evil. This is important not only for the ethics of the patient, but in considering the ethicality of a health care provider cooperating in active suicide.

The notion that suicide is wrong has been supported by a number of arguments. The first argument is religious and theological. It holds that our lives belong to God and are merely loaned to us, so we have no right to dispose of our own lives, even though we have the right to use them within limits. In this view, we have no more right to kill ourselves than we would have to take the life of another. This is a strong argument for those who believe in the basic premises. Even the proponents of this argument, however, must admit that God might, at least by way of exception, grant a person permission to commit active suicide. While they are very hesitant to admit exceptions in cases of active suicide, they do permit some passive suicide. They admit, for example, that a patient is not required to use extraordinary means to continue existence. As noted in chapter 3, this amounts to saying that in certain circumstances passive suicide can be justified by a proportionate reason. Indeed, these religious writers praise the person who lays down a life for a friend or suffers martyrdom for the sake of religious faith, although they are quite clear that a person ought not to go about looking for martyrdom.

The second argument holds that human life is so precious that to act against it is to act against the greatest of all human goods, or at least against the good on which all other human goods depend. These assertions might appear true in the abstract, as long as one does not specify the specific condition of that life. The abstract consideration overlooks several important truths. In the concrete, life may be experienced as an overwhelming burden, and the word *life* may designate no more than a vegetable existence in a specific case. Furthermore, life can be so painful and so crushing that it renders all other goods impossible. Finally, life can be barely recognizable as human, as in the cases of those who are in a permanent vegetative state. Those who have been in real pain know how pain eats up all other consciousness and abolishes control of much activity, even as it makes us insensitive to the feelings of those who love us. Even though medical science has become adept at controlling pain, it often succeeds at the cost of the patient's consciousness. When the choice becomes overwhelming pain or unconsciousness, it appears that life is no longer the substratum for all other good things. In the

concrete, then, life may not be the greatest of all goods or that good upon which all other goods depend. In short, life is not an unambiguous reality such that it is always a good. We shall return to this issue in the second part of this chapter.

Those who hold that life is precious and the basis for all other goods can also recognize the fact of the vegetative state and of pain. Often, then, they will permit an ethical, passive suicide for a proportionate reason, even though they reject active suicide, that is, the direct killing of oneself.

The matter cannot be settled merely by permitting passive suicide for a proportionate reason. There is need for a longer look at the value of life and the relative importance of the quality of life. We will return to this question after we outline the remaining arguments against suicide.

A third argument, this one consequentialist, condemns suicide because it harms the community. This, too, is a bit oversimplified. As a matter of fact, not all suicides harm the community. Some suicides may be a positive benefit to the community. If Americans over age 70 committed suicide at the first sign of serious illness, there would be tremendous savings in Medicare and Social Security costs. Of course, these financial savings may be offset by the economic productivity or other contributions of people over 70, but the point remains that suicide is not simply harmful to the community.

As noted in chapter 1, the individual person and not the community is the intrinsic good, and the individual should not be automatically or unnecessarily subordinated to the community. Certainly, the individual must consider the impact of his or her actions on the society, but the effects on society are not the decisive factor. In short, the harm to the community must be considered in judging proportionality, but the good of the community is on the level of means and is not the intrinsic good. We shall return to this shortly. Thus, the mere fact that a suicide might hurt the community does not settle the issue.

A fourth argument proposes that suicide is wrong because it has substantially harmful consequences for other individuals. Once again, we agree that these consequences must be considered, but we insist that they are not the only factors to be considered in judging the proportionality of the goods and evils involved. The value of the human person is not solely, or even primarily, dependent on her or his utility for others, either singly or in a group. Thus, the actual and potential harm to the patient can at times be the decisive factor in deciding the balance of good or evil in the suicide situation.

While some writers might theoretically accept the exceptions we have just pointed out, they will argue that, in practice, suicide should be forbidden because of the wedge principle in its logical or empirical form. That is, they argue from the long-term consequences of allowing exceptions. Their arguments, based on each of the principles, deserve study.

The empirical form of the wedge principle, which argues that exceptions will lead to the dramatic spread of suicide, seems to have little foundation.

Suicide will never become popular for the simple reason that most people are attached to their lives even when they are very difficult. Admitting reasonable exceptions to the general condemnation of suicide hardly seems likely to change this.

The logical form of the wedge principle, which argues that we should be consistent, hardly seems applicable for the practical wisdom theorist who consistently insists on the need for considering the effect on dignity of all the elements of the situation and refuses to rely on oversimplified analysis. We suspect that an emotional need for clear and certain moral rules, rather than consistency, motivates most objections to exceptions.

This much seems clear: active suicide, although generally an evil, is not universally evil. All major theories appear to allow room for exceptions. Certainly, the follower of practical wisdom must admit exceptions, because in some cases the person can quite reasonably decide that, all things considered, continued existence is more evil than the termination of existence. When one is already dying and life is consumed by pain, the value of biological existence may, in the view of some patients, evaporate into nonsense and at the very least becomes a serious moral question for loved ones.

Summary: Suicide and the Ethics of the Patient

The distinction between passive and active suicide remains important for this discussion. Both the arguments above and the treatment of beneficence from the patient's point of view (chapter 3) make it clear that the refusal of treatment, even considered as passive suicide, is ethical given a proportionate reason, all things considered. The present chapter also points to the argument that even active suicide can be ethical for the patient, granted proportionality of all things considered.

To say that it is ethical for a patient to commit active suicide in certain circumstances is not, however, to say that patients have a right to do so. To put it another way, the ethical correctness of active suicide does not necessarily imply a right not to be interfered with (a liberty right), let alone a right to have others help them (substantive right). For example, this point by itself does not answer the question of the ethical correctness of physician-assisted suicide. It is necessary, then, to consider first the health care provider's ethics of active suicide prevention and then the ethics of cooperating with a suicide. After this, we will return to the simpler case of the health care provider cooperating with passive suicide.

An Alternative View

This review of arguments against suicide reveals a common thread in the suggestion that the life of the individual is an element of a larger picture that morally limits the individual's actions. This establishes a tension between the individual's autonomy and the moral limits on the exercise of that autonomy

(see the discussion of physician-assisted suicide later in the chapter). Becker describes a different view held by Japanese Buddhism, where "the acceptability of suicide, even in the early Buddhist community, depended not on terminal illness alone, but upon the state of selfless equanimity with which one was able to pass away" (Becker, 1990, p. 619). The central concern is not one of power (who has the authority to do what) or the nature of the action itself, but of the state of one's consciousness. If one is angry or fearful, one is not ready for death no matter how it comes. This position is connected with a strong belief in an afterlife and rebirth. For the Buddhist it matters how one dies, for this influences what happens to the soul in the next world.

HEALTH CARE PROVIDERS AND THE ETHICS OF SUICIDE PREVENTION

In chapters 1 and 2, we stressed the fact that private individuals, including health care providers, do not have a right to interfere with the activities of others unless authorized to do so by society. In addition, we stressed the fact that, in general, even society is justified in interfering and authorizing others to interfere only for overriding social interests.

In the present context of suicide prevention in the United States, several points seem clear. First, society has a clear interest in the preservation of life itself. As we have seen, life has a fundamental value, and an important advantage to living in society is the protection social life affords to life itself. Second, although the value of the individual is not purely and simply his or her value to society, most individuals are valuable to society, and society has a legitimate interest in preserving most of its citizens. At times, there may even be a very strong overriding social interest, since the individual in question may be particularly valuable to society. Society could, then, legitimately forbid suicide or cooperation with suicide on the grounds that the suicide robbed society of someone valuable. In addition, societies recognize that suicides do affect the rights of others. Spouses and children, in particular, have important legal and moral claims on a would-be suicide. For example, if a child's claims to such things as food and shelter are not met because of a suicide, society will be burdened with the child's support. For these reasons, many societies have made suicide a crime, that is, an offense against the society. Finally, the society may conclude that groups, such as the health care professions, need to be insulated from the active suicide to protect the functioning of the profession.

In the United States, most states make cooperating with suicide a crime, although suicide itself is not. This acknowledges that, even though a person may be free to commit suicide, the society does not want to encourage it and definitely does not want others helping, since that help can easily turn into homicide. Yet, as we shall see, there are cases in which society might well authorize controlled cooperation with suicide.

Even though it does not make suicide a crime, American society authorizes medical and police personnel to frustrate and restrain attempted suicides and to initiate a due process that can lead to involuntary commitment to a mental institution for those who are judged to be a danger to themselves or others. It should be noted, however, that in some states, such as New York, suicide refers only to self-inflicted harm and not to a decision to refuse life-sustaining treatment (New York State Task Force on Life and the Law, 1986).

When danger is limited to the patient, that is, when there is no damage to society or spouses and children, this societal practice raises serious questions. Szasz (1977) and other libertarians (those who believe in the maximum freedom compatible with the rights of others) object strenuously. Szasz writes:

The individualistic position on suicide might be put thus: A person's life belongs to himself. Hence, he has a right to take his own life, that is, to commit suicide. To be sure this view recognizes that a person may also have a moral responsibility to his family and others and that, by killing himself, he reneges on those responsibilities. But those are moral wrongs that society, in its corporate capacity as the state, cannot properly punish. Hence the state must eschew attempts to regulate such behavior by means of formal sanctions, such as criminal or mental hygiene laws. (p. 76)

The Szasz position ignores the fact that society might still have a legitimate interest in coercing a person into fulfilling her or his responsibility to family and others, as well as in preventing harm to other individuals or groups. Laws authorizing the prevention of suicide can have legitimate social purposes. There may also be room for a legitimate form of the weak paternalism discussed in chapter 2.

This weak paternalism is found in the position of Greenberg (1974), who insists that many who attempt suicide do not really want to die and that efforts to save them are justified. Greenberg, however, notes that a suicide prevention policy should interfere as little as possible with those who, after due consideration, still want to commit suicide. Thus, the prevention would be temporary, with the purpose of ensuring the patient's autonomy. This position, however, recognizes that in general the state should not interfere unless for an overriding state interest or the protection of the rights of others.

In this context, it needs to be stressed that the prevention of suicide by involuntary commitment requires legal procedures and is not simply a medical question. These legal procedures have been made increasingly strict in recent times, since in the past the power of commitment was often abused. This was particularly true when a simple physician with no psychiatric training had sufficient authority in court to assure the commitment.

The laws on active suicide and involuntary commitment of those who are suicidal are not without their problems. Sometimes, the law and its application seem more paternalistic than guided by an interest in protecting society.

In some cases, the law can be questioned with regard to the lack of full due process or clear norms for commitment. Whether we approve of these laws or not, they are there, and the reasons for their existence must enter into the decisions of health care providers.

HEALTH CARE PROVIDERS AND THE ETHICS OF THE DEATH OF A PATIENT

It is time now to return to one of our basic questions: Is it ethical for the health care provider to cooperate when a competent patient refuses treatment? Further, may a health care provider cooperate with a patient's active suicide? In using the word *cooperation*, we mean to stress that the competent patient has asked for or consented to the cooperation. When there is an incompetent or doubtfully competent patient or only surrogate consent, we are dealing with an even more delicate problem that we will discuss separately.

Cooperation with a Patient Who Refuses Treatment

Let us now turn to a health care professional's cooperation with the patient's refusal of treatment or the demand that life-sustaining treatment be withdrawn. The laws that forbid cooperation with active suicide do not forbid cooperating with such a refusal. Increasingly, court decisions affirm the right of the patient to refuse treatment, including nutrition and hydration. As noted in chapter 2, such a person cannot be treated against his or her wishes without a court order. Such orders are not automatically granted. Indeed, the right to refuse treatment and to refuse nutrition and hydration has been recognized not only in the case of terminal patients, but in the case of competent nonterminal patients, as well as being recognized in surrogates for such patients.² However, the question is far more complex than the mere legal aspects, and we must now consider the ethical complexities.

In these cases of passive suicide, the patient or surrogate exercises the right to refuse treatment or demands the discontinuance of treatment in order to avoid suffering or to avoid the difficulties of continued treatment; generally this also implies that discontinuing treatment will speed up dying. (In no case does discontinuing treatment imply discontinuing care.) As we saw in chapter 2, the competent patient has the right to refuse or discontinue treatment. Yet a variety of court cases on the subject indicate that there are more complicated emotional and ethical problems for health care providers and for society. In a sense, there is a landscape in which such refusal can be more or less acceptable, depending on whether the patient is terminal with death imminent; merely terminal; terminal and in a permanent vegetable state; nonterminal and in a permanent vegetable state; nonterminal, noncomatose, and incompetent; nonterminal, noncomatose, and competent, but with difficult life prospects; or even nonterminal, noncomatose, competent,

and without difficult life prospects. These considerations are particularly important for surrogate decisions.

When the patient is terminal and death is imminent, no treatment is medically indicated (see chapter 3), and the competent patient's rightful refusal of treatment does not conflict with the health provider's form of beneficence. There may be an emotional problem in admitting defeat, but there should be no ethical problem. We note that, although the patient may not be competent at the end, refusal of treatment may be accomplished through a living will or a surrogate, especially through a surrogate who has durable power of attorney for health matters. We will return to the objections against the living will later.

When the patient is terminal but death is not imminent, for example, when the disease or injury progresses slowly, and granted the consent of the patient or surrogate, it appears ethical to omit *treatment* on the ground that nothing can be accomplished in thwarting the progress of the disease. But it is not ethical to omit *care*, since human dignity is to be respected (see below).

The American Medical Association's Council on Ethical and Judicial Affairs (2012) takes a clear stand on the issue:

2.20 Even if the patient is not terminally ill or permanently unconscious, it is not unethical to discontinue all means of life-sustaining medical treatment in accordance with a proper substituted judgment or best interests analysis.

The treatments include artificially supplied respiration, nutrition, or hydration. In its opposition to physician-assisted suicide, the American Medical Association (AMA) has strongly endorsed a program to education physicians to the appropriateness of switching from therapeutic treatment to palliative care. We shall return to the special problems of nutrition and hydration later in this chapter.

As we shall see later, this position on discontinuing treatment is reinforced by the law in those states that recognize living wills and durable powers of attorney. These legal instruments will be discussed later in this chapter.

Discontinuing Treatment

Let us look at the reasoning behind the ethical correctness of not beginning or of stopping treatment in the case of the consenting patient who is terminally ill. First, the health care provider has no obligation to prolong dying merely for the sake of prolonging it. That is, it makes no sense to prolong life when the true result is the prolongation of the dying process. Furthermore, when treatment is only prolonging the agony of the patient, its continuation is unethical as an insult to human dignity. In such cases, the health care provider would be ethically justified in discontinuing treatment *except when the patient insists on treatment*. Even in this case, however, there can be exceptions. When there

is a severe shortage of medical resources, the physician might be justified in stopping nonindicated treatment even over the protests of the patient. We say "might be justified," since justification would depend, among other things, on a new social consensus about the duties of health care professionals and on a reasonable certainty that a shortage exists. There are also problems in discontinuing treatment when the patient's surrogate(s) objects. We shall return to these questions later.

It should be noted that cessation of life-sustaining treatment does not always bring about a swift and painless death, even though it may speed up the process of dying. For example, if kidney dialysis is discontinued, the person can at times remain conscious and suffer vomiting, internal hemorrhage, and convulsions. The removal of a respirator may not lead to death immediately, and an alert patient can suffer the pain and panic of suffocation. But if the removal leads to hypoventilation, then it is a quiet peaceful death. It is always the obligation of the physician to ensure that the patient receives proper continuous care. This obligation to care for the patient demands that every ethical effort be made to alleviate these sufferings with drugs and other methods that will not prolong life. Much recent research suggests that physicians are particularly deficient in their willingness and ability to provide adequate pain palliation for dying patients (SUPPORT, 1995; American Medical Association, 1995). There have been very significant recent efforts to educate physicians in all forms of pain palliation, and even a subspecialty in palliative care has emerged (Landro, 2005). This could be one of the main concerns that drive the interest in physician-assisted suicide. Beyond this, when such pain relief is not possible for the patient, or when the harm is not the pain, but the insult to dignity, there arises the difficult problem of actively cooperating in the suicide of the patient.

Feeding and Hydration

In our treatment of the health care provider's formulation of the principle of beneficence in chapter 3 we touched on the problem of feeding and hydration in the context of the final Baby Doe rule. We now return to the question of whether nutrition and hydration are medically indicated for terminal patients.

Before answering this question, it is necessary to show that the nutrition and hydration in question are generally not matters of sipping liquids or spooning in chicken soup, but of serious, uncomfortable, and occasionally painful medical procedures. A brief look at the methods will show their medical nature.

There are several methods of intravenous nutrition and hydration. Nearly everyone is familiar with intravenous, or IV, feeding, in which a tiny tube is inserted into a vein in the arm or hand. This method is only temporarily useful for improving hydration and electrolyte concentrations. Often the patient

has to be restrained from tearing out the tube. Another IV method involves inserting a catheter (small tube) into a major vein in the chest. This is a more costly method that increases the risk of infection and again often leads to restraint of the patient.

There are also two methods of feeding and hydration by inserting tubes into the intestinal tract. The first method involves inserting a tube into the person's nose and down the throat and then into the digestive tract. This method is very annoying to both patients and families and, although inexpensive, often leads to pneumonia. The second method involves cutting an opening in the abdomen and inserting a tube directly into the stomach. The hole is then closed surgically.

We are dealing with medical procedures, not with simple tasks of everyday living. The question, then, is whether these procedures are medically indicated. That is, do they do more harm than good for the patient? In treating a terminally ill or irreversibly comatose patient, the physician should determine whether the benefits of treatment outweigh its burdens. At all times, the dignity of the patient should be maintained. The AMA Council on Ethical and Judicial Affairs quoted earlier expressed the emerging consensus that it is not wrong to withdraw these treatments under appropriate circumstances.

The appropriate circumstances might be found in the following types of cases: (1) the procedures are futile, since the procedures are unlikely to achieve their purpose; (2) the procedures would be no help to the patient even if successful; (3) the burdens outweigh the benefits (Lynn and Childress, 1983).

The following are examples of futile treatments (taken from Lynn and Childress, 1983): (1) the patient has burns over most of his body and a severe clotting deficiency that would make it nearly impossible to control the bleeding caused by the burns and (2) the patient has severe congestive heart failure with cancer of the stomach, which delivers food to the colon without passing through the intestine and being absorbed. In this case the fluids introduced by hydration will kill by acting on the congestive heart failure when not much of the food is absorbed in any event.

In a second class of cases, there is *no possibility of benefit* to the patient who has permanently lost consciousness, as in patients with anencephaly, persistent vegetative state, and preterminal coma. In these cases, feeding is sometimes done for the sake of the family, but it is not medically indicated. Finally, there are cases in which feeding and hydration impose a *disproportionate burden*. These are as follows: (1) the patient's need for nutrition arises only near death, a point at which hydration causes terminal pulmonary edema, nausea, and mental confusion and (2) patients who, although they might benefit in one way, have fairly severe dementia, such that restraints are needed, with the result that the patient suffers constant fear and discomfort as he or she struggles to be free. Life is prolonged, but in a captive state.

All this may be summarized by saying that, when hydration and nutrition become medical procedures, the ethics of their omission is based on the ethics of medical indications and not on commonsense notions. Some will argue that life is to be preserved at all costs, but as we saw earlier in this chapter, most ethics theories allow that the value of life has limits for the individual and for society.

A word of caution is appropriate here. When a competent patient is sedated to control pain, his resulting incompetence is due to the sedation. Hydration and nutrition probably cannot be withdrawn at that time, if his incompetence (or unconsciousness) is cited as part of the justification for the withdrawal. The physician cannot create an adverse condition and then use that as justification for ceasing treatment.

In some cases nutrition and hydration are indicated on the compassionate ground that such a death is sometimes more painful than death from the particular disease. The patient may be faced with the choice between a slow death from cancer with adequate pain control or a slightly more rapid and more painful death from dehydration and starvation. In such a case, the omission of feeding and hydration would be cruel. Health care professionals involved in hospice work have observed that, although deprivation of nutrition and hydration is painful in healthy people, they do not as a rule produce pain and suffering in the terminally ill (Cox, 1987). Medications can almost completely eliminate the possible discomforts associated with the deprivation of nutrition and hydration. One cannot, then, simply assume that starvation or dehydration is always painful, or for that matter that it is never painful. Each case must be evaluated individually, and ultimately the choice of the manner of death belongs to the competent patient.

The complexities arising from statute law and court decisions are enormous (Meisel, *supp.* 1991, pp. 191–193). Thus, although some states have an outright prohibition of a living will ordering the discontinuance of hydration and nutrition, most require nutrition and hydration *only if necessary for the comfort of the patient*. Still others concern themselves only with simple spoon feeding and permit the withdrawal of artificial medical forms of feeding. In short, the health care professional must be aware of the law in his or her state, as well as of the ethical principles.

Antibiotic: Omission or Withdrawal

Before discussing the ethics of omitting or stopping treatment with antibiotics, it is important to recall that the medical indications principle requires that the *patient as a person* gain more than she or he loses from the medical treatment. It may not be the case that the treatment of a particular disease or condition is of benefit to the patient if the patient has other problems. Thus, if antibiotic treatment cures pneumonia only to prolong the slow death of a terminal cancer patient, it is not medically indicated, since the cure of the

pneumonia leads to a medical net loss for the patient. Indeed, it is very much like the cruelty of prolonging the life of a condemned man so that he will be alive for his hanging. On the other hand, if the pneumonia is adding to the cancer patient's discomfort, antibiotic treatment is medically indicated, since the patient will enjoy a net gain as a result of the treatment. Despite the language of some living will legislation, we believe that this principle holds whether or not the patient is technically terminal.

Here, as elsewhere in this chapter, the warnings about patient or surrogate consent should be kept in mind. Medical indications alone do not give the final ethical answer.

First, let us treat the use of antibiotics in terminal cases. It makes no sense to treat the pneumonia of a terminal cancer patient with antibiotics, since this will merely prolong his or her dying and so the pain. On the other hand, it makes sense to treat the decubitus ulcers of the terminal cancer patient, if they are painful to the patient and treating them will not prolong his or her life. To put it another way, it makes sense not to prolong life for the terminal cancer patient, but it does not make sense to increase the pain. The good of the patient in all its complexity must be considered.

With the general principle clear, we may now consider a series of cases in which (1) the patient may or may not be terminal, that is, in the end stages of a terminal disease other than that which is being considered for treatment; (2) the patient is in a persistent vegetative state; and (3) where the patient is considered severely and irreversibly demented.

In case 1, antibiotics seem to be medically indicated, although the patient and her or his surrogate have a right to refuse them. In case 2, the antibiotics do not appear to be medically indicated although some families and health care workers may comfort themselves with hope for a miracle. In case 3, the severely and irreversibly demented patient can still profit from the antibiotics, although on a minimal level. Granted surrogate consent, antibiotics should be administered to this patient.

Although many physicians do not consult patients in these cases, they have an ethical obligation to explain the medical indications and obtain a consent or refusal of consent from a competent patient or a competent surrogate. When there is no surrogate, no competent patient, and no advanced directive, the physician must fall back on the medical indications principle alone and omit the antibiotic when no net gain for the patient is anticipated. The societal issue must also be considered as we now know that the use of antibiotics, especially when not indicated, has contributed and will contribute to the rising number of resistant organisms.

Cooperation with the Refusal of Treatment by a Nonterminal Patient

The most emotionally difficult cases arise when the patient refusing treatment is not terminal, but will become so when the respirator is unplugged

or the treatment is not started or is stopped. This can occur when the patient judges that it is not worthwhile living on a respirator forever or being fed artificially for years. It occurs when the patient chooses not to live at a level below his or her ideal. In all these cases, the treatment is medically indicated from the health care provider's point of view, but does not produce a proportionate good from the patient's point of view. Regardless of the emotional turmoil suffered by the provider, here (as in chapter 3) the patient retains the right to refuse treatment. Only a court order or a court-appointed guardian has the right to overrule the patient in these cases. The justice of even such court rulings is not beyond question if the death will not injure society or third parties.

What, however, is to be said of the case in which the nonterminal patient not only refuses medically indicated treatment, but also asks the health care provider to keep her comfortable while she dies? This was one issue in the Bouvia case (see case 2 at the end of this chapter). In this case, the patient refused food and drink, but asked to be made comfortable in the hospital while she starved to death.

The health care provider can ethically refuse to cooperate in such situations, not only on the ground of individual conscience, if that is the case, but also because the health care professions should not be involved in helping nonterminal patients to shorten their lives significantly. We note, however, the complicated result that, in the long run the California courts ordered the hospital to comply with Ms. Bouvia, but she did not carry out her plans. Granted that health care providers have no right to force treatment on patients, it seems clear that healthy or mildly ill patients do not have the right to force physicians or hospitals to provide positive support for their attempts at self-destruction. As noted in chapter 3, health care providers who refuse to cooperate with a patient already in their care must provide for continuity of care, such as involving another physician, lest they be guilty of abandonment. But cases in which there is a reasonable disagreement on the meaning of the prospects of the patient must be decided on a case-by-case basis, recognizing the concerns of both parties.

PHYSICIAN INITIATIVES

Under certain circumstances, it may be appropriate for a physician to take the initiative in discussing termination of care for the patient. The physician is obligated to inform the patient clearly and completely about his condition in order to obtain consent for treatment. This should include an accurate description of the burdens and benefits of continued treatment and the odds of success. At times, this means the physician must tell the patient when it is likely that the patient will die no matter what is done. Also, the physician is obligated to provide treatment that does not harm the patient. Treatment

that is not reasonably likely to work should not be provided; it misleads the patient and it wastes resources. These considerations lead to the issues of do-not-resuscitate orders (DNR) and medical futility.

The No-Code Order

A *no-code order* is a written order to do nothing if certain situations arise. Most commonly, it is a DNR order, that is, a written order not to attempt resuscitation in cases of cardiac arrest (Standards and Guidelines, 1986). A slow code, also called a show code or merely a walk slowly code, involves a verbal order to the staff to respond slowly when the patient has a cardiac arrest. Winslade and Ross (1986) note that this is often used to give the appearance of resuscitating, especially to the family. There are also partial codes, which limit the resuscitation efforts. Each of these codes needs separate consideration.

The Joint Commission on Hospital Accreditation requires every hospital to have a no-code policy. While hospital policies should be consulted, a no-code order may be ethically issued when the treatment in question or resuscitation is not medically indicated. In other words, a no-code order is correct when, from a medical point of view, more harm than good will be done to the patient by treatment or resuscitation. This is usually the case when there is no further therapy for the underlying disease process for a terminally ill patient. The order is also justified by the patient's express wish that resuscitation not be attempted. It should be noted that this is a written order for which the physician accepts public responsibility and that should be medically justified on the chart. Granted these conditions and consent, except in the limited circumstances indicated previously, the no-code order is ethical.

The slow code is used to give families the impression that everything is being done for the patient in situations in which most of the time a no-code order would be medically and ethically justified. The temptation to issue such an order can be great when a family insists against all reason that a patient be kept alive, even when the patient is brain dead. Nevertheless, the deception involved should be condemned as unethical. The fact that there is no written order and, so, a refusal to take public responsibility for the decision is also reprehensible.

We note again that the family may have nonmedical reasons for prolonging the life, even the vegetative life, for a while longer. They may want time for one last relative to arrive to enter into the farewells and the grieving process. There may be legal complications involving the moment of death. When respecting such reasons does not cause the patient additional pain and suffering, the reasons should be given some weight. Certainly, they should not be ignored and the family deceived about what is going on.

The partial code is a written order to omit some medical interventions, but to employ others. There may be sound medical reasons to attempt chest