

**Case III (Continued).** Mrs. D. comes to the ED as described previously. In this version of the case, however, she adamantly denies that she has any medical problem. Although the toes of her left foot are necrotic and gangrenous tissue extends above the ankle, she insists that she is in perfect health and has been taking her daily walk every day, even this morning. Her neighbor asserts that Mrs. D. has been housebound for at least a week, a fact that had led the neighbor to drop in to see whether there was a problem.

**RECOMMENDATION.** In this version, Mrs. D. seems decisionally incapacitated. She is denying her infirmity and her need for care, and she appears to be delusional. She has given no previous directions about care. In Mrs. D.'s best interests (see Sections 2.7.2 and 3.0.3), the appointment of a surrogate should be sought and a decision about surgery considered.

### 2.2.3 Evaluating Decisional Capacity in Relation to the Need for Intervention

Usually a patient's capacity is not seriously questioned unless the patient decides to refuse or discontinue medically indicated treatment. When patients reject recommended treatment, clinicians may suspect that the patients' choice may be harmful to their health and welfare and assume that persons ordinarily do not act contrary to their best interests. It has been suggested that the stringency of criteria for capacity should vary with the seriousness of the disease and urgency for treatment. For example, a patient might need to meet a only low standard of capacity to consent to a procedure with substantial, highly probable benefits and minimal, low-probability risk, such as antibiotics for bacterial meningitis. If a patient refuses such an intervention, it must be quite clear that the person understands and freely decides what he or she is about to do. Likewise, greater decisional capacity is necessary to consent to an intervention that poses high-risks and offers little benefit. This stringency test can be helpful to the clinician in deciding whether the refusal should be simply accepted or whether to take further steps to investigate and even take action to counteract the refusal by legal means.

### 2.2.4 Delirium, Confusion, and Waxing and Waning Capacity

Decisional capacity often is compromised by the pathological condition called *delirium*, which is a disturbance of consciousness characterized by disorientation to place and persons, distraction, disorganized thinking, inattentiveness or hypervigilance, agitation or lethargy, and sometimes

perceptual disturbance, such as hallucinations. Delirium usually is of abrupt onset and variable in manifestation. It often accompanies trauma or sudden illness, and it is not uncommon in the elderly. The phenomenon called "ICU psychosis" is, more properly, delirium. Also, in the so-called "sundowner syndrome," a patient's mental capacity waxes and wanes: early in the day the patient may appear clear and oriented but later is assessed as confused.

**Example.** Mrs. Care, with multiple sclerosis (MS), is now hospitalized. In the morning, she can converse intelligibly with doctors, nurses, and family. In the afternoon she confabulates and is disoriented to place and time. In both conditions, she expresses various preferences about care that sometimes are contradictory. In particular, when questioned in the morning about surgical placement of a tube to prevent aspiration, she says no to the placement; in the afternoon, however, she speaks confusedly and repeatedly about having the tube placed.

**RECOMMENDATION.** Unlike coma or dementia, delirium can be variable in presentation. Mrs. Care's waxing and waning of mental status is itself the manifestation of the variability of delirium. In general, a delirious patient should be considered to have impaired capacity. If, however, the patient expresses consistent preferences during periods of clarity, it is not unreasonable to take them seriously. Still, supportive evidence about those preferences should be sought before they are taken as definitive.

## 2.3 BELIEFS DUE TO RELIGIOUS AND CULTURAL DIVERSITY

Certain religious groups hold beliefs about health, sickness, and medical care that may be unfamiliar to providers. Sometimes such beliefs will influence the patient's preferences about care in ways that providers might consider imprudent or dangerous. Similarly, persons from cultural traditions differing from the prevailing culture may view the medical practices of the prevailing culture as strange and even repugnant. In both cases, providers will be faced with the problem of reconciling a clinical judgment that seems reasonable to them, and even an ethical judgment that seems obligatory, with a patient's preference for a different course of action. The appropriate response to such situations will be treated under the three topics where they usually appear: truthful disclosure (see Section 2.4), competent refusal of treatment (see Section 2.5), and the role of family in making decisions (see Sections 4.1.2 and 4.1.2 P). Some general comments about appropriate responses are given in the following paragraphs:

(a) Some clinicians who encounter unfamiliar beliefs may consider these beliefs "crazy" and assume that anyone who holds them must suffer from impaired capacity. This response is wholly unjustified: it reveals bias and ignorance. The mere fact of adherence to an unusual belief is not, in and of itself, evidence of incapacity. In the absence of clinical signs of incapacity, such persons should be considered capable of choice.

(b) In institutions with a high volume of patients from a particular religious or cultural tradition, providers must educate themselves about the beliefs of those patients, have competent translators available, and make use of cultural mediators, such as clergy or educated persons who can explain the beliefs and communicate with those who hold them. At the same time, the mere fact that a person speaks the same language or comes from the same country or religion as the patient does not guarantee competence as a translator or intermediary. Also, providers should be careful to avoid cultural stereotypes, as there are individuals from particular cultures who depart, in their values, preferences, and lifestyle, from the predominant mode of their cultures.

(c) To the extent possible, a treatment course that is acceptable to the patient and provider alike should be negotiated. It is first necessary to discover the common goals that are sought by the patient and the physician and to settle on mutually acceptable strategies to attain those goals. The ethical response to a genuine conflict in an essential matter is dependent on the circumstances of the case and is discussed in the sections on truthful communication (Section 2.4) and refusal of care (Section 2.5). Cases in which cultural differences play a significant role are discussed in Sections 2.5.1, 2.7.5 P, and 4.5.

## 2.4 TRUTHFUL COMMUNICATION

Communications between physicians and patients should be truthful; that is, statements should be in accord with facts. If the facts are uncertain, that uncertainty should be acknowledged. Deception, by stating what is untrue or by omitting what is true, should be avoided. These ethical principles should govern all human communication. However, in the communication between patients and physicians, certain ethical problems about truthfulness may emerge. Does the patient really want to know the truth? What if the truth, once known, causes harm? Might not deception help by providing hope? In the past, medical ethics has given ambiguous answers to these questions: whereas some authors favored truthfulness, others recommended beneficent deception. More recently, with the prominence of the doctrines of

autonomy and truthfulness has been commended as the ethical course of action.

Beauchamp TL, Childress JF. Veracity. In: *Principles of Biomedical Ethics*. 5th ed. New York: Oxford University Press; 2001:283–292.

Lo B. Avoiding deception and nondisclosure. In: *Resolving Ethical Dilemmas. A Guide for Clinicians*. 3rd ed. Baltimore: Lippincott Williams & Wilkins; 2005:45–53.

**Case 1.** Mr. R.S., a 65-year-old man, comes to his physician with complaints of weight loss and mild abdominal discomfort. The patient, whom the physician knows well, has just retired from a busy career and has made plans for a round-the-world tour with his wife. Studies reveal mild elevation in liver functions and a questionable mass in the tail of the pancreas. At the beginning of his interview with his physician to discuss the test results, Mr. R.S. remarks, "Doc, I hope you don't have any bad news for me. We've got big plans." Ordinarily, a needle biopsy of the pancreas to confirm pancreatic cancer would be the next step. The physician wonders whether he should put this off until Mr. R.S. returns from his trip. Should the physician's concern that Mr. R.S. may have pancreatic cancer be revealed to him at this time?

**COMMENT.** In recent years, commentators on this problem have moved away from the traditional medical ethics, which favored beneficent deception, toward a strong assertion of the patient's right to the truth. Their arguments are as follows:

1. There is a strong moral duty to tell the truth that is not easily overridden by speculative, possible harms of knowing the truth.
2. Suspicion on the part of the physician that truthful disclosure would be harmful to the patient may be founded on little or no evidence. It may arise more from the physician's own uneasiness at being a "bearer of bad news" than from the patient's inability to accept the information.
3. Patients have a need for the truth if they are to make rational decisions about actions and plans for life.
4. Concealment of the truth is likely to undermine the patient-physician relationship. In case of serious illness, it is particularly important that this relationship be strong.
5. Toleration of concealment by the profession may undermine the trust that the public should have in the profession. Widespread belief that physicians are not truthful would create an atmosphere in which persons who fear being deceived would not seek needed care.

6. Recent studies have shown that most patients with diagnoses of serious illness wish to know the diagnosis. Similarly, recent studies are unable to document harmful effects of full disclosure.

**RECOMMENDATION.** Mr. R.S. should be told the truth: he probably has cancer of the pancreas. In our opinion, the considerations in favor of truthful disclosure are conclusive in establishing a strong ethical obligation on the physician to tell the truth to patients about their diagnosis and its treatment. The following considerations are relevant:

(a) Speaking truthfully means relating the facts of the situation. This does not preclude relating the facts in a manner measured to perceptions of the hearer's emotional resilience and intellectual comprehension. The truth may be "brutal," but the telling of it should not be. A measured and sensitive disclosure is demanded by respect for the patient's autonomy and sensitivities. It reinforces the patient's ability to deliberate and choose; it does not overwhelm this ability. It is advisable to open such a conversation with a question about how much the patient wishes to know and whether the patient may wish some other person to be informed.

(b) Truthful disclosure has implications for Mr. R.S.'s plans. Further diagnostic studies might be done and appropriate treatments chosen. The trip might be delayed or canceled. Estate and advance care planning might be considered. Mr. R.S. should have the opportunity to reflect on these matters and to take control of his future.

**Case II.** Mr. S.P., a 55-year-old teacher, has experienced chest pains and several fainting spells during the past 3 months. He reluctantly visits a physician at his wife's urging. He is very nervous and anxious and says to the physician at the beginning of the interview that he abhors doctors and hospitals. On physical examination, he has classic signs of tight aortic stenosis, confirmed by echocardiogram. The physician wants to recommend cardiac catheterization and probably cardiac surgery. However, given his impression of this patient, the physician is worried that full disclosure of the risks of catheterization would lead the patient to refuse the procedure.

**COMMENT.** In this case, the anticipated harm is much more specific and dangerous than the harm contemplated in Case I. Hesitation about revealing the risks of a diagnostic or therapeutic procedure is based on the fear the patient will make a judgment detrimental to health and life. Also, in this case there is better reason to suspect this patient will react badly to the information than will the patient in Case I.

**RECOMMENDATION.** The arguments in favor of truthful disclosure apply equally to this case and to Case I. Whether or not catheterization is accepted, the patient will need further medical care. In fact, the situation is urgent. Above all, this patient needs the benefits of a good and trusting relationship with a competent physician. Honesty is more likely to create that relationship than deception. Also, the physician's fears about the patient's refusal may be exaggerated. The physician also might be concerned about the family's reaction if Mr. S.P. died unexpectedly during catheterization. The physician would be at serious ethical fault if the patient consented to the procedure without adequate disclosure and then died or if the patient died without having had the opportunity to consent to or refuse treatment. Finally, the physician could be legally accountable for failing to advise the patient about the seriousness of his problem.

**Case III.** A traditional Navajo man, 58 years old, is brought by his daughter to a community hospital that is authorized by the Indian Health Service to serve Native American patients. He is suffering severe angina. Studies show that he is a candidate for cardiac bypass surgery. The surgeon discusses the risks of surgery and says, as is his custom, that there is a slight risk that the patient may not wake up from surgery. The patient listens silently, returns home, and refuses to return to the hospital. His daughter, who is a trained nurse, explains: "The surgeon's words were very routine for him, but for my Dad it was like a death sentence."

Carrese JA, Rhodes LA. Western bioethics on the Navajo Reservation. *JAMA* 1995;274:826-829.

**COMMENT.** This case of truthful disclosure represents an example of disregard of culturally diverse beliefs (see Section 2.5.1). In Navajo culture, language has the power to shape reality. Thus, the explanation of possible risks is a prediction that the undesirable events are likely to occur. In that culture, persons are accustomed to speak always in positive ways and to avoid speaking about evil or harmful things. The usual practice of informed consent, which requires the disclosure of risks and adverse effects, can cause distress and drive patients away from needed care. Similar reservations about the frankness of informed consent are found in other cultures. This issue is discussed again in Section 4.1.1, where we discuss the role of the family.

**RECOMMENDATION.** Physicians who understand this feature of Navajo life should shape their discussions in accordance with the expectations of the patient. The omission of negative information, even though it would be unethical in dealing with a non-Navajo patient, is appropriate. This ethical advice rests on the fundamental value that underlies the rule of

informed consent, namely, respect for persons, which requires that persons be respected, not as abstract individuals but as formed within the values of their cultures.

### 2.4.1 Completeness of Disclosure

Disclosure of options for treatment of a patient's condition should be complete, that is, contain all information that a thoughtful person would need to make a good decision on his or her own behalf. It should include the options that the physician recommends and other options that the physician may believe are less desirable but still medically reasonable. In so doing, physicians may make it clear why they consider these other options less desirable. However, it might be asked whether the obligation of truthful disclosure requires telling a patient about even those interventions that are not medically reasonable but which a patient may wish to consider.

**Case 1.** A 41-year-old woman has a breast biopsy that reveals cancer. The physician knows that this patient has a history of noncompliance and cancellation of medical appointments. In light of this, the physician believes that the best treatment approach would be a modified radical mastectomy, which would require less continued care than a lumpectomy and 5 weeks of out-patient radiotherapy. Should the physician also describe an alternative approach that includes lumpectomy, breast reconstruction, and a 5-week course of radiation therapy? The physician is concerned that, after a lumpectomy, the patient may not keep her radiotherapy appointments.

**RECOMMENDATION.** The entire range of options should be explained with a careful delineation of the risks and benefits of each. Making a strong argument in favor of the option the physician considers best is ethically permissible. Persuasion, however, should leave the patient free to choose, even if the physician believes she may choose the less effective option. Coercion and manipulation of the patient must be carefully avoided. Ultimately, the patient must make decisions about breast surgery and keeping appointments. The physician must provide the patient with information and encourage her to complete whatever form of treatment she elects to receive.

### 2.4.2 Disclosure of Medical Error

Medical errors occur frequently (see Section 1.0.7). Some errors are due to negligence, but the majority are due to accident, misinformation, or organizational malfunction. Some errors do not cause harm; others

effect serious harm. When medical errors occur, what obligations do physicians have to disclose them?

**Case.** The patient described in Section 2.4.1 is treated by modified radical mastectomy and reconstructive breast surgery. Postoperatively, she develops persistent swelling and drainage of the breast and a fever consistent with a breast abscess. She is returned to the operating room for exploration of the operative site. The surgeon discovers that a sponge had been left in the surgical wound. The sponge is removed, and the abscess is treated. The patient recovers and is discharged. Should the physician inform the patient that a mistake had been made?

**RECOMMENDATION.** Disclosure is required because harm was done to this patient by the medical error. Although the outcome was satisfactory, the patient required a second operation with attendant risks; her hospital stay, with its attendant risks, was prolonged; chemotherapy was delayed; and costs were incurred. A fundamental duty of respect for persons dictates that apology be offered the patient for harms of this sort. The surgeon should inform and apologize to the patient and report the error to the institutions, which also should apologize. Appropriate compensatory measures should be taken.

**COMMENT.** Any inclination to hide medical mistakes must be discouraged. Secrecy is unethical and may be counterproductive. Mistakes must be reported for risk management and quality assurance purposes, and organizations should have effective methods to do so. Organizations also should institute strong systems to prevent errors that might be due to system faults. Charges should be waived and appropriate compensation provided; settlement of financial claims, even without suit, may be considered. A climate of disclosure and honesty is necessary to maintain patient confidence and trust in the relationship with their physicians and with the health care institutions. Malpractice actions certainly are possible, particularly if the error is the result of negligence, but fear of legal claims most probably is misplaced if the context of confidence and honesty is sustained. Errors that are truly harmless, without any adverse effects for the patient, must be reported within the system for control purposes. Although it is not obligatory to disclose harmless error, it is advisable to do so to sustain the climate of honesty in the relationship between the patient and physician.

### 2.4.3 Placebos

Placebo is defined as a substance given in the form of medicine but lacking specific activity for the condition being treated. This must be distinguished

from the "placebo effect," which is the psychological, physiologic, or psychophysiologic effect of any medication given with therapeutic intent but which is independent of any actual pharmacologic effects. The placebo effect is believed to occur as the result of many different influences: faith in the physician, administration of a medicine that the physician believes to be effective pharmacologically but is not, or actions of the physicians that are not in themselves therapeutic, such as taking a history or performing a diagnostic test. Thus, the placebo effect usually occurs without deliberate deception. In this broader sense, the placebo effect is a significant feature of medical practice, and the supposed benefits of a placebo treatment appear to depend on the qualities of the patient-physician relationship. Many studies of the placebo effect currently are being conducted, particularly with regard to alternative and complementary medicine.

The problem of deception occurs when the physician knows that the intervention does not have the objective properties necessary for efficacy and when the patient is kept ignorant of this fact. Examples of such deception are monthly shots of vitamin B<sub>12</sub> for fatigue without a diagnosis of vitamin B<sub>12</sub> deficiency or penicillin administered for a viral sore throat. In some cases, the deception is an outright moral offense, motivated solely by the desire to keep the patient's fees or to "get the patient off my back." In other cases, placebo deception may raise a genuine ethical question. The duty not to deceive seems to conflict with the duty to benefit without doing harm.

Placebo agents now are commonly used in controlled clinical trials of therapy for non-life-threatening conditions. Research subjects are informed that they will be randomized and may receive either an active drug or an inert substance. No deception is involved, and this practice certainly is ethical.

Beauchamp TL, Childress JF Intentional nondisclosure. In: *Principles of Biomedical Ethics*. 5th ed. New York: Oxford University Press; 2001:83-88.

**Case I.** A 73-year-old widow lives with her son. He brings her to a physician because she has become extremely lethargic and often confused. The physician determines that, after the woman had been widowed 2 years before, she had difficulty sleeping, had been prescribed hypnotics, and now was physically dependent. The physician determines the best course would be to withdraw her from her present medication by a trial on placebos.

**Case II.** A 62-year-old man had undergone a total proctocolectomy and ileostomy for colonic cancer. Evidence of any remaining tumor is

absent; the wound is healing well, and the ileostomy is functioning. On the eighth day after surgery, he complains of crampy abdominal pain and requests medication. The physician first prescribes antispasmodic drugs, but the patient's complaints persist. The patient requests morphine, which had relieved his postoperative pain. The physician is reluctant to prescribe opiates because repeated studies suggest that the pain is psychological, and the physician knows that opiates will cause constipation. She contemplates a trial of placebo.

**COMMENT.** Any situation in which placebo use involves deliberate deception should be viewed as ethically suspect. The strong moral obligations of truthfulness and honesty prohibit deception; the danger to the patient-physician relationship advises against it. Any exception to this strict obligation would have to fulfill the following conditions: (1) the condition to be treated should be known as one that has high response rates to placebo, for example, mild mental depression or postoperative pain; (2) the alternative to placebo is either continued illness or the use of a drug with known toxicity and addictability, for example, hypnotics as in Case I or opioids in Case II; (3) the patient wishes to be treated and cured, if possible; and (4) the patient insists on a prescription.

**RECOMMENDATION.** Use of a placebo in Case I is not justified. The patient is not demanding medication. The problem of addiction should be confronted directly. There will be ample opportunity to develop a good relationship with this patient. Subsequent discovery of deception might undermine this relationship. Use of placebo in Case II is tempting but not ethically justifiable. In favor of placebo use, the patient is demanding relief. Morphine has adverse side effects. A short trial of placebo may be effective in relieving pain and avoiding the harm associated with opioids. However, explanation may be as effective as placebo use. The deceptive placebo can destroy the trust that creates the important and therapeutic "placebo effect" and can undermine the patient's confidence in the physician. A participatory style of decision making is based on honest communication. It may be possible, for example, to perform a "mini-experiment" with the patient's consent: explain that two forms of pill will be offered, one active, the other inert, and the patient will blindly choose which one to take. Consultation with the hospital pain service is recommended.

## 2.5 COMPETENT REFUSAL OF TREATMENT

Persons who are well informed and have decisional capacity sometimes refuse recommended treatment. If the recommended treatment is elective or if the consequences of refusal are minor, ethical problems are

unlikely. However, if care is judged necessary to save life or manage serious disease, physicians may be confronted with an ethical problem: Does the physician's responsibility to help the patient ever override the patient's freedom? Refusal of care by a competent and informed adult should be respected, even if that refusal would lead to serious harm to the individual. This is ethically supported by the principle of autonomy and legally supported by American law. The patient's refusal of well-founded recommendations often is difficult for the conscientious physician to accept. It is made more difficult when the patient's refusal, although competent, seems irrational, that is, deliberately contrary to the patient's own welfare.

**Case I.** Ms. T.O. is a 64-year-old surgical nurse who 5 years ago had a resection for cancer of the right breast. She visited her physician again after discovering a 2-cm mass in the left breast. She agrees to a treatment program that includes lumpectomy, radiation therapy, and 6 months of chemotherapy. After her first course of chemotherapy, during which she experienced considerable toxicity, she informs her physician that she no longer wants any treatment. After extensive discussions with her physician and with her two daughters, she reaffirms her refusal of adjuvant therapy.

**Case II.** Mr. S.P., the patient with aortic stenosis described at Section 2.4, Case II, has cardiac symptoms that indicate the need for coronary angiography. After hearing his physician explain the urgency for this procedure and its benefits and risks, he decides he does not want the procedure.

**RECOMMENDATION.** Ms. T.O. makes a competent refusal of treatment. She is well informed and she exhibits no evidence of any mental incapacitation. Even though the physician might consider the chances for prolonging disease-free survival good, Ms. T.O. values her risks and chances differently. Her refusal should be respected. The physician should continue to observe Ms. T.O., particularly for the next several months during which a change of mind in favor of adjuvant therapy would still be beneficial. In Case II, Mr. S.P. also is competent. Even though his refusal seems contrary to his interests, from the point of view of his ability to anticipate his health needs it is an expression of his autonomy. It must be respected. That respect, however, also should encourage the physician to explore more fully the reasons for the refusal and to attempt to educate and persuade. An early follow-up visit should be scheduled for both patients to assure them that their physician remains supportive and concerned to help them deal with the consequences of their decision.

**Case III.** Mr. Cope (discussed in Section 2.2.2) was admitted to the hospital for diabetic ketoacidosis, which was treated with insulin, fluids, electrolytes, and antibiotics. That treatment was initiated over his objections but was authorized by his surrogate, Mrs. Cope, who was advised that his objections were the result of metabolic encephalopathy. After 24 hours, he awakens, talks appropriately with his family, and recognizes and greets his physician. He does not remember having been brought to the ED. He now complains to the nurse and physician about pain in his right foot. Examination of the foot reveals that it is cold and mottled in color, and no pulses can be felt in the right leg distal to the right femoral artery. A vascular surgery consultation recommends an emergency arteriogram to examine the leg arteries. The benefits and risks, including impairment of renal function, of the procedure are explained. Mr. Cope declines to consent to arteriography. The surgeons explain to him that they cannot perform angioplasty unless they know what vessel is involved. The surgeons warn the patient that he faces a greater risk of losing his leg than of losing renal function. Mr. Cope participates in these discussions, asking appropriate questions, and acknowledging the doctors' comments. He then declines again to have the arteriography.

**COMMENT.** Although 24 hours ago Mr. Cope was clearly decisionally incapacitated and was properly treated for pneumonia and ketoacidosis, despite his insistence to be left alone, the current situation is entirely different. He now has regained decisional capacity, can understand the situation, can consider the risks and benefits, and make up his mind. His physician, nurses, and the consulting vascular surgeon agree that his decision is unwise: the low risk of worsening his renal function is more than compensated for by the substantial benefit of saving his leg. Mr. Cope does not agree. His family is divided, some siding with the doctors and some with Mr. Cope.

**RECOMMENDATION.** Mr. Cope's decision must be respected. Efforts can be made to persuade him otherwise; time can be given for reconsideration. Still, Mr. Cope shows no signs of incapacity and has the legal and moral right to make the decision that seems suitable to him. That decision may not be the best one from the viewpoint of medical indications, but law and ethics require respect for the patient's preferences in such circumstances.

### 2.5.1 Refusal on Grounds of Religious or Cultural Belief

We noted the problem of evaluating unfamiliar religious and cultural beliefs in Section 2.3. Persons who hold such beliefs sometimes refuse medical recommendations.

**Case.** Mr. G. comes to a physician for treatment of peptic ulcer. He says he is a Jehovah's Witness. He is a firm believer and knows his disease is one that eventually may require administration of blood. He shows the physician a signed card affirming his membership and denying permission for blood transfusion. He quotes the biblical passage on which he bases his belief:

"I (Jehovah) said to the children of Israel, 'No one among you shall eat blood, nor shall any stranger that dwells among you eat blood.'"

Leviticus 17:12

The physician inquires of her Episcopal clergyman about the interpretation of this passage. He reports that no Christian denomination except the Jehovah's Witnesses takes this text to prohibit transfusion. The physician considers that her patient's preferences impose on her an inferior standard of care. She wonders whether she should accept this patient under her care.

**COMMENT.** As a general principle, the unusual beliefs and choices of other persons should be tolerated if they pose no threat to other parties. The patient's preferences **should be respected, even though they appear mistaken to others.** The following general considerations apply to this case:

(a) Jehovah's Witnesses cannot be considered incapacitated to make choices unless there is clinical evidence of such incapacity. On the contrary, these persons usually are quite clear about their belief and its consequences. It is a prominent part of their faith, insistently taught and discussed. Thus, whereas others may consider it irrational, adherence to this belief is not, in itself, a sign of incompetence.

(b) Courts almost unanimously have upheld the legal right of adult Jehovah's Witnesses to refuse life-saving transfusions. However, if unusual beliefs pose a threat to others, it is ethically permissible and may be obligatory to prevent harm by means commensurate with the imminence of the threat and the seriousness of the harm. Thus, courts have consistently intervened to order blood transfusions for the minor children of Jehovah's Witnesses. Courts once were inclined to order an adult transfused for the sake of the adult's minor children but now rarely do so because alternative care for children usually is available.

(c) The refusal of transfusion includes whole blood, packed red blood cells, white blood cells, plasma, and platelets. It forbids auto-transfusion. It may allow administration of blood fractions, such as immune globulin, clotting factors, albumin, and erythropoietin. Dialysis and circulatory bypass techniques are permitted. It is advisable for the

physician to determine exactly the content of a particular patient's belief from the patient and from church elders.

California Blood Bank Society. [www.cbbsweb.org/erf/2001/JehovahPolicy.html](http://www.cbbsweb.org/erf/2001/JehovahPolicy.html).

(d) Refusal of blood transfusion differs in a significant way from refusal of all therapy or of recommended treatments. Jehovah's Witnesses acknowledge the reality of their illness and desire to be cured or cared for; they simply reject one modality of care.

(e) Refusal of transfusion may lead the physician to consider whether transfusion is necessary in this clinical situation. A more careful consideration of the indications for transfusion has led to more conservative use of transfusion without serious harm. Some competent surgeons have undertaken to provide surgical procedures for Jehovah's Witnesses without the use of blood transfusion; bloodless surgery centers have been instituted in some places.

(f) The physician's inquiry about the interpretation of the biblical passage is interesting. Presumably, she would feel more comfortable with a belief she knew was endorsed by her own religious tradition. The validity or truth of a religious belief is not relevant to the clinical decision. Instead, the sincerity of those who hold it and their ability to understand its consequences for their lives are the relevant issues in this type of case.

**RECOMMENDATION.** Mr. G.'s refusal should be respected for the following reasons:

(a) If a Jehovah's Witness comes as a medical patient, as did Mr. G., the eventual possibility of the use of blood should be discussed and a clear agreement should be negotiated between physician and patient about an acceptable manner of treatment. Under no circumstances should the physician resort to deception. A physician who, in conscience, cannot accept being held to an inferior or dangerous standard of care should not enter into a patient-physician relationship or, if one already exists, should terminate it in the proper manner (see Section 2.9.3).

(b) If a Jehovah's Witness, who is known to be a confirmed believer, is in need of emergency care and refuses blood transfusion, the refusal ordinarily should be considered decisive. Even if a known believer is mentally incapacitated at the time of the emergency, it can be presumed that the refusal represents the person's true wishes, although confirmatory evidence should be sought. Witnesses often carry wallet cards stating their preference. If little is known about the patient and his or her status as a believer cannot be authenticated, treatment should be provided. In the face of uncertainty about personal preferences, it is our position that response to the patient's medical need should take ethical priority.

### 2.5.1 P Refusal of Treatment by Minor Children on Grounds of Religious Belief

Children sometimes may refuse medical treatment because they belong to religious groups that repudiate medical care. This poses a difficult problem for physicians.

**Case I.** James, a 14-year-old boy with acute lymphocytic leukemia, suffers his second relapse and fails to respond to chemotherapy. He is anemic and thrombocytopenic. He understands that transfusion would make him more comfortable, reduce the possibility of life-threatening bleeding, and perhaps allow him to leave the hospital. He affirms his belief as a Jehovah's Witness and refuses transfusion. His parents concur with his choice.

**COMMENT.** This boy is making an important decision: He is weighing his own discomfort against a belief about his eternal salvation. The medical value of the transfusion is, at best, limited. The boy is aware of his impending death and of the nature of his illness. He seems to show those characteristics of responsible decision making that we require in adults, even if we might suspect that, if more mature, he would see his beliefs differently. It is unethical to insist that he abandon his beliefs for so transitory a benefit.

**Case II.** Karen, a 13-year-old girl, is sent from class to the school nurse complaining of severe headache and malaise. Noting her fever and irritability when moved, the nurse suspects meningitis. She calls the patient's mother, saying that she is taking Karen immediately to the emergency room of a nearby hospital. The mother says she will come to the hospital. When she arrives, she informs the nurse that she and her husband are Christian Scientists. She says she will take Karen home where a Christian Scientist practitioner will pray for her. Karen's father soon arrives and reinforces the mother's position. When the nurse and the emergency room physician warn them about the extreme seriousness of Karen's condition, Karen's parents remind them that Christian Scientist practitioners are considered health professionals under the law of their state. When the nurse asks Karen whether she wishes to be seen by a doctor, she affirms that she, too, believes in the doctrines of Christian Science and declines.

**COMMENT.** The consequences of refusing medical treatment for meningitis are very serious. Even if this youngster were not disoriented because of her illness, it is dubious that she would appreciate the dire consequences. Also, Karen's illness, unlike James's, is sudden and unexpected, and it is

curable. Legally, her parents' refusal can be viewed as neglect and subject to the sanctions of state law. However, many states have enacted legislation exempting parents from charges of child abuse and neglect when they refuse medical interventions for religious reasons. Courts have taken divergent positions. Providers should be aware of these statutes and judicial decisions in their locale.

**RECOMMENDATION.** James's refusal of transfusions should be respected. Care should be directed to ensuring his comfort. Karen's refusal of medical care should not be accepted, and her parents' refusal should be opposed by clinicians, using the appropriate legal means. As a general rule, the wishes of maturing children should be seriously considered in decisions about their care. Signs that the child has some comprehension of the situation and some appreciation of the consequences should be sought. Solicitous attention should be paid to helping them understand. The influences of fear and distress should be noted. Consultation with persons familiar with the psychology of the maturing child should be sought. Above all, nothing should be done to undermine the trust of the child in the adults who are responsible for care and upbringing.

### 2.5.2 Irrational Refusal of Treatment

Occasionally, refusal of care may appear irrational, that is, contrary to the welfare of the person making the decision without any reasonable justification. It is difficult to discern why a person should refuse an obvious benefit or to know whether they are really refusing.

**Case.** As discussed in Sections 2.1 and 2.2.2, Mr. Cure came to the ED with signs and symptoms suggestive of bacterial meningitis. When he was told his diagnosis and that he would be admitted to the hospital for treatment with antibiotics, he refused further care, without giving a reason. He would not engage in discussion with the staff about his refusal. The physician explained the extreme dangers of going untreated and the minimal risk of treatment. The young man persisted in his refusal and declined to discuss the matter further. Other than this strange adamancy, he exhibited no evidence of mental derangement or altered mental status that would suggest decisional incapacity.

**COMMENT.** In this case, the initial consent for diagnosis was implicit in the young man's allowing himself to be brought to the ED. The patient's refusal of treatment, however, unexpectedly introduced an incongruence between medical indications and patient preferences. It might be argued that the physician should simply permit the patient to refuse treatment and suffer the consequences, because the patient showed no



objective signs of incapacitation or serious psychiatric impairment and because competent patients have the right to make their own (sometimes risky) decisions. However, when the risk of treatment is low and the benefit is great, the risk of nontreatment is high and the "benefits" of nontreatment are small, it is ethically obligatory for the physician to probe further to determine why the patient inexplicably refused treatment. Despite explanation, has the patient failed to understand and appreciate the nature of the condition or the benefits and risks of treatment and nontreatment? If the patient seems to understand the explanation, is he denying that he is ill? Is the patient acting on the basis of some unexpressed fear, mistaken belief, or irrational desire? Through further discussion with the patient, some of these questions might be answered.

Assume, however, that after the most thorough investigation possible under the urgent circumstances, evidence that the patient fails to understand is totally lacking, and nothing emerges to suggest denial, fear, mistake, or irrational belief. Should the patient's refusal be respected? Because the medical condition is so serious, should treatment proceed even against the patient's will? This case poses a genuine ethical conflict between the patient's personal autonomy and the paternalistic values that favor medical intervention for the patient's own good. A clinical decision to treat or release the patient must be made quickly; good ethical reasons can be given for either alternative.

**RECOMMENDATION.** This patient's refusal is enigmatic. Evidence of an incapacity to choose because of an altered mental state is not present (although the patient's high fever and brain infection might lead the physician to suspect some derangement, the patient is oriented and organized in communication). In addition, the patient has not expressed any religious objection to antibiotics. The patient simply refuses and provides no reason for the refusal. Given both this enigmatic refusal and the urgent, serious need for treatment, the patient should be treated, even against his will, if this is possible. Should there be time, legal authorization should be sought.

This is a genuine moral dilemma: The principle of beneficence and the principle of autonomy seem to dictate contradictory courses of action. In medical care, dilemmas cannot merely be contemplated; they must be resolved. Thus, we resolve it in favor of treatment against the expressed preferences of this patient. In offering this counsel, we favor paternalistic intervention at the expense of personal autonomy. It is difficult to believe this young man wishes to die. The conscientious physician faces two evils: to honor a refusal that might not represent the patient's true preferences, thus leading to the patient's serious disability

or death, or to override the refusal in the hope that, subsequently, the patient will recognize the benefit.

In this case, we accept as ethically permissible the unauthorized treatment of an apparently competent person. Recall that we endorsed Mr. Cope's refusal of a useful therapeutic procedure (see Section 2.5, Case III). How do these apparently inconsistent recommendations differ? We offer the following explanations:

(a) The medical indications are significantly different. Mr. Cure has a critical disease, and low-risk antibiotic treatment will be effective in preventing serious harm. An opportunity is present for complete achievement of all medical goals. Mr. Cope is at risk of gangrene but is not now critically ill.

(b) The consent situation is significantly different. In neither case is there behavioral evidence of psychiatric impairment, yet in both cases, the common psychological mechanism of denial may hinder good judgment. However, in the case of Mr. Cope, the refusal occurs after full disclosure of his problem, the proposed procedure, and its risks. An opportunity for discussion, persuasion, and argument has been presented. In Mr. Cure's case, discussion is truncated. Efforts to discuss are rejected. Yet he has willingly come to be treated. One might suspect that some crucial element of this negotiation is missing. It is this suspicion that leads the physicians, given the medical situation, to treat him against his wishes.

(c) Subsequent inquiry revealed that Mr. Cure's brother had nearly died 10 years ago of an anaphylactic reaction to penicillin. But while in the ED, Mr. Cure did not, and could not, recall this event, and probing did not uncover it. Mention of antibiotics had triggered a psychological response of denial, which manifested itself in a refusal without reason. The circumstances of his particular illness drew the physicians in the direction of rapid treatment. Even though they made an effort to uncover the source of the problem, they failed to do so, and urgent need for treatment took priority.

(d) The case illustrates that physicians often are pressured by circumstances to make decisions before all relevant information is known. Thus, the rightness or wrongness of the clinical decision always must be assessed with respect to the clinician's knowledge at the time of the decision. One can only strive to render decisions that are as fully informed and analyzed as the circumstances permit.

### 2.5.3 Refusal of Information

Persons have a right to information about themselves. Similarly, they have the right to refuse information or to ask the physician not to inform them.

**Case I.** Mr. A.J. is scheduled for surgery for spinal stenosis. The neurosurgeon begins to discuss the risks and benefits of this surgery. The patient responds, "Doctor, I don't want to hear anything more. I want the surgery. I realize there are risks, and I have confidence in you." The surgeon is concerned that he has not completed an adequate disclosure.

**Case II.** Mrs. Care, with MS, had shown little interest during the early years of her illness in learning about the possible course of her disease. She refused frequent offers by the physician to discuss it. However, on one of her repeated admissions for treatment of urinary tract infection, she states that, had she known what life would be like, she would have refused permission for treatment of other life-threatening problems. The patient's mental status is difficult to evaluate; some clinicians think she shows signs of early dementia. Should she have been informed of her prognosis at an earlier time even though she had been unwilling to engage in such discussions with her physician?

**COMMENT.** We are concerned with what the physician communicates and should communicate about diagnosis and, particularly, prognosis. Should the physician override the patient's stated preference not to know about her condition? Should physicians withhold unpleasant information about prognosis to protect the patient from depression or other negative, potentially damaging emotions?

**RECOMMENDATION.** In Case I, Mr. A.J.'s refusal of information should be respected. His surgeon has no obligation to press the matter but may repeat the offer of information at appropriate times. The surgeon must make a full notation in the chart that the patient has refused information. It is desirable to seek the patient's permission to discuss the details of the procedure with an involved family member. If and when patients desire additional information, clinicians should be prepared to offer it.

Case II poses a difficult case. Here we opt for more rather than less disclosure, because the condition, although untreatable, is long-lasting. Thus, the patient's long-term autonomy is respected more by providing as much information as possible to enable her to make more choices while she is physically and mentally able to learn coping mechanisms in advance. Although it might be tempting to withhold information to protect the patient, a better alternative would be to give the patient general information sufficient to indicate the seriousness of her condition as well as the uncertainty about the time, severity, and extent of the problems that MS can cause. This avoids the extremes of withholding too much too long or disclosing too much too soon. Considerable tact is required to find the proper balance of disclosure and reticence.

Furthermore, the disclosures made as the condition worsens must be adjusted in light of the impairments to the patient's capacity. In some cases of late-stage MS, an associated dementia appears. Thus, it would be advisable to make disclosures before the patient's capacity is so severely impaired that she cannot understand.

## 2.6 ADVANCE PLANNING

Persons who are in good health rarely contemplate how serious disease or disability might affect them. The principle of autonomy urges that persons have the responsibility and the right to make decisions about how they should be treated during serious illness. However, serious illness often deprives patients of the abilities to make decisions in their own behalf. In recent years, the concept of "advance planning" has been widely promoted as one solution to that problem. Advance planning encourages individuals to make known to physicians how they would wish to be treated at a future time when they might be unable to participate in decisions about their care and to inform the physician about the persons they most trust to decide on their behalf. The most important features of advance planning is discussion with one's family and a conference with one's doctor. The physician will document this conversation in the patient's record where it will be available in time of crisis. Advance planning has become more common in routine medical care and is especially important in terminal care.

In addition to this conversation, the wishes of the patient should be stated in legally acceptable documents, generally called "advance directives." There are several forms of advance directives: (1) the "durable (or medical) power of attorney for health care," (2) the legal instrument entitled "Directive to Physicians" in the natural death acts enacted by various states, and (3) the less formal "living will." Each of these forms is explained in Section 2.6.2.

The idea of advance directives has become both familiar and accepted in ethics and in law. Medicare regulations require hospitals to provide patients with information about their rights under state law to accept or refuse recommended care and to formulate advance directives. In 1990, Congress passed the Patient Self-Determination Act requiring that all hospitals and other health care facilities receiving federal funds, such as Medicare and Medicaid payments, must ask patients at the time of admission whether they have advance directives. If they do, patients are asked to submit copies for their records; if they do not, they are to be informed that they have the right to sign such a document and be given information about it. Physicians should encourage their patients to prepare

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*Sixth Edition*

# Clinical Ethics

A Practical Approach  
to Ethical Decisions in  
Clinical Medicine

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