necessary to benefit the patient. This has been understood to include violating the autonomy of the patient. Physicians in the name of Hippocratic paternalism have refused to tell patients their diagnoses, prescribed placebos, refused to prescribe drugs believed dangerous, and have engaged in all manner of violations of the autonomous choices of patients. They have done so not out of a concern to protect the welfare of others or to promote justice, but rather out of concern that the patient would hurt himself or herself. Classical Hippocratic professional ethics contains no moral principle of respect for autonomy.

By contrast, the moral principle of autonomy says that patients have a right to be self-determining insofar as their actions affect only themselves. The principle of autonomy poses increasingly difficult moral problems for health professionals, first in determining whether patients really are sufficiently autonomous so that the principle of respect for autonomy applies, second, in deciding whether persons who are, in principle, sufficiently autonomous are being constrained by external forces that control their choices, and finally in deciding whether it is morally appropriate to override autonomy in order to protect the patient's welfare. The following cases confront these issues.

DETERMINING WHETHER A PATIENT IS AUTONOMOUS

Some persons may lack the capacity to make many substantially autonomous decisions. They may, through age or brain pathology, lack the neurological development to process information necessary for making choices. They may suffer from severe mental impairments, delusions, or errors in understanding.

In the easy cases, this capacity is totally lacking. In these cases, such as in small children, we presume by public policy that autonomy is absent and designate someone as a surrogate, such as a parent or court-appointed guardian. In adults in whom autonomy appears to be totally lacking, matters are more complex. First, the adult may have made choices while competent that are thought to be still relevant. Second, public policy does not automatically designate any adults incompetent (as with someone under the age of majority). It is here that we are still striving to develop legal and public policy mechanisms for transferring decision-making authority.[4] Presently no clear legal authority exists for health professionals, on their own, to declare incompetency and assume the role of surrogate decision-maker. Competence is a legal term that can only be determined by the courts.

Since adults are normally presumed competent until adjudicated otherwise, there is a real problem for adults in need of medical treatment who appear to lack the capacity for making autonomous choices and yet need medical treatment immediately. Legally, consent is presumed in cases of emergency.[5] That presumption is not valid, however, for situations that are not emergencies. For instance, if a physician is planning to write a medical order not to resuscitate a patient in the case of a cardiac arrest, it normally is not an emergency.

The presumption of incompetency is also probably not valid for emergencies in which the patient is coherent enough to demand not to be treated. As a society we are moving toward a consensus that in cases in which the patient is so lacking in capacity that he or she cannot respond coherently to a declaration of incompetency, the transfer of decision-making to the appropriate surrogate is acceptable, even without a formal court review.

That presumption of incompetency leaves open the question of who the appropriate surrogate should be. Normally, we would want as a surrogate someone committed to looking out for our interests and, if possible, someone who knows our particular values. These criteria point in the direction of someone who knows the full range of our values and interests, such as a family member, but we would also want to guard against someone who has a conflict of interest. The pattern emerging seems to be that it is the next-of-kin, rather than the health professional, who is in charge.

In cases in which the patient can respond to a declaration of lack of capacity by the care provider, it is much less clear what should be done. If the patient acknowledges that he or she cannot make decisions and accepts the suggestion that the next-of-kin take on that role, it seems reasonable to proceed, but if the patient claims to be able to make his or her own decisions, no clear policy guides health professionals on what to do. If there is enough time, it is probably best to seek informal help from an ethics committee or a formal, legally binding review from a court. If there is not enough time, it is far less clear what should be done.

CASE 6-1

Borderline Competency: Deciding About Major Heart Surgery

William Maxwell was admitted to the hospital with chest pain, intermittently severe, poorly relieved by nitroglycerin. He was sixty-nine years old, moderately obese, hypertensive, and diabetic. Initial evaluations indicated severe ischemic heart disease, believed to be life threatening. A recent diagnosis of dementia had been made, but his competency to make autonomous decisions was variable. Dr. Nina Sandstedt considered cardiac catheterization necessary before any cardiac operative procedure could be planned.

On evaluation by Dr. Sandstedt and consultants, Mr. Maxwell was noted to be awake, showing capacity for pleasure and pain, but disoriented. He could state his name but did not know what city he was in. Family members were available and his wife, Esther, was available to act as a surrogate. He could identify her by name.

Evaluation of surgical mortality of coronary artery bypass surgery (CABG) for him suggested he had approximately a 10 percent chance of not surviving the procedure. Postoperative pain following placement of coronary bypass grafts would be considerable but could be controlled with medication. Pneumonia and other complications could occur.

The professional dilemmas included satisfactory assessment of Mr. Maxwell's mental capacity for decision-making, and successive discussions with him or surrogates as options for surgical treatment were clarified. A hospital administrator did not assess the possible procedures as extraordinary in cost or in use of personnel and equipment. Dr. Sandstedt believed that the procedure would be a major trauma for a patient in Mr. Maxwell's condition, but she believed that, if it were she, she would opt for the operation if the catheterization showed evidence that an operation would be beneficial. There was general agreement that the probable benefits of surgical intervention outweighed his risks and possible complications. On the other hand, she knew some patients with Mr. Maxwell's degree of chronic heart impairment who had refused such procedures. When Mr. Maxwell was asked, he seemed to resist the proposal of an operation, but his capacity to refuse consent was questionable. Dr. Sandstedt knew she could not operate without a valid operative permit. Mr. Maxwell had not discussed questions of life-prolonging treatment prior to the development of his dementia. Should she rely on Mr. Maxwell's apparent refusal? Should she invite Esther Maxwell to function as his surrogate? What if she also refused what Dr. Sandstedt believed was a reasonable recommendation to proceed with the procedure?

CASE 6-2

A Mature 12-Year-Old Who Refuses a Heart Transplant

Twelve-year-old Emma Ogden had suffered all her life from a congenital heart defect that had led to over forty operations during her short life. Still, she was not doing well. She suffered cardiac episodes periodically while in school or on the street leading to repeated calls to the emergency medical services (EMS) personnel. Up to this point, they had always been able to resuscitate her and transport her to the emergency room (ER) where eventually her condition was stabilized.

Now Dr. Abdul Hamid, the transplant surgeon at the hospital, had informed Emma and her parents that her only long-term hope was a heart transplant. The child's condition was so severe that she would not survive much longer without the operation. Even with a transplant, her prognosis was not good: no more than 10–20 percent chance of five-year survival with likely repeated crises related to her damaged lungs and circulatory system.

Emma was a remarkable young woman. She had recently been conducting class sessions in school trying to help her classmates understand what was happening when she would lose consciousness in school, leading to rescue personnel rushing in and her fellow students being evacuated from the classroom until she could be removed. She had written an essay published in their local community newspaper describing her situation. The teachers had told her parents that, in spite of her many missed school days over the years, she tested three years above her grade level.

She had read everything she could find about her condition. She knew her chances of survival were not good. She had had about all she could take of hospitals,

operations, and medical crises. After considerable thought she came to the conclusion that the transplant was not worth it. She knew the alternative was certain death in the near future. She had also come to understand that an adult in this position would have the legal right to refuse consent for the procedure. She told Dr. Hamid that she did not want the transplant.

She had discussed the matter at length with her parents who had reluctantly come to understand her position. They would support her if that is what she wanted to do.

Dr. Hamid was taken aback. In all his years of cardiac transplant surgery, he had never had a case like this one. Occasionally, an elderly patient who was rapidly declining and had been advised that he or she was unlikely to survive heart transplant had accepted his advice and declined the extreme procedure, but never before had he been confronted with a 12-year-old who could potentially survive many years if everything worked just right.

Dr. Hamid considered the possibility to getting consent from her parents but realized that they might also refuse. He turned to an ethics committee, who explained to him that some adolescent minors were considered sufficiently mature that they had the authority to make medical decisions on their own behalf. (Some pregnant adolescents have consented to abortion on this basis, for instance.) On the other hand, the committee members had never invoked the mature minor rule on someone as young as twelve and for a decision as momentous as a life-ending transplant refusal. Their alternative was to treat her as other 12-year-olds, some of whom might express resistance to needed medical procedures. Parental consent is normally acceptable in such cases. Dr. Hamid knew, however, that the parents might themselves refuse, which would leave him the only option of seeking a court order to operate against the wishes of both the girl and her parents. Should he accept the girl's refusal, rely on the parents' judgment, or attempt to get the court order?

COMMENTARY

Case 6-1 and 6-2 both raise questions of the mental competence of patients to make crucial medical choices. Had Mr. Maxwell been more severely impaired, the ethical and clinical problem posed by the first of these cases would have disappeared or been changed significantly. Had Emma Ogden been five years old and refusing a major operation, we would have no difficulty disqualifying her from any role in deciding about her transplant.

Both of these patients show some signs of mental capacity to understand the decisions that need to be made. In Case 6-1, Mr. Maxwell shows signs of dementia and had no documented record of his views about life prolongation prior to his current illness. Dr. Sandstedt seems to be of the view that operation might be warranted and that catheterization should be performed to provide a more reliable basis for making that decision. Clearly, if Mr. Maxwell has the capacity to consent or refuse consent, the catheterization would be pointless if he knew he would not give that consent.

Assessment of capacity to consent is not a precise science. Dr. Sandstedt, perhaps with the help of a psychiatric consultant, could initiate such an assessment leading to a judgment on her part of whether Mr. Maxwell is sufficiently autonomous that she should rely on his consent or refusal. In the past, some physicians have determined competency on the basis of the plausibility of the patient's choice. The reasoning is, "Refusing a life-saving operation would be crazy; the patient is refusing so I should treat him as lacking the capacity to consent because of his unreasonable refusal." This determination of capacity to consent on the basis of the reasonableness of the patient's choices is not generally considered acceptable. An independent assessment is called for, based on whether the patient understands the nature of the choice and the likely effects of various options. If the patient is found to have capacity to understand and is not coerced or otherwise constrained in the choice he makes, then respect for patient autonomy requires respecting the choice made, at least if the patient's welfare would be the basis for overruling the patient.

If Dr. Sandstedt and those assisting her in the assessment of Mr. Maxwell's capacity decide he has sufficient capacity to consent and she accepts the moral principle of respect for autonomy, she seems locked into the conclusion that she should not do the catheterization even though she might herself find it the better choice. Only if Dr. Sandstedt remained committed to a more Hippocratic perspective based on the principle of beneficence, with a more paternalistic imposition of the physician's choice on the patient, would she consider overriding Mr. Maxwell's decision.

If she finds Mr. Maxwell lacking in the capacity to understand the choice he might be asked to make, Dr. Sandstedt is in a more complex position. That would still not lead to giving her the authority to make the decision on her patient's behalf. It is possible that she and her patient could disagree on his capacity to decide. It is for cases like this that some now recommend informing the patient of the physician's decision that the capacity is lacking. The patient might concur, leading to agreement that some other decision-maker would have to be found. If the patient disagreed, then further work would be in order. Dr. Sandstedt might seek additional consultation, might ask for an ethics committee's review, or might, in an extreme case, seek to have Mr. Maxwell declared incompetent by a court.

If she proceeds, based on a decision that Mr. Maxwell lacks capacity, then a valid surrogate is needed. Esther, the patient's wife, seems like the obvious candidate here. Technically, there is some ambiguity in the law. Whether the law specifically authorizes it as it does in some states, most clinicians work on the presumption that the next-of-kin is the legitimate and valid surrogate. In a case such as this one in which there is even difference of opinion among competent clinicians, it seems reasonable to accept the surrogate's choice as long as it is within reason. That could include the possibility that Esther Maxwell would, after taking into account what she knows about her husband's values, decide against an operation.

In cases such as this, in which a questionably competent patient and surrogate presumed to be valid agree on the course to be followed, the clinician may not have to spend a great deal of time and energy sorting out whether the

decision comes from the patient or the surrogate, but Dr. Sandstedt should realize that potentially down the road Mr. Maxwell and his wife may reach a choice about which they do not agree. At that point Dr. Sandstedt would have to be clear on which person really has the authority.

In Case 6-2, we also have a case in which a physician, Dr. Hamid, needs to know whether he will treat the patient herself as the agent with the capacity to make medical decisions or will rely on a valid surrogate. Normally for children as young as twelve, there is no doubt that they lack sufficient capacity, especially for momentous life-and-death choices such as heart transplant. The parents would be presumed to be surrogates in a legitimate position to consent to the treatment. In this case, however, Emma has shown remarkable capacity to understand. She has extensive experience with being a surgical patient and with coping with her condition. She has the unusual maturity to have thought long about her options and to have taught and written about her situation.

Although we begin with the presumption that anyone under the age of majority lacks capacity to make critical medical decisions, there are exceptions. Minors may be classified as "mature," that is, capable of sufficient autonomy to make their own choices. This occurs with some frequency for older teenagers, especially when faced with a decision such as birth control in which, for confidentiality reasons, they might resist getting parents involved. Some minors are also treated as "emancipated" even though they may lack sufficient maturity to make their own choices. De facto, emancipated minors become their own decision-makers if they are married, living independently, or otherwise emancipated from their parents.

Emma Ogden is not emancipated, but a case can be made that she is sufficiently mature to make her own medical choices, even a major life-and-death crisis. If she is deemed mature, then the views of her parents are technically irrelevant (except as they might serve as advice to their daughter). There remains controversy over whether clinicians can, on their own, declare a minor to be sufficiently mature or whether they need a declaration by a court before relying on the minor's consent or refusal. If the clinicians unilaterally decide to treat a minor as mature, their action could be challenged by the parents, relatives, or by other health professionals.

If a minor is not emancipated or classified as mature for purposes of medical decision-making, then the parents are the surrogates with responsibility to make medical choices until the time that they are disqualified by a court. If Emma were not deemed mature, they would clearly have the right to consent to the transplant even in the face of their daughter's objection.

In this case, the parents seemed to concur in Emma's choice to refuse the transplant. Dr. Hamid faces additional decisions at that point. He could honor Emma's own choice on the grounds that he deems her a mature minor. He might do so without the determination by a court of her status. Alternatively, he could classify her as not sufficiently autonomous to make such a major decision and rely on the parents' decision. If he follows this course, however, he could run into an additional problem. While patients deemed sufficiently autonomous have an almost unlimited right to refuse medical treatment, parents

acting as surrogates have somewhat less freedom. We know Jehovah's Witness and Christian Science parents can be overruled on grounds of patient welfare, even though the parents are acting in good faith.

It is theoretically possible that Emma, a mature minor, has the authority to refuse the transplant but that her parents could be challenged as not being sufficiently reasonable if they are the ones asked to consent or refuse. In that case, Dr. Sandstedt would have to be clear on whether she was relying on the patient's own refusal (on grounds that she was a mature minor) or on parental surrogate decision-making.

In both of these cases the patient's authority to refuse consent to potentially life-saving treatment is made complicated by constraints on the capacity of the patient to make substantially autonomous decisions. In Mr. Maxwell's case, the problem was his dementia; in Emma's case it was her age. In either case, however, clinicians could confront a choice between treating the patient as possessing sufficient capacity to consent or treating the patient as lacking that capacity, thus relying on a familial surrogate. The policies and limits of decisional authority differ in the two courses. The constraints, insofar as they exist, are what is sometimes called "internal" in both these cases. They are problems with the capacity of the patient related to some condition that exists within the patient. In the following cases we examine limits on autonomy based on external constraints.

External Constraints on Autonomy

Persons may be substantially autonomous in the sense that they have the neurological and mental capacity as well as adequate knowledge but still be constrained for specific choices by external forces. Persons in special institutions, sometimes called "total" institutions, such as prisons, boarding schools, or the military may be subject to forces that exert substantial control on their choices. Persons may also be under the threat of physical force. One interesting problem in this area is whether persons have their autonomy violated when they are pressured by "irresistibly attractive offers." For example, if an imprisoned sexual offender is offered release if, and only if, he agrees to an implant of a long-acting hormone that is expected to control his sexual aggression, is such a person able to autonomously choose to accept or reject the offer? If not, is it because the offer is made while he is in prison or is it because the option seems so attractive compared to the alternative? Ethical problems of respect for autonomy can be created by the external forces such as these. The following case illustrates the problem.

CASE 6-3

Readdicting a Heroin User: Are Prisoners Free to Consent to Research?

Forty-eight-year-old Harry Henning was in the fifth year of a twenty-year sentence in the state prison for a third offense of possession of heroin and attempting to sell.