

retain the right to refuse dialysis if it were offered. Since he has already refused other treatment proposals, he might also refuse the dialysis. That would eliminate any moral controversy in the case.

Assuming he did not decline the dialysis, respect for autonomy introduces another issue. Does his autonomously chosen decision to be noncompliant negate his claim of justice to receive the dialysis? Some would argue that justice requires that persons who are among the worst off be given opportunities for benefit. If, however, Mr. Beato has had opportunities to be better off but has rejected them, this could leave him in a morally different position from those who are among the worst off without having had such opportunities. Does autonomously chosen non-compliance lessen Mr. Beato's claim of justice? That will depend on one's interpretation of the principle of respect for autonomy, the principle to which we now turn.

Notes

- 1 Beauchamp, Tom L., and James F. Childress. *Principles of Biomedical Ethics*. 6th ed. New York: Oxford University Press, 2009, pp. 240–281.
- 2 U.S. Department of Health and Human Services, Health Resources and Services Administration. "Organ Procurement and Transplantation Network; Final Rule." *Federal Register* 42 CFR Part 121 (20 October 1999): 5650–5661.
- 3 Heiney, Douglas A., director, Department of Membership, UNOS. "Memorandum: Proposed Liver Allocation Policy Development Plan for Public Comment." Richmond, VA: UNOS, February 15, 2000.
- 4 Veatch, Robert M. "A New Basis for Allocating Livers for Transplant." *The Kennedy Institute of Ethics Journal* 10 (March 2000): 75–80.
- 5 Cohen, L. M., et al. (2000). "Dying Well after Discontinuing the Life-Support Treatment of Dialysis." *Archives of Internal Medicine* 160 (September 11): 2513–2518.

Chapter 6

Autonomy

Learning Objectives

1. Define the principle of respect for persons.
2. Describe the psychological and moral meanings of autonomy.
3. Define paternalism.
4. Describe components of a substantially autonomous decision.
5. Apply the principle of respect for autonomy to cases in which the capacity of the person to decide is unclear.

Other Cases Involving Autonomy

- Case 4-1: Stimulants as Performance Enhancer
- Case 4-2: The Benefits and Harms of High-Risk Chemotherapy
- Case 4-4: Blocking Transplant for an HMO Patient with Liver Cancer: Serving the Patient and Serving the Community
- Case 5-3: Antibiotic for a Child's Otitis Media
- Case 5-5: Dialysis in an End-Stage HIV-Positive Patient: Justice, Benefit, and Patient Autonomy
- Case 11-2: Dwarfism: When Is a Fetus Normal?
- Case 11-4: Surrogate Motherhood: The Case of Baby M

- Case 11-6: Using Genes to Treat Brain Cancer
- Case 12-2: Obesity: Medical Problem or Lifestyle Choice?
- Case 12-4: The Jesus Christian Transplant: Brainwashed into Donating a Kidney?
- Case 14-1: Donation, Salvaging, and Incentives for Transplantable Organs
- Case 14-3: Tainted Organs: Donors with High-Risk Lifestyles
- Case 14-9: Patients with Alcohol Dependency and Their Rights to Livers for Transplant

Also see the cases of Chapters 7, 9, 10, and 17.

In the previous chapter we saw that in social ethics the principles of beneficence and nonmaleficence (maximizing aggregate total net benefits) may not be the only morally relevant consideration. The principle of justice affirms that certain patterns of distribution of the good, such as distribution based on medical need, may also be morally relevant. Justice, when it is considered a principle of fair distribution, is not the only moral consideration that can provide a check on the principles of beneficence and nonmaleficence. In this and the following chapters we shall explore several other moral principles—respect for autonomy, veracity, fidelity, and avoiding killing—principles that all, in one way or another, refer to right-making elements, actions, or practices that do not involve maximizing the net good produced.

Justice is concerned with the distribution of goods in morally preferred patterns. It, therefore, always involves more than one person who is the potential beneficiary. The remaining principles are relevant, however, even if there is only one person our actions affect. Thus these principles are particularly important in traditional clinical health care ethics in which the professional is thought of as acting on one and only one patient. In fact, we increasingly recognize that, even in these clinical situations, many people are affected by the clinician's actions. There is not only one patient but also other patients whom the clinician could be treating. Family members of the patient, friends, and citizens may be affected by each treatment decision, as can fellow health professionals.

Nevertheless, many ethical decisions in health care can be analyzed as if there were only one party who is principally affected. When we contemplate violating a patient's autonomy, lying to a patient, breaking a promise such as the promise of confidentiality, or mercifully killing a patient, it is the patient's moral interests that are primarily affected. Other people's interests are much more indirect. Therefore, while remembering the important ethical issues raised by the principle of justice in the previous chapter, the cases in this and the following chapters in this part of the book will focus primarily on the more individual ethical concerns. These begin with the moral principle of autonomy.¹ This principle is more accurately referred to as the principle of respect for autonomy, since it does not require that people act autonomously, only that their autonomy be respected.

Autonomy is both a psychological and a moral term. Psychologically, autonomy is a term describing the mental state of persons who are free to choose their own life plans and act on those plans substantially independent of internal or external

constraints. One leads the life of an autonomous person to the extent one is free to be "self-legislating." Autonomy means creating one's own legislation. As such, being autonomous is always a matter of degree. No one is "fully autonomous" in the sense of being totally free from internal and external constraints. Some people may be totally lacking in autonomy—infants and the comatose are examples. Many people whom we call nonautonomous, however, possess some limited capacity to make their own choices. Small children, the mentally retarded, the mentally ill, and the senile all may be able to make limited choices based on their own beliefs and values and yet are hardly autonomous enough to be called self-determining in any meaningful way. Thus being autonomous is decision-specific as well as a matter of degree. We treat those persons who have a sufficient degree of autonomy as being essentially self-determining; we call them "substantially autonomous persons." For purposes of public policy, we assume that persons below the age of majority, usually 18, are lacking sufficient autonomy for a range of publicly significant decisions unless proven otherwise. We admit that some 16-year-olds may have both the internal knowledge and intellectual capacity and be sufficiently free from external constraints to be as autonomous as some adults. The courts will occasionally recognize such minors as "mature" for purposes of making medical decisions on their own. But the working presumption is that minors lack competence to make many substantially autonomous decisions.

By contrast, those who have reached the age of majority are presumed to be substantially autonomous unless there is adequate evidence to the contrary. One type of evidence comes from a judicial determination of lack of competence. There is a striking problem with patients who are clearly unconscious. They are obviously not capable of making autonomous decisions, yet they have never been declared incompetent through any formal proceedings such as in a court. One approach is to require that if a clinician or a family member believes such persons are totally lacking in competence, he or she must take reasonable steps to inform the patient of that belief. Of course, if the patient is unconscious, no such action would be necessary, but if the patient is capable of disagreement and the patient coherently expresses that disagreement, then he or she should be presumed to be competent until adjudicated otherwise. If he or she fails to disagree, then a presumption of lack of capacity to make substantially autonomous choices seems reasonable.²

This, however, does not mean automatically that a clinical caregiver is free to do what seems reasonable to those who are not substantially autonomous. In the case of children, we presume that only parents and those designated by the courts are free to act as surrogate decision-makers. In the case of adults, even if the presumption of lack of autonomy is warranted, we still need to determine who is authorized to speak for the individual. The health professional—physician, nurse, pharmacist, or other health worker—does not automatically have that authority.

Even if one is believed to be substantially autonomous, it does not necessarily follow that he or she should be free to make all decisions about his or her actions. For example, if one's actions are likely to harm others, we routinely accept the idea that

they can be restrained. This might be supported on what can be called the "harm to others" principle. From the time of John Stuart Mill, this limit on action has been well recognized, even among defenders of human liberty.³

The principle of justice might also be a basis for constraining actions that affect others. That is, we may want to control people because of the effect of their action on the distribution of goods as well as because of the total amount of harm one's actions will bring to others. Still others believe that it is acceptable to constrain people who we believe are substantially autonomous in order to produce a greater good for society. Constraining someone in order to produce good for others is, however, more controversial than constraining to protect others from harm or to promote justice. Finally, some people believe it is acceptable to constrain those who are substantially autonomous in order to produce good for those individuals themselves. This is what is called *paternalism*.

If a person's substantially autonomous actions have no appreciable effect on other people, it is an open question whether it is ethically right for others to constrain his or her behavior, that is, to act paternalistically. Even if their free choices only affect themselves, some people have held that it is morally appropriate to constrain actions. Laws requiring motorcycle riders to wear helmets, laws restricting access to drugs with dangerous side effects, and, in some cases, laws authorizing restraint of persons who are of danger to themselves have all been defended as justifiable infringements on personal freedom. When these restraints are imposed on substantially autonomous persons, such laws are paternalistic.

This is where autonomy surfaces as a *moral* principle. The moral principle of respect for autonomy holds that an action or practice is morally wrong insofar as it attempts to control the actions of substantially autonomous persons on the basis of a concern for their own welfare.

Classical Hippocratic ethics in the health care professions has been committed to the principle that the health care worker should do whatever is 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.

Borderline Competency: Deciding about Major Heart Operations

William Maxwell was admitted to the hospital with chest pain, intermittently severe, poorly relieved by nitroglycerin. He was 69 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 graft (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. 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 consent. Mr. Maxwell had not discussed questions of life-prolonging treatment prior to the development of his dementia.

Questions for Thought and Discussion

- 1. Should the physician rely on Mr. Maxwell's apparent refusal?
- 2. Should the physician invite Esther Maxwell to function as his surrogate?
- 3. What if Mrs. Maxwell also refused what Dr. Sandstedt believed was a reasonable recommendation to go ahead with the procedure?

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 at play 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 child. 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 refusal by a 12-year-old who could potentially survive many years if everything worked just right.

Dr. Hamid considered the possibility of 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 12 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. However, since the parents might themselves refuse, his only option would be to seek 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

Cases 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 5 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 the 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 the assumption of next-of-kin surrogacy, 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 down the road Mr. Maxwell and his wife might 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 12, 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 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.

He had been convicted within a few years of completing college. Since entering the prison he had been drug free, but often recalled the “rush” of his drug of choice. The state prison was notoriously overcrowded, with three prisoners per cell and limited time for exercise or recreation.

Marc Turner, MD, was a research pharmacologist who had devoted his career to problems of addiction. For the past five years he had been doing research on a new agent that was a specific heroin receptor cell blocker.

The drug, which could be administered by an implant, was designed to provide long-term blocking of the effects of heroin. It had been tested in mice and in three other species of animals and was now ready for initial trials in humans.

Dr. Turner turned to the state prison to find research subjects for a phase-one trial of his new compound. On the basis of animal studies, he had good reason to believe it would be safe in humans and effective in blocking the addiction response by interfering with the site at which heroin binds in the brain. He proposed to recruit former heroin addicts, administer the implant, and then administer heroin to study the response.

State regulations permitted the use of certain prisoners for research but prohibited payment of undue compensation, defined as any amount significantly different from what prisoners could earn in other prison employment. Dr. Turner realized that if his study went as planned, the subjects would experience none of the traditional pleasures of heroin. Nevertheless, in case the drug did not work as hoped, he wanted to make the initial trial of the drug on persons whose environment would be tightly controlled for several years. Furthermore, he needed to control the environment of the subjects during the research period.

In order to provide this control, he proposed to do the research on prisoners with long enough sentences that they would have time to recover should something go wrong with the experiment. To provide adequate control of the environment during the research, he proposed to move the prisoner subjects to the hospital ward of the prison where the prisoner would be placed in a private room with bath. Each prison hospital room had a TV and easy chair as well as a hospital bed.

When Harry Henning saw the notice recruiting subjects, he figured he was an ideal candidate. He had had his life destroyed by his uncontrollable addiction and would like to make a contribution to society to prevent similar problems with others in the future. The private room was also appealing. Should the institutional review board responsible for approving research in the prison permit prisoners such as Mr. Henning to volunteer for this research? If so, can a prisoner in this environment give an adequately free and informed consent?

Questions for Thought and Discussion

- Given the external constraints of life in a prison, can prisoners ever make substantially autonomous decisions?
- What guidelines should be in place to protect prisoners who may want to volunteer for research studies?

Commentary

Former drug addict Harry Henning has become a candidate for a research project, a clinical trial of a new narcotic antagonist that potentially could treat heroin addicts by blocking the effects of that drug. The general questions of the ethics of clinical trials will be discussed in Chapter 16 and those of informed consent in Chapter 17. Here, the issue of debate is whether Harry Henning is a substantially autonomous person for the purposes of deciding whether to participate in the proposed research and whether the institutional review board (IRB) should approve the study.

There is no reason to believe that Mr. Henning lacks the innate capacity to understand the information presented during the consent conversation or process it. He lacks none of the factors inherently necessary to be an autonomous person. He is not mentally ill, retarded, or ill to the point that he cannot think clearly. The real problem is whether his environment provides such external constraints that his decisions in this setting cannot be substantially autonomous ones.

There is evidence in the case that Mr. Henning probably would not (or should not) consent to be part of this study if he were not incarcerated. He is a former addict, and the study poses a real if small risk of readdicting him or producing other side effects. It seems clear that the main reason Mr. Henning would agree to participate is because he is incarcerated. (The other possibility is that he realizes that the drug designed to attach to the same receptor that binds heroin could actually produce the heroin-like euphoria he remembers so vividly. The drug is designed to attach to the site in such a way that it blocks the heroin from the receptor but does not itself trigger the heroin response, but there is a chance that this would not be the result in humans so that a heroin euphoria could result from the drug and he would be readdicted.)

Does the incarceration present external constraints on his behavior that make his choice nonvoluntary? Mr. Henning is presented with two options: returning to his present life in the crowded cell block or moving to the new, more comfortable surroundings and taking a chance the narcotic antagonist won't work. Is that an unacceptable offer? If so, is it simply because it is irresistibly attractive?

Consider someone who is dying from cancer who is told the only chance she has of a cure is to agree to a nauseatingly unpleasant chemotherapeutic agent. Presumably that agent is at least as unattractive to the cancer patient as the narcotic antagonist medication is to Mr. Henning. Yet the offer must appear to be irresistibly attractive considering the alternative (which is death in the case of the cancer patient). Yet we do not normally argue that the cancer patient cannot consent to the chemotherapy because the offer is so attractive. If someone tried to ban the offer because it is so attractive we would probably protest—precisely because the offer is so attractive. People should have access to very attractive options even when their choices are very limited.

What is the difference between the prisoner's case and the cancer patient's? The prisoner's choices are "artificially constrained" by the incarceration. Yet let us assume that Mr. Henning is justifiably imprisoned. Should he not be allowed to

make limited choices, say, between two different work details, even though his environment is artificially confining? If so, should he not be allowed to choose a “work” option of being a research subject, even if the offer is terribly attractive? Is he less autonomous if he is given the additional option that is very attractive? Would it be more ethical to conduct the research if the living conditions were made much worse, say, as bad as those in which he would otherwise be living?

Overriding the Choices of Autonomous Persons

Up to this point, this chapter has dealt with persons whose autonomy is debated, either because of inherent lack of the internal capacity to make substantially autonomous choices or because of external constraints that could make specific choices nonautonomous. Some persons, however, are substantially autonomous. They possess both the internal capacity to make choices according to their life plan and are in an environment that offers them reasonable freedom to choose without external constraints. Still, the choices they make may seem to be very foolish. They may seem to offer risks of harms that far exceed any benefits that could be gained. Assuming a person is substantially autonomous, is there ever a time when it is ethically justified to constrain his or her actions for the individual’s own good, or does respect for autonomy always win out, requiring that the autonomous individual’s own choices be respected insofar as it is only that individual whose interests are jeopardized?

The answer will depend on how one’s ethical theory handles cases of conflict among principles. In these situations involving clearly autonomous people constrained by neither internal nor external factors, if the principle of autonomy holds sway, then no interference can be justified even to provide great benefit or prevent great harm as long as the benefit and harm involved are those of the person who would be the target of such intervention. On the other hand, some ethical theories balance competing claims when two principles come into conflict. In that case, if the principle involved other than autonomy becomes weighty enough, autonomy may lose out. The most common case is one in which beneficence and nonmaleficence conflict with respect for autonomy as in the following cases.

Case 6-4

A Diabetic Who Refuses Treatment for an Infection

Horace Johnson is a 60-year-old, wheelchair-limited patient suffering from insulin-dependent diabetes mellitus (IDDM) of ten years’ duration. He has an infected, draining toe with bone exposed, cellulitis, and x-ray evidence of osteomyelitis brought on by the poor arterial circulation related to his IDDM. He is noncompliant in visits to the outpatient clinic for care of his infection, has no insurance coverage, refuses social worker and psychiatric consults, and now is refusing further debridement of the decaying tissue around the infection.

Mr. Johnson had on previous visits been seen by a consulting psychiatrist who found him to be eccentric, a semiretired man who had done janitorial work and odd jobs through his adult life. The psychiatrist had found some depression but no evidence of mental illness that would have made it possible to declare him incompetent.

Dr. Maria Garcia was very concerned about the infection. She was afraid that he would lose the toe or, worse, the foot, from gangrene if Mr. Johnson did not receive aggressive treatment.

She contemplated hospitalizing him and using sedation in order to treat the foot. She could not imagine his losing a toe or foot simply because he was so stubborn he would not agree to her recommendation.

Commentary

Mr. Johnson has made a choice that most of us would find strange. He refuses a treatment that any physician would consider essential to avoid an amputation. To be sure, the physician’s recommendation for debridement involves a value judgment—that it is better to suffer the discomfort of the aggressive treatment including debridement than to lose a toe or foot, but the value judgment seems so obviously right that most would be tempted to claim it is a “fact.” Many would be tempted to say that anyone such as Mr. Johnson who would choose to take the very real risk of losing the toe or foot has simply made a mistake. Either the person has very strange values or is mentally ill and unable to make a rational evaluation of the options.

Dr. Garcia had previously followed a reasonable course of asking for a psychiatric consultation, learning that at that time Mr. Johnson was not a candidate for a declaration of incompetency. Had that been possible, the ethical problems related to the principle of respect for autonomy would have vanished. If Mr. Johnson were not competent, his autonomy would not be violated if he were treated against his will. He would not have sufficient autonomy for the principle to come into play. On the basis of the previous consult, however, Mr. Johnson has been treated as possessing enough autonomy that treating him against his wishes would be considered a violation of that autonomy. It could, of course, be that his mental condition has deteriorated since the psychiatric consultation. Dr. Garcia could seek to have him declared incompetent so that a guardian could be appointed to authorize treating him. She seems to understand, however, that she would likely fail in trying to get a declaration of incompetency. Mr. Johnson, whatever his strange behavior, does not appear sufficiently deranged to warrant such a declaration.

That leaves Dr. Garcia with two stark choices: respect his autonomy by letting his infection go without the needed treatment, or invoke the principle of beneficence—the moral imperative to benefit the patient—as a justification for admitting him to the hospital, sedating him and treating him without his consent. Is this a case in which beneficence should triumph over respect for autonomy?

Brought to the ER after a Suicide Attempt

Max Perrin, a 55-year-old male, was brought to the emergency room (ER) by the local rescue squad following a suicide attempt by means of consuming rat poison. The ER physician, Dr. Christopher LeMarke, recognized him immediately, as did the ER nurses. He had been a regular in the facility, having visited for his primary medical care and for two previous suicide attempts within the past eighteen months. During the previous visits his history had been explored completely. He was divorced, alienated from his adult children, and chronically depressed but was not considered sufficiently impaired that he could be declared incompetent.

On the basis of state law, such patients could be held for up to seventy-two hours on the signature of two physicians if they were deemed dangerous to themselves or others. Mr. Perrin had never before engaged in any behavior that would suggest he was dangerous to others, but he surely was a danger to himself. He had on past admissions received short-term psychotherapy and prescriptions for antidepressant drugs, but he had stopped taking them because he said they made him feel sleepy.

He was now in the ER, incoherent and semiconscious. Should Dr. LeMarke sign the involuntary commitment, enlist another physician to sign as well, and initiate another round of therapy?

Commentary

This patient is certainly facing a serious crisis. He is suicidal and will die if not treated. Dr. LeMarke has the legal authority to commit him involuntarily and treat his medical problems that result from his suicide attempt. If Mr. Perrin were sufficiently mentally ill as to be treated as incompetent, as not sufficiently autonomous to make his own medical choices, the case would be relatively straightforward from the point of view of the ethics involved. He could be committed and treated without violating the ethical principle of respect for autonomy.

Mr. Perrin has previously been evaluated by a psychiatric consultant, however, and has been found to be sufficiently in touch with reality that he cannot be considered lacking in capacity. He seems to understand what he is doing. He has merely reached the conclusion he would, in his circumstances, rather die than live. Given his chronic depression that has not responded adequately to previous therapy, his isolation from his family, and his continuing problems, he has made the choice that life is not worth living. He is what some would call "rationally suicidal," that is, suicidal while having an understanding of his situation and capable of understanding the choices available to him.

Most commitment laws still permit retaining persons who are deemed dangerous to themselves or others. Committing those who are dangerous to others

seems relatively uncontroversial. No matter how competent and rational, it is unacceptable to pose a serious, credible threat to others. Retaining such persons does not involve paternalism because paternalism requires that the action be undertaken for the good of the one who is restrained.

Committing those who are dangerous to themselves is more complicated. These laws were written in an era in which it was widely assumed that anyone who contemplated suicide was either mentally ill or morally wrong. While that is often the case, the interesting situations are the ones in which mental illness is ruled out or is at least of such a mild degree that the person cannot be declared incompetent.

This presents a group of cases of people who are of danger only to themselves and not sufficiently mentally ill to warrant restraint on the grounds that they are unable to know or control what they are doing. They are suicidal but mentally competent, and they are of danger only to themselves. Restraining such persons using state laws permitting such restraint is paternalism in its most robust sense.

This poses an unexpectedly complicated problem. On the one hand, we generally accept the right of adults not only to hold any belief they choose but also to act on those beliefs, provided their actions do not have an unacceptable impact on others. This might lead us to challenge Dr. LeMarke if he decided to use the existing paternalistic provisions of the current state law. On the other hand, the physician historically has been committed to preserving life. Especially in a case like this one, in which a life can be preserved for the foreseeable future (until a suicide attempt is successful), many doctors will feel morally obliged to take advantage of the present state law and commit the patient even if he is sufficiently mentally competent to understand what he is doing.

Competent adults generally have the legal and moral right to refuse life-saving treatment once they are determined to be mentally competent. Is there any reason why an exception should be made in the case of suicide?

Ignoring a Daughter's Do Not Resuscitate (DNR) Decision

An 88-year-old Hispanic man, Roberto Gonzalez, was admitted to Jefferson White Hospital Emergency Department with a diagnosis of cerebral hemorrhage and coma. Before Mr. Gonzalez's daughter could get to the hospital, the consultant pulmonologist, Melanie Caldarone, administered cardiopulmonary resuscitation (CPR) and admitted him to the intensive care unit (ICU). Upon Ms. Gonzalez's arrival at the hospital, she explained that she did not want CPR or other life-sustaining measures based on past communication with her father. She showed them a letter from Mr. Gonzalez stating his concern about a friend who ended up "helpless on machines." There was no formal advance directive, however, just this one example of Mr. Gonzalez's worry about his friend. The family physician and consultant

neurologist had authorized extubation and removal of the respirator in the medical record but did not insist on that course because of the pulmonologist's insistence that Mr. Gonzalez was "not brain dead." He was maintained on support for three days and then expired.

The insurance department of the health maintenance organization (HMO) funding Mr. Gonzalez's hospitalization refused to pay for the ICU expenses because of the family's decision for DNR, charging that the hospital and staff had overused the facilities and nursing staff and for which the HMO accepted no financial responsibility.

Questions for Thought and Discussion

- 1. Is the information in the letter from Mr. Gonzalez to his daughter sufficient to determine his views on the use of life-sustaining treatment? Why or why not?
- 2. Should the treatment team accept Mr. Gonzalez's daughter as his surrogate decision-maker? Why or why not?

Commentary

Perhaps reflective of a fear of criticism from those who believed physicians have a duty to use their skills to preserve life or perhaps out of intimidation by the pulmonary consultant's specialty credentials and aggressive stance, the attending physician essentially relinquished his professional and moral authority by taking the strange step of authorizing, but not insisting on, removal of the tube and withdrawal of the respirator. Perhaps the attending physician did not want to alienate this colleague. This is not good medical practice. Usually, disagreement among staff physicians does not cause lasting estrangement. The case is further complicated by the mistaken belief on the part of the pulmonologist that only "brain death" justifies withdrawal of respirators. This is a confusion of the question of whether a patient can be pronounced dead with the question of when a treatment becomes futile in the sense of not offering benefits to the patient. We shall examine in Chapters 9 and 18 these questions of the relationship between brain death and decisions to forgo life support. Here our focus is on the question of the principle of respect for autonomy and how it impacts decisions to attempt resuscitation.

If Mr. Gonzalez were the author of the instruction to his physicians not to attempt resuscitation and he had given the instruction (in writing or orally) when he was clearly competent, this case would be relatively straightforward. Competent persons currently have the legal and moral right to refuse any medical treatments whatsoever, provided they are offered for their own good. This includes end-of-life support with devices such as respirators. The principle of respect for autonomy is taken to require respect for the substantially autonomous decisions of persons including refusals of life-supporting medical care.

The case is made more complex by the fact that Mr. Gonzalez is not competent; he is in a coma. Moreover, the only evidence we have is a letter with indirect reference to his wishes. It is his daughter who interpreted the letter to mean that her father would not want to be resuscitated. She did so in her presumed capacity as Mr. Gonzalez's surrogate decision-maker.

This raises the question of how such decisions relate to the principle of autonomy. As we shall see in more detail in the cases of Chapter 18, surrogates who step in to make medical decisions for formerly competent adults such as Mr. Gonzalez must first attempt to do what the patient would have wanted, based on what is known about the patient's beliefs and values. If the patient has explicitly stated his desires, this could be relatively easy. If the patient had signed a written advance directive refusing respirators or other means of resuscitation in these circumstances, we would be respecting the patient's autonomy. In a very real sense, autonomy of the patient can be extended into the period of incompetence in this way.

If, however, his daughter has no direct evidence of what her father would have wanted for his own care, extending patient autonomy is impossible. She then takes on the surrogate role, guided at most by her general knowledge of her father's life choices, beliefs, and values. As the degree of certainty about her father's wishes decreases, the possibility of patient autonomy being the basis of the choice decreases as well. In the limiting case, familial surrogates may have to make choices based entirely on what they believe is best for the patient, unguided by the patient's own beliefs, values, and preferences. What, then, is the place of the principle of respect for autonomy in such cases?

In such cases, the question arises of why the daughter has any authority to make choices at all. Some defend her role because they believe that the one who knows the patient best will be the one who has the best chance of choosing what the patient would have wanted. In Mr. Gonzalez's case this may be true, but that certainly does not provide a reason for familial surrogate decision-making in the case when the patient is an infant or a severely impaired older person who has never formulated beliefs about terminal care. Even in these cases, however, we generally favor giving the next-of-kin the role of surrogate. Until such time that the next-of-kin is shown to be too foolish, too malicious, or simply unwilling to serve in this role, the familial surrogate is given the responsibility of deciding what is best for the patient.

In this role, family members may well retain some discretion in choosing what they think is best based on the family's beliefs and values rather than those of the patient. To the extent that this is done, we may see something that can be called "familial autonomy." On the basis of an analogy to the respect shown for the decisions of autonomous individuals, those who believe in some role of special importance for the family hold that the family unit, represented by the next-of-kin, has a special place in choosing what is best for the patient whose own views cannot be determined. In this sense, they have some range of discretion, some autonomy, in deciding on the plan that is best for the patient.

Clearly, family discretion is more limited than that given to competent and formerly competent patients. Family surrogates cannot go beyond reason. This notion will be explored further in Chapter 18. What is critical here is that the principle of respecting autonomy may have a place not only in requiring respect for substantially autonomous individual decisions but also in giving a family unit some space in making choices consistent with the family's beliefs and values.

There is a final question raised by this case: whether the HMO insurance staff was justified in denying coverage for those last three days. That question will be addressed in Chapter 15.

Notes

- 1 For good discussions of the principle of autonomy and related concepts see Feinberg, Joel. "Legal Paternalism." In his *Rights, Justice, and the Bounds of Liberty: Essays in Social Philosophy*. Princeton, NJ: Princeton University Press, 1980, pp. 110–129; Dworkin, Gerald. "Moral Autonomy." In *Morals, Science, and Society*. H. Tristram Engelhardt and Daniel Callahan, eds. Hastings-on-Hudson, NY: The Hastings Center, 1978, pp. 156–171; Faden, Ruth, and Tom L. Beauchamp in collaboration with Nancy N. P. King. *A History and Theory of Informed Consent*. New York: Oxford University Press, 1986; Rehbock, Theda. "Limits of Autonomy in Biomedical Ethics?: Conceptual Clarifications." *Cambridge Quarterly of Healthcare Ethics* 20 (No. 4, 2011): 524–532; Shuman, Andrew G, and Andrew R. Barnosky. "Exploring the Limits of Autonomy." *The Journal of Emergency Medicine* 40 (No. 2, 2011): 229–232; and Beauchamp, Tom L., and James F. Childress, eds. *Principles of Biomedical Ethics*, 7th ed. New York: Oxford University Press, 2013, pp. 101–149.
- 2 See the extended discussion of this approach in The Hastings Center. *Guidelines on the Termination of Life-Sustaining Treatment and the Care of the Dying*. Briarcliff Manor, NY: The Hastings Center, 1987, pp. 20–29.
- 3 Mill, John Stuart. *On Liberty*. New York: The Liberal Arts Press, 1956.
- 4 Areen, Judith. "The Legal Status of Consent Obtained from Families of Adult Patients to Withhold or Withdraw Treatment." *Journal of the American Medical Association* 258 (No. 2, 1987): 229–235; Veatch, Robert M. "Limits of Guardian Treatment Refusal: A Reasonableness Standard." *American Journal of Law and Medicine* 9 (Winter 1984): 427–468.
- 5 Appelbaum, Paul S., Charles W. Lidz, and Alan Meisel. *Informed Consent: Legal Theory and Clinical Practice*. New York: Oxford University Press, 1987, pp. 66–69.

Chapter 7

Veracity: Honesty with Patients

Learning Objectives

1. Define the principle of veracity.
2. Describe the various ways honesty is addressed in professional codes of ethics.
3. Assess the moral soundness of the common reasons health professionals lie to patients.
4. Describe the connection between the principles of veracity and fidelity.

Other Cases Involving Veracity

- Case 1-1: Disclosure of a Terminal Diagnosis
- Case 8-7: Dishonest Colleagues: Intentionally Shorting Tablet Counts
- Case 10-6: Sterilization of an Economically Deprived Woman
- Case 17-1: Therapeutic Privilege: Scaring the Patient to Death with News about Risks