3 American Pharmaceutical Association. *Code of Ethics for Pharmacists.* Washington, DC: American Pharmaceutical Association, 1995.
4 American Nurses Association. *Code of Ethics for Nurses with Interpretive Statements.* Washington, DC: American Nurses Association, 2001, p. 14. http://www.ana.org/ethics/code/protected_nwcoe303.htm, accessed September 8, 2006.
5 Beauchamp, Tom L. "Internal and External Standards for Medical Morality. *Journal of Medicine and Philosophy* 26 (No. 6, 2001): 601–619; Veatch, Robert M. "The Impossibility of a Morality Internal to Medicine." *Journal of Medicine and Philosophy* 26 (2001): 621–664.
6 Bentham, Jeremy. "An Introduction to the Principles of Morals and Legislation." In *Ethical Theories: A Book of Readings.* A. I. Melden, ed. Englewood Cliffs, NJ: Prentice-Hall, Inc., 1967, pp. 367–390.
7 Weinstein, Milton C., and William B. Stason. "Foundations of Cost-Effectiveness Analysis for Health and Medical Practices." *New England Journal of Medicine* 296 (1977): 716–721; Kaplan, R. M., and J. W. Bush. "Health-Related Quality of Life Measurement for Evaluation Research and Policy Analysis." *Health Psychology* 11 (1982): 61–80; Mehrez, Abraham, and Amiram Gafni. "Quality-Adjusted Life Years, Utility Theory, and Healthy-Years Equivalents." *Medical Decision Making* 9 (1989): 142–149.
8 Smith, Cedric M. "Origin and Uses of *Primum Non Nocere*—Above All, Do No Harm!" *Journal of Clinical Pharmacology* 45 (2005): 371–377.
9 This case is based on the PBS documentary, *On Our Own Terms: Moyers on Dying*, which first aired September 10–13, 2000. More information and a study guide are available at http://www.pbs.org/wnet/onourownterms/about/index.html (accessed September 19, 2007).
10 American Medical Association, Council on Ethical and Judicial Affairs. *Code of Medical Ethics: Current Opinions with Annotations, 2002–2003 Edition.* Chicago, IL: American Medical Association, 2002.
11 http://query.nytimes.com/gst/fullpage.html?res=9B06E1DC173AF93AA15752C0A96E958260&sec=health&pagewanted=print, accessed September 15, 2006.
12 World Medical Association. "Declaration of Geneva," Adopted by the 2nd General Assembly of the World Medical Association, Geneva, Switzerland, September 1948, revised periodically, most recently at the 173rd Council Session, Divonne-les-Bains, France, May 2006. http://www.wma.net/e/policy/c8.htm, accessed September 8, 2006.

Chapter 5

Justice: The Allocation of Health Resources

Learning Objectives

1. Define distributive justice.
2. Distinguish among principles of justice such as need or prognosis.
3. Identify conflicts between the principle of justice and other ethical principles.

Other Cases Involving Justice and Resource Allocation

Case 14-10: Do Children Have Low Priority for Adult Lungs?
Case 14-11: Multiple Organs for a Famous Governor
Case 16-1: Chemotherapy Risks: Is Going without Chemotherapy a Benefit?
Case 16-7: Justice in Research Design: Being Fair to the Critically Ill
Case 18-7: Demands for Futile Care
Also see the cases of Chapter 15.

In the previous chapter, the principles of beneficence and nonmaleficence—of doing good and avoiding harm—were introduced. One of the problems raised was the conflict between the welfare of the patient and the welfare of other parties. The utilitarian solution to this problem is to strive to maximize the total amount of good that was done regardless of the beneficiary. We saw that sometimes the utilitarian approach conflicted with the Hippocratic ethic, which requires that the health professional focus exclusively on the welfare of the patient.

Physicians and other health professionals often find themselves in situations in which the interests of their patients are in conflict. The care professional must choose between patients or between a patient and those who are not patients. Whether to provide health care services for those who cannot pay the full costs and shift the costs onto those who can is one example.

The Hippocratic mandate to serve the interests of the patient (in the singular) does not help. However, it seems ethically crass simply to count up the total amounts of good and harm and choose the course that maximizes total social outcome regardless of the impact on the individuals affected. That could lead, for instance, to refusing to provide services to those who are not useful to society or to those who can benefit only modestly from health care services.

Some ethical theories introduce a new ethical principle to deal with this problem—the principle of justice.[1] While beneficence and nonmaleficence are devoted, respectively, simply to producing as much good and preventing as much harm as possible, justice is concerned with *how* the goods and harms are distributed. Justice is concerned with the equity or fairness of the patterns of the benefits and harm.

Among those who hold that there is a principle of justice that is concerned about the ways goods and harms are distributed, many schools of thought exist regarding what counts as a just or equitable distribution. One type of just distribution might focus on the effort of the various parties (even if sometimes those exerting great effort do not produce beneficial outcomes). Others, especially in health care, look at the *need* of the parties. In health care, those who are in the greatest need (usually those who are the sickest) may not be the most efficient to treat. In such cases, a choice must be made between using health care services in the way that will do the most good (sometimes treating healthier, more stable patients) and treating those with the greatest need. Any ethical principle that focuses on maximizing the good done for patients would tolerate—indeed require—that those with the greatest need be sacrificed. However, a principle of justice that focuses on need would accept the inefficiencies of an allocation of health resources that concentrates on the neediest.

Transplanting human organs is an example of a good in health care that is inevitably scarce. Often we face the question of whether to give the organ to someone who will get a great deal of benefit, even though that person may be healthy enough that he does not need the organ right away. The alternative might be to give the organ to someone who is so sick she will die soon without the organ. That second person may, however, be so ill that it can be predicted that she will get less benefit from the organ. In this case, the principle of beneficence would favor the less needy person who will predictably get more benefit while justice might favor the more needy person even if she cannot benefit as much. The cases in this chapter look at various problems of health resource allocation and the conflict between maximizing efficiency, called for by the principles of beneficence and nonmaleficence, and distributing resources equitably, called for by the principle of justice.

Justice among Patients

Some physicians accept the traditional Hippocratic ethic that limits the focus of the clinician's ethical responsibility to the welfare of the patient. They hold that it is simply outside the moral scope of the health professional's role to worry about saving society money, catching welfare cheaters, or serving other societal interests.

Even the Hippocratic physician sometimes still must allocate resources. He or she may face a direct conflict between the interests of different patients. The next two cases raise such conflicts.

Case 5-1

Under the Gun: Staying on Schedule in the HMO

A key concern of a health maintence organization (HMO) is efficiency (production) by the professionals, rather than allowing the MDs, physician's assistants, and nurse practitioners to spend whatever time they think is desirable with individual patients. At a major HMO, patients are scheduled at fifteen-minute intervals. Dr. Daniel Hamilton was seeing Stephanie Wanzer, a 58-year-old high school teacher, for a routine six-month visit during which he monitored her high blood pressure and chronic sinus infections. He repeated the blood pressure readings that had already been taken by the nurse and began an examination of the head and neck. The blood pressure readings were a bit high, 150/90, and he confirmed Ms. Wanzer's complaint that her sinuses were giving her trouble. He reviewed her medications—an ACE inhibitor and an antihistamine—and determined that they could be refilled. He adjusted the ACE inhibitor dose, increasing it slightly.

At this point, Ms. Wanzer took out a piece of paper indicating she had several concerns she wanted to raise. She had heard there was a new antihistamine on the market she wanted to ask about. She was also concerned about difficulty sleeping and about a rash that had recently appeared on

her upper thigh. This was a pattern Dr. Hamilton had come to expect from her. Generally, he enjoyed having her as a patient. She often had a long list of questions. She was intelligent and took notes on Dr. Hamilton's responses. At the same time, Dr. Hamilton realized he was slipping behind on his schedule. The examination had already consumed ten minutes. He needed the time for evaluation of the symptoms, exploration, and clarification of the physical exam. He had had to wait for the nurse to return as a chaperone for the examination of the rash. He needed the remaining five minutes for ordering tests and recording notes on the computer. He needed to allow time to write the new prescriptions and complete the patient's chart notes. The result was no health education and no consideration of prevention. He felt that he was becoming a test-orderer and prescription writer, usually completed by rapid judgment or reasonable guess. This behavior, he believed, was driven by the market system and merely "first aid," far beneath what was owed to a patient in a professional setting. As the fifteen-minute mark passed, Ms. Wanzer was still making her way down her list.

Dr. Hamilton's next patient had arrived fifteen minutes early. She was an 70-year-old patient with chronic obstructive pulmonary disease (COPD) and was declining with each visit. She was very sick, but Dr. Hamilton feared there was not much he could do but adjust her medication and comfort her, although he knew well that part of his obligation to patients is to spend time with them in any way that might serve their needs for understanding and for emotional support, even if treatment success was not possible.

Questions for Thought and Discussion

- Should Dr. Hamilton terminate the session with Ms. Wanzer or steal some time from the next patient?
- What principle of justice supports your decision?

Case 5-2

Unfunded Dialysis at the Expense of Other Patients

Tilly Hawthorne was a 77-year-old Jamaican in chronic renal failure. She was an undocumented immigrant living in a large East Coast American city. Dialysis, which she received three times a week at the hospital dialysis program, had improved her condition, but it left her physically weak and largely home-bound at a single-room occupancy hotel where she lived. She had no health insurance and was ineligible for Medicaid.

Dr. Jeffrey Morsch, her primary care physician, had taken her case two months earlier and was responsible for her treatment at the clinic where she was an outpatient. He knew that, given her serious medical condition and desperate financial situation, she was unlikely to thrive. She had no one to care for her in the hotel room and was not eating well. Her treatment costs were being absorbed by the hospital, which meant they were being passed on to Dr. Morsch's other patients in the form of higher fees for their dialysis. This practice is sometimes referred to as "cost-shifting." Dr. Morsch knew that if Ms. Hawthorne and similar nonpaying patients continued receiving unfunded dialysis at the clinic, other services for other patients, some of which Dr. Morsch believed would be more beneficial, would have to be forgone. He was also the physician-in-charge for these other patients.

The alternative for Dr. Morsch was to discharge Ms. Hawthorne and urge her to return to Jamaica where her family could provide better support. He had no idea whether she would receive dialysis once she got home. Since Ms. Hawthorne is not doing well on the clinic's dialysis program and could find a more supportive environment in Jamaica, does Dr. Morsch owe it to his other patients to discharge her?

Questions for Thought and Discussion

- An estimated 11.2 million undocumented immigrants live in the United States. Undocumented immigrants are currently ineligible for the major federally funded public insurance programs, which includes the program for the treatment of end-stage renal disease. Should the fact that Ms. Hawthorne is an undocumented immigrant change the way that Dr. Morsch views his decision?

Commentary

Case 5-1 and Case 5-2 both present problems that the doctor cannot escape even if his approach is purely Hippocratic; that is, if the doctor is committed to the welfare of his patients. Some might argue that the real problem here is that the health care institution—the hospital or the HMO—is not providing adequate resources so that clinicians can do what is best for all their patients. This could mean enough time for both Ms. Wanzer and the woman with the COPD. It could mean dialyzing all patients in need.

There are two issues raised by that response. First, in the real world, physicians will have to continue practicing medicine in settings in which they are constrained by their institutions, not getting the resources they would like for their patients. Second, some would claim that it would not be good for institutions to provide such unlimited resources to their physicians and patients. The institutions must obtain funding from somewhere—from fees charged from patients, from HMO subscriber fees, from charitable contributions, or government

budgets. Since resources are inevitably scarce, providing all the funds desired by clinicians would necessarily come at the expense of other worthwhile purposes. Subscribers and taxpayers would in all likelihood protest if budgets were funded at a level at which there were no constraints at all on staff. It may well be that funding is not adequate and that more resources should be made available by increasing subscriber premiums or taxes or by decreasing profits in the case of profit-making health care institutions, but even if this were to occur, there would still be scarcity. Let us assume, for the remainder of this discussion, that Drs. Hamilton and Morsch will inevitably find themselves confronted with pressures of time and budget.

In Case 5-1 Dr. Hamilton may insist that his only concern is to benefit his patient, but here more than one of his patients is in need of his attention. He cannot give his sole attention to both at the same time.

First, consider what Dr. Hamilton would do if he were only acting on the basis of the more social version of an ethic of beneficence and nonmaleficence. In other words, what would he do if his only goal were to do as much good as possible considering the sum of the effects on both his first patient, the high school teacher, and the patient in the waiting room with the COPD? He would have to calculate the benefits and harms much as was done in the cases in Chapter 4, asking what the relevant effects would be of giving attention to each of these patients.

It would appear that Dr. Hamilton has considerable help to offer Ms. Wanzer. She has real questions and will adjust her life according to the advice given. She understands the complexities of medicine and could gain from further discussion. The pulmonary patient, on the other hand, presents a case in which calculating benefit will be very difficult. Dr. Hamilton can offer little for her medically, although comforting her could prove important. A strong case can be made that, even though Ms. Wanzer is clearly much better off medically than the patient with COPD, she will probably benefit more from some extra minutes with Dr. Hamilton than the pulmonary patient would benefit from those minutes. If that is true, then one who is focusing exclusively on the benefit that can be offered to the patients would support giving more time to Ms. Wanzer.

Now consider what else Dr. Hamilton might take into account other than the sum of the benefits and harms. It is plausible to conclude that more good would come from giving extra time to Ms. Wanzer, but it seems clear that the pulmonary patient is sicker. This raises the question of whether worse-off patients have a special moral claim on a clinician. The ethical principle of justice may come into play here, potentially competing with considerations of how much net benefit is done, that is, the consideration of the principles of beneficence and nonmaleficence.

The principle of justice focuses on the pattern of the distribution of benefit and harm. One pattern that emerges in health care is distribution of health resources according to the person who is sickest. In Case 5-1 the pulmonary patient is clearly sicker than Ms. Wanzer. The morally intriguing case is the one in which one use of Dr. Hamilton's time would produce the greatest good (spending extra time with Ms. Wanzer) while another use would provide benefit to the sickest patient (the pulmonary patient) even though less good is likely to be done.

Another pattern that arises in discussions of the principle of justice is one based on equality. In some areas of life, equal treatment seems to require equality. The most clear example of this would be the maxim of "one person, one vote." One might consider having an HMO give equal fifteen-minute slots to all patients, but that makes little sense, at least at the point of scheduling. Some patients can be known in advance to require longer appointments; others, shorter times. There is no good reason to hold that all patients deserve equal time. In this case, however, the two patients have been scheduled, rightly or wrongly, for equal fifteen-minute appointments. Is that a reason why Dr. Hamilton should stop his conversation with Ms. Wanzer? Whether this should be thought of as a kind of promise that could influence Dr. Hamilton's decision will be considered in the cases of Chapter 8.

In Case 5-2, Dr. Morsch's dilemma about whether to continue caring for the dialysis patient, similar problems arise when the costs of Tilly Hawthorne's care are shifted to other patients. The approach based on consideration of benefit and harm would require Dr. Morsch to estimate the amount of good that could be done collectively for the other patients with the funds involved, then compare that with the good using those funds for Ms. Hawthorne's care. This would, of course, be a difficult calculation for Dr. Morsch to make. He would have no way of knowing how the other patients, once a surcharge for unfunded care was imposed, would otherwise spend those resources. He would not even know for sure whether the costs would be passed on to other patients or could be taken from profits that would otherwise go to shareholders in the hospital. This calculation would even be difficult for administrators, who might more appropriately be expected to make the decision about continued provision of unfunded treatment for Ms. Hawthorne.

If the principle of justice were introduced, the calculation would still be difficult, but the question would be somewhat different. Dr. Morsch would need to ask not what the relative benefit and harm would be from providing Ms. Hawthorne's dialysis and discharging her to fend for herself in Jamaica; rather, he would ask whether Ms. Hawthorne or the others who would end up funding her care have a greater claim of justice to the resources. If justice claims are based on who would be worse off, Ms. Hawthorne's case would seem to be a strong one, but the judgment would require making some estimate of how poorly off the other patients (or the owners of the hospital) would be if they ended up providing the funds for Ms. Hawthrone's treatment.

Another principle of ethics might also come into play in this case. Some people might argue that the other patients are the legitimate "owners" of the funds that they would be required to pay if Ms. Hawthorne's care were funded by cost-shifting, by a surcharge on the care of other patients. Is there something unfair about a health care institution including a surcharge to generate the funds needed to pay for the care of those not otherwise able to pay?

Justice between Patients and Others

In both of the previous cases, patients were competing among themselves for scarce resources—two patients for a physician's time in the first case, the funds to support dialysis in the second. Sometimes, however, a physician must choose between the patient and others who are not his or her patients. Of course, in purely Hippocratic ethics, the patient is the only interest that is morally relevant. Neither other patients nor those who are not patients count morally. Either way, the health professional has a duty to totally ignore the interests of others. The following case makes clear that that is sometimes hard to do.

Case 5-3

Antibiotic for a Child's Otitis Media

Mrs. Linda Beauclair brought her 2-year-old son, Tommy, to the pediatrician for an unscheduled visit because he had suffered ear pain and fever for two days. He had screamed most of the night, leading her to call Dr. Richard Rust early the next morning. He was able to work Tommy into his schedule at the end of the afternoon appointments.

Just as he had suspected, Dr. Rust found a case of otitis media, typical of young children. Dr. Rust was certain that it was a common viral infection that would resolve in a few days. The medical evidence had accumulated, showing no long-term ill effects of what can be an unpleasant but relatively benign infection. He urged Mrs. Beauclair to keep Tommy away from other children but offered no medication.

Mrs. Beauclair asked rather aggressively if Tommy could have an antibiotic. She wanted to do something for him.

Dr. Rust explained that antibiotics were only effective against bacterial infections and that there was almost no chance that Tommy's ear problems were caused by bacteria. He also explained that extensive use of antibiotics when they are not necessary can lead to the development of resistant strains of bacteria. This could eventually mean that some child will develop an infection from the resistant strain and suffer consequences much more serious than Tommy's earache because antibiotics had been used too often to attempt to treat minor infections, especially those that the antibiotic is very unlikely to help.

Mrs. Beauclair responded by stating rather angrily that she was Tommy's mother, not the mother of all the children in the future. She pressed Dr. Rust on whether there was any chance—even a small one—that Tommy's infection was from a bacterium that could respond to the antibiotic. She wanted to do everything possible to make sure Tommy did not spend another night like he had spent the previous one.

Dr. Rust had always accepted the common wisdom that antibiotics were being overused and should be avoided except in cases in which they are necessary to avoid serious medical problems. The antibiotics, he believed, should be saved for the truly most needy cases. Still, he acknowledged to himself that the risks of today's antibiotics are very low and that there was some small mathematical chance that Tommy had a bacterial infection that would respond to the antibiotic. He realized that, if he focused solely on his patient, Mrs. Beauclair was making a good case. Mrs. Beauclair made him realize that, as a physician who had always believed in the Hippocratic Oath, his job was really more to serve the interests of his patient, just as a mother's job is to protect her child. Neither was in a role in which they were supposed to pursue the best interests of some imagined needy hypothetical persons in the more distant future. Should Dr. Rust consider these more needy people or remain committed to maximizing Tommy's welfare?

Questions for Thought and Discussion

- In this case, a mother is asking for a treatment for her child that could have negative impact on other children in the distant future. How does this differ, if at all, from public health requirements for vaccinations for children to protect them from communicable diseases such as pertussis or measles? What if a parent refuses such vaccinations for her child? Should physicians consider promotion of public health their primary duty or remain committed to the care of the individual child?

Commentary

This case raises issues that are similar to the two previous cases. Dr. Rust seems to concede that Mrs. Beauclair might be right that the potential benefit of an antibiotic for her son, however, remote, may exist. Furthermore, given the relative safety of today's antibiotics, the risk is small. From the point of view of the welfare of the patient, Tommy, a case can be made that he has a little to gain and very little to lose with the antibiotic. Not all clinicians would necessarily reach that conclusion. The risks of some antibiotics have to be taken into account, but if Dr. Rust ends up sharing Mrs. Beauclair's opinion that the benefits to Tommy outweigh the risks, and if he is Hippocratically committed to working only for the welfare of his patient, he seems to be locked into a conclusion that he ought to prescribe the antibiotic. The harms to some future, hypothetical people who would be infected with drug-resistant strains of bacteria are off the table.

Not all medical ethics would resolve this case in that way, however. Some are more classically utilitarian. They would consider the benefits and harms not only to Tommy but also to all people affected by Tommy's prescription. In a vague, but very real sense, some people in the future will be put at very serious risk if Dr. Rust and other pediatricians prescribe antibiotics every time a child has otitis media and his or her mother insists on a prescription. If Dr. Rust is permitted to include the effects on all future users of antibiotics in his calculation, he may reach a different conclusion.

There is another moral dimension to this case. While Tommy is uncomfortable and his mother feels compelled to do whatever she can to promote his well-being regardless of the impact on others, Dr. Rust might consider taking into account something more than the aggregate benefit to all those in the future who would be subject to drug-resistant strains of bacteria. The aggregate total of benefit to all future people is an unimaginably large benefit because the number of people is potentially enormous. But there is another factor as well. The future people who will be put at risk by the indiscriminate use of antibiotics is not only very large in number; those people are potentially much worse off than Tommy.

Many ethicists resist utilitarian appeals to aggregating benefits across all future generations. They consider such mathematics unfair. Those committed to the principle of justice will focus not on the aggregate effect but on those persons who are worst off. In this case, the future people in need of antibiotics may not only be harmed greatly in aggregate, they may also include very poorly off persons—persons much worse off than Tommy. Should Dr. Rust remain Hippocratic and work only for the welfare of his patient or should he consider future sufferers from bacterial infection as well? If he should consider future sufferers, is it the total amount of benefit that is morally relevant or the fact that some of those future sufferers are potentially much worse off than Tommy?

Finally, what difference, if any, does it make that one of the parties is a patient while the others are not? Is the difference morally relevant for Dr. Rust in deciding when to prescribe antibiotics?

Justice in Public Policy

The questions of justice in the allocation of resources arise not only in clinical situations but also in matters of policy. A key difference is that the health professional facing policy decisions does not have a specific patient or patients in mind whose interests can be served. If a specific patient's case is debated, it is as an example of a more general policy question in which the interests of a group are at stake or in a community whose interests must be treated fairly. The health professional in such cases is not so much acting as an agent for the specific patient as for the entire group.

Case 5-4

Allocating Livers for Transplant

In the late 1990s, controversy arose over the national policy in the United States for allocating livers obtained from deceased donors. Such livers are very scarce and offer life-saving benefit to those patients in liver failure who are chosen to receive them. At the point that the controversy erupted, livers were allocated first to the organ procurement organization (OPO) in the metropolitan area in which the liver was procured. There are approximately sixty such OPOs in the country. Within the OPO, the liver was assigned first to the sickest patient who was a suitable match for size and blood type. Those near death, normally in the intensive care unit, got first priority. Next priority were the patients in the area who were less sick but still hospitalized, after which home-bound patients even less sick were selected. Only if no local patients could use the liver would it pass beyond the local OPO to another area of the country. This was the policy, even if the liver could have gone to a patient in some other area who was in desperate need and near death for lack of a liver. The relatively healthy local patients got priority over the most urgent cases beyond the local area.

The federal officials in the Department of Health and Human Services (DHHS) challenged this policy, demanding that there be greater equity or fairness in the allocation of livers. A rule was established requiring the United Network for Organ Sharing (UNOS), the organ procurement and transplantation network controlling all organ allocation in the United States, to develop a policy that would spread livers more fairly.[2]

Officials at UNOS resisted the rule.[3] They did not deny that livers were more readily available in some communities than others and that the result was that some people who were very ill had a high probability of being transplanted, while equally sick people in other communities had a much lower chance of getting an organ. They argued, however, that there were significant benefits of the "locals-first" policy that led to greater overall good being done than if livers were transported to the sickest patients in other communities.

First, they noted that the transportation of the livers itself meant livers suffered potential damage from greater "cold-ischemia time," that is, time when the livers were not receiving blood. Second, they argued that the sickest patients were often the most difficult to treat. They had less of a chance of surviving with a donated liver than the healthier local patients currently receiving the organs. Finally, they claimed that a locals-first policy had the effect of increasing willingness of grieving families to donate a loved one's organs. If "locals" believed it was going to help a neighbor, transplant personnel believed this would increase the likelihood

of donation. In short, at least three reasons supported a policy of keeping the organs locally unless there was no one locally who could use them, even if the recipients were relatively healthy.

The government officials, led by then-Secretary of HHS Donna Shalala, pressed for a more fair system even if the impact was a decrease in the number of life years expected per organ transplanted and a decrease in the supply of organs. Officials at DHHS challenged the claim that locals-first would increase the rate of donation. They claimed there were no data to support this belief, but insisted that, even if this were true, the moral mandate had to be to produce an organ allocation system that was fair. This, they said, meant equally sick patients throughout the United States should have an equal chance of getting an organ. This could be accomplished only by transporting organs to other OPOs when necessary. Should the liver allocation system be maximally fair or maximally efficient at producing added years of life from organ transplant?[4]

Commentary

In this case the moral choice *is* not one that can be made by individual clinicians at the bedside. The questions are for policymakers to decide—the national officials responsible for setting policy for allocating donated livers for organ transplant. Transplant surgeons are not in a position where they can make these choices. In fact, if they attempted to make them, they would quickly find themselves with a conflict of interest. Historically, their moral duty has been to be advocates for their patients. Transplant surgeons asked to decide whether an organ should go to their own patients or to some stranger in some other community would face the traditional commitment of health professionals to work always for the benefit of their patients. The result could be that the allocation was neither fair nor efficient in allocating organs.

Thus, surgeons responsible for patients are in a particularly bad position to make resource allocation decisions. These choices are made at the level of public policy, by professional organizations or by government health policy officials.

In Case 5-4, the policymakers are presented with a choice between an option that will be maximally efficient at producing benefit from the use of a scarce resource (maximizing the number of life year's expected) or distributing the resource so that the benefits are distributed more fairly, even if the aggregate amount of good produced is somewhat less. Giving the organs to the sickest was defended as the policy required by an ethical principle of justice, one that favors allocating scarce resources so that they benefit the worst-off members of the relevant community (even if the aggregate benefit is less).

The moral principle of justice is concerned about the pattern of the distribution of the benefit—to the worst-off patients—while the policy that would produce the most aggregate benefit would be the one favored by the moral principles of beneficence and nonmaleficence (doing good and avoiding harm). Neither principle is consistent with the classical Hippocratic notion of doing as much good as possible for the individual patient. That seems beside the point when the policy question is whether to do as much good for the population as a whole or to spread the benefit fairly among members of the community.

Case 5-5 raises another interesting problem. The debate was stimulated because the members of the Clinton administration, a more liberal Democratic administration oriented to greater fairness, issued a rule requiring greater fairness, while the UNOS, dominated by members of the medical profession, was strongly committed to maximizing efficient production of benefit. Here is a case in which public officials seemed to favor one moral principle, justice, while the medical profession favored another, beneficence. This repeats a pattern that is seen in other circumstances and is consistent with a profession that has long maintained an ethic driven by beneficence and nonmaleficence—producing good and avoiding evil—rather than concern growing out of the principle of justice, a principle that has been absent from professional codes of ethics, at least until very recently. What should happen when public officials favor one ethical principle and health professionals support another?

Justice and Other Ethical Principles

We have, throughout this chapter, been examining how the principle of justice relates to the principles of beneficence and nonmaleficence. Nonutilitarians hold that right-making characteristics of actions other than the net amount of good produced are morally relevant. Justice, that is, some morally right pattern of the distribution of benefits and burdens, is just one such principle of rightness. In later chapters, other principles that are sometimes identified as right-making characteristics will be discussed. These include respect for autonomy, truth-telling, fidelity to promises, and the duty to avoid killing (the topics of Chapters 6–9). We shall see that sometimes these principles come into conflict. When they do, a full ethic will have to have some method for resolving the conflict. One approach is to view the various principles (the right-making characteristics) as elements that identify characteristics that will tend to make actions right. Then considering only the single dimension, the action can be said to be right. It would be right if there were no conflicting considerations pulling in the other direction. If ethical principles are used to identify these right-making elements, they are sometimes called *prima facie* principles. They identify characteristics that would make an action right "other things being equal." In the following case, we can identify what justice requires but might also have to take into account that other principles pull the decision-maker in another direction. Here is an example of a conflict between the principles of justice and other ethical principles—beneficence and autonomy.

Case 5-5

Dialysis in an End-Stage HIV-Positive Patient: Justice, Benefit, and Patient Autonomy

Ron Beato, a 30-year-old male, was admitted to the hospital with severe weight loss (he weighed 119 pounds), severe shortness of breath, fever, chills, and generalized fluid retention. A crack and cocaine user, admitting to multiple sex partners, he was married and the father of one child. Examination confirmed renal and/or heart failure, and lab studies determined he was indeed in kidney failure. His diagnoses were terminal acquired immunodeficiency syndrome (AIDS), end-stage renal disease, chronic anemia, and possible bloodstream infection (sepsis).

He refused additional diagnostic procedures and blood transfusion. Antibiotic therapy was instituted. Generally, he was poorly compliant with medical advice. He also had spells of crying and apparent depression. The physicians assessed his mental competency as adequate for decision-making and discussed with him and his family options for advance directives, including cardiopulmonary resuscitation (CPR), which he declined. Hemodialysis was not offered as a treatment option because it would be of "no benefit to life expectancy." (The nephrology consultant agreed.) After three days of hospitalization, he was transferred to a hospice program.

Commentary

The central question here is whether not offering dialysis was fair to Ron Beato. The moral principle of justice requires a fair allocation of resources; that is, an allocation that distributes resources following a pattern that gives people their due. Most contemporary theories of justice when applied to health care understand a fair pattern for health care to be one that orients to the person who is the worst off. Mr. Beato surely is among the worst off of patients. He is suffering from a fatal disease with awful symptoms. Thus, from the point of view of the principle of justice, one might conclude that he has a high-priority claim on the hospital's resources.

Even though this seems to be what the principle of justice requires, there are complexities. First, even if Mr. Beato, as one among the worst off of patients, has the highest priority claim on any resources that could benefit him, the principle of justice is a principle that distributes *benefits*. If dialysis is of no benefit, no purpose would be served in providing it to Mr. Beato, and it therefore need not be provided.

Matters of treatment options, including no treatment, are often debatable, particularly in end-of-life situations. It is common for competent, thoughtful clinicians and patients to disagree. The primary responsibility of professional decision-making is that of the attending physician, unless he or she refers the patient to a consultant. The patient in this case appears not to have been consulted about whether he thinks dialysis would be beneficial.

This raises the question of whether the physicians in this case can know, objectively, that dialysis is of "no benefit." There are cases in which dialyzing a patient who is near death will temporarily extend life in a manner in which many people would claim that this temporary extension is of no benefit. Others, however, might believe that even temporary extension of life is an important benefit (so that relatives may gather, for example). Even if the dialysis is determined not to extend life at all, it may provide other benefits—keeping the patient lucid at the end, for example.[5] Thus, the claim of the physicians that they can know that the dialysis would be of "no benefit" is controversial.

One interesting possibility is that the dialysis would be seen by the patient to be somewhat beneficial. We probably cannot know without asking him. It is possible that the patient could reasonably reach the conclusion that the dialysis offers some benefit even if all the physicians saw it to be of no value from their perspective. If the dialysis were deemed beneficial, even marginally beneficial, a principle of justice would support giving the treatment to the patient. Assuming he is among the worst off, the standard interpretation of the principle requires arranging whatever resources are available to benefit him.

Even though this seems to be what the principle of justice requires, several other moral principles may come into play in this case. These other principles may have implications that conflict with the principle of justice. One might ask if the principle of justice should prevail in such a circumstance. Particularly, if the patient saw the benefit as small—as giving him only a short additional time or making him only slightly more comfortable—some might ask if the dialysis would be worth it. If the same resources could be used to produce significantly more benefit for some other patient who is ill but better off than Mr. Beato, we have a classic conflict between the principle of justice and the principles of beneficence and nonmaleficence. Justice (understood as requiring distribution of resources so as to benefit the worst off) would require one allocation; beneficence and nonmaleficence would require a different one. Utilitarians—those who hold that the principles of beneficence and nonmaleficence should prevail—would withhold the resources from Mr. Beato if those resources would do more good some place else. This decision would then depend on whether the principle of justice or the utility maximizing principles of beneficence and nonmaleficence should take priority.

There is still another dimension to this case. Mr. Beato has a history of noncompliance. This introduces consideration of how another ethical principle—the principle of respect for autonomy—should come into play. This principle holds that competent persons should be free from interference in leading their lives according to their own life plans. That could include the choice to be noncompliant with medical recommendations or to refuse medical treatments being offered such as CPR or other means of life support. Respect for autonomy will be the focus of the cases in the following chapter, but in this case we need to understand how this principle intersects with the principles of justice, beneficence, and

nonmaleficence. For starters, we should recognize that Mr. Beato would surely 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 noncompliance 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