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CHAPTER 5

Justice: The Allocation of Health Resources

Other Cases Involving Justice and Resource Allocation

4-5: Blocking Transplant for an HMO Patient with Liver Cancer: Serving the Patient and Serving the Community
12-5: Posttraumatic Stress Disorder: Funding Therapy for a Preexisting Condition
14-5: Whites Only: The KKK and Socially Directed Donation
14-6: Is an Organ Swap Unfair?
14-8: Patients with Alcohol Dependency and Their Rights to Livers for Transplant
14-9: Multiple Organs for a Famous Governor
15-1: The Sixth Stool Guaiac: A Classic Cost-Containment Case
15-3: The $300,000 Marginal Treatment
15-5: Promoting Patients' Rights by Denying Insurance Coverage
15-7: Hospital Bureaucracy and the Uninsured
16-6: Justice in Research Design: Being Fair to the Critically Ill
18-8: 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. 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. The 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 an 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 appropriate 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 sixth-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. 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 84-year-old patient with metastatic cancer of the breast and was declining rapidly. She was very sick, but Dr. Hamilton feared there was not much he could do but 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. Should Dr. Hamilton terminate the session with Ms. Wanzer or steal some time from the next patient?

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 a nonresident alien living in a large East Coast American city. Dialysis, which she received three times a week at the hospital dialysis program, 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?

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 breast mass. 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 in reality 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, 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 metastatic cancer of the breast. 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 cancer 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 breast cancer, she will probably benefit more from some extra minutes with Dr. Hamilton than the cancer 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 cancer 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 who is sickest. In Case 5-1 the cancer 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 cancer 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 simply. 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 the other patients collectively could do with the funds involved and 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. 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 cases make clear that sometimes that is 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?

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. However, the physician is also expected to follow professional standards of care in such frequently occurring problems. 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 uncom fortable 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 takin into account something more than the aggregate benefit to all those in th 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, as the HMO subscribers in the following case, or in a community whose interests must be treated fairly. The pharmacist in such cases is not so much acting as an agent for the specific patient as for the entire group.

CASE 5-4

Dental Sealants for Children's Teeth: Justice or Utility?

Some years ago, a new technology in dentistry was developed that permits placing a resin sealant on the teeth of children, greatly reducing the risk of dental cavities.[1] A National Institutes of Health consensus development panel quickly concluded that the sealants were both safe and effective.[2] Moreover, sealants significantly reduced the costs of dental care. For maximum efficiency the sealants should be placed on the teeth of children at about six years of age when their first set of teeth is complete and at twelve when adult dentition is in place.

Although the long-term cost-effectiveness is clear, a community-wide campaign to provide sealants for all eligible children would be costly. Some counties have decided to provide pilot programs for low-income children, identifying certain political districts for initial funding. The problem faced by public health officials is how to select the communities for the pilot program.

In one such county, some communities are on water systems that are fluoridated, while other communities obtained water from private wells or from nonfluoridated community water systems. An initial proposal suggested basing the decision about which children should receive the sealants during the pilot project on the basis of whether their communities fluoridated their central water supplies. The issue of moral controversy was over whether the children who already receive community-based fluoridated water deserve the highest or lower priority for the sealants. Fluoride is especially effective in reducing caries on proximal surfaces while the sealants protect what are called "pit and fissure" areas (the crevices on the biting surfaces of the teeth). This leads to an unexpected moral puzzle. The sealants are more efficient on children who also have the protection of fluoride. This is because the children need fewer restorations in the areas given the protection from fluoride, so the sealant will be damaged less often. This means that fewer sealants will be destroyed.

Thus, public health officers committed to maximizing the efficiency of the sealant program and getting as much protection as possible with the limited funds available for the program are advocating that the sealants be used in communities that already fluoridate.

This had the effect of providing the benefit of the sealants to the very children who are already better off in terms of their dental health. They have the protection of fluoride, which would qualify them for additional protection from the sealants.

Others criticized this approach arguing that it is precisely the children who do not have the fluoride protection and thus have the worst dental health who deserve the benefit of the sealant program.

The advocates of allocating the initial funds to the communities without fluoride faced several issues. Do the families that have chosen not to fluoridate deserve priority because they have made a choice that is contrary to the dental well-being of their children? Is not this unfair, at least to the children in families in which the parents had advocated fluoridation and had lost the political struggle? A community-wide program that either includes or excludes sealants will mean that some children in the communities that do not fluoridate will suffer even though their parents have voted in favor of fluoridation and may even provide fluoridation through individual application using fluoridated toothpaste, vitamins, or direct application to the teeth. The advocates for children in the communities that did not fluoridate on a community-wide basis in the water supply argued that at least the children who were getting fluoride applications deserved to have their teeth sealed. Opponents responded, however, that efficiency for a pilot program required that, in order to maximize the benefit, the program decisions had to be made on a community-wide basis. Should the county pilot program be directed to the communities that use community-fluoridated water, thus maximizing efficiency from the budget for dental sealants, or should it be directed to the communities that do not fluoridate in order to give these children, who statistically would have worse dental health, an opportunity for the protection the sealants would provide? However, the program would be less efficient because the seals would in some cases have to be destroyed to repair the teeth damaged from lack of fluoride.

CASE 5-5

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.[3]

Officials at UNOS resisted the rule.[4] 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?[5]

COMMENTARY

In neither of these cases is the moral choice one that can be made by individual clinicians at the bedside. The questions are for policy-makers to decide—the county public health officers deciding how to allocate their scarce funds for a pilot program involving dental sealants and the national officials responsible for setting policy for allocating donated livers for organ transplant. Local dentists and 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 in 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 and dentists responsible for the dentition of their pediatric 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 both of these cases, Case 5-4 and Case 5-5, the policy-makers 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 dental cavities prevented per dollar invested in Case 5-4 and maximizing the number of life year's expected in Case 5-5) 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 sealants to the children without the benefits of fluoride and 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 5-6

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

Ron Beato, a 30-year-old male, was admitted to 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 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 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 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 ("don't just do something, stand there") 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.[6] 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 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 resources 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 Proceedings of a Symposium on Pit-and-Fissure Sealants. "Is It Time for a New Initiative?" *Journal of Public Health Dentistry* 42 (Fall 1982):295–336.

2 National Institutes of Health. "Consensus Development Conference Statement: Dental Sealants in the Prevention of Tooth Decay." *Journal of Dental Education* 48 (Supplement, February 1984):126–131.

3 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.

4 Heiney, Douglas A. Director, Department of Membership, UNOS, "Memorandum: Proposed Liver Allocation Policy Development Plan for Public Comment." Richmond, VA: UNOS, February 15, 2000.

5 Veatch, Robert M. "A New Basis for Allocating Livers for Transplant." *The Kennedy Institute of Ethics Journal* 10 (March 2000):75–80.

6 Cohen, L. M., M. J. Germain, D. M. Poppel, A. L. Woods, P. S. Pekow, C. M. Kjellstranc. (2000). "Dying Well after Discontinuing the Life-Support Treatment of Dialysis." *Archives of Internal Medicine* 160 (September 11):2513–2518.

CHAPTER 6

Autonomy

Other Cases Involving Autonomy

5-6: Dialysis in an End-Stage HIV+ Patient: Justice, Benefit, and Patient Autonomy
14-8: Patients with Alcohol Dependency and Their Rights to Livers for Transplant
Also see the cases of Chapter 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 or actions or practices that do not focus on 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 well as fellow health professionals.