

Ethics committees and distributive justice

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Objectives

1. Distinguish distributive justice questions from other types of ethical questions that hospital ethics committees face.
2. Identify competing conceptions of the health professional's ethical role in making cost containment and rationing decisions at the bedside.
3. Explain the importance of developing institutional policies to guide the distribution of scarce healthcare resources, and the response to needy and vulnerable patient groups.
4. Appeal to justice principles to formulate and defend a hospital policy for responding to needy patients, then apply this policy to an individual case.

A physician brings the following case to the ethics committee.¹

Case

Mr. Nguyen, 54, presented to clinic with a devastating surgical complication: his abdominal incision had split open 1 week after emergency surgery. He was taken back to the operating room, and the deepest layer of his abdominal wall was sewn closed. Doctors treated the infection that had caused his wound to fall apart. Yet he still had a 3-inch crevice along the middle of his belly. Until the edges contracted and the gaping expanse filled in on its own, he and his wife were instructed to pack damp gauze into the wound daily to keep it clean and help it heal. A few weeks after discharge, Mr. Nguyen was seen in clinic by the treating physician, Dr. Morris, who noticed that the gauze was packed more loosely and changed less frequently than the patient was instructed. What should have been white and fluffy looked dried and yellowed, and his wound was no longer clean and healthy, but covered with crusty patches. As the physician began to discuss with the patient the importance of dressing changes, the patient leaned over to interrupt. "Hey, Doc," Mr. Nguyen said, pointing to the pile of unopened gauzes the physician had brought into the room, "Could I have the extra? This stuff isn't cheap."

Dr. Morris subsequently learned that Mr. Nguyen had been cutting back on the gauze and changing the dressing less often because he couldn't afford the supplies. And while the physician had dutifully educated the patient about the science behind the treatments, the physician had been completely oblivious to how much Mr. Nguyen had to pay or if he could afford the expense.

¹ Adapted from Chen P W (2010). When the patient can't afford the care. *New York Times*, February 5.

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Dr. Morris brought this case to the ethics committee. The patient continues to be seen in clinic, and the physician is wondering how to handle the case going forward. She tells the ethics committee that Mr. Nguyen's situation is probably representative of many patients the hospital serves. She felt that she, and perhaps other health professionals, had completely lost touch with the economic realities of their patients' lives. The physician wanted to know what her responsibility was in this situation. She had always believed that being a good doctor meant knowing the clinical facts down cold, and that worrying about other details would diminish her ability to do so. Now she was not so sure.

Introduction

This case raises a number of complex ethical questions for the hospital ethics committee (HEC). When patients are unable to comply with best medical advice because they simply cannot afford the treatments prescribed, what should physicians do? To what extent are health professionals responsible for knowing about their patients' social and economic circumstances before prescribing a treatment plan? Does the patient have a responsibility to share such information? Is a hospital, which may be inundated with requests for financial assistance from the community it serves, obligated to help each and every patient? In the case of Mr. Nguyen, although the cost of providing needed wound dressing may seem minimal, what if many surgical patients served by the hospital need this kind of help? Are we, as a society, responsible for helping Mr. Nguyen and others like him, to obtain needed healthcare?

These are clearly challenging questions, and it is far from clear how the ethics committee should respond. Mr. Nguyen's case may force the ethics committee to tread on unfamiliar ground by raising the broader question of what the HEC role should be in helping the needy and by establishing a right to healthcare within the institution. While it is easy to say that HECs should serve as advocates for patients and promote their best interests, it is more difficult to determine what the HEC's responsibility is in addressing larger justice issues.

In this chapter, I propose that much is to be gained by expanding, rather than restricting, the scope of the ethics committee's response. More expansive thinking not only enables us to map this case in a larger moral domain, it also enhances our understanding of the specific values and principles at stake. Cases like that of Mr. Nguyen force the committee to consider the just distribution of healthcare services, as well as the scope and limits of the hospital's and the providers' responsibility to Mr. Nguyen.

Understanding justice: the role of providers

Dr. Morris was mistaken when she initially assumed that attention to the economic and social dimensions of healthcare would interfere with being a "good doctor." Not only is it possible to learn about the economic and social aspects of patients' lives while immersed in the details of biology, physiology, and pharmacology, but in fact it is necessary to do so in order to be a good doctor. To see that this is so, it is helpful to begin by considering the scope and limits of the physician's role as patient advocate.

It is well established that a paramount responsibility of health professionals is to advocate on behalf of their patients' best interests and to respect and support patients' preferences. Clearly, it is in Mr. Nguyen's best interests to have the wound dressing he needs, and his non-compliance with instructions for wound dressing is based on socioeconomic barriers,

not on patient preference. Mr. Nguyen is actively seeking to obtain the wound dressings that he cannot afford by asking the physician to give him the extra dressing. Suppose Dr. Morris responds to Mr. Nguyen by handing over the hospital supplies, perhaps opening the cabinet to pull out some additional boxes of sterile bandages, tape, and other materials, in an effort to do whatever it takes to get Mr. Nguyen the care he needs. This kind of response we shall call *unrestricted patient advocacy*.

1. *Unrestricted advocacy* holds that the provider's primary responsibility is to advocate on behalf of the individual patient's best interests. Cost containment and rationing are simply incompatible with this role.

According to this understanding, patient advocacy imposes upon health professionals an obligation of fidelity. Fidelity requires faithfulness, loyalty, and unswerving allegiance to another person or to a bond between persons. The loyal health professional does everything possible to promote the welfare of his or her patient. It is not Dr. Morris's responsibility to control hospital costs, nor can she be expected to ration care effectively by saying no when Mr. Nguyen asks for medical supplies.

In defense of such a position, it can be said that as a physician, Dr. Morris is responsible to do whatever it takes to help her patient. One of the earliest formulations of the role and duties of physicians, the Hippocratic Oath, requires physicians to swear allegiance to the welfare of their patients: "I swear by Apollo . . . to follow that method of treatment which, according to my ability and judgment, I consider for the benefit of my patients, and abstain from whatever is deleterious and mischievous." To use the language of contemporary bioethics, ethical principles of beneficence and non-maleficence support a recommendation that Dr. Morris's primary responsibility is to advocate on behalf of Mr. Nguyen's best interests.

Moreover, the alternative of placing providers in the role of society's gatekeepers, charged with containing costs and rationing care, has adverse effects, such as undermining trust in the provider-patient relationship. If Dr. Morris denies Mr. Nguyen the supplies he needs to take proper care of his incision, this may erode the patient's trust. Mr. Nguyen may begin to doubt that his doctor is putting his interests first. He may conclude that saving money for the hospital matters more to the doctor.

Finally, it is society at large, not healthcare workers, who have the ethical and political mandate to make allocation decisions. Moreover, health professionals do not have the training, knowledge, or expertise to ration care at the bedside of individual patients. Such decisions are best left to policy-makers at other levels within the healthcare institution, and ultimately to the broader society.

A second and very different approach holds that restrictions on patient advocacy are ethically justified. Let us call this position restricted advocacy.

2. *Restricted advocacy* holds that duties to patients are limited, and must be placed in a broader ethical context. Patient advocacy is qualified and restricted in light of other significant duties, including the duty to promote the welfare of society as a whole, or at a minimum to promote the welfare of other patients served by the institution.

In support of this position, it can be noted that a commitment to serve the public has always gone hand in hand with a commitment to advocate on behalf of individual patients. Thus, in its very first code of medical ethics, the American Medical Association held "As good citizens, it is the duty of health professionals to be ever vigilant for the welfare of the community." The American Nursing Association's Code for Nurses (2001) affirms a

similar commitment: “The nurse collaborates with other health professionals and the public in promoting community, national, and international efforts to meet health needs.”

In addition, it can be argued that health professionals, and physicians in particular, are recipients of numerous benefits from society. Massive amounts of money are regularly spent to fund medical education, the research on which medical practice rests, the institutions in which most medical activity occurs, and the demand for medical services. Accepting such benefits places health professionals under an obligation to benefit the society granting them.

A third and final position attempts to strike a middle ground between patient advocacy and social responsibility. I call this response justly restricted advocacy.

3. *Justly restricted advocacy* maintains that providers can ethically ration care provided they can be reasonably certain that their individual measures will contribute to a larger system or plan for healthcare that is itself just. This approach requires that restrictions on patient advocacy conform to standards of justice and fairness.

In support of this view it can be said that it succeeds where the other two views do not. Unrestricted advocacy asks too much: the sky is the limit, and patients are entitled not just to a basic level of care but to anything that stands to benefit them. But restricted advocacy asks too little. It permits limiting care, but does not require that restrictions on care meet justice standards.

In support of this view, it can also be noted that when denials of care are not part of an explicit system or plan, they run the risk of not being thought through, applied consistently, accountable to the public, decided democratically, and insulated from arbitrary and unfair manipulation. By contrast, when rationing is part of an explicit policy or plan, these mistakes are less likely to occur.

Finally, ethical rationing must meet justice standards. As the name suggests, justly restricted advocacy has the advantage of requiring that rationing be held to justice standards, such as ensuring a basic level of care. Rationing that falls short of justice requirements would not be considered justly restricted advocacy.

Following the requirements of justly restricted advocacy clarifies the obligations of Dr. Morris to Mr. Nguyen. It would not be acceptable for Dr. Morris to take boxes of wound dressing or other medical supplies from the hospital and hand them over to Mr. Nguyen free of charge, as unrestricted advocacy would allow. It would also not be ethically defensible for Dr. Morris to tell her patient that she is on her own and the wound dressing belongs to the hospital, as restricted advocacy might suggest. Instead, the model of justly restricted advocacy suggests that Dr. Morris ought to ask the ethics committee to develop an explicit policy to help such patients, thereby enabling physicians to serve as just advocates for their patients. Even if she cannot rob Peter to pay Paul, there is much Dr. Morris can and should do. After all, in this and many cases like it, it helps not only the patient, but also saves money for the hospital and the insurance company, if Mr. Nguyen’s postsurgical recovery goes smoothly and further complications are avoided. There is every reason to have a more just policy in place and to direct physicians to identify and assist in cases like this.

Understanding justice: the role of hospital ethics committees

There are many advantages to developing an explicit policy for allocating resources within the hospital. In the absence of such a policy, decisions about how to respond to Mr. Nguyen and patients like him will continue to be made, but will be made in an unsystematic and

haphazard way. If patients do not receive the care they need, rationing will occur by default, in an implicit manner, without the advantage of open discussion and consideration of the pros and cons of different approaches. This is problematic because such an approach does not even aspire to meet justice standards. Implicit rationing is typically

- not thoroughly considered
- not applied consistently
- not accountable to the public
- not decided democratically
- not insulated from arbitrary and unfair manipulation.

These objections suggest the need for a more open and publicly debated set of ethical guidelines.

The HEC can respond to this need on several different levels.

1. *Hospital policy.* The ethics committee can respond first and foremost by developing hospital policies that aspire to meet justice standards, set out fair procedures for distributing scarce resources, and address the needs of vulnerable populations served by the institution.

For our purposes, justice refers to the ethical problem of distributing scarce resources. While distributive justice traditionally referred to the distribution of income and wealth in a society, we interpret this idea more broadly to include the distribution of other social goods, such as healthcare. Whenever the problem of distributive justice arises, the background condition is a scarcity of some resource. In healthcare, for example, there are more patients with end stage cardiac disease than there are cadaver organs available. Hospitals and patients are also finding it harder to get some medications because drug companies have stopped making them. And there are not always enough hospital beds in intensive care units to meet the needs of patients.

The case of Mr. Nguyen does not involve any obvious scarcity of this kind. Yet, it nevertheless raises profound questions of distributive justice. Mr. Nguyen cannot afford the prescribed treatment and so he does not receive it. Bandages and wound dressing may not at first blush seem like scarce resources. However, it is important to understand scarcity more broadly. “Scarcity” refers not only to limits in the resources necessary to make a healthcare service available, but also to limits in the money available to spend on healthcare. Although wound dressings are not scarce in the former sense, they are clearly scarce in the latter sense. Other examples of fiscal scarcity may include the inability to pay for follow-up care, home health aides, glasses, dental care, asthma medication or other goods and services that benefit patients.

A variety of solutions to the problem of distributive justice have been proposed, and should be considered by the HEC in the course of developing a hospital policy. It has been proposed, for example, that the ultimate criterion for the distribution of scarce goods should be:

- *Equality.* If interpreted strictly, equality may require that if anyone gets a healthcare resource, it should be available to everyone. Interpreted more moderately, inequality may place certain limits on justified inequalities. For example, no matter how poor surgical patients are, they should have access to bandages and dressings necessary for their surgical incision to heal properly. This is the floor below which no patient should fall.

- *Need.* This requires that we have some basis for rating people's needs for resources and provide a scarce resource first to those whose needs are greatest. For example, in the distribution of influenza vaccine, priority should be given to those who are more vulnerable to getting the flu and are more likely to die from it if they do.
- *Ability to benefit.* We should provide scarce healthcare resources to those with the greatest quality, length, or likelihood of medical benefit. For example, do not provide a lifesaving surgical procedure to patients who will die soon regardless of our best medical effort.
- *Effort to maintain health.* Scarce resources should go first to patients who exert the greatest effort to stay well and make healthy choices. For example, patients with liver cancer should receive liver transplants before patients whose livers fail as a result of abusing alcohol. In the case of Mr. Nguyen, the HEC will need to consider the patient's effort to maintain his health given that he has limited resources to pay for compliance with best medical advice.
- *Social worth.* Persons who contribute most to the social good should receive scarce resources before those who contribute less, and before those who create positive social harms. For example, police officers, teachers, and nurses should receive priority over citizens who are not contributing vital community services; law-abiding citizens should come before those convicted of violent crimes.
- *Supply and demand.* Scarce resources should be doled out on the basis of people's ability to pay. For example, surgical patients who can afford dressings should have them, and those who cannot afford them should go without. If this criterion is used, Mr. Nguyen does not have a right to the wound dressings required to properly care for himself postsurgery if he cannot pay for them, and he should look elsewhere, e.g., to charitable groups or organizations, to obtain the help he needs.

In the final analysis, the HEC will need to evaluate and weigh these kinds of competing values. Its final policy recommendations should make explicit the ethical values at stake that support alternative policy choices. The ultimate decision about Mr. Nguyen may depend on the hospital's underlying institutional values and mission, e.g., as a charity hospital, for-profit, or religiously affiliated organization. While such a charge is daunting, the alternative of letting decisions continue to be made by default, and in the absence of any explicitly formulated plan, is ethically unsupportable.

2. *Education.* The ethics committee can also respond by educating its health professionals, patients, and the broader community about the nature and scope of this problem, the hospital's response, and the importance of community involvement. As noted already, the case of Mr. Nguyen raises a particular kind of ethical problem, which has to do with justice and fairness in the allocation of scarce resources. Notice that all of these proposed solutions to this problem discussed above share certain common features. First, they all purport to tell us what people deserve or what they have a right to possess. For example, some may think that people deserve to have their needs met, while others may hold that people deserve or should rightfully possess the product of their labor. Second, all of the proposed solutions make a distinction between justice and charity. Justice deals with what we ought to do in order to keep from violating the rights of others. Charity addresses what we ought to do if we want to choose what is the most compassionate action or the most responsive to the good of other human beings. One important difference between duties of justice, on the one hand, and duties of charity,

on the other hand, is that it is generally thought to be morally blameworthy to fail to do (or allow) what justice requires. By contrast, failing to do what charity requires is often considered to be indecent or inhumane, not wrong. Finally, all solutions to the problem of distributive justice have tended to take either liberty or equality or some particular mix of liberty and equality as a fundamental moral ideal. In general, the more emphasis is placed on equality, the more restrictions on liberty are needed to bring about transfers of wealth. The more emphasis is placed on liberty, the more departures from equality are likely to be tolerated.

3. *Ethics consultation.* In individual cases, such as Mr. Nguyen's, the HEC can serve as a resource for making recommendations, and can modify and amend hospital policy based on how well or poorly such policies serve in promoting ethical decisions for patients. This supports not only the population of patients who are served by hospital policies, but also providers who may feel caught between a rock and a hard place when patients like Mr. Nguyen ask for help. It would be irresponsible for Dr. Morris to dismiss Mr. Nguyen as "non-compliant" and move on to the next patient. By unpacking the notion of "non-compliance," and distinguishing between non-compliance based on informed decisions and non-compliance resulting from social and economic barriers, providers can better meet their obligations to patients.

Conclusion

At the outset of our discussion, Dr. Morris asked the HEC for a recommendation about how she should respond to her patient who cannot afford the wound care she has prescribed. Based on our discussion in this chapter, we can say that Dr. Morris has an obligation to promote Mr. Nguyen's best interests, and help him to obtain needed care. However this does not mean that Dr. Morris would be justified in stealing hospital supplies and handing them over to the patient. Instead, the HEC should urge Dr. Morris to advocate for her patient in a manner that is just and fair to all patients served by the hospital.

If an institutional policy is in place to guide the response to needy patients, the HEC should point to such a policy in assisting Dr. Morris in helping this patient. In the absence of such a policy, the committee should use the case consultation as an occasion to reflect on, and develop, a consistent approach that reflects the values of the institution and of the patients it serves. A central advantage of formulating an explicit policy is that we can aspire to meet justice standards. The substantive justice principles discussed in this chapter can guide the development or refinement of hospital policy.

Finally, the HEC should assume responsibility for educating providers, patients, and the broader community about the plight of needy patients. The goal is not only to raise understanding about the scope of the problem, but also to seek advice and broader community representation in responding in a just and compassionate way to patients.

Discussion questions

1. *Conceptual:* Is caring for Mr. Nguyen required as a matter of justice, or is it instead an act of charity? What are the implications of your answer to this question?
2. *Pragmatic:* What are the barriers in your institution to responding to patients like Mr. Nguyen?
3. *Strategic:* Propose a policy for addressing patients' needs. What substantive justice principles lend support to your proposed policy?

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