Special Section:
Praxis: Ethical Issues in Medical Education and Training

Helping Residents Live at Risk

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Residents in long-term care facilities and rehab hospitals sometimes ask healthcare professionals (HCPs) to help them do things that HCPs judge to be on balance harmful. A person with respiratory problems may ask for a cigarette, a diabetic for alcohol, a dysphagiac for food or fluids by mouth, a person at risk for falling for her walker, and so on. These requests raise two kinds of problems. The first pits residents against HCPs. Should HCPs ever help residents do what they consider harmful? The second pits HCPs against HCPs. If HCPs disagree among themselves—some thinking that the resident should receive the assistance, others thinking not—what should be done?

These are the questions I take up here. In discussing them I assume that there is no question of legal liability or professional censure that would prevent giving the help. I also assume that the help cannot be refused because rendering it will increase healthcare costs. I make these simplifying (but often realistic) assumptions because I want to concentrate on the ethics of saying no on the basis of harm to the resident and on the logic of teamwork. Let us take the above questions in order.

Residents versus HCPs: Resident Autonomy versus HCP Autonomy

In this section, I am concerned with residents who have full decisionmaking capacity. Although residents with compromised decisionmaking capacity also pose difficulties, requests from absolutely unimpaired residents are extremely common and, because of their unimpaired status, typically found more troublesome. It will be useful to pursue our questions in the context of a case:

M. K. is a 72-year-old man who lives in a long-term care facility. A few years ago he suffered a brain-stem stroke. He is now independently mobile in his wheelchair and cognitively intact. He has, however, swallowing difficulties. Tests show that his swallowing reflex is greatly diminished, and the speech-language pathologist recommended that he receive nothing by mouth. His physician recommended the same. But M. K. has a taste for ice cream. The other residents get ice cream for lunch every day, and he wants it served to him as well. He currently buys it at the cafeteria and eats it regularly. He had to be hospitalized last year for aspiration pneumonia and has been told that regularly eating ice cream will almost certainly shorten his life. His brother and

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wife say that it has always been impossible to tell M. K. anything and that the ice cream should be given. M. K. is prepared to sign a waiver.

Should the nurses bring M. K. the ice cream? Excluding considerations of legal liability—which a waiver would obviate—and costs to the system—which would be inconsistent with allowing others in society to live at risk without waiving rights to full healthcare—the case for refusal turns entirely on risk to the resident. The team was divided on what ought to be done. A few nurses argued that M. K. should receive the ice cream. Others said that they would bring the ice cream if the physician wrote an order for ice cream (which the physician said he would not do). Most said that they would not bring the ice cream even if the physician wrote the order.

Those who opposed bringing the ice cream were adamant that this was not paternalism. They did not think M. K. should be prevented from going to the cafeteria and eating ice cream there, or even from bringing it back to the unit to eat. He was entitled to put himself at risk, but he was not entitled, they argued, to have them help him live at risk. The issue is thus not one of paternalism but of professional autonomy: the right of HCPs to refuse requests for assistance.

HCPs have a professional obligation, typically articulated in their various codes of ethics, to hew to two principles. The first, the principle of autonomy, states they ought to do what those under their care request. The second, the principle of nonmaleficence, states they ought not to harm those for whom they care. As long as these principles point in the same direction, no problem arises. But they can conflict, and when they do (as in our case) we have to decide which is to supervene. I will proceed on the assumption that the principle of nonmaleficence puts a limit on the scope of the principle of autonomy, and thus HCPs can refuse to help residents harm themselves. I do this partly because I think it is plausible and partly for a pragmatic reason. That is the assumption typically made by HCPs, and thus if the recommendations to follow are to have effect on the practice of HCPs, it is best to begin with shared ground.

Refusing to do something on the basis of the principle of nonmaleficence requires three things. First, an *on-balance* judgment of harm. It is not enough to show that the patient is at risk of a negative health effect such as pneumonia, emphysema, or broken bones. It must also be shown that avoidance is worth forgoing the good sought (e.g., ice cream, cigarettes, or a walk) as well as engendering the feelings of resentment and anger that a refusal to help typically brings. It cannot be easy for a resident with full decisionmaking capacity to want to do something, think that he is entitled to do it, but be dependent on HCPs to carry it out, and have his request for assistance denied because HCPs think that it is bad for him.

Second, that there is *evidence* to support the judgment of on-balance harm. Nursing philosophy sometimes holds that there are ways of knowing things other than on the basis of evidence (e.g., by intuition). But we cannot divorce the principle of nonmaleficence from evidential requirements without legitimating the most whimsical decisions imaginable.

Third, that the evidence support the judgment that on-balance harm will come about (at a minimum) *on balance of probability*. It is not enough that the evidence show a *theoretic possibility* of on-balance harm, for then HCPs would be entitled to refuse helping residents do anything at all. It is too much to insist that the evidence show that on-balance harm will *virtually certainly* result, for

then HCPs could hardly ever refuse to render assistance. It is arguable that freedom of choice is so important that HCPs must demonstrate that it is *beyond reasonable doubt* that on-balance harm will come about before they can say no. I select the "on balance of probability" requirement for the strategic reason that, because it gives the principle of nonmaleficence the biggest moral bite that can be plausibly claimed for it, any obligations to assist that can be derived on this assumption should meet with least resistance.

We can now transform the question of when HCPs can refuse to render requested assistance as: When can HCPs have evidence that helping a resident do something will probably result in on-balance harm to the resident? There are, I contend, only two such circumstances.

The first is where a resident's request for help is predicated on a factual belief that HCPs have firm evidence to suppose is mistaken. A resident may disagree with HCPs on whether an action has a certain degree of risk. The resident may say that, if the HCPs were right, it would not be worth doing, but they are not right. It is salutary to remind ourselves that HCPs are not always right in their predictions of negative health outcomes. But, generally, HCPs are in the best position to make such judgments; and if they have firm evidence that the action does carry a degree of risk that the resident acknowledges would not be worth chancing, they have firm evidence that the resident is asking for help with something that is probably on balance harmful to the resident.

The second circumstance is where the resident is asking for help to do something that will predictably result in a negative outcome that is imminent, serious, and virtually certain. Residents are generally in a much better position than HCPs to say what risks are worth what benefits for themselves. They have an intimate understanding of their likes, dislikes, hopes, fears, preferences, how they have lived their lives, and how they want to continue to do so. HCPs look at them merely from without. Thus, as John Stuart Mill put it, "with respect to his own feelings and circumstances, the most ordinary man or woman has means of knowledge immeasurably surpassing those that can be possessed by any one else."[1] But ordinary people can also sometimes be quite wrong. When they seek to do things that will result in immediate, serious, and virtually certain harm, there is no realistic chance that the benefits are worth the risks, and thus others can have evidence that what they are seeking is probably on balance harmful.

But when these two conditions do not obtain, HCPs cannot refuse to render assistance to any resident with full decisionmaking capacity. It is unlikely that they could have evidence that what they want is on balance harmful, and even if they could, they should never act on it. Once we stipulate that the resident is not undertaking the activity with any misunderstanding of the risks (which the absence of the first condition guarantees), and that the thing requested has some chance of success (which the absence of the second condition guarantees), the only way in which residents can be mistaken is for them to misestimate the goods and harms involved. They must either overestimate the value of the good sought (i.e., think that they will value it more than they will) or underestimate the harm of the downside (i.e., not think that it is as bad as they will find it to be), and thus wrongly take a risk to be worthwhile.

Such misestimations can occur. M. K., for example, may overrate the importance of ice cream and the ability to make decisions that insisting on ice cream exemplifies, or underrate the horror of choking to death or loss a foreshortened

life will bring. The question, however, is not whether residents can be mistaken; it is whether HCPs, in the teeth of the resident's fixed and settled opinion to the contrary, can have *evidence* to show that the resident is likely making this sort of misestimation.

To provide such evidence is a daunting task. For instance, what evidence could HCPs adduce to show that from M. K.'s point of view (as distinct from their own or that of most people) he is misreading his values? On what observations can that conclusion be based? What is the nature of the inference? What reason is there to think that the evidence is stronger than the testimony of the resident to the contrary? I do not know how to argue that HCPs could never provide such evidence, but the occasions on which they can are surely rare.

Even if such evidence can be provided on occasion, it is wise to have a rigid rule (similar to the common prohibition on paternalism) forbidding HCPs from acting on it. It is standard practice in palliative care to accept patients' declarations about their pains at face value. If they say they are in pain, they are; if they say the pain is severe, it is. Sometimes HCPs wonder if the pains are as patients advertise them. No matter; they do not challenge the reports, and for good reason. If they did challenge the reports, although they may sometimes prevent overmedication, more often they will cause undermedication, and that would not be worth it.[2]

Similarly, if HCPs were allowed to question whether what residents say they value is what they really value, we could expect the policy to likewise result in more harm than good. Given that HCPs are typically not slow to hold opinions about what is in a resident's interest, we could expect refusals to help. And because HCPs are also typically in a much worse position than residents to say what is worth what for residents, we could expect most of the refusals to be misplaced. If we can anticipate on-balance harm from a policy that allows HCPs to invoke the principle of nonmaleficence to refuse requests from the residents in question, a thoroughgoing application of the principle of nonmaleficence would forbid the exercise of that judgment.

I thus conclude that if residents have full decisionmaking capacity, absent the two conditions discussed earlier, HCPs cannot invoke the principle of nonmaleficence to justify refusing to do what the resident wants. In acute care, where these conditions are satisfied HCPs will provide patients with interventions such as surgery, chemotherapy, or resuscitation to extend the quantity of their lives, even though there is a low probability of success and a high probability of a negative quality of life, if the patient thinks the gamble worth it. Requests from residents to improve the quality of their lives by putting the quantity in jeopardy should be treated with no less respect. There is no reason to think that quantity of life is more important than quality of life, that residents are more likely mistaken when they are prepared to compromise quantity of life for quality of life than the reverse, or that HCPs are more likely to spot errors in others' quality of life judgments than in their quantity of life judgments.

HCP versus HCP: Teamwork

The conclusion of the preceding section still leaves ample room for judgment and, therefore, disagreement among HCPs. The possibility of disagreement

brings a number of fresh problems. Should each HCP act according to his or her own lights? Or should a team decision be made that is binding on all? And if the latter, how should that decision be arrived at?

Ideally, decisionmaking should satisfy three conditions:

(1) The decision should be a team decision. Healthcare is so complex and fragmented that a single person cannot know everything. Team members have to contribute their expertise and perspectives, and these contributions must be consolidated in a team decision if care is to be optimal.
(2) The decision should result in a plan that provides uniform action directed toward the resident. Residents should not receive inconsistent treatment from their caregivers.
(3) The decision should not compromise professional autonomy. Physicians should not have to write orders they disagree with, and staff should not have to follow orders they disapprove of.

Is it possible to simultaneously satisfy these desiderata?

This, applied to the healthcare context, is the question that Jean Jacques Rousseau in his *Social Contract* (1762) identified as the central question of political philosophy: Is it possible to find some form of political association in which citizens can join together to make decisions binding on all and yet remain as free as before? Our problem is nothing but Rousseau's writ small, and it will be useful to tour the territory with the help of ideas drawn from political philosophy.

The short answer to Rousseau's question, and ours, is that (except in those circumstances in which all agree) it is not possible to have everything we ideally want. The argument goes as follows.[3] If we want to have decisions binding on all that will result in uniform action, there are only two plausible ways to achieve this. One is to have a single person make the decision (analogous to dictatorship—the term understood to carry no negative connotations—in the political realm). In this case we abandon team decisionmaking and, given that those who disagree are obligated to do things they disagree with, professional autonomy. The other is to have the team vote and let the majority of votes carry the day (analogous to majoritarian democracy). In this case we preserve team decisionmaking but again abandon autonomy. The only way to preserve autonomy is to abandon binding decisions and let team members follow their own judgment. We can call this (again appropriating a term from political philosophy, again purging it of all negative connotations) the anarchist position. More argument is needed (some of which will be presented in the sequel) for this argument to rise to a demonstration that Rousseau's problem cannot be solved, but a solution does not look hopeful. If the three desiderata cannot be simultaneously satisfied, we have to make some hard decisions, and the above is a map of the alternatives. What, then, should we compromise, and why that?

Sometimes it is essential that healthcare providers display uniform behavior toward the resident, as in delivering medication or rehabilitation therapy. Sometimes, also, legal liability falls predominantly on a particular person, or the decision calls for special expertise. Under these conditions, it makes sense to follow the dictatorship model and allocate decisionmaking authority to a person or subgroup.

But sometimes, as in our case, uniform action is not absolutely essential (some can provide ice cream and others not, without significantly impairing patient care), and the dispute does not concern issues of legal liability or professional knowledge but rather ethics pure and simple. Even so, there is still a case for the dictatorship model. Two quite different sorts of considerations can be invoked in its support.

The first comes from Plato. In his *Republic*, Plato argued that there is such a thing as moral knowledge and that ruling is a difficult art or skill calling for it. The ruling function, then, should be left to those possessing that knowledge. Following in this tradition, one may argue that there are ethics experts and ethical decisions should be left to them. Thus ethics committees or consultants should be called in to decide vexed questions. The cult of expertise is so common in healthcare that this idea comes easily to many. But ethics experts are not well fitted to do this, and to ask them to do it is to misconstrue their role. Their role is to draw distinctions, point out alternatives, and provide arguments for, and objections to, various positions. In short, their role is to clarify the issues and to thus facilitate the decisions of HCPs. They do not have more accurate moral compasses than others and cannot be expected to make better decisions.

The second consideration comes from Thomas Hobbes. In the *Leviathan* (1651) Hobbes argued that society has a choice between a sovereign invested with the absolute authority to make and enforce decisions, and social chaos—a state of nature in which, to use his famous description, "the life of man is solitary, poor, nasty, brutish, and short." Given this, the choice is easy. A healthcare team, especially one composed of moral skeptics who hold that there are no right or wrong answers in ethics, may take a similar view. If one decision is as good as any other, the important thing is to arrive at decisions as efficiently as possible. Thus a Hobbesian model suggests itself: pick a person and agree to abide by that person's decision. The problem that plagues Hobbes's philosophy, and this extrapolation from it, is that there is no reason to think that we have to choose between dictatorship and chaos. The possibility remains of a democratic decision where the group decides, and this option promises to be superior.

The genius of democracy is to try to harmonize the obligation to obey the law with the autonomy of the individual. Democracy means self-rule, and the idea is that citizens can be obligated to obey the law, and yet remain as free as before, if they are the authors of the laws to which they are subject. This works if all members agree to all laws. The problem arises when the members disagree. There a decision seems to call for majoritarian procedures, and this seems to compromise the autonomy of those in the minority.

Rousseau argued that, first appearances to the contrary, this is not so. If citizens aim at what Rousseau described as the "general good"—that is, what is good for the community as a whole rather than one's own good—whatever the majority decides is the general good *is* the general good. Thus if a citizen voted in the minority, that person should conclude that his or her view was mistaken. Majoritarian democracy hence reconciles the obligation to obey and the autonomy of the individual. This suggests a model for healthcare teams. Healthcare providers have an aim, analogous to that of Rousseau's citizens: the good of the patient. Thus if HCPs aim at the good of the patient and set aside personal enmities and interests, the suggestion is that whatever the majority

decides is the good of the patient *is* the good of the patient. Rather than chafe at losing the vote, the minority should be grateful for the correction. Sadly, however, Rousseau's argument is unsound. There is no reason to hold that if the majority (however conscientiously directed and pure of heart) thinks X is best, X is best. If not, there is no reason for those in the minority to revise their view just because they are in the minority. It follows that Rousseau fails to reconcile autonomy and majoritarian democracy.[4]

Societies that adopt majoritarian democracy often recognize this apparent incompatibility and try to soften the consequence by building into the law a "conscientious objector" status. Such a status exempts citizens from the law of the land in matters that are of the greatest importance to them (typically, participation in combat). Conscientious exemptions are also common in healthcare. If one is conscientiously opposed to doing something—participating in performing abortions is the outstanding example—one is not forced to do so.

Thus a healthcare team may adopt majoritarian decisionmaking procedures and whittle away at how this compromises professional autonomy by deploying a conscientious-objector clause to excuse those who conscientiously disagree with the decision from helping to carry it out. For instance, if the majority of the team decides that ice cream should be brought, those who think the decision unprofessional would not have to bring it. Given that the majority thinks it should be the decision, schedules should be able to be arranged so that the resident and dissenting staff can both be accommodated.

The problem is to explain how we can stop here. Suppose that the team decides that the ice cream should *not* be provided. Are those who think it should be provided bound by this, or may they bring the ice cream? It must be as professionally galling for HCPs to be prevented from doing what they think they ought, as it is to be forced to do what they think they ought not. If concern for professional integrity justifies exemption in the latter case, why should it not in the former too?

If we combine majoritarian decisionmaking procedures with a robust conscientious-objector status that permits one to perform as well as refrain, this amounts to (what I identified earlier as) the anarchist position. This may result in lack of uniform action, but it will preserve the professional autonomy of healthcare providers, and uniform action may not be essential. The problem is that individual HCPs may exercise spectacularly bad judgment. A team may do so as well, but the odds of it doing so are less, partly because of the numbers, and partly because of the conservative nature of HCPs. Faced with this problem, we can retreat to majoritarian decisionmaking with an exemption only to refrain. Alternatively, we can distinguish two ways in which one can judge something wrong. One is to hold that, whereas one personally would not do that thing, it is not wrong for others to do it if they wish. (Physicians who do not perform abortions on conscientious grounds but who refer patients to abortionists must hold this view.) Another is to hold that it is not only wrong to personally do that thing, it is wrong for anyone else to do it either. (Physicians who refuse to refer patients to abortionists presumably hold this view.)

Using this distinction, the team can be asked to say which way its vote against honoring a patient's request is to be taken. If the bulk of the majority just thinks it wrong for themselves, then those who disagree can be released, with the team's blessing, to act on their own judgment. But if they think that it

is wrong for them, and wrong for everyone else too, then the decision of the team can be taken as binding on all. This does not completely harmonize authority and autonomy, but I put it forward as the best compromise. It provides the maximum amount of professional autonomy that is compatible with the integrity of the team and safety of patients.

Conclusion

In the end, the quality of decisions does not (as Plato argued) depend on decision procedures or rules and guidelines, however important they may be, but on character. In healthcare, this means acting as a professional, and that is largely a matter of getting the heart right. To explain this, it will be useful to return to Rousseau.

Rousseau, as discussed previously, argued that for citizens to fulfill their function as citizens they must aim at the general good and scrupulously exclude influences that may get in the way of that aim. HCPs have to do something similar to act as professionals. HCPs sometimes dislike their colleagues, jobs, and those under their care; or fear litigation and the disapproval of others. They also often see that they can make their lives easier by refusing to respond to requests for help from residents. Who in healthcare has not seen decisions driven by these factors to the cost of the resident? Following Rousseau, HCPs must put all this aside. Citizens must enter the voting booth with a firm commitment to the good of the public; HCPs must enter team deliberations with a firm commitment to the good of the patient.

We have also come some distance in identifying what that commitment amounts to. We live in days of autonomy, where the watchword is patient- or family-centered care. As argued earlier, this means that HCPs must respect the preferences of those under their care as long as the principle of nonmaleficence does not forbid them from doing so. And, as argued in the first section, that means subordinating their judgment of what is best for the resident to the judgment of the resident as long as the resident's decisionmaking capacity is unimpaired, the resident has an accurate understanding of the risk, and the risk does not amount to imminent, substantial, and virtually certain harm. If HCPs are looking for an excuse to say no, they can almost always find one. If they are looking for a way to say yes, they can almost always find that, too. If the heart if right, HCPs should be looking for the latter.

Notes

1. Mill JS. *On Liberty*. 1859:chap. 4, para. 4.
2. McCaffery M, Pasero C. *Pain: Clinical Manual*. St. Louis, Mo.: Mosby; 1999:38–42.
3. For this dialectic of the problem I am indebted to: Wolff RP. *In Defense of Anarchism*. New York: Harper & Row; 1970.
4. See note 3, Wolff 1970:48–58.