AMA Journal of Ethics®

June 2017, Volume 19, Number 6: 550-557

ETHICS CASE

How Should Physicians Respond When the Best Treatment for an Individual Patient Conflicts with Practice Guidelines about the Use of a Limited Resource?

Commentary by Edmund G. Howe III, MD, JD

Abstract

The case presents a physician's ethical conflict, due to limited resources, between his obligations to meet the needs of a community and those of his patient. Elements of the decision-making process (and who should make the decision) are discussed, including the limitations of what ethical reasoning can offer and risks of arbitrary outcomes. Additionally, potential benefits to physicians and their patients of discussing these conflicts, including reducing the physician's moral distress, are noted. I argue that physicians' abilities to make "right" decisions in such situations are limited, and I suggest ways in which physicians can try to preserve their relationships with patients.

Case

Dr. Ellis is an urologist at a community hospital. He treats several patients with bladder cancer who require treatment with Bacillus Calmette-Guérin (BCG) therapy. However, there is a current worldwide shortage of BCG due to manufacturing problems. There are no national policies in the United States governing the dispensation of BCG in the setting of a shortage, so a multidisciplinary task force was recently convened at Dr. Ellis's hospital in order to decide how the hospital should respond.

The hospital task force, of which Dr. Ellis is a member, voted unanimously to adopt guidelines similar to those adopted by other hospitals, namely, to offer a one-third dose of BCG for induction and maintenance courses up to one year. These guidelines are based on a randomized trial by the European Organisation for Research and Treatment of Cancer that showed no difference in toxicity between one-third dose BCG and full-dose BCG [1]. Notably, however, the lower dosage resulted in higher recurrence rates. Dr. Ellis and many of his colleagues also recently attended a urology conference where a study of patients eligible for treatment with BCG during the shortage was presented: 87 percent of patients had treatment regimens that did not follow the standard of care, but the recurrence rate was highest among those who required induction BCG therapy and those who received an alternative to BCG [2]. The presenters recommended prioritizing patients who need induction BCG therapy.

When Dr. Ellis returned from the conference, he saw a patient named Jaan that he has had a long relationship with due to his history of prostate problems. Jaan is a fairly healthy 61-year-old man who has just been diagnosed with bladder cancer requiring BCG therapy. Dr. Ellis is aware that from a population and organizational perspective, he should not recommend the full dose of BCG treatment for Jaan but believes that he might be at higher risk for recurrence of his bladder cancer if the alternative regimen is used.

Talking to a colleague about Jaan's clinic visit, he says, "I voted to implement the BCG guideline, but I believe this patient should get the full dose." His colleague advises, "Give him the full dose of BCG. The guidelines aren't mandatory; guidelines have legitimate exceptions. You have to do what is best for the patient in front of you." Dr. Ellis considers this advice, but later he thinks, "Making an exception for Jaan means other patients might not receive BCG at all. How do I know that, down the road, another patient might be as worthy of being granted an exception to the guideline as Jaan? If I grant too many exceptions, the guidelines I helped implement won't mean much." Dr. Ellis continues to consider what to do.

Commentary

This case raises critical questions regarding the conflict physicians might face when the interests of many patients whom they don't know clash with those of their own patients due to medical resources being limited. The specific questions I shall address here are what they should do when they face this dilemma and how they might best handle the moral distress it arouses. In addition, I shall raise another issue that physicians in this situation should consider: discussing this ethical quandary with the patient or patients whom they treat and whose interests are at stake. Physicians who take this approach of sharing their dilemma with patients might benefit these patients by preserving their relationship with them and might also reduce their own moral distress.

Should Jaan Receive Full-Dose BCG Therapy?

In this case, the ethical principle of justice, expressed as community-based utility of a limited resource for many, conflicts with the principle of beneficence for Jaan, a particular patient. Utility for all here involves trying to do the greatest good for the greatest number. This principle is routinely applied in disaster settings, as when large numbers of seriously injured patients must be triaged and treated [3]. The application of this principle, however, is not straightforward. During disasters, lines might have to be drawn, for example, between patients with more and less serious injuries. Physicians typically treat first the patients who are the most seriously injured but still treatable [4].

In this case, some of the ethical issues that might arise during disasters aren't present. There is no question, for example, regarding when, if ever, the hospital should change its triage criteria based on more patients with bladder cancer "arriving" over time than

initially expected. There is also no direct conflict between the value of possibly saving more patients' lives, on one hand, and that of relieving other patients' profound suffering, on the other. But the case still involves a trade-off. The hospital task force adopted guidelines that recommend prioritizing patients who need induction BCG therapy, which implies that treatment with BCG should be at the expense of those who need long-term maintenance therapy.

In this case, as in many ethically complex cases, it might be that ethical analysis is limited in the extent to which it can lead to solutions [5] and, in particular, answer or indicate unequivocally which of two competing, mutually exclusive actions is morally best. Reasonable persons may therefore continue to differ on how an ethical question should be answered because they have different views regarding which core or foundational value should prevail. When disagreement occurs, the preferable ethical question and thus ethical approach may be not *what* the decision should be but *who* should decide. In this case, then, Dr. Ellis faces two questions: If *he* makes the decision about whether to recommend full-dose BCG for Jaan, what should his decision be; and should he himself decide, or should he refer this decision back to the task force?

This emphasis on who should decide is common in many clinical contexts. Deciding to let a child's parents decide—whether, for example, to withhold or withdraw life-supporting treatment when it clearly will not benefit the child—is a path often chosen when a child is so seriously ill that death is imminent and thus there seems to be no sound ethical basis for deciding whether to maintain the child's life or to allow the child to die. We allow parents in this situation to make this decision in large part because they are the people closest to their children and will be most affected by what they decide.

The decision in this case—whether or not Dr. Ellis should recommend induction BCG therapy for Jaan—may be like the decision of whether to withhold or withdraw life-sustaining treatment for a child facing imminent death; it might be one about which reasonable persons could reasonably disagree. There might be no self-evident ethical solution that will emerge even after a most thorough, conscientious discussion. Thus, in this case, as in the case of the dying child, who should decide could be more important than what the decision is.

By making the decision himself, Dr. Ellis could take into account his feelings, which might add to the ethical quality of his decision. If he feels compassion for Jaan, for example, it might motivate him to try to achieve for Jaan an exceptional benefit that goes beyond the benefit to which most other patients would be entitled. Although making a decision solely on this basis might be unjust, Dr. Ellis's sense that this patient is suffering might be an intuitive clue that the patient is worse off than others and thus needs this benefit more. Conversely, if Dr. Ellis made this same decision based on feelings such as having a prior relationship with Jaan, it would be unjust.

There are several arguments against Dr. Ellis making this decision alone (or even with just the colleague whom he previously consulted). First, his decision could reflect conscious or unconscious personal bias [3, 6]. This bias could favor Jaan in that he is Dr. Ellis's patient, or it could work against Jaan in that Dr. Ellis might strive too much to avoid acting on the basis of favoritism. Second, other physicians' personal biases might differ for a plethora of reasons. One clinician might favor Jaan because Jaan is his or her patient, whereas another, more concerned about the risk of unjustly favoring his or her patient over others, might strive to avoid this risk. Whether Jaan gets induction BCG therapy thus might depend more on the extent to which his physician fears favoring him than on anything else. If, then, the therapy Jaan receives stems in any degree from the extent to which his physician feels this fear, Jaan's outcome—which could be life or death—would be arbitrary. Patients' outcomes should not depend on which clinician, with which personal biases, they just happened to have seen. If the risk of Jaan's outcome depending on his physician's personal bias can be reduced by some other approach, ethically, this other approach would be a better process for decision making.

Dr. Ellis might, for example, ask the task force to decide what dose of BCG Jaan should receive (recusing himself, as a task force member, from participating in the decision-making process). In deciding whether to consult the task force, Dr. Ellis must consider first that it has already spoken (by issuing guidelines). Why the task force decided what it did we don't know. The task force, however, only issued *guidelines*, not rules, as Dr. Ellis's colleague accurately points out—possibly for "political" reasons. The members may have wanted above all else to leave the physicians in their hospital still free to decide what they believed to be best for their own patients, arbitrarily factoring in the interests of other patients. If this was the task force's rationale, it might be less ethically justifiable than other rationales that give greater priority to what would be best for the greatest number of patients, whatever the decision would be in an individual case.

In any case, if Dr. Ellis consults the task force, the task force, in addition to deciding for Jaan, could influence the decisions of all clinicians facing this same decision. The task force could make clear that it intends for physicians like Dr. Ellis to use their discretion or that it more strongly believes that the guidelines it expressed should be followed. This is not to say that what the task force decides would be from some ethical standpoint or other "more right." Any person or institution as, for example, our Supreme Court, might, of course, make wrong decisions. We cannot assume that by referring a decision to the best body to make the decision that the decision-making body will get it right. Subjecting such questions to the best *process* might be, however, the best that we can do.

The task force, itself, of course, can also be biased. Its guidelines could, for example, represent too much the professional bias or biases of certain clinicians who value giving priority to public health or greater moral weight to utility—for example, saving more

persons' lives. If so, this professional bias might need correction by making the task force membership more inclusive. Such groups frequently include patient representatives and members of the community. Inclusion of lay members and at least one member not affiliated with the institution is required, for example, on institutional review boards (IRBs) [7].

Dr. Ellis can, of course, advocate for Jaan's receiving full-dose BCG therapy before the task force *whether or not his recommendation reflects Dr. Ellis's own personal beliefs* [8]. Why might he do so if this would betray his own personal convictions? Dr. Ellis might favor Jaan's being able to express and pursue his best interests, as Jaan sees them (to the degree that he can) over everything else. Dr. Ellis's assisting Jaan in pursuing his best interests, in addition to being ethically justifiable in itself, could also help preserve their relationship and relieve Dr. Ellis's moral distress, as we shall now see.

How Might Dr. Ellis Best Relieve His Moral Distress?

If Dr. Ellis feels constrained by the guidelines to make a decision that goes against Jaan's best interests, he might experience moral distress. Jaan might feel abandoned and betrayed. Their relationship and their feelings may be the key deciding factors in Dr. Ellis's decision if acting in Jaan's best interests and following the task force's guidelines have, as it were, equal moral weight. In cases involving a clinician's moral conscience, patients' and clinicians' competing commitments may in fact be regarded as having equal moral weight [9]. Below I suggest some ways in which Dr. Ellis might resolve his dilemma while relieving his moral distress.

One strategy would be for Dr. Ellis to convey to Jaan his bind in this situation, especially since it is Jaan's interest that is most at stake. Dr. Ellis should not, however, ask Jaan to contribute to the decision by giving weight to what Jaan believes Dr. Ellis should do. If Dr. Ellis did so, he would be asking Jaan to consider sacrificing his own needs for other patients. Including Jaan in the decision-making process would most respect Jaan's autonomy but could also place Jaan in a most painful position. How could he not advocate for his own interest, unless he were motivated by altruism? On the other hand, this approach might be subtly coercive. Jaan might be inclined to state, contrary to his wishes, that he would sacrifice his own needs in order to be in Dr. Ellis's eyes a good person. The result of giving each patient like Jaan a say in the outcome might mean that those patients who are most self-serving would gain whereas those who are most self-sacrificing or susceptible to subtle coercion would lose out.

Dr. Ellis could also share with Jaan his rationale, why he believes he has only one choice—to follow the hospital guidelines—if he in fact believes this, and how truly sorry he is about this choice. If Jaan feels enraged, Dr. Ellis should support Jaan's reaction using recommended strategies for working with "difficult" patients [10]. He should then say that he understands: "I expect I would feel just like you, but perhaps feel even angrier."

He could further say that he would wholly understand if Jaan wants to see someone else and would ask no questions to save Jaan the pain of answering. Dr. Ellis could also offer to help Jaan find another physician if this is what he would like to do. Indeed, Dr. Ellis might have to provide a referral if he feels he cannot betray his own core beliefs. Moreover, Dr. Ellis, if making this decision himself, should explain why. This openness is paradigmatic of the openness regarding all other aspects of this decision that Dr. Ellis also should show and could include his even sharing with Jaan his fear regarding wrongly favoring Jaan on one hand or wrongly going too far to not favor his interests on the other. This sharing could increase mutual trust regardless of what Dr. Ellis feels he must do and could also help each, in this most painful situation, feel less alone.

Although Dr. Ellis might feel that he has failed Jaan, by making these offers and disclosures, he might feel *some* relief, knowing that this is the best that he can do for Jaan under these circumstances.

Conclusion

Physicians might not be able to find a best solution or process for resolving more difficult ethical dilemmas, such as how they should best distribute limited resources. They could, however, pursue a path that most respects and benefits their patients and themselves. Whatever they decide, they should have well-considered reasons. Their decisions should be based on ethical reasoning in addition to, and as checks on, what they might feel. They might *feel* compelled to favor their patients, for example, but they should not give this feeling sole or even overriding moral weight. In a given case, however, ethical reasoning might not determine which option is right. Doctors then may ask instead *who* should decide. Ethical reasoning can help us decide who should decide. An example is allowing some parents to decide for their children, as noted above.

Clinicians, should, in general, discuss their ethical dilemmas with their patients, to this extent at least making them shared. They should, if at all possible, hope to leave the hospital with their patients "hand in hand." This outcome may seem impossible if doctors in Dr. Ellis's situation make a decision that to any degree goes against the best interests of a patient like Jaan. They should seek to preserve their relationship with their patient in such instances, regardless. Patients like Jaan might understand their physician's dilemma, and the patient-physician relationship might then become even stronger.

References

1. Oddens J, Brausi M, Sylvester R, et al. Final results of an EORTC-GU cancers group randomized study of maintenance bacillus Calmette-Guérin in intermediate- and high-risk Ta, T1, papillary carcinoma of the urinary bladder: one-third dose versus full dose and 1 year versus 3 years of maintenance. *Eur Urol*. 2013;63(3):462-472.

2. Parker W. Study weighs impact of BCG shortage on outcomes. *Urology Times*. February 16, 2016. http://www.cancer-alert.com/cancer-prevention/study-weighs-impact-of-bcg-shortage-on-outcomes/. Accessed February 3, 2017.
3. Howe EG. Medical ethics in disasters. In: Ryan JM, Buma APCCH, Beadling CW, et al., eds. *Conflict and Catastrophe Medicine: A Practical Guide*. 3rd ed. London, England: Springer; 2014:91-110.
4. US Department of Health and Human Services Office of Inspector General. HHS public health and medical services emergency support preparedness. https://oig.hhs.gov/oei/reports/oei-04-11-00260.pdf. Published November 2012. Accessed February 23, 2017.
5. Holmes RL. The limited relevance of analytical ethics to the problems of bioethics. *J Med Philos*. 1990;15(2):143-159.
6. Dubois JM. Increasing rates of organ donation: exploring the Institute of Medicine's boldest recommendation. *J Clin Ethics*. 2009;20(1):13-22.
7. Protection of Human Subjects, 45 CFR sec 46 (2017).
8. Bergman EJ. Identifying sources of clinical conflict: a tool for practice and training in bioethics mediation. *J Clin Ethics*. 2015;26(4):315-323.
9. Howe EG. Harmful emotional responses that patients and physicians may have when their values conflict. *J Clin Ethics*. 2016;27(3):187-200.
10. Fiester A. Contentious conversations: using mediation techniques in difficult clinical ethics consultations. *J Clin Ethics*. 2015;26(4):324-330.

Edmund G. Howe III, MD, JD, is a professor of psychiatry and medicine and the director of ethics for the School of Medicine at the Uniformed Services University of the Health Sciences (USUHS) in Bethesda, Maryland, where he is also a senior scientist at the Center for the Study of Traumatic Stress. He is the editor-in-chief of the *Journal of Clinical Ethics*, chairs an institutional review board at USUHS, and sees patients at the Walter Reed National Military Medical Center.

Acknowledgements

I would like to thank members of the editorial staff at the *AMA Journal of Ethics* for their incredibly insightful and thorough suggestions of ways to improve this manuscript.

Related in the *AMA Journal of Ethics*

Allocation of Drugs in Short Supply, August 2013
Are There Blueprints for Building a Strong Patient-Physician Relationship?, March 2009
Exploring Physicians' Attitudes about and Behavior in Communicating with Patients, July 2012
Identifying Bedside Rationing, April 2011
Who Should Ration?, February 2017

Disclaimer

The opinions or assertions contained herein are the private views of the author and are not necessarily those of the Armed Forces Radiobiology Research Institute, the Uniformed Services University of the Health Sciences, or the US Department of Defense. The funders had no role in study design, data collection and analysis, decision to publish, or preparation of the manuscript.

The people and events in this case are fictional. Resemblance to real events or to names of people, living or dead, is entirely coincidental.

The viewpoints expressed in this article are those of the author(s) and do not necessarily reflect the views and policies of the AMA.

ISSN 2376-6980