To Isaiah

THANK YOU FOR LETTING ME SHARE THIS GLORIOUS DAY with you and your loved ones. Feel good. Feel proud. You've earned it.

In preparation for today, I asked your dean of students what she thinks is on your mind. So, she asked you. The word you used—many of you—was this one: Worried. You're worried about the constant change around you, uncertain about the future of medicine and dentistry. Worried about whether you can make a decent living. You've boarded a boat, and you don't know where it's going.

I can reassure you. You've made a good choice—a *spectacularly* good choice. The career you've chosen is going to give you many moments of poetry. My favorite is the moment when the door closes—the click of the catch that leaves you and the patient together in the privacy—the sanctity—of the helping relationship. Doors will open too. You'll find ways to contribute to progress that you cannot possibly anticipate now, any more than I could have dreamed of standing here when I was sitting where you are 40 years ago.

But look, I won't lie; I'm worried too. I went to Washington to lead the Centers for Medicare & Medicaid Services, full of hope for our nation's long-overdue journey toward making health care a human right here, at last. In lots of ways, I wasn't disappointed. I often saw good government and the grandeur of democracy—both alive, even if not at the moment entirely well.

But, like you, I also found much that I could not control—a context torn apart by antagonisms—too many people in leadership, from whom we ought to be able to expect more, willing to bend the truth and rewrite facts for their own convenience. I heard irresponsible, cruel, baseless rhetoric about death panels silence mature, compassionate, scientific inquiry into the care we all need and want in the last stages of our lives. I heard meaningless, cynical accusations about rationing repeated over and over again by the same people who then unsheathed their knives to cut Medicaid. I watched fear grow on both sides of the political aisle—fear of authentic questions, fear of reasoned debate, and fear of tomorrow morning's headlines—fear that stifled the respectful, civil, shared inquiry upon which the health of democracy depends.

And so, HSDM and HMS Class of 2012, I'm worried too. I too wonder where this boat is going.

There is a way to get our bearings. When you're in a fog, get a compass. I have one—and you do too. We got our compass the day we decided to be healers. Our compass is a question, and it will point us true north: How will it help the patient?

This patient has a name. It is "Isaiah." He once lived. He was my patient. I dedicate this lecture to him.

You will soon learn a lovely lesson about doctoring; I guarantee it. You will learn that in a professional life that will fly by fast and hard, a hectic life in which thousands of people will honor you by bringing to you their pain and confusion, a few of them will stand out. For reasons you will not control and may never understand, a few will hug your heart, and they will become for you touch points—signposts—like that big boulder on that favorite hike that, when you spot it, tells you exactly where you are. If you allow it—and you *should* allow it—these patients will enter your soul, and you will, in a way entirely right and proper, love them. These people will be your teachers.

Isaiah taught me. He was 15 when I met him. It was 1984, and I was the officer of the day—the duty doctor in my pediatric practice at the old Harvard Community Health Plan. My nurse practitioner partner pointed to an exam room. "You better get in there," she said. "That kid is in pain."

He was in pain. Isaiah was a tough-looking, inner-city kid. I would have crossed the street to avoid meeting him alone on a Roxbury corner at night. I'm not proud of that fact, but I admit it. But here on my examining table he was writhing, sweating in pain. He was yelling obscenities at the air, and, when I tried to examine him, he yelled them at me. "Don't you f-----g touch me! Do something!"

I didn't figure out what was going on that afternoon. Nothing made sense. I diagnosed, illogically, a back sprain, and I sent him home on analgesics. Then, that evening, the report came: an urgent call from the lab. Isaiah didn't have a back sprain; he had acute lymphoblastic leukemia. And we didn't have his phone number.

The police helped track him down that night, to a lonely three-decker, third floor, a solitary house in a weedy lot on Sheldon Street in the heart of Roxbury. Isaiah lived there with his mother, brothers, and his mother's foster children.

What followed was the best of care . . . the glory of biomedical science came to Isaiah's service. Chemotherapy started, and he went predictably into remission. But we knew that ALL in a black teenager behaves badly. Unlike in younger kids, cure was unlikely. He would go into remission for a while, but the cancer would come back and it would kill him. Three years later, he relapsed.

I drove to his apartment one evening in 1987 and sat with Isaiah and his graceful, dignified mother around a table with

A Piece of My Mind Section Editor: Roxanne K. Young, Associate Senior Editor.

a plastic red-checkered tablecloth and explained the only option we knew for possible cure—a bone marrow transplant, not when he felt sick, but now, at the first sign of relapse, when he was still feeling fine. He was feeling fine, and I was there to propose treatment that might kill him.

They didn't hesitate. Isaiah wanted to live. He got his transplant, from his brother. His course was stormy, admission after admission followed, then chronic complications of his transplant—diabetes and asthma. His Children's Hospital medical record that year took up five four-inch-thick volumes. But he got through. Isaiah was cured.

We became very close, Isaiah and I, through this time and for years after—long conversations about his life, his hopes, his worries. He always asked me about my kids. And his mother, close, as well. An angel—a tough angel raised by her sharecropper grandfather on a North Carolina farm, who read Isaiah the riot act when she had to and who fiercely protected him—and who, during the darkest times of his course, continued to tend her ten foster children, as well as her own.

I came to know Isaiah well, but it wouldn't be quite right to call us friends—our worlds were too far apart—different galaxies. But my respect and affection for Isaiah grew and grew. His courage. His insight. His generosity.

But there is more to tell.

Isaiah smoked his first dope at age 5. He got his first gun before 10, and, by 12, he had committed his first armed robbery; he was on crack at 14. Even on chemotherapy, he was in and out of police custody. For months after his transplant he tricked me into extra prescriptions for narcotics, which he hoarded and probably sold. Two of his five brothers were in jail—one for murder; and, two years into Isaiah's treatment, a third brother was shot dead—a gun blast through the front door—in a drug dispute.

Isaiah didn't finish school, and he had no idea of what to do for legitimate work. He got and lost job after job for not showing up or being careless. His world was the street corner and his horizon was only one day away. He saw no way out. He hated it, but he saw no way out. He once told me that he thought his leukemia was a blessing, because at least while he was in the hospital, he couldn't be on the streets.

And Isaiah died. One night, 18 years after his leukemia was cured, at 37 years of age, they found him on a street corner, breathing but brain-dead from a prolonged convulsion from uncontrolled diabetes and even more uncontrolled despair.

Isaiah tried to phone me just before that fatal convulsion. He had my home number, and I still have the slip of paper on which my daughter wrote, "Isaiah called. Please call him back." I never did. He would have said, "Hi, Dr Berwick. It's Isaiah. I'm really sick. I can't take it. I don't know what to do. Please help me." Because that is what he often said.

Isaiah spent the last two years of his life in a vegetative state in a nursing home where I sometimes visited him. At his funeral, his family asked me to speak, and I could think of nothing to talk about except his courage.

Isaiah, my patient. Cured of leukemia. Killed by hopelessness.

I bring Isaiah today as my witness to two duties; you have both. It's where your compass points.

First, you will cure his leukemia. You will bring the benefits of biomedical science to him, no less than to anyone else. Isaiah's poverty, his race, his troubled life-line—not one of these facts or any other fact should stand in the way of his right to care—his human right to care. Let the Supreme Court have its day. Let the erratics and vicissitudes of politics play out their careless games. No matter. Health care *is* a human right; it must be made so in our nation; and it is your duty to make it so. Therefore, for your patients, you will go to the mat, and you will not lose your way. You are a physician, and you have a compass, and it points true north to what the patient needs. You will put the patient first.

But that is not enough. Isaiah's life and death testify to a further duty, one more subtle—but no less important. Maybe this second is not a duty that you meant to embrace; you may not welcome it. It is to cure, not only the killer leukemia; it is to cure the killer injustice.

Antoine de Saint-Exupéry wrote, "To become a man is to be responsible; to be ashamed of miseries that you did not cause." I say this: To profess to be a healer, that is, to take the oath you take today, is to be responsible; to be ashamed of miseries that you did not cause. That is a heavy burden, and you did not ask for it. But look at the facts.

In our nation—in our great and wealthy nation—the wages of poverty are enormous. The proportion of our people living below the official poverty line has grown from its low point of 11% in 1973 to more than 15% today; among children, it is 22%—16.4 million; among black Americans, it is 27%. In 2010, more than 46 million Americans were living in poverty; 20 million, in extreme poverty—incomes below $11 000 per year for a family of four. One million American children are homeless. More people are poor in the United States today than at any other time in our nation's history; 1.5 million American households, with 2.8 million children, live here on less than $2 per person per day. And 50 million more Americans live between the poverty line and just 50% above it—the near-poor, for whom, in the words of the Urban Institute, "The loss of a job, a cut in work hours, a serious health problem, or a rise in housing costs can quickly push them into greater debt, bankruptcy's brink, or even homelessness." For the undocumented immigrants within our borders, it's even worse.

For all of these people, our nation's commitment to the social safety net—the portion of our policy and national investment that reaches help to the disadvantaged—is life's blood. And today that net is fraying—badly. In 2010, 20 states eliminated optional Medicaid benefits or decreased coverage. State Social Services Block Grants

and Food Stamps are under the gun. Enrollment in the TANF program—Temporary Assistance to Needy Families—has lagged far behind the need. Let me be clear: the will to eradicate poverty in the United States is wavering—it is in serious jeopardy.

In the great entrance hall of the building where I worked at CMS—the Hubert Humphrey Building, headquarters of the Department of Health and Human Services—are chiseled in massive letters the words of the late Senator Humphrey at the dedication of the building in his name. He said, "The moral test of government is how it treats people in the dawn of life, the children, in the twilight of life, the aged, and in the shadows of life, the sick, the needy, and the handicapped."

This is also, I believe, the moral test of professions. Those among us in the shadows—they do not speak, not loudly. They do not often vote. They do not contribute to political campaigns or PACs. They employ no lobbyists. They write no op-eds. We pass by their coin cups outstretched, as if invisible, on the corner as we head for Starbucks; and Congress may pass them by too, because they don't vote, and, hey, campaigns cost money. And if those in power do not choose of their own free will to speak for them, the silence descends.

Isaiah was born into the shadows of life. Leukemia could not overtake him, but the shadows could, and they did.

I am not blind to Isaiah's responsibilities; nor was he. He was embarrassed by his failures; he fought against his addictions, his disorganization, and his temptations. He tried. I know that he tried. To say that the cards were stacked against him is too glib; others might have been able to play his hand better. I know that; and he knew that.

But to ignore Isaiah's condition *not* of his choosing, the harvest of racism, the frailty of the safety net, the vulnerability of the poor, is simply wrong. His survival depended not just on proper chemotherapy, but, equally, on a compassionate society.

I am not sure when the moral test was put on hold; when it became negotiable; when our nation in its political discourse decided that it was uncool to make its ethics explicit and its moral commitments clear—to the people in the dawn, the twilight, and the shadows. But those commitments have never in my lifetime been both so vulnerable and so important.

You are not confused; the world is. You need not forget your purpose, even if the world does. Leaders are not leaders who permit pragmatics to quench purpose. Your purpose is to heal, and what needs to be healed is more than Isaiah's bone marrow; it is our moral marrow—that of a nation founded on our common humanity. My brother, a retired schoolteacher, tells me that he always gets goose bumps when he reads this phrase: "We, the people . . . " We—you, and me, *and* Isaiah—inclusive.

It is time to recover and celebrate a moral vocabulary in our nation—one that speaks without apology or hesitation of the right to health care—the human right—and, without apology or hesitation, of the absolute unacceptability of the vestiges of racism, the violence of poverty, and blindness to the needs of the least powerful among us.

Now you don your white coats, and you enter a career of privilege. Society gives you rights and license it gives to no one else, in return for which you promise to put the interests of those for whom you care ahead of your own. That promise and that obligation give you voice in public discourse simply because of the oath you have sworn. Use that voice. If *you* do not speak, who will?

If Isaiah needs a bone marrow transplant, then, by the oath you swear, you will get it for him. But Isaiah needs more. He needs the compassion of a nation, the generosity of a commonwealth. He needs justice. He needs a nation to recall that, no matter what the polls say, and no matter what happens to be temporarily convenient at a time of political combat and economic stress, that the moral test transcends convenience. Isaiah, in his legions, needs those in power—you—to say to others in power that a nation that fails to attend to the needs of those less fortunate among us risks its soul. That is your duty too.

This is my message from Isaiah's life and from his death. Be worried, but do not for one moment be confused. You are healers, every one, healers ashamed of miseries you did not cause. And your voice—every one—can be loud, and forceful, and confident, and your voice will be trusted. In his honor—in Isaiah's honor—please, use it.

Donald M. Berwick, MD, MPP

Author Affiliations: Former President and CEO, Institute for Healthcare Improvement; former Administrator, Centers for Medicare & Medicaid Services; and Department of Health Care Policy, Harvard Medical School, Boston, Massachusetts (donberwick1@gmail.com).

Conflict of Interest Disclosures: The author has completed and submitted the ICMJE Form for Disclosure of Potential Conflicts of Interest and none were reported.

Disclaimer: Dr Berwick is a member of the *JAMA* Editorial Board and was not involved in the editorial review of or the decision to publish this article.

Additional Contributions: Thanks to Clifford Marks for help with research on statistics. He was not compensated for this work.

Editor's Note: This speech was given at the Harvard Medical School Class Day, Boston, Massachusetts, May 24, 2012.

Altruism, Self-interest, and Medical Ethics

Nothing more exposes a physician's true ethics than the way he or she balances his or her own interests against those of the patient. Whether the physician is refusing to care for patients with the acquired immunodeficiency syndrome (AIDS) for fear of contagion (the subject Zuger and Miles[1] discuss in this issue of *JAMA*) or withdrawing from emergency department service for fear of malpractice suits, striking for better pay or fees, or earning a gatekeeper's bonus by blocking access to medical care, the question raised is the same. Does medicine entail effacement of the physician's self-interests—even to the point of personal and financial risk? Is some degree of altruism a moral obligation, or is nonmaleficence the limit of the physician's mandatory beneficence? How far does physician advocacy go?[2] What does the concept of physician as advocate mean?[3]

See also p 1924.

As Zuger and Miles' article points out, although the question is not new, the historic and ethical precedents are inconsistent. Even now, with respect to caring for AIDS patients, the guidelines are confusing. Item VI of the current American Medical Association Principles affirms the physician's right to choose whom to treat. The Ethical and Judicial Council acknowledges the tradition to treat but permits "alternate arrangements" for physicians emotionally unable to comply. On the other hand, the American College of Physicians and the Infectious Disease Society of America are unequivocal about the physician's duty to treat.[4]

These inconsistencies cannot be resolved without a more explicit choice between two fundamentally opposed conceptions of medicine itself. One conception calls for self-effacement by the physician, while the other accommodates physician self-interest. Not to choose between these two is to reinforce the cynics, discourage the conscientious, and undermine the moral credibility of our whole enterprise. Some of us would argue that there is a right answer, but that a wrong answer is more honest than no answer at all.

The arguments of those who defend refusals to care for AIDS patients are several: AIDS was not in the social contract when they entered medicine, obligations to self and family override obligations to patients, physicians who contract AIDS are permanently lost to society and their patients, treating patients when one is fearful or hostile only compromises their care, some physicians are emotionally unable to cope, and house staff carry an unfair share of the risks.

Leaving aside the fact that the risks of contagion are disproportionate to the fear, these arguments are cogent only if we accept the conception of medicine that undergirds them, ie, medicine is an occupation like any other, and the physician has the same "rights" as the businessman or the craftsman. Medical knowledge belongs to the physician to be dispensed in the marketplace on terms set by its owner. Being ill and in need of care is no different from needing any other service or commodity. Competence and avoidance of harm are all that can legitimately be demanded of physicians.

Zuger and Miles lament the inadequacy of current models of the physician-patient relationship in countering this conception of medicine. They rely on a return to the virtuous physician who will instinctively grasp the duty of altruism. Necessary as virtue is to medical ethics, it is not sufficient. It is always a scarce commodity and its definitions vary depending on the conception of medicine that we use to set the standard of virtue. It is the conception that altruism is nonobligatory that is erroneous—not the arguments built on it.

There are at least three things specific to medicine that impose an obligation of effacement of self-interest on the physician and that distinguish medicine from business and most other careers or forms of livelihood.[5]

First is the nature of illness itself. The sick person is in a uniquely dependent, anxious, vulnerable, and exploitable state. Patients must bare their weakness, compromise their dignity, and reveal intimacies of body and mind. The predicament forces them to trust the physician in a relationship of relative powerlessness. Moreover, physicians invite that trust when offering to put knowledge at the service of the sick. A medical need in itself constitutes a moral claim on those equipped to help.

Second, the knowledge the physician offers is not proprietary. It is acquired through the privilege of a medical education. Society sanctions certain invasions of privacy such as dissecting the human body, participating in the care of the sick, or experimenting with human subjects. The student is permitted access to the world's medical knowledge, much of it gained by observation and experiment on generations of sick persons. All of this, and even financial subsidization for medical education, is permitted for one purpose—that society have an uninterrupted supply of trained medical personnel.

The physician's knowledge, therefore, is not individually owned and ought not be used primarily for personal gain, prestige, or power. Rather, the profession holds this knowledge in trust for the good of the sick. Those who enter the profession are automatically parties to a collective covenant—one that cannot be interpreted unilaterally.

Finally, this covenant is publicly acknowledged when the physician takes an oath at graduation. This—not the degree—is the graduate's formal entry into the profession. The oath—whichever one is taken—is a public promise that the new physician understands the gravity of this calling and promises to be competent and to use that competence in the interests of the sick. Some degree of effacement of self-interest is thus present in every medical oath. That is what makes medicine truly a profession.

These three things—the nature of illness, the nonproprietary character of medical knowledge, and the oath of fidelity to the patients' interests—generate strong moral obligations. To refuse to care for AIDS patients, even if the danger were much greater than it is, is to abnegate what is essential to being a physician. The physician is no more free to flee from danger in performance of his or her duties than the fireman, the policeman, or the soldier. To be sure, society and the profession have complementary obligations to reduce the risks and distribute the obligation fairly. However, physicians and other health professionals cannot avoid the obligation to make their knowledge available to all who need it.

Two divergent conceptions of medicine oppose each other in

medical ethics today. One entails self-effacement, the other rejects it. What the AIDS epidemic and, in their own ways, the commercialization of medicine have done is to force an explicit choice. To make that choice, we need something we do not yet have—a moral philosophy of medicine, something that goes beyond professional codes, or the analysis of ethical puzzles. What is called for is a return to the normative quest of classic ethics—the quest for what it is to be a good physician and for what kind of person the physician should be.

This is the enterprise to which the Spanish philosopher José Ortega y Gasset called us more than a half century ago: ". . . but perhaps in no medical school the world over is there anyone seriously occupied with what it really means to be a good physician, what the modal type should be in our times."[6]

Edmund D. Pellegrino, MD
Joseph and Rose Kennedy Institute of Ethics
Georgetown University
Washington, DC

1. Zuger A, Miles SH: Physicians, AIDS, and occupational risk: Historic traditions and ethical obligations. *JAMA* 1987;258:1924-1928.
2. Sade R: Medical care as a right: A refutation. *N Engl J Med* 1971; 285:1288-1292.
3. Hotchkiss WS: Doctor as patient advocate. *JAMA* 1987;258:947-948.
4. Health and Public Policy Committee, American College of Physicians and the Infectious Disease Society of America: Acquired immune deficiency syndrome. *Ann Intern Med* 1986;104:575-581.
5. Pellegrino ED, Thomasma DC: *The Good of the Patient: The Restitution of Beneficence in Medical Ethics.* New York, Oxford University Press Inc, in press.
6. Ortega y Gasset J: *Mission of the University,* Nostrand HL (trans-ed). New York, WW Norton & Co Inc, 1944, p 64.

Patients Without Physicians: The New Risk of AIDS

Into whatever houses I enter I will go into them for the benefit of the sick and . . . while I continue to keep this oath unviolated may it be granted to me to enjoy life and the practice of the art, respected by all men at all times but should I trespass and violate this oath, may the reverse be my lot.

Oath of Hippocrates

It has often been remarked that "professionals" are those whose vocational objectives are to remove their own reason for existence. The dentist tries to eliminate dental caries; the physician attempts to wipe out disease. A profession can be distinguished by its altruistic goals: the educating of the young, the protection of the innocent, the healing of the sick, or the comforting of the soul. In fact, a "professional," unlike a person who chooses another career, is one who "professes," who takes an oath, a sacred vow . . . *I swear by Apollo the physician.*

See also p 1924.

And there exists an indelible element of self-sacrifice surrounding anyone who aspires to one of the learned professions. It can be argued that students of medicine are not only well aware of the arduous hours ahead of them, but that this heroic life-style may be one of medicine's attractions.

In particular, physicians understand that theirs is a profession in which they must expend a great deal of their time if they wish to become skilled enough to be allowed to practice its art. Students are also indoctrinated in the tradition that they in turn must give a portion of their lives to the teaching of other acolytes . . . *and to teach them this art if they should wish to learn it.*

In exchange for the long hours and psychological stresses, they will be honored as ones who serve their fellow man. Physicians are entrusted as no other group with the inner thoughts and secrets of those to whom they administer . . . *whatever I may see or hear in the lives of men which ought not to be spoken abroad I will not divulge.*

This trust stems from both the unspoken contract established between physician and patient and the admiration felt for anyone who chooses the heroic path—the respect we have for the person who adheres to moral and ethical principles . . . *with purity and with holiness I will pass my life and practice my art.*

But medical students also learn from the beginning that to aspire to be a physician is not without physical and emotional risk. They will be continually confronted with the unpleasantness of infirmity and disease. By the nature of their craft, they will be inextricably linked to the fears and hopes of their patients, and experience the pain of watching others suffer and die. Indeed, they continually put themselves at risk for contracting whatever disease afflicts those for whom they are caring.

In this issue of THE JOURNAL, Zuger and Miles[1] discuss the history of physician reaction and behavior when confronted by potentially communicable diseases. That behavior has at times been less than admirable, but the fear demonstrated in past epidemics was at least explicable in light of their profound ignorance of disease transmission, or even the existence of microorganisms.

Perhaps the fear of contracting AIDS on the part of some physicians would also be explainable if it were not for our understanding of viral diseases and in particular the epidemiology of the human immunodeficiency virus (HIV). The virus itself is neither particularly contagious nor hardy. Its modes of transmission are extremely limited, and it seems to be easily susceptible to the most common of antiseptic procedures. But the fear that AIDS engenders apparently stems from the fact that infection with the virus will likely lead in time to fatal immunosuppression.

It would be cavalier to suggest that absolutely no risk exists when caring for a patient harboring HIV infection, but in reality the chances of infection even after the most careless of exposures remain slight. In fact, physicians for years have chanced contracting hepatitis B viral infection, whose risk of exposure is many times higher and for which a preventive measure (hepatitis B vaccine) exists but is seldom taken advantage of.

What, then, should be the attitude of physicians in taking on the responsibility of treating patients with HIV infection? Some would opt for avoiding even the smallest of risks and transferring the responsibility to another physician. Others, realizing that the risk is minuscule, will take ordinary precautions and treat those patients no differently from anyone else with an infectious disease. And there are those who will take up the challenge of personal risk and, putting the patient's welfare ahead of their own, will reaffirm their vow to serve their fellow man . . . *I will follow that method of treatment which, according to my ability and judgement, I consider for the benefit of my patients.*

Bruce B. Dan, MD

1. Zuger A, Miles SH: Physicians, AIDS, and occupational risk: Historic traditions and ethical obligations. *JAMA* 1987;258:1924-1928.