

FROM
THE HEART

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My Transcatheter Aortic Valve Replacement

Before I retired, I led small discussion groups with second-year medical students on the topic of medical ethics. The lectures often focused on the big 4 of bioethics: autonomy, beneficence, nonmaleficence, and justice. Autonomy—the patient is the decision maker—was emphasized most. Beneficence and nonmaleficence seemed obvious to the students—justice came last.

I thought I was knowledgeable about the topic, but something happened that made me realize I had more to learn. Up until then, bioethics had mainly been a head-knowledge topic for me. That something was aortic valve replacement using a catheter technique, the transcatheter aortic valve replacement (TAVR).

I had known for years that I had a bicuspid aortic valve. Annual echocardiograms showed I was developing moderate aortic stenosis. One day I nearly passed out after walking up a couple of flights of steps at a museum an hour and a half from home. It worried me enough that I paged my cardiologist on the spot. He scheduled another echocardiogram, which I underwent the next day. My aortic stenosis had become severe. As a cardiologist, I knew the implications of untreated symptomatic aortic stenosis: an increased chance of heart failure and death. I had 2 options. One was open-heart valve replacement, the other, TAVR. My cardiologist left the decision to me, and I opted for the less invasive TAVR. I was taken to the catheterization laboratory and my aortic valve was replaced. I was home in 2 days and had no more episodes of presyncope.

I was grateful. I'd been treated promptly, had sailed through the procedure with no complications, and had been able to have the new valve put in place without being put to sleep, having my chest cracked open, and being put on cardiopulmonary bypass.

Up to that point, it seemed like what I taught and believed about bioethics all hung together. It was I who made the decision to have the less invasive TAVR rather than open heart surgery to replace the aortic valve. I was fully informed about my options. My cardiologist's aim was to do good, and he did. He didn't want to do harm, and he didn't. Check them off. Autonomy, beneficence, nonmaleficence.

But as I reflected on what had taken place, it suddenly hit me: what about that fourth element of bioethics? What about justice? I imagined a woman from a low-income country, out of breath lugging home 2 buckets of water from a stream a mile away, who has no physician to see. If there was a physician, and she was found to have aortic stenosis, she'd have no option for aortic valve replacement. Where was the justice?

Then a week after I returned home, I received the bill for the procedure: a half a million dollars! The price of the valve alone was \$430 000! That had to be wrong. Wasn't it "only" \$43 000 and I had just misread the bill? So, I called billing. Yes, it was \$430 000. What if I was

uninsured? I would have gotten a 55% discount; I would have owed "only" \$200 000. Billing would have worked out a schedule of payment for me. I had a new appreciation for the call I received from my insurance company, before the procedure, saying my valve replacement was approved, and the cost would be covered.

Now, I thought, not just about the woman out of breath lugging buckets of water up from the stream, but about the man who maybe lived in the same city as me, less than 5 miles away, with no medical insurance who opened his mail 3 weeks after his TAVR and saw that 6-digit number. Would he have to declare bankruptcy? Work at paying off the bill until he dies, then pass on the payments to his kids? Maybe he had the choice but opted out of medical insurance. Maybe not. Maybe he had purchased all the insurance he could afford, and that insurance didn't cover a TAVR, or only a small portion of the bill. Was he aware of the trade-off he had made by living in a country in which he would have to mortgage his house to get the needed procedure? Had he known of the cost, perhaps he would have opted not to have his valve replaced.

What about the fairness of charging nearly half a million dollars for an item that arguably cost tenths of the asking price? Yes, as a physician I understand research and development and the cost of studies to determine the safety and efficacy of a new treatment, but still. (And it also made me think: how many patients have I referred for TAVR, not having any idea if they did or did not have medical insurance? Had I known the cost of the valve and procedure, would that have changed anything?)

In health care, justice in part refers to the philosophical concept that all persons should be treated fairly and equitably. As I thought about the various theories of distributive justice,¹ I wondered how they might apply to my situation. The libertarian concept posits that each person is responsible for his or her own health. Everyone pays, directly or indirectly, for their own health care needs and is not responsible for the health care of others. Fine, I suppose, if everyone has the ability to pay. I could pay but certainly the way our health care system is set up, not everyone can.

The communitarian concept is not based on the individual but on what is best for society at large. This is related to the notion of what is considered "necessary" health care—is a TAVR in a symptomatic 75-year-old man necessary? If so, it's not making it available to all in the society, or if it is available, at a higher cost for some than others.

The egalitarian view on justice is that there ought to be equality among all citizens. That is, if the procedure is available and beneficial to some, then it ought to be available to all who are similarly situated. Our health care system is certainly not egalitarian, and outside our own health care system, the fact that the woman laden with pails of water would not even have the procedure

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available means, quite obviously, that the world system of health care is not egalitarian either.

And then there's the utilitarian variation. Utilitarians contend that fairness occurs when the distribution of services results in the greatest good for the greatest number. In the case of TAVR, decisions about laying out money for the interventions are based on a calculation about how to benefit the most people and prolong the most life (perhaps correcting for quality of life). What happened to me doesn't fit that scheme: half a million dollars to maybe prolong my life another 6 months, if that.

This makes me uneasy for a number of reasons. I benefited from a procedure that cost me little beyond my monthly insurance payment. Some in our country may opt to not have the procedure because they cannot afford it or do so at great financial burden. Some, in other parts of the world, do not have the option to have it done at all.

I am sure my salary, over the years before I retired, was higher than it would have been had items like prosthetic aortic valves been

less costly. Would I have been willing to take a pay cut to make a TAVR more affordable and more available? Despite the injustice I so well recognize, I let them take me to the cardiac catheterization laboratory and replace my aortic valve with one that costs \$430 000, and if the situation arose, I'd do it again.

I no longer facilitate discussions of ethical issues with second-year medical students. But if I did, after this experience, I wonder what I would do. I think Paul Farmer, the physician-anthropologist who recently died, was right when he said, of the medical ethics taught to medical students in the US: "The countless people whose life course is shortened by unequal access to health care are not topics of discussion."^{2(p174)} I wonder what Paul Farmer would have done had he been the one with symptomatic aortic stenosis. He'd probably have done more than write about it. Part of me would use my case to spark discussion, part of me would be hesitant to do that. How would I justify the preferential treatment I received? I am uneasy because there seems to be little I can do about this injustice—or am willing to do.

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1. Roemer J. *Theories of Distributive Justice*. Harvard Press; 1996.

2. Farmer P. *Pathologies of Power. Health, Human Rights, and the New War on the Poor*. University of California Press; 2005.