

The Road Less Traveled

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My heart was removed and replaced on May 17, 2006. No melodrama is intended here, just an unadorned factual statement. Transplants are transformative. In my case, that transformation led to bioethics.

Am I part of the new, younger generation of bioethicists? No. I reside at age 68, which, if anything, is somewhere at the end of the currently active generation. In Robert Frost's poem "The Road Not Taken," the traveler must choose between two roads. This is the story of my choice: how I got here, why I set out to involve myself in bioethics, and what I have done in the field.

Grateful patients often find themselves in love with healthcare. This love affair sometimes takes the form of philanthropy or of a career change. In my case, I never set out to change my career, and philanthropy is beyond my means. Rather, people and events converged to suggest bioethics as the basis for a newly extended life.

The transplant occurred at age 63, after 13 years of forced early retirement from a career as a corporate lawyer. After a massive myocardial infarction, my heart function slowly declined, reaching the point at which it produced 15 percent of the normal volume of oxygenated blood. Physical and mental fatigue, symptomatic of heart failure, led to an increasingly limited life. Then, in 2006, I received a different heart. (I never call it "new," because it came from someone else.)

From the first moment of consciousness, and even with the aftereffects of

surgery and an opened chest still raw, there is a sense of energy and clarity of thought. The heart is pumping blood at a normal rate to all of the limbs and the brain. Large doses of prednisone add impatient surges of energy. One doctor put it this way: "No one wakes up from a heart transplant and complains."

The literature speaks of transplantation as physically transformative. For me, the transformative effects reached beyond my physical condition. During recovery in the hospital, a transplant recipient learns the lifelong regimen of required medications. The nursing staff repeats a mantra: "You have a responsibility to take care of your heart." They mean always taking cyclosporine and other antirejection drugs and giving attention to diet and exercise. I understood that. But the nurses' words prompted another interpretation.

I have someone else's heart. It is an extraordinary, powerful fact; something I think about every day. My responsibility is to use my newly extended life in a way oriented to people as opposed to business or corporate needs. Who wants an epitaph that says, "He wrote the longest, best contract in the world?" I needed a new beginning. If this sounds trite, then it is because transplants create an opportunity for mind and body alterations understood best by those who have had the experience.

After a year of posttransplant infections and a cascade of side effects from powerful drugs used to treat these infections, an active life became possible. My cardiologist, a renaissance man, is

an expert beyond competence in his field, someone interested in art, literature, and music, and a compassionate and kind physician possessed of practical wisdom. He has all the characteristics and virtues used to define the “good doctor.”

At one appointment he and I discussed my future. Medical school was out; I was too old. Nursing seemed attractive. “We need good nurses,” he said. But, as he cleared his throat, his lack of enthusiasm was evident. He knew me better than I knew myself. (Besides, I was still on heavy doses of prednisone.) Then, he handed me a paper, “Beyond the Physician Charter.”¹ The paper compares duty-based and virtue-based medical professionalism.

What ethical obligations accompany the privilege of practicing medicine? What defines a good doctor? I know something about that subject. Technical competence and a sense of duty limited by that competence are not enough. More is required. Bioethics seemed to provide the intellectual heft and the opportunity for practical and even immediate impact on patient care.

Following this conversation, I enrolled in the M.A. program offered by the Department of Bioethics at the Case Western Reserve University Medical School (CWRU). At age 66, on the third anniversary of my heart transplant, I received my degree. Now, like the traveler in Robert Frost’s poem, I face reality and the choices carried with it: what to do with my degree. At the moment I’m following two parallel, hopefully not diverging, paths.

The first draws on my intensive experience as a patient. My cardiologist friend suggested that I speak as the voice of the patient, informed by my background in law and newly acquired “expertise” in medical ethics.

Not surprisingly, I was drawn to the ethics of a physician’s response to a patient who no longer wants the life-sustaining

therapy provided by an implanted cardiovascular device (e.g., a pacemaker, ICD, or multipurpose device). This issue first confronted me when I attempted to discuss deactivation of the pacemaker that had been implanted in my 102-year-old mother when she was 99. No dice. As my illness progressed, I, too, thought that a shorter life of quality and dignity might be preferable to the punishing, continuing burden of illness.

A minority, but an extremely vocal group, of physicians resists patient decisions to deactivate pacemakers, although ICD deactivation is now generally accepted. They see the possible death of a patient after withdrawal of device therapy as a form of “killing.” In contrast, mainstream medical ethics recognizes that deactivation is another instance of withdrawal of life-sustaining treatment (such as withdrawal of ventilator therapy), and death in this circumstance is the underlying cardiac or other disease.

I addressed this subject in an article published in June 2009 issue of *Circulation-Arrhythmia and Electrophysiology*. The article summarizes the reasons for concluding that deactivation is ethical in response to an authentic decision made by an informed patient or surrogate. And, as a patient representative, I was appointed to a writing group designated by the Heart Rhythm Society to produce guidelines for the deactivation of cardiovascular implanted devices. Our work culminated in publication of these guidelines in June 2010.

Have I had an impact on the patient’s right of self-determination? I think so and see this effort as a start in fulfilling the obligations that came with my transplanted heart. The challenge now is to use the limited time available to me in a measured, important way.

My second, but by no means secondary, path in medical ethics involves the bioethics program at CWRU. No

question, I was the senior student by 35–40 years and could have fathered all of my classmates and some of the professors. Most of the younger students were smart and all had backgrounds in the sciences. But they demonstrated no meaningful knowledge of poetry, fiction, or even the famous medical authors. I was astounded. Unlike my classmates, I frequently saw parallels or could draw insightful references to literary classics, films, and paintings that illuminated ethical issues.

Struck by this gap, I proposed a program to introduce the M.A. candidates to examples of literature and art that could be used as platforms to discuss bioethics. For example, I use Toni Morrison and Zora Neale Hurston as springboards to discuss discrimination in medical practice as it impacts on access to care and adverse outcomes for minority populations. Abraham Verghese's book *My Own Country* is now required reading before classes begin. The book introduces the foundation bioethics course and deals with such topics as confidentiality, end-of-life decisions, the physicians' obligation to treat, and disclosure requirements for informed consent.

The humanities have a new missionary. I bring civilization to those students who

know much about molecular biology and genetics but little about the atrocities committed during World War II. All of my material emphasizes our shared responsibility for one another, medicine as patient centric, the universal love of families, and the effects on patients of compassion, kindness, and even a simple touch. I am a shameless advocate of the virtue-based practice of medicine.

My small initiative is not groundbreaking. But I'm doing it, and some of the students (I hope most) like the readings and art. I've opened the eyes of these students; they will be better nurses, physicians, and bioethicists for it.

My life is now in an unexpected second chapter. With that life comes an obligation to use it. In Frost's poem the traveler faces two diverging roads:

Two roads diverged in a wood, and I—
I took the one less traveled by,
And that has made all the difference.

I could have chosen a life on the beach.
Instead, I chose the bioethics road.

Note

1. Swick H, Bryan C, Longo L. Beyond the physician charter: Reflections on medical professionalism. *Perspectives in Biology and Medicine* 2006;49(2):263–75.