In this series of essays, The Road Less Traveled, noted bioethicists share their stories and the personal experiences that prompted them to pursue the field. These memoirs are less professional chronologies and more descriptions of the seminal touchstone events and turning points that led—often unexpectedly—to their career path.

Murder, Sex, Neonates, and Other Forays into Bioethics

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When asked by a former student—who is now a deputy district attorney of Santa Clara County, California—to give an after-dinner speech on bioethics and the law to some 150 lawyers and judges, I inquired what specific topic would be of interest. He replied, "I've looked over your curriculum vitae. You are into murder, sex, neonates, and the economics of healthcare delivery. Skip the economic stuff—and explain how a Jesuit priest got involved in such things."

I certainly did not set out to get into bioethics. In fact, there was no such field when I finished my graduate studies. My interests were social ethics and constitutional law. My concern about the role of courts getting involved in disputes between families and physicians on medical decisionmaking led to an article on how decisions are made by courts for the never-competent patient. The case, *Superintendent of Belchertown State School v. Saikewicz*[1] involved a profoundly retarded man who had been institutionalized all his life. At age 67 he was diagnosed with leukemia. The dilemma facing the physicians at the University of Massachusetts Medical School was whether or not to attempt chemotherapy treatments on a patient who had a 30–40 percent chance of a 3- to 13-month remission of his cancer. The difficulty was that Mr. Saikewicz strenuously resisted attempts to insert the IV lines needed to administer the chemotherapy. As his treating physician noted, almost all competent patients with leukemia elect treatment. Should Mr. Saikewicz, because of his limited mental status, be denied similar care? "Wouldn't," they asked, "such action devalue the life of the cognitively impaired and thus constitute discrimination against the retarded?"

The Massachusetts Supreme Judicial Court, in its landmark *Saikewicz* decision, ruled that by the process of "substituted judgment" the court could "don the mental mantle of the incompetent" and discern what the never-competent Joseph Saikewicz would want. It determined that because Joseph Saikewicz would experience the pain of treatment without any of the hope that leads competent patients

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to elect the burdensome treatments, he would not want the treatment. The court went further and ruled that in every case of withholding or withdrawing life-sustaining treatment from a now-incompetent patient—including those who were once competent—a probate court must make a judicial finding through the process of "substituted judgment" to determine whether or not the treatment should be withheld or withdrawn.

That officious and gratuitous intrusion of the judiciary into the daily practice of medicine struck me as not only wrong but also totally misguided. At the time I was teaching social ethics and constitutional law at Holy Cross, which, like UMass Medical School, was located in Worcester, Massachusetts. Being an academic, I did what college faculty do: I wrote an article on the topic. It was entitled "Decision Making on Withholding Life-Support Treatment for the Mentally Incompetent."[2] That essay, which was focused on the untoward consequences of courts being thrust into end-of-life decisionmaking, was read by an attorney. She showed it to her husband, Ed Landau, who was a gastroenterologist at UMass Medical School. Dr. Landau was intrigued by the question of decisionmaking for the never-competent and invited me to discuss the topic with a dozen or so young residents. I did. Apparently Dr. Landau found the talk of broader interest, because several weeks later he called and asked if I would give grand rounds on the topic to the some 200 physicians in the Department of Internal Medicine.

I demurred. I told him that such a lecture would be exactly what I had been criticizing judges for doing: speaking in areas in which they had no expertise. Dr. Landau then asked a question that radically altered my life: "How would you like to learn some medicine?" He volunteered that his program did attending rounds on Tuesdays from 1:00 to 3:00, in which the faculty reviewed particularly challenging cases on their service. He invited me to join the group.

Those rounds soon led to meetings with the oncology and palliative care teams and then an encounter with an incredibly thoughtful and caring surgeon, Garry Fitzpatrick. Dr. Fitzpatrick had me accompany him to all his meetings with his patients so I'd see medicine from the patient's perspective. The hopes, fears, successes, and failures—all must be experienced, he explained, if one is to comment on "what should be done." For Fitzpatrick medical ethics was not an abstract theory; it was the practical involvement of the physician with the patient in some of life's most demanding choices.

For several months my "education" continued, until one day during regular gastroenterology rounds I was asked my opinion on whether or not an elderly woman in hepatorenal failure who had contracted pneumonia should be treated with antibiotics. I protested I was just there to "learn." "Your learning cycle is over," intoned the chief of gastroenterology, Greg Eastwood. One physician questioned the wisdom of prolonging the dying. Another replied that antibiotics were "ordinary" means and could never be withdrawn. I was supposed to play Solomon and provide the wisdom that would resolve the dispute. Rather than turning to Aristotle or Kant for insights into how to resolve the question, I turned to my Irish Catholic tradition for insight and guidance. I asked, "What will happen if we give their patient, an elderly Irish Catholic woman, five-star treatment?" Dr. Eastwood replied that she would, at best, survive a couple of more weeks in her comatose status.

I then projected the discussion into the future. Two weeks from now she will be laid out at Callahan Brothers Funeral Home. What will be the response of the

family and friends who come to the wake? The comments, as those who have ever attended the wake of an elderly Irish Catholic woman can attest, would be something to the effect of, "Doesn't she look wonderful. She looks just like herself." And then, "It is a blessing. At last she is at peace. Thank God her suffering is over."

I then asked how the woman's two middle-aged daughters would reply if Dr. Eastwood informed them at the wake that there was a new miracle drug that could restore their mother to exactly the way she was two weeks ago. They would think he had gone mad. Of course they would not propose bringing their mother back to reexperience the misery of her final two weeks in the ICU. My query then to the assembled team of physicians was, "If it is crazy in retrospect to restore the corpse to her present status for two more weeks of dying, why do we think it an ethical imperative to utilize antibiotics to produce the same result today?"

Thus began my career in medical ethics. It began not with great theoretical insights from philosophy, theology, or the law but with the caring concern for the human dimension of living and dying that I learned from my grandmother at an early age as I witnessed her caring and comforting her elderly sisters through the end of life's journey.

Narrative ethics—not abstract theories, legal fantasies, or philosophical distinctions—provide the basic insight. The rest can be filled in as needed. Those insights likewise guided my initial foray into the courts, that area which, for woe or weal, we Americans use to resolve our moral dilemmas. That tendency, which was first noted by Alexis de Tocqueville in the 1830s,[3] transforms moral dilemmas into legal disputes, as if judges, unlike the rest of us mere mortals, can somehow resolve the mysteries of life and death dispassionately and definitively.

The first of what are now more than 70 court cases in which I've been involved concerned a 21-year-old woman, Melanie Bacchiochi, who had suffered an anesthesia accident in the dentist office while undergoing the extraction of her wisdom teeth. The diagnosis at the hospital in Stafford Springs, Connecticut, was brain death. Her husband requested the ventilator be removed, but the treating physician, in the absence of a statue recognizing brain death, would not do so without a court order or a grant of immunity. He did not want to be charged with murder. During some several hours of testimony before a judge who personally questioned me directly for more than two hours, I noted that if we were to transport the patient some 10 miles across the border into Massachusetts, the patient would be "dead." Would putting the ambulance in reverse after crossing the border, I asked, produce her resurrection? That inquiry forced us to realize that the primary question in ethics ought not be "What should we do?" but "What is going on? What is the status of the patient? How will our involvement alter that status? To what end?" The judge in the *Bacchiochi* case ruled that, under the Uniform Anatomical Gift Act, if the patient had checked "organ donor" on her driver's license, she would have waived her common law "right" to death by irreversible cessation of heart and lungs, and her vital organs could be harvested. But because Melanie Bacchiochi had not done so, he ruled, she could not be considered dead in Connecticut.

That finding, bizarre in itself, did not resolve the issue of withdrawal of the ventilator. The resolution occurred only when the judge was persuaded that he should not order the removal of the ventilator, thereby transferring a medical decision into a legal one, nor should he grant immunity for the doctor's action, a step that would encourage physicians to petition the court for a protective order every

time a difficult decision arises. Rather, he should return the issue to the treating physician and ask him to make a decision that was consistent with the appropriate care of someone in the patient's condition. If the primary care physician did not know the proper "care" for a brain-dead individual, there were many physicians in the state who did. They are called neurologists. That evening, with the husband present at his wife's side, the treating physician disconnected the ventilator from the brain-dead woman. Moments later, when the heart monitor produced a flat line, the physician pronounced the patient dead.

The role of the ethicist in court hearings can prove problematic for bioethicists. The danger is that they will be nothing more than hired guns—the equivalent of the psychiatrists who, for a sufficiently high fee, can be found to defend any side of an issue. Training in ethics does not by itself qualify one to discuss any ethical issue. My practice when approached by attorneys seeking my testimony as an expert in bioethics is to tell them I'll do three things: I will review the materials to see if there is an ethical issue; I will let them know if I think an ethicist would be helpful to their side; and I will let them know if I am willing to be the expert.

The danger that lurks in the courtroom for a bioethicist is that one might go beyond the areas in which one has a depth of knowledge or experience. One example will suffice as a warning about the road best not traveled.

I received a call from an attorney who told me he represented a cardiovascular surgeon who had heard me speak at a surgical conference and wanted me to testify on his behalf. It turned out the procedure under question was not a cardiovascular surgery but phalloplasty. This took place in the era before we were regularly bombarded with advertisements on erectile dysfunction, and I naïvely had to inquire what phalloplasty was. On learning that it involved penile enlargement and girth enhancement, I immediately replied "NO." I could see the tabloid headlines: "Jesuit Testifies Longer Is Better."

When pressed by the defense lawyer to assess the plaintiff's claim that a $750 nonrefundable down payment before gaining an appointment with the surgeon—in which the patient would learn that the procedure involved not only the cutting of the suspensory ligaments but also the wearing of two-pound weights four to six hours a day for four months to assure that the "enhanced length" was not lost to surgical contractions—violated the free and voluntary characteristics required for a contract, I (once I regained enough composure to respond) told the defense lawyer that I agreed with the plaintiff. There ended my involvement in that case.

My journey into bioethics has involved deeply satisfying opportunities to help patients and families wrestle with and resolve moments of deep crisis. Being present in the NICU to baptize a 420-gram newborn whose life was destined to be measured in minutes not years, guiding parents though the maze of issues to a decision on whether or not to undertake a Norwood procedure on their child born with hypoplastic left heart, or convincing a physician of the truth of John Milton's insight that "they also serve who only stand and wait"—at a time when God is summoning a dying person home—is a priestly calling of the highest order.

The worlds of theory and of practice, of law and of medicine, and of the practical and the problematic—death and dying, genetics, managed care, the human genome project, and new forms of reproduction—all are material for articles, lectures, conferences, and policy formulations. It has been a grace to have been given the opportunity to explore, examine, and participate in such topics.

The book of Acts tells us that Paul of Tarsus was struck by a bolt of lightning and fell to the ground before his conversion. Fortunately, my journey into bioethics involved nothing more than responding "yes" to Dr. Landau's inquiry, "Would you like to learn some medicine?" That "yes" led to a road that, once taken, has proven to be both a human and a spiritual venture.

Notes

1. *Superintendent of Belchertown State School v. Saikewicz*, 373 Mass 728, 370 N.E. 2d 417 (1977).
2. Paris JJ. Withholding life support treatment from the mentally incompetent. *Linacre Quarterly* 1978;45:237–48.
3. De Tocqueville A. *Democracy in America*. New York: Oxford University Press; 1947.