

How I Lost—or Found?—My Way in Bioethics

DANIEL CALLAHAN

When I was invited some months ago by Tomi Kushner to contribute my memories on how some of us early birds came into bioethics, I hesitated. At the end of 2013 I published a memoir of my life in bioethics over nearly 50 years: *In Search of the Good: A Life in Bioethics* (MIT Press). I felt I had said all I wanted to say in that book about my life and couldn't imagine doing it again, even in a short article. I was terminally bored with the topic—me.

But as time went on I realized that something unnoticed, even by me, had changed in my thinking and writing in recent decades, something that almost but not quite pushed me to its borderlines—and that was not touched on directly in my memoir. I had drifted toward large-scale policy issues, well removed from clinical and biological topics. In some four books in recent years—on rationing elder healthcare, the limits of medical progress, the relationship between medicine and the market, and the economic hazards of endless medical technological innovation—I rarely used the word “ethics,” or cited authors in bioethics, or overtly framed the issues as ethical dilemmas or problems. But, then again, as I explain in greater detail below, I actually did see them as ethical problems, but of a different kind than in most bioethics. My interest was (and remains) focused on how necessary changes and reforms in society that require fundamental shifts in deeply embedded values, behavior, and ways of life can be brought about. There are surely some analogies in mainline bioethics, such as working to change the science-oriented culture of medical education and practice to a more patient-oriented culture, but my interest is in changing whole societies. I had served at Harvard as an assistant to a professor interested in the way societies are shaped, and that was no doubt where the seeds of an interest in culture were planted. It took 20 years for them to germinate.

But before continuing with that story, let me give the short version of my beginnings and how much of my work thereafter came about. Life, it turns out, can change, shape, and reshape a person as it moves along. Inspired by Socrates the gad fly, I decided to get a degree in philosophy. I chose Harvard after no investigation whatever into its philosophy department. I thought the campus was beautiful, and Yale (the hot department in those days) had turned me down. Once there, I discovered that the Harvard philosophy department was in the tight grip of Oxbridge analytic philosophy, which I had not heard of before I arrived on campus. It was big on concept and language analysis, thought experiments, and, even in ethics, a total dissociation from ordinary human life. I was warned to stay away from a course on existentialism, which would give me black eye with the other professors. As for my hero, Socrates, and my desire to ask questions and make trouble in the marketplace, one of my professors put down those ideas by, in effect, telling me, “We don't do that kind of thing anymore here kid.” That experience convinced me I did not want a career in academic philosophy. I got my Ph.D.

but then went to New York, got a job as a magazine editor there, and, along the way, did some university stints as a visiting professor, one of which was at Brown University for a semester. But after some seven years I decided I did not want to be either a magazine editor or a university professor. What then to do?

Toward the end of the 1960s, I wrote a book on abortion and began encountering other newly emergent ethical issues in biology and medicine, the fruit of great advances in the post-World War II years. In this context, it occurred to me, maybe I could play a kind of Socratic role. Like Art Caplan I had spent some miserable times in hospitals as a child, and that may have had something to do with it also. Next came the idea of starting a think tank on bioethics (though the term “bioethics” had not even been coined then), a place that was not in a university, required no teaching, and could be interdisciplinary. I then recruited a neighbor—Willard Gaylin, a prominent psychiatrist and writer—in my small town of Hastings-on-Hudson, 20 miles up the river from Manhattan, to join me. In March 1969 we officially became an IRS-blessed nonprofit organization, with fancy engraved “Planning Office” stationery (which for a year happened to be in my home bedroom, with additional files and copy machines in Will’s house). But we were off and running, the first really formal organization on bioethics. If perhaps it could not be said that we invented the field, we were surely the first to institutionalize it. It turned out to be a good idea, and Will and I became successful entrepreneurs. We were soon joined in that kind of adventure by Steve Jobs and Bill Gates at more or less the same time. I have been told they did well also.

As time moved along, over the early years I wrote articles on just about every issue in the field save for human subject research (which I found a great bore, even though it was surely important: how many articles can one read on ever-fresh formulations of “informed consent”?). I particularly enjoyed working up articles on radically different kinds of problems, taking a chance with new issues and ways of looking at ethics. I became known as an autonomy-basher, not because I objected to autonomy as an important human value but because I objected to an undercurrent trend that seemed to reduce ethics itself to nothing but individual free choice disconnected from an even more important question: what counts as a good or bad choice, a good or bad person, or a good or bad society? Those questions seem to make Tea Party-like autonomy zealots acutely uncomfortable.

Unlike many others, I was not drawn, even as a philosopher, to the obsession with standard ethical theories as a foundation for ethical decisionmaking. The deontology-versus-utilitarian debate seems to me to offer little help with the complexity of many multilayered clinical and policy dilemmas. Nor was I drawn to the work of John Rawls on justice. I had been at Harvard before his arrival and was never caught up in the adulation of him that came with the next generation of young philosophers. His ideas seemed to me in the end to focus on individual good, not community good. I was, for instance, much more drawn to the European embrace of social solidarity as the community basis of universal healthcare than to justice, and, in any case, it seemed clear to me, in U.S. health reform debates over the decades, that justice as a concept had little purchase in our culture; its only real force is in universities, there is little attraction to it in the broader society (save for negative rights—although I concede that solidarity as a value has little attraction either). But then, we have little common language now to have civilized arguments.

In 1987 I was asked to serve on a government panel to examine the likely impact of new and expensive technologies on the future of Medicare costs, many of which were likely to be unsustainable in a few decades as baby boomers retired in ever-larger numbers. So it has come to pass. Medicare is the most costly and contentious government entitlement program. The government cannot afford to pay for it at ever more costly levels; the elderly are outraged at the very idea that benefits might be cut; there is little movement to increase taxes to pay for it; and, for legislators, all those reasons make it an issue able to induce heart attacks. Or, even worse, this issue could result in failure to get reelected if one comes out on the wrong side, whatever that is. Moreover, I noticed, every developed country in the world was beginning to wrestle with the aging problem, however its healthcare system is organized. Ours just happens to be the worst organized, but we are not alone in having the problem.

Over time, however, I had come to think that those obstacles could not be overcome by merely organizational and management change in healthcare systems. Such systems would remain important, but only if accompanied by a more basic rethinking of some underlying goals, values, and assumptions of the modern medical enterprise.

I wanted to directly challenge what I take to be the present “reigning goals” of medicine, its *de facto* working agenda: (1) that death is an inherent evil to be pursued relentlessly and without limits—and by this I mean the search for cures for lethal disease, not end-of-life care when a cure is no longer possible (an important distinction); (2) that the royal road to curing disease is medical research and technological innovation; (3) that meeting healthcare needs trumps other societal needs when they clash; (4) that the notion of limits to progress and innovations is heretical, a threat to all the values bequeathed to us by the Enlightenment; (5) that nature is to be dominated and manipulated to human ends; and (6) that it is individual good and autonomy that takes priority over the common good.

I got into all that by way of first thinking about aging. It is a steadily growing problem for all societies, rich and poor. As the developing countries gradually come out of poverty, the average life expectancy increases and, with it, the chronic diseases of aging now prevalent in rich countries (but now starting a decade earlier than in developed countries). At the same time, of course, it is not possible to separate aging from the coming of death, which is its endpoint. Hence, it is wholly insufficient to think of end-of-life care as simply a matter of empowering patients to make their own choices. How should they think about what to choose? Such care continues to be difficult not just because of a lack of advance directives or access to hospice but because that care is embedded in the modern medical culture. That culture has set its face against death, and continues to believe that more and better technology can and must be sought and used. That is the story medical students are taught, the one embraced by the public, trumpeted by the research community, and fed by a media that thrives on new “breakthroughs” and “promising” research—and on the constant threats to our lives that arise in daily life. Genetic research and screening will tell us about all the likely genetic evils (maybe, possibly, could be) in our life to come. Even better, our newborn children will have the benefit of that forewarning, and they soon can be introduced into pre-K programs. But not to worry kids: personalized medicine will eventually find ways to treat the down-the-road health threats.

Those are the kinds of thoughts that took shape in my later career. The early years of bioethics were marked (at least for many of us) by three basic questions: How will the medical advances coming on fast and furiously affect our understanding of the goals and practice of medicine? How will they affect our understanding of health and well-being? How will they affect the way we live our lives? We now live longer because of medical progress, understand health (mental and physical) in a much broader way, and have much more choice about parenthood and its place in the lives of men and women.

Those three questions seem to me to be still fundamental, but I believe they got sidetracked early on in the field as it emerged in the 1970s and 1980s. There was a move away from asking basic questions of that kind toward more concrete clinical and policy issues. The advent of an intense interest in human subject research in the 1970s, and the focus of the first government commission in 1974, signaled that shift. Bioethics had to be practical and immediately useful to the daily practice of medicine and biomedical research if it was to make its way in government and healthcare policy. As a fundraiser to support the Hastings Center I quickly learned that the field had to be “relevant,” the catchword of that era. End-of-life care was well suited to that need (not highfaluting discussions of the meaning of death), as were problems of infertility, especially for couples who were beginning to marry later (not reflections on the changing place of parenthood in modern life). I certainly did not object to such issues, but it gradually became clear that too heavy a focus on policy issues pushed the larger questions aside.

Some critics of Leon Kass’s presidential commission made fun of it because its meetings and reports seemed too much like classroom seminars, far from the nitty-gritty of policy. To me, that is just what made them interesting and often more relevant for policy than straight policy talk. At the same time, I should add, I was not the least drawn to the philosopher’s sometimes excessive anxiety about the failure of bioethics to develop a firm grounding in ethical theory. Such a foundation was not found in the start-up years, nor has it been found since then, and with little lost. Indeed, failing to get caught up in tidy rationalistic schemes of ethics, I remained intrigued by the pervasiveness and power of rarely confronted cultural forces and ideologies: what kind of people from what kind of cultures and subcultures tend to make what kinds of moral judgments on what kind of issues?

I found, after a few years of bioethics, that if I knew some key things about someone’s biography, I could with fair accuracy predict how he or she would come out on the leading issues in the field. Earlier I had the naïve idea that, with rationality and free will, no such patterns could be discerned with individuals. But we are, in a profound sense, who we are because of where we come from and where we are now, shaped by the people and culture we are immersed in. Alastair MacIntyre has argued that, in the end, we can only do ethics in the context of our particular culture; there is no outside standpoint available to us. That understanding seems to come close to sheer moral relativism but is saved from it by the possibility that if one is in a culture that makes self-examination and self-criticism possible, this offers a way out, a way to explore other cultures and to critique our own.

I was also drawn back to culture and the way we are situated in it by my particular set of interests in the goals of medicine, medical progress, and healthcare reform, as outlined previously. Our own American culture is particularly messy,

a mixture of sharply conflicting political ideologies, ethnic and racial differences, economic and educational inequalities, and a clumsy hybrid of markets and government. To this I would want to add a gap between the kind of ethical and political theorizing that marks the academic world and the hurly-burly outside of its walls. It is now impossible to have a civilized debate on healthcare rationing in the larger society. The word seems to terrify most Americans. But it can flourish well in the academy, where the test is how it flies with one's peers in the academy. The unfortunate result is some elegant and careful writing in professional journals, but with little, if any, impact beyond. This is what I think of as hothouse ethics, of which I have done my goodly share. It is easier to get published in those journals than to get an op-ed published in the *New York Times* (which is useless for getting tenure anyway), and it is almost impossible altogether to crash the mainline healthcare expert cadre that had considerable sway in the health reform debate leading up to the ACA legislation. That cadre is made up of healthcare economists and empirical analysts, with a few political science gurus thrown in (e.g., Ezekiel Emmanuel). None of us working on ethics and healthcare reform were invited to take part. But they talk the way Washington talks. The elegance of Rawls and Norman Daniels's "accountability for reasonableness" is not their way. By contrast, I believe that bioethics has found a warmer audience in clinical medicine—at least when it avoids thought experiments and mixes it up with real people and the confusion of experience at the bedside level.

The main conclusion I draw is that bioethics has to eschew intellectual elegance and peer acceptance, seeking to reach the public and policymakers. Live more boldly. It took a certain boldness on the part of those who started the field of bioethics in the first place to take up interests and issues unknown to most people, to risk tenure by going outside of the disciplinary silos, and to find ways of talking about it all that would make sense in the interdisciplinary mix that constitutes the field. My first news for new staff members was that we did not offer employment contracts, much less tenure. The first rule was that no one discipline could ever pull rank on everyone else ("as a doctor . . ." or "as an economist . . .") and that, after a year, visitors to the center should not be able to guess one's discipline, so clear and crisp and understandable was one's way of talking and writing. I wanted to remain a philosopher but hated the idea that I might sound like one.

My latest book project, and probably my last ambitious one, is a comparative study of five global crises (so labeled by the World Health Organization): global warming, food shortages, water quality and shortages, obesity, and chronic illness. I call them the five horsemen, and I chose them for their unique common feature: after some 30–40 years of international government and private efforts and research, and after the spending of billions of dollars, they are all getting steadily worse, with little progress of any serious kind being made. Perhaps there is a certain masochism (or maybe hubris) in going after such a difficult and often depressing topic, but there was another reason for my choice as well: in every case there is agreement that dealing with the problem requires massive changes in deeply embedded cultures, behavior, and ways of life. It is our industrial societies that have given us prosperity but also global warming, our extended life spans that have brought with them huge increases in chronic illness, and the improvements in our diets that, ironically, have brought about the cheaper food that also gives us obesity, which is on the rise in poor countries

(where citizens can now afford meat). How do we change the ways of life that turn the initially good into the bad?

Is that a bioethics problem? Not quite, by the usual notions of what bioethics is all about. But if bioethics is what people in bioethics do, and I am in bioethics, then why not? Some of us who started the field can perhaps introduce some new possible directions. The fact that I am utterly over my head, with no background at all in the case of three of my five horsemen, is part of the charm for those of us who seek variety and adventure.