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# The Triumph of Autonomy in Bioethics and Commercialism in American Healthcare

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## **Abstract**

Justifying his proposal for "health savings accounts," which would allow individuals to set aside tax-free dollars against future healthcare needs, President Bush has said that "Health savings accounts all aim at empowering people to make decisions for themselves." Who could disagree with such a sentiment? Although bioethicists may be among those who express skepticism that personal health savings accounts will be part of the needed "fix" of our healthcare financing system, self determination has long been part of their mantra. Indeed, the field of bioethics played an important role in advancing this idea in the medical world when physician paternalism was regnant. Has its popularity caused it to become so vapid as to be ripe for misuse?

## **Comments**

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## *The Triumph of Autonomy in Bioethics and Commercialism in American Healthcare*

JONATHAN D. MORENO

Justifying his proposal for “health savings accounts,” which would allow individuals to set aside tax-free dollars against future healthcare needs, President Bush has said that “Health savings accounts all aim at empowering people to make decisions for themselves.”<sup>1</sup> Who could disagree with such a sentiment? Although bioethicists may be among those who express skepticism that personal health savings accounts will be part of the needed “fix” of our healthcare financing system, self determination has long been part of their mantra. Indeed, the field of bioethics played an important role in advancing this idea in the medical world when physician paternalism was regnant. Has its popularity caused it to become so vapid as to be ripe for misuse?

The hardy band of early bioethicists who gathered around tables in Hastings-on-Hudson, New York, in Washington, D.C.’s Georgetown, and at several other institutions in the late 1960s had much on their collective mind: organ transplants, the new genetics, life-extending technologies, allocating dialysis machines, doctor–patient communication, and other esoteric topics.<sup>2</sup> The emergence of patient autonomy as a touchstone of the emerging field was hardly intended to bolster an increasingly commercialized healthcare economy, but I contend that this is exactly what has happened. Moreover, empowering patients to determine the course of their medical care has not only turned them into consumers in a more overt sense than has traditionally been the case in healthcare; more to the point, bioethics has provided a neat justification for this qualitative change.

This tale, like so many others in human affairs, is one of unintended consequences, but not unpredictable ones. Patient autonomy has dovetailed nicely with that extreme version of commercialism: consumerism. This phenomenon is perhaps best exemplified in the move toward direct-to-consumer advertising, an effort to go over or around the heads of physicians to patients themselves. Although commonly touted as a means of patient education (the standard rationale used by all advertisers), the familiar result is that patients increasingly determine what therapies are likely to be considered among their treatment options. I say “increasingly” advisedly, because if our temporal aperture is wide enough, this phenomenon is not new, but is the reappearance of advertising practices that were common in the patent medicine era of the mid- to late 19th century but that were abandoned in the early 20th century.

Similarly, patient autonomy has also fueled the ability of physicians to “off-load” hard decisions to their patients, decisions that were historically in

their province. How many times in the past decade or so have I heard patients report that their doctor told them it was unethical for him or her to tell them what to do with regard to their medical choices, that to do so would be to interfere with their “autonomy”? Just as the old-fashioned therapeutic privilege once served doctors’ interests in not being the bearers of bad news, so the new-fashioned ethics of autonomy serves the interests of doctors who prefer not to make tough calls for their patients.

In the mid-1980s, following her lecture on informed consent to a group of first-year medical students, Gail Povar, a physician colleague at George Washington University, approached me with a wry smile. “What’s so funny?” I asked her. “One of the medical students just came up to me and said, ‘I’m really interested in this autonomy stuff. How can I have autonomy as a doctor?’” By then the word autonomy was hardly ever linked to the physician, but nearly always to the patient. This earnest student’s question was therefore unfashionable in the 1980s. Especially in discussions of the right to healthcare, the idea that the doctor’s autonomy trumped that of the patient had been pretty much buried in bioethics circles. Along these lines, a paper by Robert Sade that was often read in early bioethics courses alleged that medical care is a doctor’s property to sell as he or she wishes, not the object of a patient’s right of access, a position that generally provoked a harsh reaction.<sup>3</sup>

The triumph of patient autonomy in the American medical ethos closely tracks the emergence of bioethics and its eventual supremacy as the reference point for those values that are supposed to be regnant in healthcare. Interestingly, the early years of the field, from 1969 to the mid-1970s, were not particularly dominated by autonomy talk. To be sure, Robert Veatch was promulgating a contract theory of doctor–patient relations, largely in reaction to perceived physician paternalism. But, as I suggested above, the atmosphere at the Hastings Center and the Kennedy Institute was more oriented to the big picture of the implications of breakthroughs in the life sciences (genetics, organ transplants, and the like) for our understanding of the human being and the manipulation of human nature—the “prophetic” bioethics of which Dan Callahan often speaks.

Two events in the 1970s seem to have pushed autonomy to the fore, and perhaps a third. The first was the reaction to the syphilis study revelations and the gradual expression of the human research ethics framework with which we have become familiar. This framework places “respect for persons” as the first principle among equals, and that, in bureaucratic practice, tends to be expressed as informed consent or “self-determination.” Although the reduction of respect for persons to a signed consent form is often bemoaned, it can hardly be denied. There is a continuing debate about whether respect for persons is an inappropriate reduction from Kant’s categorical imperative or if something like respecting autonomy is indeed at the core of Kantian respect for persons.<sup>4</sup>

The second event that moved autonomy front and center was the Quinlan case, ironically a circumstance in which the patient could not exercise autonomy but one that made many people aware of how much they valued this alleged right. If Karen Ann Quinlan could “voice” her autonomy even when in a vegetative state, then others of us who were still competent insisted on doing the same. These two events also helped boost the institutionalization of bioethics through IRBs and ethics committees and made bioethicists the rightful

interpreters of holy scripture like the Belmont Report, the subsequent federal research rules, consent forms, and advance directives.

The third event I have in mind had a more shadowy but more culturally powerful effect on the promotion of the concept of autonomy: the 1972 decision in *Roe v. Wade* and the consequent valorization of choice. Allegedly building on previous cases in which the court under Chief Justice Earl Warren examined the constitutional bases for a right to privacy and its applications, *Roe* has come to signify either the dignity that has for eons been denied women or the deterioration of respect for human life. Surely this moment in our legal history has done more to foster the “culture wars” we are now experiencing than any other event, with neoconservative critics arguing that the *Roe* decision gave license to an autonomy run mad. At this writing, with a supreme court definitively shifted to the right, the latter view appears ascendant.

Autonomy-driven bioethics became a convenient and nearly reflexive touchstone for the analysis of nearly every bioethics issue in the 1980s, so much so that those who advanced considerations of safety, public health, or the prudent distribution of resources and did not presuppose a “trumping” right of autonomy in their analysis often had to start from a defensive posture. For example, in the mid-1980s, Ronald Bayer, a political scientist who is now a professor at the Columbia University School of Public Health, and I published papers on the impact of motorcycle helmet laws.<sup>5</sup> The advocates of personal choice in the wearing or not wearing of helmets then and now used an autonomy-based argument to the effect that riders had the right to feel “the wind in their hair.” Yet the critics of the unabashed autonomy view noted that all of us pay the price of peeling such “free riders” off the pavement, that there is a real cost to such personal choice, a cost that can be expressed in dollars. Bayer and I were sympathetic to this latter position, but we further contended that economic considerations alone could not provide an adequate *moral* response to the autonomy-based right-of-riders-to-feel-wind-in-their-hair argument. We argued that there is a social moral obligation to worry about the well-being of riders *as well as* the financial cost of motorcycle accidents to society. Thus we advanced an ethical argument on behalf of the interests of the “commons,” a distinctly minority approach in mainstream bioethics, then and now. (I do not think we impressed anyone but a few professors of public health; the states still have various helmet laws, evidencing the lasting power of autonomy as a rhetorical device, at the very least.)

Of more significance, the development and adoption of new models for fast-tracking trials of new potential anti-HIV medications clearly benefited from autonomy-based access arguments in the late 1980s. AIDS activists claimed that no one but the disease sufferer had the right to decide how much of a research risk was worthwhile when facing a deadly illness, and that it was unethical to assign some participants to placebo. Experts on clinical trials pointed out that the “cleanest” data from a study involving a new drug therapy usually comes when that drug has been tested against a placebo and when the trial has been allowed to run long enough to obtain a significant result. Worries that data would be compromised in these trials because volunteers could not be randomized to placebo and because trials were stopped earlier than they might have been were largely eclipsed. Years later even some of those who had advocated modified study design expressed reservations.

During the past 15 years or so, the increased sophistication of medical consumers who insist on exercising their “autonomy” has dovetailed brilliantly with corporate interests. This phenomenon is apparent in both research and clinical medicine. Those who are ill and possess some personal resources aggressively seek clinical trial enrollment without regard for bioethicists’ warnings about the “therapeutic misconception,” the concern that no matter how clearly the nontherapeutic intent of a study is stated the sick patient will still believe it is being done for her benefit.<sup>6</sup> (In truth, later phase three trials—which generally involve drugs that have proven beneficial to a small number of select patients—might well be a pretty good bet for those who have “failed” other treatment and not the product of a misconception.) Rapid trial enrollment is a key element in cost-effective drug development.

On the clinical side, it is hard to find a primary care doctor who has not had a patient present a printed page from a Web site touting a medication or, still more commonly, refer to a television advertisement. The social acceptability of direct-to-consumer marketing owes something to the triumph of autonomy. So do the imaging centers and DNA scan shops that traffic in the illusion of personal control through information. And so did Myriad Genetics, the holder of the patent on the BRCA1 and -2 gene tests, which in 2003 announced a direct-to-consumer advertising plan for a home-test kit but pulled back following criticism from this writer and many others.

I am not arguing that the fact of autonomy’s ascendancy in bioethics theory made the world safe for the increasingly commercialized medicine of the late 20th century, but rather that both trends were part of the *Zeigeist*, the spirit of the age. Considering that academic bioethics is often viewed as a captive of liberal academia, which is presumed to harbor anticapitalist sentiments, this result is ironic. Still more shocking, consider that the emergence of autonomy as a moral litmus test in the 1970s owes much to the antiauthoritarian politics of the post-Vietnam, post-Watergate era. Paradoxically, the same moral principle that grounded *Our Bodies, Our Selves*, that of personal autonomy for women in healthcare matters, also set the stage for several formulations of medication for erectile dysfunction, the paradigmatic “lifestyle” drug. Here, male consumers can feel justified that they are simply attaining a medication that allows them to control their bodies. As autonomy claims intensify, one imagines that physicians are unsure whether to prescribe the drugs for those many men who wish to use the drug to enhance sexual performance rather than achieve an erection. After all, if autonomy is the wedge, who can say better than the patient whether an unfulfilled desire is a disorder or a natural limitation?

But is that not what the father of capitalist theory Adam Smith was trying to tell us all along? Individual autonomy is the core concept of a liberal society, in which personal choice and interpersonal competition are two sides of the same coin. The ironic story of modern bioethics is that one side or the other might not be obvious, but it has been always there. Recently the valorization of autonomy has been a grave concern among those who consider themselves conservative bioethicists, and, though I do not place myself in that category, I do urge that a reassessment of the way that the principle of autonomy (however one conceives it) has been adopted in a capitalist society is a proper bioethical task.

## *Triumph of Autonomy in Bioethics*

### **Notes**

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