

PRESIDENTIAL ADDRESS: BIOETHICS AND SOCIAL RESPONSIBILITY

DANIEL WIKLER

What is a bioethicist? We might suppose that we can define this role by describing the subject matter of the field. But this keeps changing. There have been, in my reckoning, three states thus far, with a fourth in the process of birth as we speak.

I. The first consisted of codes of professional conduct. Bioethics (more precisely: medical ethics) in this sense consisted of rules against advertising, or speaking ill of another doctor; and against such practices as fee-splitting and kickbacks.

II. The second phase, dubbed 'The Birth of Bioethics' by Prof. Jonsen and his fellow-historians, turned tables on the doctors. Where Stage I bioethics involved doctors talking to peers in order to define what the medical profession stood for, Stage II set loose a swarm of critics, some of them doctors and many others not, who questioned virtually every medical tradition. Age-old patterns of paternalism and husbanding of the truth were successfully challenged. Bioethicists were the academic allies of the patients' rights movements, arguing for a renegotiation of the doctor-patient relationships.

III. Daniel Callahan, in his 1980 Shattuck Lecture, pointed out that the doctor-patient relationship and all of the concerns of Stage II bioethics were shaped and controlled to a large (but scarcely visible) extent by the structure, financing, and management of the health care system. Callahan called on his colleagues to engage in these issues at the macro level, learning enough about these larger-scale issues and choices to speak usefully to the ethical basis of the system as a whole.

It was not easy to respond to Callahan's urging. Bioethicists needed, but did not possess, detailed knowledge of health economics and politics. New philosophical resources were needed, too: not the morality of individual action, nor the traditional ethical codes of defining the medical profession, but social and political philosophy, particularly theories of distributive justice.

Bioethics in this new, third mode began as a trickle. Norman Daniels's *Just Health Care* was an early landmark. The flow of books

and articles has by now turned into a torrent. Bioethicists learned arcane details of health care policy and economics and have been consulted by health ministries around the world. In the United States, Hilary Clinton's health care reform commission boasted its own committee of distinguished bioethicists.

IV. At the III World Congress of the IAB, there was evidence that a fourth stage is approaching: what can be termed a bioethics of population health. Like the second stage, it is more than a code of professional conduct, and involves not only practitioners of medicine but the entire public. Like the third stage, it transcends the doctor-patient relationship, and draws on a wider literature of biological and social sciences, along with the humanities and management sciences. It differs from the earlier three stages, in a number of respects:

1. In this phase, high-tech medicine will lose its pride of place at the center of bioethical concern. Up to now, perhaps because bioethics originated in the wealthiest countries, the field seems to have been most intrigued by the most advanced, costliest treatments and technologies. In the fourth stage, we will be less fixated on the high-tech questions, whether in the form of the clinician's dilemma ('Who gets to use the dialysis machine?') or the health planner's question ('Should we let use of the dialysis machines be determined by ability to pay?'). Rather, we will aim to focus on many determinants of health, one of which one is high tech medicine.

2. Our focus, therefore, will be on health, just as much as on health care. The latter is of interest because it is a source of employment, and of profit, and because we all want it once we become sick, but of course we have first of all an interest in staying healthy. We therefore can ask not only: who has access to this or that health service, but who is sick and who is not, and how equitable is this pattern? How do we measure health status and improvements in health, and what values should guide policy built on these measurements? To what extent is health a function of social status, income, race, or ethnicity, and what response ought society have to differences in health status keyed to these factors?

3. A bioethics of population health will entail an appreciation for the importance of numbers — of people, that is. There are 250 million in the US but 6 billion on the planet. A full 40% of the health care dollars spent on the planet are spent by and for Americans. We American bioethicists can be concerned with professionalism of American doctors, or with the right of American patients to have the truth told to them, or with how the trillion dollars we spend on our care every year — more, by the way, than the GDP of the entire South American continent — is allocated among us. But that still leaves 5

and 3/4 billion human beings, all of whom we suppose are equal to us, unaccounted for and indeed unmentioned. Of these half are poor. We 'first-world' bioethicists have simply closed our eyes to their plight. We have had nothing to say on the equity of both international and national allocations of wealth, environmental hazards, sharing of health care resources, and other health-affecting factors.

4. A bioethics of population health requires, and engenders, a more vivid sense of priorities, particularly priorities for the worst off. For most people outside the Euro-American-Japanese world are much worse off, and those who are sick are usually at the very bottom. If we sometimes believe that we should allocate health care resources according to need, how might we also allocate bioethical energies?

5. Finally: we may also require a new conceptual apparatus. Just as new ideas were needed, and have been fashioned, for the transition from purely clinical bioethics to consideration of advanced health care systems, so too the move toward a bioethics of population health may necessitate fresh approaches and the appropriation of concepts and theories from other fields. Jonathan Mann, in his keynote speech to the III World Congress of the IAB, has urged that we turn to the vocabulary of human rights. This is not a subject which many of us feel comfortable with. Human rights do not have secure status in contemporary philosophical thinking about social justice. But if we lack the theoretical resources to do the job that Dr. Mann believes that human rights do, we must re-think this subject matter. Or — perhaps I should say 'and' — we must come up with alternatives.

If I am correct in seeing the beginnings of a fourth stage of bioethics, then have we decided what a bioethicist is?

Not yet. There is an ambiguity in the notion of a bioethicist. Some think this figure is a scholar; others, a reformer. Some of us would define ourselves the first way, others the second. The divide is quite deep. For the former, bioethics does not take any positions on any issues for granted, but looks for uncertainties and spurious conventional pieties and challenges them all. In this view, the bioethicist as reformer begins with certainty — certainty over what is right — which is instead what should be the ending place of bioethical inquiry. And to the scholar, the bioethicist as reformer mistakenly identifies the field of bioethics with certain positions taken on the issues. The point is not that the reformer takes the wrong stand on these questions, be they patients' rights, protection of experimental subjects, or distributive justice; rather it is that there is room in bioethics for scholars who take all sides of these issues: even those who believe in paternalism, who urge researchers to pursue science at the expense of the well-being of their subjects, or who are happy with the inegalitarian results of the health care marketplace.

The reformers, on the other hand, wonder over the motivation for a 'value-free' bioethics. What, after all, is the point? And why would anyone be interested in bioethics if it weren't a movement in favour of patients' rights, protective of human subjects of clinical investigations, and a force for equality in access to health services?

I beg the reader to indulge me the unnecessarily-sharp division I'm imagining between these scholars and reformers. Of course most of us are both. But if we had to choose, my own lot, for what it is worth, would be cast in the scholar camp. I am happy to recognize as a colleague, as fully deserving of the name bioethicist, those writing on these subjects who disagree with every position I've ever taken. I am therefore comfortable in the IAB, which has no tendency toward doctrinal purity or political correctness, and which as a result offers each of us the chance to have our most fundamental assumptions challenged.

This having been said, the reformers are right on one score. There's little point to bioethics if we are not trying to set the world right. Other fields pose more intriguing intellectual puzzles. Let me come clean: as a graduate student, I did no bioethics and only a bit of ethics; my dissertation was on the semantic properties of demonstratives. But when I thought about what to do with a lifetime, I realized that I did not want to wake up at the age I've now attained and tell myself I've spent my life as a professor of chess. Bioethics was just then starting up as a respectable discipline, offering the chance to do something which felt like philosophy but on subjects which seemed inherently important. This impression has become stronger over time.

As scholars, we do not begin our investigations with a sure sense of the outcome. How, then, does one pursue a reform agenda? The answer, as we all know, lies in the choices one makes among potential research projects. We can maintain fidelity to traditional academic standards, yet try to improve the world, by bringing to the light of day, and to the attention of those with the capacity to effect change, the plight of those who are unfairly treated and the concepts of equity which, if used to guide policy, would result in the needed rectification.

Here is my message in this address: to fulfil one's social responsibility in bioethics, one would do well to volunteer as midwife to bioethics' fourth stage, based on population health. To accomplish this task, we will all have to pursue continuing education, acquiring knowledge in unfamiliar fields of public health, international health, cost-effectiveness analysis and health metrics, and subjects still further afield. I am abysmally ignorant in almost all of this, and I realize that I will have to cut down on other commitments in order to gear up for studies in the bioethics of population health.

Some of us can avail ourselves of courses in nearby schools of public

health. But I would urge that we take an even wider view. The bioethical issues considered in this phase grade off seamlessly into the fundamental issues of the economics, history, and politics of the era — and not just in the arena of health or health care. We are living in a time of great social upheaval and transition, even though it is largely a time of peace; and though these trends affect everything we study in bioethics in this fourth stage, they tend to be invisible to us unless we made a determined effort to ask the questions and pursue the answers in books and journals of low circulation.

During most of my own life, we have been comforted by the promise that science and technology were gradually, if unevenly, rescuing humankind from the threat of suffering and early death posed by disease and disability. Under the leadership of WHO and other international health agencies, diseases were controlled, even fully eradicated.

Progress continues in many parts of the world today. But as we have heard in other sessions in this congress, the most recent news from abroad is disturbing, even in some cases alarming. Cholera has become endemic in parts of South America which had seen few cases in decades. Diphtheria is up 400% in Russia. Low birthweight births in a region of Nigeria doubled during the late 1980s. In Costa Rica, which continues to be cited as the model developing country in its concern for population health, malaria jumped from 110 recorded cases in 1982 to 1,142 in 1990 and then 6,000 in 1992. China's once-renowned health care system in poor rural areas, as we have been told, is a shambles; it exists, but it relies mostly on payments by patients, which few can afford, and public facilities are overwhelmed.

These are warning signs, and there are many others: warnings of backsliding, of the possibility that for huge numbers of people, health may grow worse rather than improving. Who (or what) is the culprit? I am not the person you would reasonably turn to for the answer to this question, but unless we attend to those who are, we will not be in a position to frame the bioethical questions whose answer might be useful in thinking about reform. One possible cause, for example, is so-called structural adjustment, an economic regimen imposed on developing countries which found themselves in the early 1980s — following the oil shocks, drops in the prices of other commodities, and the failure of borrowed funds to result in economic growth — desperately dependent on the willingness of Western banks to continue credit. Under structural adjustment, countries such as Costa Rica are pressured to pare down the state: decentralize, privatize, and target social welfare spending to the worst off.

Economists differ over whether this regimen is the key to overall economic growth — the results are mixed — but there is no doubting

that structural adjustment hits a lot of less-favoured people hard. Structural adjustment is an umbrella term for a host of policies which call for downsizing the state's role in many fields. Its stated aim is to enhance economic growth, but on this way to this goal it increases overall inequality, sometimes enormously. The effect on a country's system of health care and public health can be severe. Countries which are induced to decentralize health services, but which can provide no additional resources, must of necessity hack away at the safety net. Privatization spells trouble for patients whom it is not profitable to treat, and imposition of user fees — a way for private insurers to avoid inappropriate use of services — inevitably keeps the poor from the hospital door. Targeting the most needy, while dismantling health systems used by larger numbers of people, reduces the stake of the public in systems used in common, overwhelms the remaining public health system, and pits adjacent classes on the lower end of the scale against each other in the competition for protection and care.

Why is this story of particular interest to a largely first-world audience? I am not claiming on this occasion that all the dangers I have alluded to are the fault of any particular party, be it the World Bank, the first world, or the New World Order. It may be fairly easy to find the link between structural adjustment and the suffering of a malaria patient in Cost Rica; but China acted on its own, and other nations maintained independence by implementing these economic regimens before they were made to do so.

But it is not necessary to trace a causal link to impress on Americans the relationship between these developing-country experiences and our own. Much of it sounds familiar. We are in some respects undergoing a similar process.

Some parallels, such as the phenomenon of decentralization of services with concomitant reduction in funding, are immediately apparent. The 'block grant' legislation of the last U.S. Congress did precisely this, much to the detriment of the needy.

Indeed, many of the features of our own health care revolution, involving the rise of managed care, involve the same kinds of ideologies and the same kinds of moves. What we are doing to others, we are doing to ourselves.

The growing inequality among Americans has become a national scandal, as has the fact that the lower half of the work force has seen declining wages, in constant dollars, over the past two decades. With inequality comes concentration of ownership, which is especially evident in the health care systems, as health plans buy one another and the bulk of the huge system comes under the domination of a handful of firms, led and owned by people who yesterday were trading

pork bellies and computer chips and who have not been socialized in any tradition of bioethics. Arnold Relman, the former editor of the *New England Journal of Medicine*, stood nearly alone a decade ago in warning of the 'medical industrial complex' of for-profit medicine. He was treated shabbily in many august forums, accused to being a patrician and an alarmist, but in retrospect it is obvious that his caution erred only in being too mild.

The effects of these changes are visited on us all. Yes, price inflation has eased, though it is possible that much of this is due to the refusal of health care institutions to bear the burden of public goods, such as research, education, and care of the indigent. In health care, the United States sees the same tendency toward tiers of service that structural adjustment imposes on developing countries, as executives avail themselves of traditional indemnity health insurance while offering their employees managed care — which, to be sure, is said to offer new and unbounded opportunities for continuous quality improvement on the basis of scientific evidence.

And just as privatization in developing countries helps those patients whom it is profitable to help, we find the same at home. In a recent industry forum, a conflict was revealed between insurers and employers over the frequency of colon cancer tests for employees known to have a gene newly discovered to predict colon cancer. Ordinarily patients in a given category get the test once every three years, but screening is indicated annually for those with the gene. The insurer reasoned that between the time of a positive test and the time of full-blown, expensive-to-treat cancer, several years would elapse, by which time the patient was more than likely to be insured by some other company. The employers wanted annual screening. Their reason was that people change jobs less often than they change insurers, and the employer would likely be stuck with the bill for cancer treatment which might be avoidable if detected early enough by the annual screen.

Neither party, needless to say, asked: what might save this person's life and health? There is no one left to ask this question under these conditions. Physicians who might have acted as advocates now stand to be threatened with expulsion for overutilization of resources or even for criticizing the insurer for the lack of annual tests; other physicians are bought off by insurers who realize that the doctor had better be working on their side, leaving as advocate for the patients only the manager of the benefits office of the patient's employer. Karl Marx would not approve.

In developing countries and ex-socialist countries alike, privatization has bred corruption on a grand scale. So-called 'spontaneous privatization' in countries from Estonia to Kazakhstan

involves the creation of a private company by chiefs of public ones, the sale at cents on the dollar of the assets of the latter to the former, and the subsequent enrichment of the new entity's owners. But we have the same phenomenon in the US health care system, and managed care and hospital chains buy up the assets of nonprofit health care systems, including buildings and also loyal subscribers, also at bargain prices. During the transition the executives of the former nonprofit now are appointed to the predator for-profit company, showered with stock options and other perquisites, while the new owner sheds public services and threatens the nursing staff with replacement by nonunion employees borrowed from one of the company's other operations.

My suggestion, to come to the point, is that we do not need much motivation to enter the fourth phase of bioethics. We must study and think about developing-country health for many reasons. One is our own role in producing their suffering. Another is the example we set as this kind of behavior becomes the norm in our once-hallowed medical profession. But the main reason is that to a distressing extent we are sharing their fate. Of course with a trillion dollars to spend it will not feel the same, but there will be enough structural similarities that we will know from our own experience what it is that our colleagues in these countries are talking about.

Bioethicists are self-selected and have to earn the right to moralize. Even so, we recall the cynical, but realistic remark, 'And how many divisions does the Pope have?'. But there is much we can do. We can point out issues. We can set benchmarks. And by airing and debating the issues — whichever side we might advocate — we can call to account.

My address has admittedly overemphasized the commonalities between the plight of developing-country masses and the experience of many patients in this richest of countries. But both groups include bioethicists. At this Congress of the International Association of Bioethics, many are with us today in this hall. We can learn much from each other, and we can accomplish much, working together.

University of Wisconsin Medical School