Special Section:
Quo Vadis? Mapping the Future of Bioethics

Developments in Bioethics from the Perspective of HIV/AIDS

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Predicting future trends in bioethics depends on the recognition of contemporary innovations. Because of the extraordinary challenges brought on by the HIV/AIDS pandemic, bioethics has had to undergo a critical examination of its own effectiveness. This essay examines 10 developments that have helped shape the future of bioethics in a time of HIV/AIDS.

First, the crisis in health is so devastating that ethicists are seeking discourse with public health officials about major population sectors. As a result, bioethicists are no longer engaging physicians and researchers as their primary interlocutors, and they are also no longer looking to the physician's office or the researchers' laboratory as the primary context of ethical analysis and concern. This shift from the private, yet interpersonal, to the social and the structural has other repercussions.

Daniel Callahan and Bruce Jennings note that this turn to public health is due to two main insights: first, the sad awareness that the preventable transmission of infectious diseases, HIV/AIDS especially, is occurring at ever greater rates, and second, that "the health of populations is a function more of good public health and socioeconomic conditions than of biomedical advances."[1] This does not mean, as they remind us, that ethicists are abandoning their original dialogue partners. Clearly, the public health official is not replacing the physician; rather, ethicists now realize a need to be in dialogue with both.

In maintaining these two conversations, bioethicists cannot construe the physician's world as simply a microcosm of the public health official's. Whereas the public health official approaches the social with insights about demographic patterns and epidemiological impacts that are fundamental generalizations, the physician offers very detailed, experiential narratives for each patient. The former are not simply summaries of those latter narratives, any more than the narratives are only encapsulations of the generalizations. Together their perspectives, the private and interpersonal as well as the social and institutional, inform bioethicists so that they may have a better grasp on human health.

Second, by engaging the public health official primarily, bioethicists stand to lose some of the "excitement" and "allure" of traditional, clinical bioethics. The world of the stem cell debate and genetics, for instance, becomes very technologically attractive, with all its allure and glamour. But public health forces us into the ordinary, the routine, the basic. It is what Giovanni Berlinguer calls an "everyday bioethics,"[2] or what Maura Ryan refers to as a "bioethics from below."[3] Bringing the bioethicist into the mundane forces us to realize that malaria and tuberculosis as well as living wages and healthcare access are very much biomedically urgent issues.

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Third, when we appreciate the shift from the clinical world to the public health world, we need to revisit the relevance of the so-called principles of biomedical ethics that Tom Beauchamp and James Childress have articulated: benevolence, nonmaleficence, autonomy, and justice.[4] These four principles have dominated bioethics for over 25 years. Though many claim them to be universally applicable, in fact, they are as local in their origin as in their relevance. They reflect a vision of bioethics, steeped in American values, that is largely focused on the professional relationship between physician and patient. Why not? After all, this perspective was born of philosophers working next door to their own university's healthcare facility. Thus benevolence and nonmaleficence pertain to particular physicians and to other members of the healthcare guild and depend very much on models dominant in the United States. In this perspective, autonomy is any patient's fundamental right and dictates most of the contemporary agenda. Justice, then, becomes a bit of a "remainder" concept, addressing whatever issues the previous three did not. For the most part, in this framework, justice considers whether the physician's particular patient gets fairly treated. Rightly or wrongly, these principles still dominate discussions between bioethicists and clinicians, but they fail when we explore the universe of discourse between bioethicists and public health officials.

When we attempt to broach the topic of justice not with the individual first world physician, but with the developing world public health official, justice moves from being a remainder concept to setting the basic conceptual framework for the bioethical discussion.[5] When conversing with public health officials, we are by necessity required to consider entire populations and their access to treatment and to prevention strategies for everyday illnesses that include infectious diseases. Thus, just as public health officials cannot imagine a hermeneutics of the so-called "Georgetown mantra" as being relevant to their primary sphere of investigation, neither can we.[6]

Fourth, this search for a new hermeneutics is at the same time a search for a new language, for language is central to understanding how we conceive of HIV/AIDS and the world in which it thrives. As Albert Jonsen notes, "The public language . . . of AIDS is as important as the science."[7] Together with public health officials, we bioethicists are now searching for language that allows us to grapple with issues long since ignored or overlooked. The challenge, then, is to look not only at the health of the patient, but to the structures that make some persons more vulnerable to this infection than others, at the contexts that make the transmission of HIV more probable, and at the conditions that assist or hamper persons in accessing information regarding both prevention strategies and treatment. In other words, unless we reflect on the social, economic, and political infrastructures in which people at risk for HIV/AIDS live, there can be no adequate hermeneutics for the ethics of health in the age of AIDS.

Three major figures in the battle against HIV/AIDS lead us in this direction. First, Paul Farmer has consistently looked at the inequity of social institutions and how they embody virulent pathologies of power. Reflecting on the deep connection between poor health and poverty, he sees the root causes of disease as being more connected to economics than to biology. He is particularly vigilant about the structural issues that make possible violence against women and girls.[8]

From a different perspective, global economist Jeffrey Sachs looks at how disease affects social structures. Disease makes people poor. Disease keeps

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people within a downward-spiraling economy. Although poverty certainly creates the conditions by which people are at risk for poor health, disease destroys their ability to escape from the very context that made them susceptible to ill health in the first place.[9] He writes:

> Disease is not only a tragedy in human lives, disease is disaster for economic development. . . . The major reasons why many of the poorest countries in the world, particularly but not exclusively in sub-Saharan Africa, are stuck in poverty is that the disease barrier is so great that it is blocking many different normal avenues of economic advance.[10]

Farmer and Sachs do not contradict one another; rather, they keep us on track to see the deep and interlocking connections between poverty and disease. It was this interconnection between poverty and disease, particularly with respect to HIV/AIDS, that prompted Jonathan Mann to challenge the hermeneutical context for doing public health in a world of HIV/AIDS.[11]

In 1997, Mann, first director of the United Nations Global Program on AIDS (predecessor to UNAIDS), had the foresight to make the connection between human rights and public health. He did this by first drawing attention to the connection between poverty and illness: "The vast majority of research into the health of populations identifies so-called 'societal factors' as the major determinants of health status. Most of the work on this area has focused on socioeconomic status as the key variable, for it is clear, throughout history and in all societies, that the rich live generally longer and healthier lives than the poor. . . . A major question arising from the socioeconomic status–health gradient is why there is a gradient."[12]

In response to this question, Mann reflected on the inability of public health to integrate into a solution what it realized was central to the problem: "While public health may cite, or blame, or otherwise identify the societal-level or contextual issues—which it acknowledges to be of dominant importance, both for influencing behavior and for determining health status more broadly—it does not deal directly with these societal factors."[13] Mann then gave three reasons for this paradoxical inaction:

- "Public health has lacked *a conceptual framework* for identifying and analyzing the essential societal factors that represent the conditions in which people can be healthy.
- "Public health lacks *a vocabulary* with which to speak about and identify commonalities among health problems experienced by very different populations.
- "There is *no consensus* about the nature or direction of societal change that would be necessary to address the societal conditions involved."[14]

He concluded by ruing the ineffectual babble that public health officials inevitably uttered without these critical tools: "Lacking a coherent framework, a consistent vocabulary, and a consensus about societal change, public health assembles and then tries valiantly to assimilate a wide variety of disciplinary perspectives, from economists, political scientists, societal and behavioral scientists, health systems analysts, and a range of medical practitioners. Yet while

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each of these perspectives provides some useful insight, public health becomes thereby a little bit of everything and thus not enough of anything."[15]

Mann appreciated in the language of human rights its integral comprehensiveness and its moral urgency. That is, human rights language could link global campaigns for the right to access available medical treatments with equally effective and strategic movements to obtain greater equality in political, economic, and social forms of life. He therefore proposed that public health had a desperate need for the conceptual framework of human rights to analyze and effectively respond to the unprecedented nature and magnitude of the HIV/AIDS pandemic: "Modern human rights, precisely because they were initially developed entirely outside the health domain and seek to articulate the societal preconditions for human well-being, seem a far more useful framework, vocabulary, and form of guidance for public health efforts to analyze and respond directly to the societal determinants of health than any inherited from the past biomedical or public health tradition."[16]

Fifth, this language and hermeneutics is effective. Consider three accomplishments in the field of HIV/AIDS. First, the Declaration of Commitment on HIV/AIDS at the United Nations General Assembly Special Session on AIDS (UNGASS) of June 2001 provided public health officials and AIDS activists with a common language of discourse to be used not only with their surgeons general or ministers of health, but also with their kings, presidents, and prime ministers. The language of human rights provides a bridge between the political and the medical.[17]

Second, this linkage of disciplines led to another building of bridges: imagining access for all and eventually conceiving this as a moral imperative. Although the 1998 international HIV/AIDS conference in Geneva had as its theme "Bridging the Gap," only AIDS activists challenged the healthcare community to imagine the possibility of treating already infected persons from the developing world with the drugs that in 1996 brought hope to patients in the industrialized world. They were opposed by many who claimed that antiretroviral therapies were really only appropriate for the industrialized world, arguing that developing world patients' inability to find appropriate water and to "understand times of administration" made provision of these drugs completely unimaginable. Thus, despite its theme, the Geneva meeting became known as the conference to "mind the gap."

By the time of the Durban International AIDS Conference in 2000 public health officials and clinicians faced the once unimaginable. It was there that the question of universal access would finally be brought to center stage. Peter Piot, Executive Director of UNAIDS, opened the conference with these words: "We are hearing and heeding the ever-louder call of people living with HIV to place the issue of access to treatment at the center of the world's moral agenda. . . . Let this be the conference the world remembers for solutions, for mobilization, and for breaking the silence."[18]

Third, at the 2002 Barcelona International AIDS conference, concrete proposals for drug access were finally being proposed by public health activists, economists, government officials, and UNAIDS. Successful programs in Thailand, Haiti, Costa Rica, and Brazil were specifically studied and invoked as examples of normative solutions. Paolo Teixeira of the Brazilian STD/AIDS program explained why and how his nation came to the decision that antiretroviral therapies should be made available to all HIV-infected citizens and singularly credited the lan-

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guage of human rights as the cogent means for validating the policy: "What we have been doing is to put into practice principles that have long been recognized by the international community. At their very core is the Universal Declaration of Human Rights, adopted more than 54 years ago."[19]

Certainly debate about human rights language continues: whose rights, how are they articulated, how are they applied, who guarantees them, and—invariably—who determines the answers to any of these questions? Nevertheless, in responding to these central issues, it is precisely the vocabulary of human rights and its conceptual framework that allow these critical discussions to occur and make possible the development of coherent, equitable, and effective policies for HIV prevention and treatment. We cannot imagine that achievements attained thus far in responding to the pandemic could have been possible without this shift in conceptual framework. Its effectiveness has been proven, and for this reason it is a key asset in the armamentarium of bioethicists for teaching about and responding effectively to our world infected by HIV/AIDS. The language of human rights provides us a way to communicate within and across disciplines not only to analyze properly the socioeconomic conditions relevant to the transmission of HIV, but also to forge consensus and to galvanize the political will to eradicate effectively these conditions.[20]

Sixth, these changes are affecting bioethicists from religious traditions as well. Catholic bioethicists, for instance, have paralleled these developments by bringing the language of the common good, social justice, solidarity, and the option for the poor into their discourse. This again arises from the shift of interlocutors, focus, context, and language. In many ways, Lisa Sowle Cahill pioneered this shift.[21] The new language of Catholic bioethics engages the traditional language of Catholic social justice at the same time that it makes the former more social and more attentive to issues of power and distribution of resources than was previously held. In a word, our religious language helps us to bridge the gap between conceptual analysis and social change: We do this because bioethics from any tradition must be socially effective.[22] Like public health officials, we realize that we cannot make the claims of what is fair unless we have the linguistic instruments to understand why there are inequities, or, to use the language of Mann, why there is the "gradient."

Seventh, HIV/AIDS physicians too have also begun to find "rights" language helpful and, in doing so, have shifted the center of moral decisionmaking. In caring for persons with HIV/AIDS, Anthony Pinching and Kenneth Boyd write: "This infection is so intensely private in its transmission, the disease so isolating and so personally devastating in its impact, it readily distinguishes the reality of what people are and do from the rhetoric of what others may feel they should be and do. AIDS has forced us to recognize that respecting individual rights is a critical safeguard for the health of the community, as well as for the person."[23]

They describe a turn from physician-dominated to patient-centered decisionmaking by explaining how severe and rapidly progressing illness, limited treatment options, and uncertain outcomes and expectations for both physician and patient prompted physicians to authorize the patient as the primary decisionmaker. This move entailed providing them with greater information and explanations about their treatments and including them in the design and oversight of clinical trials. They conclude: "As treatments have improved, so the content of the debate between clinician and patient has shifted. . . . Empower-

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ment has shifted control back to the patient, giving the clinician a more appropriate role as guide and enabler."[24]

Eighth, when physicians address the social phenomena surrounding HIV/AIDS, they find themselves necessarily in the role of patient advocate. Pinching and Boyd describe the impact HIV/AIDS has had in motivating both patients and physicians to enter the advocacy arena. After recognizing that women in childbirth, parents of sick children, and patients with a variety of chronic conditions had already started down the path of advocacy, often with medical encouragement, "many people with HIV wished to go further and faster, forcing their clinicians to think through the ethical issues until they were able to articulate a 'joined-up' rationale for what increasingly made practical sense to them. . . . Their message about empowerment and partnerships (from AIDS specialists and palliative care specialists) began to sound increasingly credible."

Reflecting on the first 20 years of AIDS in the *New England Journal of Medicine*, New York's Kent A. Sepkowitz comments: "In the 1970s, Washington-based, organized advocacy groups that focused on particular diseases were few; now at least 150 organizations exist. Activism by patients with AIDS has influenced advocates for patients with other diseases, including breast cancer, Parkinson's disease, Alzheimer's disease, and juvenile diabetes. Using creative approaches rather than following the established rules of lobbying, AIDS activists created a new model. . . . Today, patients are routinely consulted regarding the design of studies, and community-based research is conducted across the country."[25]

This advocacy has had concrete results, particularly in the development and approval of novel therapies, not only for AIDS, but for other diseases as well. As Sepkowitz notes, "AIDS has radically altered the development of drugs. Before the AIDS epidemic, the US Food and Drug Administration (FDA) was often viewed as a remote bureaucracy. With the advent of AIDS and the community that formed around it, numerous innovative approaches were developed to expedite the development of new drugs and patients' access to investigational drugs. The FDA became substantially more efficient: in 1986 the average interval between a drug application and the granting of FDA approval was 34.1 months; by 1999, it had decreased to 12.6 months."

Ninth, this entry into the advocacy arena is found not only in the industrialized world or solely among clinicians. At the opening ceremony of the XIVth International AIDS Conference held in Barcelona in July 2002, Italy's Stefano Vela, President of the International AIDS Society, highlighted the unprecedented shift seen around the world in the self-understanding of both physicians and basic scientists regarding their responsibilities: "I have never seen in the history of medicine such a growing scientific activism in that all of us included access to medication and to care to the South of the world in our scientific agenda. This is something I think that never really happened in the history of medicine. I think that all scientists progressively understood that they should take the lead with the idea that the advancements of medicine should not be reserved to small numbers of people."[26]

In short, researchers and clinicians are actively entering into a highly social and political world from their offices, laboratories, and healthcare facilities. Their efforts couple well with the intellectual investigations of theological and philosophical bioethicists and public health officials.

Tenth, a coherent conversation among researchers, clinicians, public health officials, and AIDS activists is beginning to materialize, and bioethicists are

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taking their place within that discussion. At present the public health officials are leading it, but as bioethicists continue to engage them, our own competencies and distinctive contributions ought to begin to emerge. As we become more involved, assuredly, we will become an integral part in developing political consensus and in moving toward greater advocacy issues regarding justice and healthcare.

Notes

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13. See note 12, Mann 1997:8.
14. See note 12, Mann 1997:8.
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24. See note 19, Pinching 2002:6.
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26. Like Vela, Los Angeles's Michael Gottlieb recognizes the significance of worldwide advocacy and goes beyond him to endorse more aggressive strategies: "We physicians must continue to advocate aggressive programs for prevention . . . and we must ensure easy access to care and medication for people who are HIV-positive. We must convince the pharmaceutical industry, foundations, and the government that there is a moral imperative to provide humanitarian relief in poor countries, to make antiviral medication affordable, and to improve medical care delivery systems." Gottlieb MS. AIDS—Past and future. *New England Journal of Medicine* 2001;344:1788–91.

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