The New Health Care Paradigm

Jonathan Mann, MD, MPH

AIDS is catalyzing a revolution in health care. No other disease in the world’s history has challenged the status quo as AIDS has done. Never before, even in the time of the great European plagues, has a health problem stimulated such a broad rethinking of health care, and ultimately social and political systems.

In confronting AIDS, no one set out to make a revolution. Rather, people tried only to prevent HIV infection, care for the infected and ill, and coordinate national and international efforts. Yet, in carrying forward this work, the deficiencies of our health care and social systems worldwide have been so starkly and painfully revealed that the pre-AIDS era paradigm of health care, its philosophy and practice, has been challenged and found to be desperately inadequate and, therefore, fatally obsolete.

What is this paradigm, this model, of health care that AIDS has called into question so forcefully? What events, what deeds, what ideas were, in retrospect, revolutionary? What are the creative themes of the new paradigm of health care?

The paradigm we inherited focused on discovering the external agents of disease, disability and premature death. Inevitably, the emphasis was medical and technological, involving experts and engineers, and, for certain purposes, this approach was quite effective. However, this paradigm envisioned a fundamental dichotomy between individual and social interests; accordingly, and in concert with the spirit of the age, governments were called upon to mediate and to prevent disease through laws and the work of bureaucracies. Attention to behavioral, social, and societal considerations was often rudimentary and naïve. Public health systems often favored coercion and compulsion without considering their effects on human rights.

During the past decade and even earlier, the limited capacity of this paradigm to cope with the health problems of the modern world has become increasingly evident. At the same time, the critical role of individual and collective behavior has been recognized. It is highlighted in the following situations: despite cheap and excellent childhood vaccines, only about half of the world’s children have been immunized; women cannot say “no” to unwanted or unprotected sex, unless they also have the social, economic, and political power to guarantee their own interests; nuclear power plants cannot be engineered to ensure absolute safety, for there was, and will always be, the so-called “human factor” of Three Mile Island or Chernobyl.

The Construction of the AIDS Paradigm

Over the past decade, the effects of AIDS on the health care paradigm have been revolutionary. First, since neither drug nor vaccine was available to fight HIV infection, behavior was immediately accorded central importance in the fight against AIDS. Each society rapidly discovered that it had neglected to consider the concept of “behavior” in its prevailing health philosophies and practices and that it was profoundly ignorant about sexual activity, the major behavior of concern.

Then, AIDS, much more than any other previous health issue, stripped away the veils that had covered the deficiencies and inequities in the ways health care and social services were organized and delivered, and highlighted the neglect of groups within society and the low priority accorded to health. People with HIV disease also articulated human needs with a clarity and passion not formerly encountered and for which the existing structures and services were often fundamentally unprepared.

Next, people infected with HIV and those labeled as members of “high-risk groups” declared their intent to participate in, rather than simply submit to, the processes of prevention, care, and research. The shock waves from this courageous determination to participate have not subsided; they have challenged, for every disease, methods of research and shaken deeply held assumptions about the roles of infected and ill people in their treatment.

Participation broadened even further as thousands of grassroots organizations responded to often desperate needs for prevention and care services, frequently reacting to the inadequate response of government. As a result, the prevailing view of government as the major actor in protecting health was challenged by the realities of community action and activism.

The key to the new paradigm is the recognition that behavior, both individual and collective, is the major public health challenge of the future.

Finally, somewhat unexpectedly, those involved in the pandemic found themselves speaking the language of human rights and dignity. In what other health area, at what other time, has there been such widespread and worldwide talk of “rights” and “social justice”? Invoking the concepts of human rights—nondiscrimination, equity, and justice—it is not only the content of policy and institutional action that has been challenged, but also the process through which policies and decisions have been reached.

These acts and many others—the understanding of AIDS as a global problem, the convening of international conferences, and the response of community organizations—have altered the way we think about health, individuals, and society. Towards what new vision, with what insight and power to promote health and prevent disease, is AIDS leading us today?

The key to the new paradigm is the recognition that behavior, both individual and collective, is the major public health challenge of the future. In shifting the major emphasis to behavior, the new paradigm will replace coercion with support, and discrimination with tolerance for diversity. The concepts of incorporation, adaptation, and symbiosis may be more relevant and useful in thinking about social interactions than old dichotomies of external versus internal, or individual versus collective. Just as AIDS blurs distinctions between the role of pathogens and the role of immunity in personal health, the next paradigm of health must embody a new understanding of the meaning of “internal” and “external,” and a new definition of what is the “self” and what is the “other.”

Solidarity

Using our current vocabulary—for new words may be required—“solidarity” describes a central concept in this emerging perspective on health, individuals, and society. The AIDS pandemic has taught us a great deal about solidarity. The basis of solidarity
is tolerance and non-discrimination: a refusal to separate the condition of the few from the fate of the many. Charity is individual; solidarity is inherently social, that is, concerned with social justice, and therefore also economic and political.

AIDS has helped us to recognize that solidarity is in part a consequence of the objective conditions of the late 20th century. For example, never before have so many traveled so far and so frequently as today: international travel has increased 15-fold since 1950. As the barriers of geographical and cultural distance diminish, the system in which we live—from the products we consume, to the air we breathe, to the viral pathogens in our environment—reflect an increasingly global linkage and interdependence. This also offers infectious agents an unparalleled opportunity for rapid pandemic spread; HIV may be the first virus to take full advantage of this situation, but it is unlikely to be the last. Fortunately, we are also beginning to understand and respond to the consequences of this globalism. Global solidarity—imperfect, struggling, yet nevertheless real—can be observed in the creation of the United Nations, the concern about nuclear war, the growing condition of the few from the fate of the many. Charity is individual; solidarity is inherently social, that is, concerned with social justice, and therefore also economic and political.

Yet solidarity can only exist when interdependence is real and felt to be so. Feeling is important; experience with AIDS has shown that some form of personal connection with people affected by AIDS is a powerful stimulus to greater human understanding. AIDS demonstrates the paradox that for an issue to become truly global, it must also become extremely personal. We may well need political innovation to help manifest solidarity and develop bridges between individuals, their local communities, and the world.

Coercion and Discrimination

AIDS has also improved our understanding of solidarity by revealing deficiencies inherent in two of its alternatives: coercion and discrimination. We all have personal experience with coercion—it has been used on us and we have used it—in an effort to influence behavior. But it is essential to ask a basic question: “Does coercion really work, and if so, to what extent and for how long?”

Available international experience with AIDS leads to skepticism, for there is little if any evidence that coercion has a positive influence on behavior. Nevertheless, people still say that infected individuals should be “punished,” and punishment may include isolation and quarantine. There is a persistent myth that quarantine is actually the most potent public health tool available, perhaps because it is the most coercive. However, on closer examination, quarantine is of limited applicability or usefulness: it has high social and economic costs, which have often been ignored, and, since it threatens people with HIV disease, its impact on AIDS prevention programs is certain to be counterproductive.

Discrimination reduces participation in HIV prevention activities, thereby diminishing effectiveness, and is also a “risk factor” for HIV infection. Vulnerability to HIV infection increases whenever people are socially marginalized: their access to information and preventive services is decreased; they have less influence on the design of prevention strategies; and most importantly, they have less power and capacity to take necessary steps to protect themselves. While measures to protect human rights will not, of themselves, ensure effective AIDS programs, the denial of human rights is incompatible with effective AIDS prevention and control.

Actions to Nurture Solidarity

Our experience with AIDS has brought us to this point: the discovery and recognition of solidarity as the touchstone of a new era. How can we now strengthen this solidarity through our work and make it responsive to the objective conditions, the aspirations for health and for freedom, that characterize our time?

First, we must recognize our power. Individuals and small groups can express and catalyze the aspirations of entire peoples. Next, we must work to broaden the participation of people in decisions that affect them.

In the process, we must also learn more about human rights, which are protected by the United Nations Charter and the Universal Declaration of Human Rights. For the first time in history, there is a written, collectively agreed-to, basis for promoting human rights, and governments can be held accountable for the way they treat their people. The goal should be not only to react to abuses of human rights, but also to help generate the conditions for promoting human rights and dignity, and this requires deliberate, active, and steady work.

As part of this responsibility, reviews of community, national, and international AIDS programs should include human rights assessments. International donor and coordinating organizations have a primary opportunity and responsibility to provide leadership in this area. Overlooking human rights issues is a form of neglect that only serves to reinforce discrimination. In addition, there must be definite responses to HIV-related human rights violations. Where institutionalized discrimination exists—as in the establishment of AIDS sanatoria of Cuba, and the mandatory screening and exclusion of HIV-infected foreigners from Saudi Arabia or China—we must speak out.

Finally, communities, corporations, and organizations must have the courage to look deeply into their own situations. The hardest problems of all are closer still to home: problems of work, health care, insurance, schooling, and discrimination in daily life.

Conclusion

To the historian of the future, many issues of current concern will be invisible, and the paradigm we are reaching towards will be, in retrospect, self-evident. Yet when this history is written, the discovery of the inextricable linkage between human rights and AIDS, and more broadly, between human rights and health care, will rank among the major discoveries and advances in the history of health and society. Solidarity based on human rights expands the levels of tolerance each society grants to its own members and to others; this is vital for AIDS, for health care more broadly, and for the future of political institutions. The historian of the future will see that we have had the privilege of being present at, and participating in, the creation of new worlds of thought and action, a revolution based on the right to health.

For beyond today, beyond us, we recognize the magnitude of the revolution in thinking that AIDS has catalyzed and how our work is linked with an instinctive striving, a visceral need, to express our human solidarity. For ours is part of a larger revolution which carries hope, not despair: hope for ourselves, hope for the fight against AIDS, and hope for the future of the world.

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Request for Submissions and Comments

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Challenges to Solidarity

Michael Helquist

Solidarity among those working on AIDS prevention is long overdue, but its application on a worldwide scale will likely be erratic and limited. The forces working against a rational, or even an emotional, appreciation of solidarity represent broad cultural traditions, corporate and governmental competition, and the grinding economic systems in most countries today. Jonathan Mann, in the accompanying article, identifies tolerance and non-discrimination—a refusal to separate the condition of the few from the fate of the many—as the basis for solidarity. Yet, effective solidarity among communities, organizations, and nations struggling to prevent HIV disease faces formidable challenges.

Public policy issues—particularly those concerning access to HIV-related information, prevention education, and medical treatment—and how they are resolved will determine whether solidarity becomes more than a missed opportunity. To the extent that public policy limits such access, it also creates roadblocks to coordinated action and solidarity. In order to ensure access and promote solidarity, AIDS educators and government officials must answer basic questions about the future of their efforts. Who will benefit from prevention programs? Who will get adequate patient services? Who will receive experimental treatments? Will governments, international donors, and community groups work together against a pandemic too large for them to handle individually?

Prevention Programs

An AIDS information campaign alone is no longer adequate for encouraging or empowering populations to change behavior. In most communities throughout the world, that task is accomplished: people have heard about HIV and most know about its transmission. No community at risk should have to settle for basic AIDS information while others benefit from more sophisticated behavior change strategies, such as a media campaign integrated with innovative face-to-face interactions. Such disparities disadvantage some populations and, further, create distinctions among people who might otherwise join together in prevention efforts.

Programs worldwide continue to show that including target audiences in the planning, implementation, and evaluation of HIV prevention efforts is the most effective way to ensure that messages and activities are popular, believable, persuasive, and viable. Yet, this fundamental tenet of health communication remains a point of debate not only in some developing countries that do not have a strong tradition of community involvement in government health programs, but also in developed nations where the communities affected by HIV disease are ostracized and ignored. As a result, people at risk continue to approach sexual encounters with high HIV awareness but low HIV protection.

Patient Services and Experimental Treatment

HIV prevention programs, as they are currently implemented, seldom incorporate patient services, that is, medical treatment and psychosocial care programs for those who are infected. This approach may be appropriate in those countries with few reported cases of HIV disease, but for all others, this lopsided strategy undermines public health, basic surveillance efforts, and HIV prevention itself. Efforts that focus on prevention alone are often based on both good will and strategic thinking—use limited funds to curb the spread of HIV and protect the larger population of people at risk but uninfected—and pay less attention to the needs of those who are already infected and whose treatment is expensive, benefits far fewer people, and is currently limited in efficacy.

Experience has shown, however, that the lack of patient services often discourages involvement in prevention strategies, such as risk reduction or safer sex programs, or HIV antibody testing. Populations that struggle with survival require a sense of immediate and tangible “benefit” as a result of their heeding HIV prevention messages. For example, people at risk for HIV may recognize no benefit in getting tested when they know there is no assistance for those who are seropositive. Such disenfranchise-ment discourages people with HIV disease, themselves excellent prevention educators, from recognizing how their experience might benefit the many.

Similarly, experimental treatments are difficult to obtain for disadvantaged people with HIV disease whether from Detroit to Dar es Salaam. The moral imperatives to provide these treatments often pale in the face of political agendas, nonexistent social service infrastructures, and other crippling health crises. As with patient services, the lack of assurance that people with HIV disease will receive effective treatments dissuades them from participating in their own care and the care of those they might help. This leads to hopelessness among providers and patients alike.

The resolution of public policy issues, particularly those related to access, will determine whether solidarity becomes more than a missed opportunity.

Collaborations

In developed countries, non-governmental organizations and community-based organizations took the first bold steps in response to the AIDS pandemic. They have been joined by a few governmental and private agencies that have traditionally provided funds to developing countries. There remains, however, no consensus on how donor agencies and community organizations should work together: community organizations often accuse donors of patronizing attitudes and unrealistic contract demands. Donors find that the organizations often expect a no-strings-attached grants system because, “The community knows best.”

AIDS funding has become even more limited, and community groups cannot expect donors to provide funds without requiring adequate financial accounting, effective management, and impact evaluation. Many donor agencies also have more experience with community development programs and communication methodologies. On the other hand, donors often demand from grassroots organizations such complicated applications and sophisticated program strategies that undermine their own stated objectives of working with and through the community. Community organizations must balance their roles of challenging the status quo, of which international donors are a part, and becoming part of the international funding system. Donors, whether national foundations or governmental aid organizations, must give these groups opportunities to do what they do best—effectively communicating with specific populations.

Conclusion

Examples of effective solidarity increase everyday, but a critical mass great enough to shape the international response to HIV disease remains elusive. Breaking down the barriers to equal access to information, services, and treatments through collaborations can clear the way for significant strategic interventions. Neglect of public policy issues often permits barriers to arise; HIV discrimination thrives in this vacuum and undercuts all efforts to work together. The use of solidarity itself as an effective HIV prevention strategy must progress rapidly from a well-conceived framework to an institutional and personal commitment.

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Recent Reports

Influences on Global AIDS Management. University of Maryland (Social Science & Medicine, September 1990).

AIDS management has been self-interested, piecemeal, and inconsistent, and has been influenced by a variety of historical, economic, and political factors, according to an outspoken review article in which a medical geographer examines the global response to the pandemic. Appropriate management requires a coordinated strategy of vaccine and drug development and dissemination, behavior modification, and education.

Social, rather than medical, factors have been most influential in determining governmental policy. Throughout the world, governments have sought to identify seropositive people and restrict their liberties, whether through mandatory antibody screening of subpopulations, limiting the access of foreign travelers with AIDS, or quarantining citizens who are HIV-infected.

There are historical precedents for these responses, all based on the concept of separating society from the infected, as much to avoid contact with people considered immoral or different—immigrants or the poor—as to avoid transmission of a biological agent. But U.S. history of the late 1970s and 1980s suggests other reasons for government responses: the recognition that some health problems were influenced by lifestyle, the fact that some health problems were influenced by lifestyle, and the fact that there is little data about its long-term toxicity, its absorption by the body, and its efficacy.

Throughout the world, money remains a critical factor in the inadequate global response to AIDS. Policy makers in the United States often seek cost-free solutions to problems and fund only those programs that are in the “national interest,” for example military defense. These ideologies have meant that the U.S.—a key economic player in the world—has decreased its funding of the World Health Organization, the primary international body working on AIDS intervention.


Lawmaking is an ineffective way to control the spread of HIV infection, and the coercion and discrimination caused by restrictions is counterproductive, according to this overview of the utility of public health law and analysis of HIV-related infection-control policies. Written by an Australian judge, it states that other measures are required to limit the spread of HIV, including international cooperation and education, innovative approaches to legal regulation of human sexuality and drug use, and efficiency in the design of new laws.

AIDS policy has produced three sets of “highly inefficient laws” each relating to mandatory antibody testing: testing the entire population of a country, testing members of “vulnerable” groups, and requiring antibody-free certification upon entering a country. Universal mandatory testing of the entire population might encourage some individuals to take measures to reduce the risk of infection. However, the cost of such a program and of isolating infected people would be staggering, and these interventions would be only marginally useful.

Mandatory testing of vulnerable groups, such as foreign applicants for residency or work permits, or foreign students, is more common than universal testing, but also has financial costs that outweigh its merits. Seronegative certification at national borders is cheaper but, while such testing may for a time slow the epidemic in a country with a relatively low incidence of HIV, few populations are free of infection. Any plan that restricts travel or immigration without reasonable grounds will cause friction among nations as each retaliates against exclusionary policies of others.


An editorial reviewing two clinical studies on the safety of Compound Q (trichostatin), also printed in this journal, concluded that while the drug deserves further study, treatment outside of clinical trials is unwise given its side effects and neurotoxicity, and the fact that there is little data about its long-term toxicity, its absorption by the body, and its efficacy.

The first, from San Francisco General Hospital, administered six doses intravenously to 18 patients with AIDS or symptomatic ARC. The second, a community-based trial by Project Inform and the University of Nottingham, administered three doses intramuscularly to seven patients and intravenously to 44 patients, all with T-helper cell counts of less than 400.

The studies found a variety of dose-related side effects that were generally reversible. These included severe fatigue, headache, muscle pain, fever, and rash, and neurological complications such as disorientation, insomnia and restlessness, dementia and coma. Patients with neurological toxicity in both studies had very low T-helper cell counts upon entry to the study.

Although the studies were not designed to determine efficacy, neither study showed, on the basis of antigen and T-helper cell levels, that Compound Q is clinically effective.

Next Month

The Hispanic population in the United States has been hit with disproportionate severity by HIV disease, and some Latin American countries are reeling under the impact of burgeoning epidemics. Hispanic cultural attitudes differ from mainstream attitudes in the U.S. and education, prevention, and health care delivery approaches must take these differences into account. In the March issue of FOCUS, Barbara Marin, PhD, a researcher at the Center for AIDS Prevention Studies at the University of California San Francisco, describes some of these differences—for example, in terms of interpersonal relations and the role of the family—and details their impact on HIV education and care.

Does HIV disease have different clinical affects on Hispanic people in the United States? Joanne E. Mantell, PhD, MSPH and Sandra Ramos, MPA, both of the AIDS Research Unit in the New York City Department of Health, review the evidence to determine how physicians should approach HIV treatment when caring for Hispanic people.