

## Understanding AIDS: Historical Interpretations and the Limits of Biomedical Individualism

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### ABSTRACT

The popular and scientific understanding of acquired immunodeficiency syndrome (AIDS) in the United States has been shaped by successive historical constructions or paradigms of disease. In the first paradigm, AIDS was conceived of as a "gay plague," by analogy with the sudden, devastating epidemics of the past. In the second, AIDS was normalized as a chronic disease to be managed medically over the long term. By examining and extending critiques of both paradigms, it is possible to discern the emergence of an alternative paradigm of AIDS as a collective chronic infectious disease and persistent pandemic.

Each of these constructions of AIDS incorporates distinct views of the etiology, prevention, pathology, and treatment of disease; each tacitly promotes different conceptions of the proper allocation of individual and social responsibility for AIDS. This paper focuses on individualistic vs collective, and biomedical vs social and historical, understandings of disease. It analyzes the uses of individualism as methodology and as ideology, criticizes some basic assumptions of the biomedical model, and discusses alternative strategies for scientific research, health policy, and disease prevention. (*Am J Public Health*. 1993;83:1477-1486)

Perhaps more than any other disease, acquired immunodeficiency syndrome (AIDS) offers a complex and vivid example of the ways in which people create multiple, contested explanations of health and illness. A plethora of social, political, and scientific actors have advanced competing claims to knowledge about the causes of AIDS. People directly affected by AIDS, especially within the organized gay community, have laid claim to both scientific and experiential knowledge and have challenged professional prerogatives; religious leaders have professed superior understanding of AIDS based on moral and biblical injunctions; politicians and the media have adopted, manipulated, and sometimes avoided the issue of AIDS depending on the rest of their social agenda and appeal to constituents; and scientists and health professionals have asserted what they consider to be rational and accurate appraisals of the problems and policies of AIDS.

From this apparent cacophony of voices and warring interpretations, some larger themes and patterns emerge. The popular and scientific understanding of AIDS, at least in the United States, has, we argue, been shaped by successive and clashing historical constructions or paradigms of disease, which have in turn been driven by our accumulating experience with AIDS.<sup>1</sup> In the first construction of its history, AIDS was conceived of primarily as a "gay plague," by analogy with the sudden, devastating epidemics of the past.<sup>2</sup> In the second paradigm, AIDS was normalized as a chronic disease to be managed medically over the long term.<sup>3</sup>

Although each paradigm certainly has captured important aspects of the AIDS epidemic, neither has proven fully adequate for understanding and preventing AIDS, and each has had its share of

critics. By examining and extending these critiques, we believe it is possible to discern the emergence of an alternative paradigm that considers AIDS to be a collective chronic infectious disease and persistent pandemic, manifested through myriad specific diseases associated with human immunodeficiency virus (HIV) infection.<sup>4</sup> This alternative paradigm emphasizes that AIDS is at once a social and biological disorder; its course cannot be understood or altered without attention to its social and political context.

Each of these three historical constructions of AIDS incorporates distinct views of the etiology, prevention, pathology, and treatment of disease; each tacitly promotes different conceptions of the proper allocation of individual and social responsibility for the problems associated with the AIDS epidemic. In our exploration of the contesting interpretations of AIDS, we have found that, although it is certainly possible to contrast scientific and popular views, it is perhaps more revealing to contrast individualistic vs collective, and biomedical vs social and historical, views of disease.

### *The First Paradigm: AIDS as Gay Plague*

Like the great epidemics of the past, AIDS first appeared as a sudden, fatal,

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AIDS quilt on display at the Lesbian and Gay March on Washington, October 1987. Photo by Rick Rocamora.

and communicable disease.<sup>5</sup> It seemed to resurrect the true meaning of *epidemic*: a disease that spreads like wildfire, consumes lives, and then burns out, leaving devastation in its wake. Epidemiologists, the first scientists to lay claim to understanding the mysterious new ailment, were struck by its seemingly exotic preference for young, homosexual men; they therefore searched for causes in the behaviors or “life-styles” common to gay men. In the process, they looked for risk factors prevalent in this “risk group” and indicted life in the fast lane, including “promiscuity,” “poppers” (amyl nitrate), and anal sex.

Fascinated by the details of gay male sexual behavior and culture, researchers at first ignored the cases of AIDS that did not fit the gay plague model, such as those among women and users of injection drugs. Indeed, the disease was initially termed GRID, the gay-related immunodeficiency disease, and those stricken who denied homosexual contacts were often assumed to be lying. The gay plague model was clearly challenged, however, by the first cases among blood transfusion recipients, hemophiliacs, and Haitian immigrants.<sup>6</sup> Thereafter, researchers began to speak of the “4-H risk groups”: homosexuals, Haitians, hemophiliacs, and heroin addicts.<sup>7</sup> To epidemiologists, risk groups were simply neutral, empirical descriptions of individuals with common identities and/or behaviors associated with an increased, but not absolute, risk of developing the disease. In popular percep-

tion, however, all members of the identified risk groups were seen as potentially contagious; from there it was but a short step to perceive those populations as “responsible” for AIDS. This in turn led to the prevalent media descriptions of the “innocent victims” of disease, such as hemophiliacs and children; by implication, the others were “guilty” culprits.

The gay and lesbian communities rejected both these characterizations: as statistical risk group and as population of disease carriers. These communities had a recently formed, self-conscious sense of their social and political identity, forged in part out of a successful struggle with the medical establishment over the psychiatric definition of homosexuality as a pathological disorder. The epidemiologists’ apparently neutral categories were perceived as an attempt to resurrect the earlier biomedical construction of homosexuality as a sickness.<sup>8</sup> This perception was heightened by the unmediated associations between homosexuality and disease that appeared in the declarations of right-wing ideologues, who lost no opportunity to castigate homosexuals in the name of “family values” and the “American way of life.”<sup>9</sup> Rejecting these attacks, the politically formed gay community began to challenge the scientists’ right to define the disease, design research, and determine social policy.<sup>10</sup>

In 1983, the identification of HIV, the AIDS virus, led to a new phase of the epidemic, in which AIDS was clearly characterized as an infectious disease.<sup>11</sup>

Once the virus was identified, scientists tended to lose interest in the social factors accompanying transmission. They instead turned to laboratory studies of the virus and its action within the body in the hopes of making new discoveries that would lead to patents, vaccines, and possibly a cure.

The identification of the virus also changed popular views of the proximate and ultimate causes of the AIDS epidemic. A virus was a familiar if vague entity in popular culture, used to explain or explain away all kinds of indefinite ills.<sup>12</sup> By the same token, a virus was perceived as something easy to catch; the idea that AIDS was caused by a virus, along with vague announcements about bodily fluids, may well have increased fears of casual transmission of the disease.<sup>13</sup> Although numerous surveys found that many people could correctly identify how HIV was transmitted—via sex and blood—they also documented widespread magical thinking.<sup>14</sup> As in other societies, where anthropologists have often noted the existence of pluralistic ideas of disease causation, many people in the United States simultaneously embraced scientific, traditional, and folk explanations of AIDS, with little sense of contradiction.

Ideas of “magical contagion” led otherwise well-informed people to fear contact with AIDS patients. For example, one study found that most people would refuse to wear a sweater previously worn by an AIDS patient, even if it had been thoroughly cleaned and even when they knew that AIDS could not be transmitted in this manner.<sup>15</sup> More generally, popular conceptions showed that the scientific search for biomedical risk factors, agents, and other proximate causes of disease had failed to satisfy the broader need for ultimate explanations—the “why” and not just the “how” of disease causation. Notions of germ theory, deep-seated moral convictions, and ancient ideas about “bad blood” and contagion were thus conflated into a rich brew of popular attitudes toward disease; the brightly colored pictures of viruses in popular magazines bore little relevance to these complex emotional responses to the epidemic.

Among health professionals, the identification of HIV seemed to clarify strategies for AIDS prevention. It shifted attention away from the early risk-group designations and highlighted the importance of risk behaviors, thus focusing attention on specific acts rather than on sexual identities.<sup>16</sup> Given the enormous scientific problems involved in developing a vaccine, public health professionals

advocated technically simple and individually oriented methods of prevention—such as condoms—to block the transmission of HIV. Campaigns to promote condom use, however, were immediately opposed by a right wing that was dead set against nonmarital sex. This conservative intransigence, sustained as it was by the Reagan White House,<sup>17</sup> made the public health approach to AIDS prevention an especially difficult and frustrating task. At the same time, these very disputes broke taboos and greatly expanded the boundaries of public discussions about sexuality.

For injection drug users, clean needles were the public health equivalent of condoms.<sup>18</sup> But the act of providing individuals with clean needles was problematic because many people perceived the distribution of needles and bleach as a possible encouragement of drug use.<sup>19</sup> Many African Americans were convinced that these programs were part of a long-standing, White-led genocidal policy against Blacks, and they called instead for drug treatment programs and jobs.<sup>20</sup> By contrast, many conservatives simply wanted drug addicts thrown into jail.

Prevention methods to curtail blood transmission were similarly framed in individualistic terms. People were urged to refrain from donating blood if they had any reason to believe they were at risk for HIV infection; people needing blood were encouraged to store their own blood prior to surgery or to collect blood from family and friends, as if only strangers' blood were dangerous.<sup>21</sup> This represented a break with the more traditional view of blood banks as a communal resource; blood was now increasingly seen as an individual possession.

Ultimately, the identification of HIV and the discovery of a blood test for HIV antibodies made possible the traditional approach to infectious disease control—identification of those infected, followed by isolation, quarantine, or other societal action to cut off transmission<sup>22</sup>—and led to battles over testing immigrants, blood donors, and individuals considered to be at risk.<sup>23</sup> From the biomedical and epidemiological point of view, the availability of a test meant that people could and should be screened; if individuals knew their serostatus, they would more readily change behaviors that put either themselves or others at risk.<sup>24</sup> However, this logic assumed that sexual behavior was a function of rational calculation; it ignored the complex power dynamics of sexual relation-

ships.<sup>25</sup> By a similar calculus of risk, many health care workers argued that if they knew the serostatus of their patients, they could take appropriate precautions.<sup>26</sup>

This general logic of the infectious disease paradigm did not consider the social reality of discrimination in health insurance, jobs, and housing that faced those diagnosed as HIV positive.<sup>27</sup> It also ignored the ethical problem that, in the early stages of the epidemic, no therapy was available; testing exposed the individual to considerable social risk while offering no medical benefit. Gay men and lesbians fought testing initiatives in terms of individual rights to privacy and confidentiality—the most viable political terms of discourse in the United States—and thus challenged the assumption that infection was the only risk that needed to be considered.<sup>28</sup> When the blood test threatened to create a new social division between those categorized as seropositive and seronegative, the lesbian and gay communities rejected this division and led a collective fight on behalf of everyone deemed at risk.

### *The Second Paradigm: AIDS as a Chronic Disease*

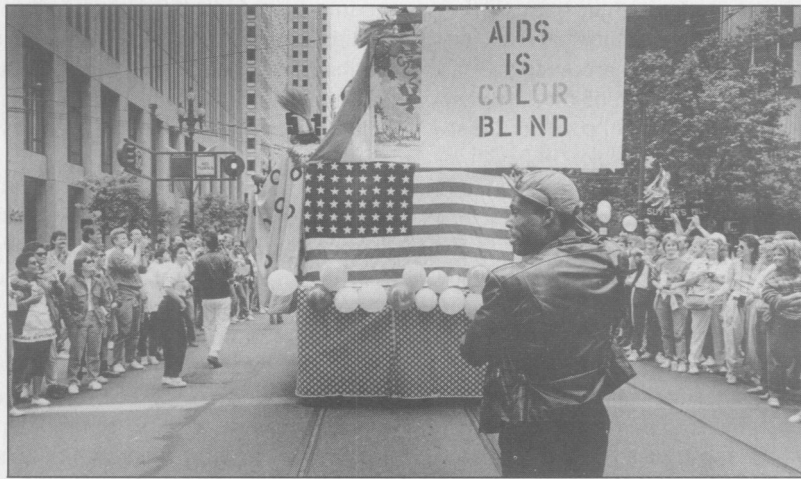
In the United States in the late 1980s, several factors contributed to shifting the framework for understanding AIDS from a plague to a chronic disease model.<sup>29</sup> First was the recognition of the lengthening time frame of the epidemic; unlike plague and cholera, AIDS was clearly not going to disappear quickly. Then, too, dire predictions about the massive spread of AIDS throughout the entire US population—the threatened “heterosexual explosion”—had not been fulfilled. Indeed, statisticians were revising downward the early estimates of the number of HIV-infected persons.<sup>30</sup>

Perhaps most importantly, people with AIDS were living longer than expected. For people infected with HIV, the emphasis changed to living with, rather than dying from, AIDS.<sup>31</sup> Researchers and health care professionals shifted the focus of their concern from etiology to pathology and from prevention to potential therapies. The development of palliative treatments such as azidothymidine (AZT) for people with AIDS (and, later, for those who were HIV positive) placed new emphasis on health services, as reflected in the growing numbers of dedicated AIDS units for both inpatient and outpatient care.<sup>32</sup> Early worries about the financing

of AIDS care had been at least partially addressed<sup>33</sup>; from the point of view of health services delivery, AIDS was becoming just another expensive disease, like cancer, with which the medical system could cope—especially if patients had adequate health insurance.<sup>34</sup>

When first conceived of as an infectious chronic disease, AIDS was likened to such diseases as tuberculosis and syphilis.<sup>35</sup> This argument was initially contested, but within a few years, the idea that AIDS was a chronic disease became widely accepted in the economically developed countries.<sup>36</sup> According to the standard chronic disease model, which was developed for conditions like cardiovascular disease and cancer that were thought to be noncommunicable, chronic diseases are debilitating and often fatal conditions that are slow to develop, persist for many years, and require long-term management.<sup>37</sup> Research focuses on disease mechanisms, usually at the cellular level, and increasingly concentrates on genetic determinants.<sup>38</sup> Based on this understanding of disease, health interventions most commonly emphasize screening, early detection, and treatment, not primary prevention; finding the right pharmaceutical cure represents the epitome of successful disease management.<sup>39</sup>

Reconceptualizing AIDS as a chronic disease inevitably brought these prevalent assumptions about chronic diseases to bear on all aspects of AIDS research, policies, and programs. The federal government, politicians, and the media, having already grown weary of contentious prevention campaigns and elusive attempts to develop a vaccine, displayed a new enthusiasm for supporting basic scientific research. Funding now flowed for studies of the natural history of AIDS, AIDS pathology, and clinical trials. Scientists vied with each other in hot pursuit of pharmaceutical agents that could slow the course of AIDS and HIV-related diseases. The success of Burroughs-Wellcome in the marketing of AZT fed the enthusiasm and entrepreneurial excitement of scientists and investors alike.<sup>40</sup> By contrast, few research dollars were expended on studies designed to improve prevention, whether for vaccines or social interventions. Certain uses of federal research funds were even proscribed. The US Congress, for example, canceled two national surveys of sexual behavior,<sup>41</sup> and until recently, the National Institute on Drug Abuse refused to fund research evaluating the effectiveness of needle-exchange programs. Testing for HIV was now encouraged



The slogan "AIDS is color blind" was prominent at the Lesbian and Gay Pride March, June 1987, San Francisco. Photo by Rick Rocamora.

more as a means of drawing infected people into early treatment than as an incentive to modify behavior.<sup>42</sup>

With the growing emphasis on health care, interested physicians began to specialize in AIDS and assumed a more important role in the management of AIDS and other HIV-related diseases. Evidence suggests, however, that most doctors were ill equipped to advise their patients about HIV disease, let alone take care of people with AIDS. One study found that more than 80% of a national sample of primary care physicians—those who might be expected to be on the front lines of patient education—said they lacked information about AIDS.<sup>43</sup> Other research reported that most physicians were reluctant to talk about the basic issues of sex and drugs, and often failed to take relevant medical histories or to offer appropriate advice.<sup>44</sup> These studies found that many doctors were uncomfortable about sexuality, nervous around homosexuals, disturbed by drug addicts, and generally uneasy with AIDS patients.<sup>45</sup> Indicating that patients were likewise reluctant to discuss sex and drugs with their doctors, surveys found that most people obtained information about AIDS from the mass media, family, and friends, and that fewer than 10% had ever discussed the disease with their physician.<sup>46</sup>

Wary of physicians' biases, HIV-positive people were not necessarily willing to assume that their doctors knew best. Some were attracted to alternative explanations of AIDS, including Peter Duesberg's widely publicized claim that HIV was only incidentally related to AIDS.<sup>47</sup> People with AIDS explored alternative therapies and unconventional drugs, often

purchasing pharmaceuticals that were only available in other countries through underground "buyers' clubs." Many of the popular books about living with AIDS challenged the hegemony of Western medicine and drew on alternative traditions ranging from classical Chinese acupuncture to New Age spirituality.<sup>48</sup> Most of these alternative traditions, like the biomedical model, placed the onus of staying healthy on the individual.

AIDS activists increasingly became concerned about access to health care and the development of new and experimental treatments. They sought to extend the official definition of AIDS, expand access to AIDS services for HIV-infected persons, speed up experimental drug approvals, and broaden participation in clinical trials to include women, people of color, and people with low incomes. Reflecting their success and also the growing understanding of the progression of HIV disease, the Centers for Disease Control revised its diagnostic definition of AIDS in 1991 to include T-cell counts and, in 1992, to include cervical cancer and pulmonary tuberculosis among HIV-associated diseases.<sup>49</sup> In a step that also had significant implications for other life-threatening diseases, the Food and Drug Administration agreed to streamline its procedures for drug approval.<sup>50</sup> Similarly, the National Institutes of Health, under pressure from women, minorities, and AIDS activists, began to require broader participation in clinical trials and research protocols.<sup>51</sup>

Reflecting the clash between the first and second paradigms of AIDS, other AIDS activists questioned the single-minded focus on treatment and emphasized prevention. Tensions existed be-

tween those concerned strictly with AIDS and those who believed that the epidemic could be addressed only in relation to the health care crisis, the military budget, poverty, and racial and gender discrimination.<sup>52</sup> Because the older AIDS organizations were largely staffed by and served the interests of gay White men, the newer constituencies of women, people of color, and injection drug users (in their overlapping permutations) created organizations to meet their own needs—and in the process competed for the same limited pool of funds.

As the epidemic persisted, individuals and cultural groups explored the personal and social meanings of AIDS through writing, video and film production, theater, art, photography, and music.<sup>53</sup> Many rejected the exclusively tragic imagery of dying in favor of diverse representations of living with AIDS. Their work incorporated the voices, faces, and experiences of people with AIDS, in contrast to the scientific and policy literature that presented the views of professional authorities.<sup>54</sup> Cultural workers held the subjective truths of those directly affected by the epidemic to be authentic knowledge, as valuable for understanding AIDS as any objective biomedical account.

As AIDS touched every aspect of public life, from art to politics to sports, increasing popular awareness of the disease led to growing acceptance of people with AIDS. When the basketball star Magic Johnson announced he was HIV positive, he was warmly applauded for his honesty and bravery. But although the language of guilt was less often applied to people ill with AIDS, the distinction between innocent and guilty "victims" lingered, as seen in the general hysteria over infected health care workers.<sup>55</sup>

The heated controversy over the minuscule risk posed by seemingly healthy HIV-positive persons working at their usual jobs was, however, more than an expression of irrational fears. It highlighted the new dilemmas created by AIDS as a "normal" chronic disease; the question remained how people living with AIDS could be incorporated into the daily fabric of society. As made manifestly clear by the chronic disease model, AIDS was here to stay.<sup>56</sup>

### *Critique of the First and Second Paradigms: Limitations of Individualism and the Biomedical Model*

Reconceptualizing AIDS as a chronic disease addresses several notable failures

of the plague paradigm, particularly the lack of a long-term perspective, but this approach may ultimately prove catastrophic. In accepting the chronic disease model's emphasis on pathology and treatment, many scientists and health care professionals have lost sight of the fact that AIDS is both infectious and preventable. The mounting number of HIV-infected persons, estimated at 12.9 million worldwide in early 1992, suggests that it may be useful to reconsider whether either paradigm is fully adequate for preventing AIDS or dealing with its social consequences.<sup>57</sup>

Questions about the utility of the traditional infectious and chronic disease models in understanding health and disease are not unique to AIDS. In the case of the infectious disease model, we now recognize that its early reputation for success in controlling epidemics was overinflated. Historians have argued that much of the decline in infectious diseases predates scientific medicine and may more correctly be attributed to improved sanitation, clean water supplies, better nutrition, and less crowded living conditions.<sup>58</sup> For contemporary infectious diseases, the "magic bullets" of antibiotics and pesticides certainly provide relief and vaccines continue to reduce the incidence of many childhood infections, but these types of measures alone have not been able to prevent the resurgence of heretofore controlled diseases such as tuberculosis, cholera, and malaria.<sup>59</sup>

If the successes of the infectious disease model have been more limited than was initially believed, the chronic disease model has fared no better. Although the incidence rates of a few cancers (e.g., stomach cancer) have declined, often for unknown reasons, the rates for many other types of cancer are stable or increasing.<sup>60</sup> When the American Cancer Society claims to be winning the war on cancer, it is generally referring to improvements in treatment and survival, not to reductions in incidence.<sup>61</sup> Although accelerated by recent attention to smoking, exercise, and nutrition, the decline in mortality from coronary heart disease began before current campaigns for heart-healthy living—again, for reasons not fully understood.<sup>62</sup> While preventive interventions based on the chronic disease model have stressed individually oriented dietary and behavioral modifications, it is unclear how much health behaviors have really altered.<sup>63</sup> One clear change is the decline of cigarette smoking, but in this case, recent initiatives to restrict tobacco use have moved be-

yond criticism of smoking as an individual bad habit to target passive smoking as a communicable hazard.<sup>64</sup>

Many of the limitations in our concepts of infectious and chronic diseases, reflected in our shifting understanding of AIDS, ultimately stem from the underlying and unstated assumptions of the biomedical model. As several critics have argued, 20th-century biomedical models typically are reductionist; they put primacy on explanations of disease etiology that fall within the purview of medical intervention narrowly construed, focus on disease mechanisms, and view social factors leading to disease as being secondary if not irrelevant.<sup>65</sup> Proponents of such models may even consider emphasis on societal factors such as poverty or discrimination to be unscientific and polemical. Despite lip service to multifactorial etiology, they seek parsimonious biomedical explanations highlighting the role of one or a few proximate agents, and they generally assume that biomedical interventions, operating on biological mechanisms, will be sufficient to control disease.

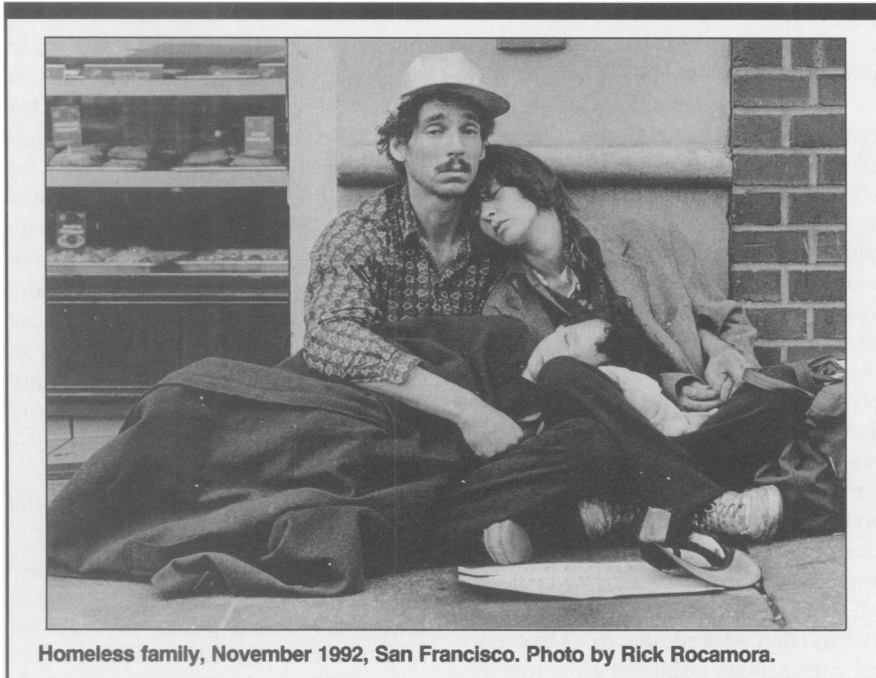
The biomedical model is also premised on the ideology of individualism. Adopting the notion of the abstract individual from liberal political and economic theory, it considers individuals "free" to "choose" health behaviors. It treats people as consumers who make free choices in the marketplace of products and behaviors, and it generally ignores the role of industry, agribusiness, and government in structuring the array of risk factors that individuals are supposed to avoid. There is little place for understanding how behaviors are related to social conditions and constraints or how communities shape individuals' lives. From this perspective, populations and subgroups within populations—including "risk groups"—consist merely of summed individuals who exist without culture or history. There is no acknowledgment of the fact that when "risk groups" succeed in identifying populations at risk of disease, it is because these risk groups typically overlap with real social groups possessing historically conditioned identities.<sup>66</sup>

The problems with the biomedical model extend beyond its exclusive focus on biological and individual-level factors and concern fundamental issues of scientific objectivity and the production of scientific knowledge. The canons of scientific objectivity, as embraced by this model, tend to discount the views and experiences of patients, the "objects" of scientific research and medical practice.<sup>67</sup>

Only scientists and physicians are seen as possessing the expertise to define disease and frame research questions; negotiation of these issues with those directly affected is rarely considered. This model assigns physicians the unique responsibility for conveying specific knowledge about disease to individual patients, and it tacitly assumes that access to medical care is universal. It regards patients' beliefs as mere superstitions or misinformation that can be overcome with therapeutic doses of factual information. Subjectivity and culture—of the scientists and health care professionals as well as of their patients—are deemed irrelevant to "truth"; scientific knowledge is held to be outside the bounds of social context.

The assumptions of the biomedical model as embodied in the paradigms of gay plague and chronic disease have shaped scientific knowledge about AIDS as well as the medical and public health responses to this epidemic. The biomedical orientation has led to an almost exclusive focus on HIV and the mechanisms—as opposed to the social determinants—of its transmission. As methodology, biomedical individualism has resulted in data being collected chiefly on individuals with or at risk of AIDS, and rarely on the social context of their lives. Working under the rubric of "objectivity" as defined by the biomedical model, scientists have failed to see how social biases affect the type of research questions they ask. Physicians and other health care workers have failed to see how similar assumptions shape the medical care they provide. And these assumptions, if not addressed, threaten to vitiate our still-inadequate response to the epidemic.

Ultimately, the biomedical model embodies an approach to analyzing disease that is fundamentally individualistic and sanctions only the physicians' or scientists' point of view. Profoundly ahistorical, it contains within itself a dichotomy between the biological individual and the social community, and then it ignores the latter. It tends to reduce individuality to the very constrained level of genetic constitution and susceptibility.<sup>68</sup> Reflecting an ideological commitment to individualism, the only preventive actions seriously suggested are those that can be implemented by solo individuals. Little attention is accorded to situations in which negotiation is required between persons with unequal power, as is often the case between sexual partners or between advocates of needle exchange and the police.<sup>69</sup> Intended or not, these attitudes implicitly accept social



Homeless family, November 1992, San Francisco. Photo by Rick Rocamora.

inequalities in health and fail to challenge the social production of disease.

In challenging the assumptions of the biomedical model, we are not suggesting that disease can be understood without reference to biology; the question, however, is what approach we should take: a biology abstracted from social conditions or a biology understood in relation to its social context? Similarly, in questioning the ideology of individualism, we do not question the importance of individuality. But rather than posit the abstract, atomistic individuals of the idealized market, we want to emphasize how individuals' lives are shaped by both personal history and the social groups to which they belong.

### ***Features of an Alternative Paradigm: AIDS as a Collective, Chronic Infectious Disease and Persistent Pandemic***

The creation of an alternative paradigm begins with the recognition that the individualistic assumptions of the existing biomedical model are simply not appropriate to AIDS<sup>70</sup>; AIDS is, in essence, a social disease. For this reason, we propose calling AIDS a collective chronic infectious disease and persistent pandemic. The term *collective* emphasizes the inadequacies of dealing with AIDS from a purely individualistic perspective; AIDS is, above all, about people in personal and social relationships. The term *chronic* acknowledges the potentially

prolonged duration of the disease and its requirements for clinical management and care. The term *infectious* is retained to highlight fundamental aspects of etiology, modes of transmission, and possibilities for prevention.<sup>71</sup> And by calling AIDS a persistent pandemic, we stress both the long time frame of the disease and its global impact.

Transforming our historical understanding of AIDS in these ways implies developing an alternative research agenda, changing the policies we perceive as relevant, and creating new strategies of prevention. This incipient process is already under way, if only in fragmentary forms. It may be helpful to step back and consider some of the general parameters of the alternative approach and then examine some of its concrete manifestations.

This emphasis upon a collective rather than an individualistic approach to disease means drawing on a different body of theory—one that stresses the social production of disease and raises questions about how the social relationships of class, race, and gender affect people's working and living conditions and thereby influence their health status.<sup>72</sup> It asks how patterns of risk are socially shaped within a historical context and why people make unhealthy life-style choices. It is thus concerned with how contemporary historical processes contribute to inequalities in health.

In asking these questions, this approach challenges investigators to de-

velop a critical self-awareness of their own social and historical context and of the disease paradigms that guide their research. It encourages public health professionals to conceive of research as a two-way process in which investigators and subjects can instruct and learn from each other. It reminds us that AIDS, like other diseases, cannot be understood or addressed solely within the parameters of the health care system. And it reemphasizes the truly public character of public health.

This alternate approach has already led to some new insights relevant to AIDS prevention. For example, one study of minority women's decisions about condoms used focus groups to uncover the personal and economic context influencing their choices and, in the process, challenged cultural stereotypes of Black and Hispanic women's lack of power in heterosexual relationships.<sup>73</sup> Another study found that injection drug users were more influenced by their material circumstances, such as access to clean needles and a private setting for drug use, than by their perceptions of risk of contracting AIDS from dirty needles.<sup>74</sup>

Much of the broadening base of AIDS prevention activities is now being directed by and for minority communities. To improve care for HIV-infected persons, several groups are producing new educational materials that inform health care workers about the variety of cultural beliefs and attitudes toward disease, sexuality, drug use, and treatment found among their clients.<sup>75</sup> Recognizing the importance of basing health education campaigns on what people really believe, researchers have begun to document the plurality of popular conceptions about health and disease causation in order to make AIDS education materials more compatible with people's own modes of understanding.<sup>76</sup>

Many AIDS prevention programs now also challenge the assumption that the key to prevention lies within the medical setting.<sup>77</sup> Ex-addicts, for example, run some of the most effective needle-exchange programs by operating illegally on street corners. Health education campaigns within the gay community have been creative—and controversial—in attempting to eroticize safer sex and thus change collective social mores with respect to acceptable sexual behavior.

Other prevention efforts go well beyond the boundaries of traditional health education directed at the "consumers" of health care. Nicholas Freudenberg thus

includes legislators among the groups in need of behavioral modification.<sup>78</sup> These more radical visions of health education recognize that the target population for policy changes should include employers, the courts, the media, and the government.<sup>79</sup> Nor need these campaigns be conducted only by health-related groups. Levi Strauss provides an example of what one company can do to provide health education to its work force, implement enlightened antidiscrimination policies, include domestic partners in insurance coverage, and fund community-based AIDS prevention groups.<sup>80</sup>

These new prevention strategies begin to acknowledge that people at risk for HIV infection do not come in the discrete packages suggested by the original epidemiological formulation of "risk groups."<sup>81</sup> Instead, real people overlap these categories in many different ways, and a single category may include a multiplicity of diverse social groups. It has been recognized, for example, that gay men belong to a wide variety of subcultures that occupy different social spaces, including local gyms, leather bars, and Wall Street. More recently, AIDS outreach workers have been learning to draw finer distinctions among cultural groups and between those men who have sex with men and do—or do not—consider themselves part of the gay community.<sup>82</sup>

Similarly, women with AIDS do not represent one homogeneous group. Some are White and some are women of color; some are working class, some are wealthy; some contracted HIV infection from their partners, some from drugs, and some from transfusions. All may face certain issues unique to women with AIDS, such as the need for treatment of gynecologic opportunistic infections, and many must deal with fears of maternal-fetal transmission, but their diversity makes it obvious that no single program can be designed to cover "women with AIDS."<sup>83</sup>

This alternative understanding of AIDS also implies changes in the ways we make health policy. AIDS has unequivocally demonstrated that populations affected by a disease—people who are usually relegated to the position of being passive recipients of services—can spur innovative and effective planning. AIDS activists initially forced a major shift in the old public health approach to infectious disease control: for example, constraints on or quarantine of those infected. The political strength of the gay movement engendered within public health circles a new sensitivity to issues of stigma, confi-

dentiality, privacy, and informed consent, and it ultimately helped democratize health policy.

If the paradigms of gay plague and chronic disease have failed to account for the many facets of AIDS within the United States, their inadequacies become even more apparent when one considers the phenomenon of AIDS as a spreading and persistent international pandemic. In most Central African, Latin American, and Southeast Asian countries, AIDS can be characterized neither as a peculiarly gay plague nor as a chronic disease; most people with AIDS are heterosexual and few can afford the luxury of extended treatment.<sup>84</sup> Within the United States, we may have much to learn from the AIDS campaigns being created in various economically underdeveloped countries, which of necessity stress prevention since expensive pharmaceuticals and high-technology medical care are of only marginal relevance to most of their inhabitants.<sup>85</sup>

The infectious disease model is, however, unlikely to prove adequate for controlling AIDS in these regions. As in the United States, the individualistic assumptions of this model fail to take into account the real conditions of people's lives and the social and material bases of disease transmission.<sup>86</sup> Recognizing this fact, the National Union of Mineworkers, for example, a powerful trade union working alongside the African National Congress, is developing community-based strategies against AIDS in South Africa.<sup>87</sup> Highlighting the links between employer-enforced working conditions, single-sex hostels, and the exchange of sex for money, the union has made clear that preventing HIV transmission will require changes in the structure of work and not just in the delivery of health services.

### *Understanding and Preventing AIDS: A Collective Enterprise*

In conclusion, there is not a single understanding of AIDS because it is not a single disease that can be objectively known and defined in a timeless manner. The understandings of AIDS are diverse and reflect not only our growing experience with the epidemic, nationally and internationally, but also the different social contexts of those who establish these meanings through their work, their lives, and their deaths. To understand AIDS is to comprehend that our knowledge at any given point in time is shaped not only by accumulating biomedical discoveries, but

also by the presence or absence of the voices of the different groups affected by the epidemic. If we are to understand AIDS better and formulate more effective prevention and health care strategies, the experiences and views of those hit hardest by the epidemic must be made more central to the conduct of scientific research and the establishment of health policy.

Transforming our approach to AIDS will not be an easy task. The issue is not simply a conflict between scientific and popular conceptions of AIDS, between "correct" and "incorrect" understandings. Instead, as we have argued, the task involves a thoroughgoing critique of the effects of individualism and the biomedical model upon our explanations of disease, our research agendas, and our policy priorities. It requires a greater appreciation of the historical and social contexts in which AIDS occurs, and of the relationships between the different social groups connected by the course of the disease. By analyzing the changing constructions of AIDS, we can begin to challenge the conventional view that AIDS will be understood and solved by science alone, and we can thereby expand our strategies to prevent this wretched and wrenching epidemic from becoming ever more entrenched. □

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### **Notes**

1. For one of the earliest analyses of paradigms (referred to as "thought collectives") in medical history, see Ludwig Fleck, *The Genesis and Development of a Scientific Fact* (1935; Chicago, Ill: University of Chicago Press, 1979). For a seminal discussion of paradigms in scientific thought more generally, see Thomas Kuhn, *The Structure of Scientific Revolutions*, 2nd ed (Chicago, Ill: University of Chicago Press, 1970). Both analyses consider paradigms to be primarily shaped by—and paradigm shifts to be mainly driven by—factors "internal" to science (e.g., level of technology, anomalous observations). Since the 1970s, however, a considerable body of literature on the social history of science, including medicine and public health, has analyzed how societal factors typically deemed "external" to science (e.g., prevailing ideologies) shape not simply the application but also the essence of scientific thought. See, for example, Hilary Rose and Steven Rose, eds, *Ideology off in the Natural Sciences* (Cambridge, Mass: Schenkman, 1979); David Dickson, *The*

- New Politics of Science* (Chicago, Ill: University of Chicago Press, 1988); and Charles E. Rosenberg and Janet Golden, eds, *Framing Disease: Studies in Cultural History* (New Brunswick, NJ: Rutgers University Press, 1992).
2. Elizabeth Fee and Daniel M. Fox, eds, *AIDS: The Burdens of History* (Berkeley, Calif: University of California Press, 1988).
  3. Elizabeth Fee and Daniel M. Fox, eds, *AIDS: The Making of a Chronic Disease* (Berkeley, Calif: University of California Press, 1992).
  4. See Elizabeth Fee and Nancy Krieger, "Thinking and Rethinking AIDS: Implications for Health Policy," *International Journal of Health Services* 23 (1993):323-346.
  5. Gerald M. Oppenheimer, "In the Eye of the Storm: The Epidemiological Construction of AIDS," in *AIDS: The Burdens of History*, ed Fee and Fox, 267-300; Randy Shilts, *And the Band Played On: Politics, People, and the AIDS Epidemic* (New York, NY: St Martin's Press, 1987).
  6. The first case of AIDS in a hemophiliac was diagnosed in 1982, and by early 1983, scientists recognized that AIDS was a blood-borne disease. See the Institute of Medicine, National Academy of Sciences, *Confronting AIDS: Directions for Public Health, Health Care, and Research* (Washington, DC: National Academy Press, 1986), 60.
  7. After diplomatic protest over identifying an entire nation with the disease, Haitians were dropped from the official risk-group listing of the Centers for Disease Control and Prevention (CDC). See Renee Sabatier, *Blaming Others: Prejudice, Race, and Worldwide AIDS* (Washington, DC: Panos Institute, 1988).
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  10. Robert A. Padgug and Gerald M. Oppenheimer, "Riding the Tiger: AIDS and the Gay Community," in *AIDS: The Making of a Chronic Disease*, ed Fee and Fox, 245-278; Paula A. Treichler, "AIDS, Homophobia, and Biomedical Discourse: An Epidemic of Signification," *Cultural Studies* 1 (1987):263-305.
  11. The story of scientific competition over the discovery of HIV is briefly but effectively told in Mirko D. Grmek, *History of AIDS: Emergence and Origin of a Modern Pandemic*, trans Russell C. Maulitz and Jacalyn Duffin (Princeton, NJ: Princeton University Press, 1990), esp 47-82. For an incompatible account, see Robert C. Gallo, *Virus Hunting: Cancer, AIDS and the Human Retrovirus: A Story of Scientific Discovery* (New York, NY: Basic Books, 1991).
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  13. Some studies have found that fear of AIDS increases with increased knowledge about the disease. See Jacquelyn H. Flaskerud and Adeline M. Nyamanthi, "Black and Latina Women's AIDS Related Knowledge, Attitudes, and Practices," *Research in Nursing and Health* 12 (1989):339-346.
  14. See, for example, K.A. Elder-Tabrizy et al, "AIDS and Competing Health Concerns of Blacks, Hispanics, and Whites," *Journal of Community Health* 16(1991):11-21; Ronald Epstein, "Patient Attitudes and Knowledge about HIV Infection and AIDS," *Journal of Family Practice* 32 (1991):373-377.
  15. Bruce Bower, "Contagious Thoughts," *Science News* 140 (1991):138-139.
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  36. By mid-1992, the concept of AIDS as a chronic disease was well established. As Lawrence K. Altman reports in "At AIDS Talks, Reality Weighs Down Hope," *New York Times*, July 26, 1992, sec 1, pp 1, 15, scientists attending the Eighth International AIDS Conference said that "the world had to learn to deal with AIDS—the acquired immune deficiency syndrome—as a chronic disease for which solutions will be long in coming" and that "infection with HIV—the human immunodeficiency virus—is taking its place with heart dis-



- ease, cancer, and many other chronic diseases." See also the discussion of AIDS as a chronic disease in Robert B. Wallace and George D. Everett, "Prevention of Chronic Illness," in *Maxcy-Rosenau-Last Public Health and Preventive Medicine*, ed John M. Last and Robert B. Wallace, 13th ed (Norwalk, Conn: Appleton & Lange, 1992), 805-810.
37. Wallace and Everett, "Prevention of Chronic Illness"; *Healthy People 2000: National Health Promotion and Disease Prevention Objectives*, DHHS publication PHS 91-50123 (Washington, DC: US Dept of Health and Human Services, Public Health Service, 1990). Since the late 1970s, however, increasing evidence has called into question the "chronic" versus "infectious" dichotomy because some chronic diseases (e.g., cervical cancer) may be caused by infectious agents and many infectious diseases (e.g., tuberculosis) have chronic as well as acute symptoms. See Elizabeth Barrett-Connor, "Infectious and Chronic Disease Epidemiology: Separate and Unequal?" *American Journal of Epidemiology* 109 (1979):245-249.
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