Introduction

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AIDS IS NO "ORDINARY" EPIDEMIC. MORE THAN A devastating disease, it is freighted with profound social and cultural meaning. More than a passing tragedy, it will have long-term, broad-ranging effects on personal relationships, social institutions, and cultural configurations. AIDS is clearly affecting mortality—though in some communities more than others. It is also costly in terms of the resources—both people and money—required for research and medical care. But the effects of the epidemic extend far beyond their medical and economic costs to shape the very ways we organize our individual and collective lives.

Social historians in recent years have pursued their studies of epidemics beyond the charting of pathogenesis and mortality to explore how diseases both reflect and affect specific aspects of culture. In writing about nineteenth-century cholera, for example, historian Asa Briggs (1961) insisted that it was "a disease of society in the most profound sense. Whenever cholera threatened European countries it quickened social apprehensions. Wherever it appeared, it tested the efficiency and resilience of local administrative structures. It exposed relentlessly political, social, and moral shortcomings. It prompted rumors, suspicions, and, at times, violent social conflicts." Similarly, historian Gordon Craig (1988) observed: "It was no accident that preoccupation with the

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disease [cholera] affected literature and supplied both the pulpit and the language of politics with new analogies and symbols."

The literature describing the impact of AIDS is burgeoning. But most studies have focused on the medical and social epidemiology of the disease. Those analyses that deal with cultural issues suggest how norms and values have influenced various aspects of AIDS epidemiology and the efforts to control and to treat the disease: how, for example, the virus entered the population, how it spread to different groups, and the ways in which social values have shaped specific institutional efforts to deal with the disease and its consequences. These contributions—e.g., on public health agencies (Bayer 1989), public schools (Kirp 1989), the U.S. Public Health Service (Panem 1988)—have been central to our understanding of the past and present forms of the epidemic.

But, AIDS will also reshape many aspects of society, its norms and values, its interpersonal relationships, and its cultural representations. Just as the human immunodeficiency virus mutates, so too do the forms and institutions of society. Current clinical, epidemiologic, demographic, and social data about AIDS suggest that the future will be different from both the present and the past.

There is an interactive and accommodative process between disease and public policy, between disease and social life. As the effects of the epidemic—and the numbers of persons infected—widen over the next five, ten, or twenty years, there will be many cultural changes. Some will be adaptive and temporary, likely to change again; others will be more permanent, structural, and likely to persist.

Epidemics—sudden, unanticipated, and devastating—introduce problems with few or no institutional or procedural precedents. Most epidemics of the past hit suddenly and swiftly, exacting a lethal toll after relatively brief episodes of acute infectious illness. But AIDS, as we now understand it, is a chronic disease—long "silent" yet still infectious—inevitably lethal in its later acute manifestations. While every epidemic, and even each newly described illness, constructs its own language, there are no precedents for the rapidity or range of terms that AIDS has elicited. The infected become the "presymptomatic" ill. They lose their immunity and progress to a "condition," reified initially as "AIDS-related complex" (ARC) and later as "HIV-related illness," and ultimately, to "full-blown AIDS." They are infectious, but only in certain ways, often associated with "immoral" or "deviant" be-

havior. The "ill" and the "immune" are neither discrete nor useful bipolar constructs when dealing with such a disease.

As a chronic disease, AIDS is testing the scope, the vision, and the viability of major institutions—hospitals, prisons, and science itself—as they struggle to handle the often unwieldy and controversial problems associated with devastating illness. While the response to AIDS has surely reflected prevailing social and moral tensions, the disease is also dramatizing, exposing, and shaping the conflicts, fears, and uncertainties endemic to American society in the 1980s. Our intention in these supplements to *The Milbank Quarterly* is to explore the cultural impact of AIDS from the perspective of the humanities and social sciences.

The notion of culture is an elusive and often confusing concept. In past decades culture has been conceptualized as a complex but relatively coherent and enduring "web" of beliefs, meanings, and values. Recently, however, scholars have emphasized the truly volatile nature of cultural constructs. Political scientists write of "fragile values," referring to the very tentative and recent cultural acceptance of the rights of homosexuals, women, and various ethnic groups (McKlosky and Brill 1983). Sociologists studying the social construction of knowledge reject the concept of "enduring values," arguing that situations, interests, and organizational pressures influence cultural definitions (Berger and Luckmann 1966). Contemporary anthropologists write of the "predicament of culture," thinking of culture "not as organically unified or traditionally continuous, but rather as negotiated present process" (Clifford 1988). They argue that changes in technology and communication, acceleration in the patterns of social mobility and migration, have blurred the boundaries between culturally accepted ways of thinking and acting. Challenging core assumptions and violating social expectations, these changes have given rise to new concepts of rights, new social relationships, and changing norms of social behavior. This is the intellectual context in which AIDS has appeared.

The epidemic also occurs in a political context in which people are in conflict about norms of sexual behavior, the changing character of the "family," acceptance of homosexual relationships, and culpability and control in intravenous drug use. Legal and political disputes over these issues reflect growing polarization. AIDS, to some, symbolizes the problems posed by the dramatic challenges to traditional values that began in the late 1960s, that developed during the 1970s, and are polarizing the public today.

AIDS also appears at a time when risks to health are a priority on the public agenda. The effects of toxic substances, chemical wastes, pesticides, food additives, and radiation are a source of fear. We are preoccupied with health—with biological fitness, diet, and exercise regimes. We are bombarded with "data" about risks and benefits of different regimens, leaving us confronted with seemingly impossible choices. We have lost our unquestioning trust in authority—government bodies, medical organizations, scientific experts—to protect our health. Metaphors of contamination and pollution, of illness and health, have dominated the cultural discourse of the 1980s and are continuing in the 1990s.

The response to AIDS has reflected the suspicion and mistrust surrounding many other risks. There is little consensus about the nature and extent of danger. Is fear of AIDS irrational or justified by the actual risk? Are experts to be trusted or suspect? And, in fact, who are the experts? Nor, in the context of changing values, is there consensus about the appropriate courses of action in response to this disease. Despite strong scientific agreement that AIDS is not transmitted through casual contact, controversial proposals—enforced quarantine, mandatory screening, closing of gay bars, constraints on marriage and childbearing, and exclusion of infected persons from work, restaurants and schools—have been fueled by prejudice and fear. When social values are changing and cultural expectations are in doubt, individuals and groups seek to avoid risks that might further undermine collective and personal security. And consensus about appropriate policy and practice becomes an elusive goal.

When people see their "way of life" threatened, they characteristically become less tolerant of differences as they seek to reinforce traditional boundaries and preserve existing social categories. They pursue isolationist strategies, in the belief that they are resisting contamination and contagion in the quest for order and social control. Societies seek to maintain order and reduce tension by emphasizing socially accepted distinctions between normal and perverse, legal and criminal, healthy and diseased.

The response to AIDS, the effect of this disruptive disease, reflects its intersection with certain social tensions that are inherent in American culture. These tensions have been manifest in the response to AIDS in an array of social institutions—schools, prisons, the military, hospitals, the law, the church—in their efforts to intervene, control, or evaluate the epidemic in ways that reflect their ideology, professional

ethos, and identification with the threat. Tensions are evident in the debates over the social relationships affected by AIDS—over appropriate sexual behavior, the role of adolescence in social life, the nature of the family, the responsibilities of the medical profession. And they are diversely expressed in cultural representations through art and the media.

Certain values in American society have always existed in a state of tension. We value individual autonomy *and* social order. Both are important to our personal and collective lives. Yet, increments to one value often can compromise the other. Similarly, we value both free choice and equity, but these, too, exist as dynamic constructs rarely, if ever, poised in a state of equilibrium. The articles in these volumes suggest how AIDS intersects with five arenas in which widely held values conflict:

1. *What is society's commitment to individual autonomy when communitarian values and objectives are at risk?* AIDS exacerbates the incipient points of tension between individual rights and social goals, as the need to protect the public health confronts the norms of privacy and confidentiality in personal life. Even within the realm of private relations, interpersonal tensions gain new poignancy: an infected person's "right to confidentiality" is pitted against the spouse's "right to know"; the infected woman's right to "reproductive choice" is poised against the fetus's right to life. Social policies reflecting perceived community values may change the way we impute responsibility for behavior or they may lead to behavioral and social constraints on individual reproductive choices that recall the eugenic policies of an earlier age.

2. *What are the limits of tolerance about conformity to mainstream values?* Only in recent times have we as a society come tentatively to accept homosexuality, the inevitability of drug use, the value of social diversity. AIDS has put new strains on continued public tolerance for these behaviors. Ambivalence in attitudes is not new; America has long struggled with the tensions between puritanism and hedonism. The society today condones—even markets—certain aspects of sexual behavior, but it also condemns those who practice them. AIDS may foster discrimination toward certain groups such as homosexuals or drug users. Individuals within these groups may be subject to stereotype and stigma. Witness the reluctance of many members of hospital staffs early in the epidemic to approach or treat gay people with AIDS. At first, this reflected misunderstandings about the transmissibility of the dis-

ease and lack of knowledge about gay life itself. Today, the persistence of such tensions in medical settings reflects the sharp contrasts between the hospital culture and the behavior patterns of drug users with AIDS. Conversely, the truly variable incidence and prevalence of AIDS may well force society to understand that the labels by which we categorize people are themselves stereotyped and dysfunctional. How the nation may ultimately regard particular groups and individuals could depend on their protection under the law.

3. *What are the appropriate roles and responsibilities of government in managing disease?* As federal, state, and local agencies try to contain AIDS, their involvement further complicates the existing debates in American society over the regulatory role of government. These debates emerge in discussions of both therapeutic measures and public health policies. Observe the changing views of risk as the Food and Drug Administration (FDA), a normally conservative organization, has begun to remove certain procedural obstacles to the availability of innovative therapies. Note, too, the debates over the government role in dispensing free needles, promoting sex education in the schools, and closing bath houses.

4. *What are the roles and responsibilities of the "family"?* AIDS places family relationships—between parents and adolescents, between married and unmarried partners—under intense strain. The disease has become a mirror of the confusion caused by the changing definition of the family and assumptions about its role. The United States Bureau of the Census has documented the extraordinary variety of nontraditional patterns of household formation, including those of single individuals, pair bondings, and cohabitating but otherwise unattached adults. AIDS gives poignancy to these impersonal findings. It underscores the changing role of the family as a reproductive unit and the difficulty of developing socially sensitive approaches to adolescent sexual behavior, reproductive choice, and contraceptive use. Tensions arise between the experimentation of teenagers in all facets of their social identities and the efforts of adults to temper adolescents' views of their invulnerability to physical and sexual "accidents," disease, and even death.

5. *What are the roles and responsibilities of professionals?* The constant struggle among equally honored yet competing values in the greater society has also complicated professional roles and responsibilities. AIDS aggravates conflicts that are inherent in the professions. The physician, for example, traditionally honors a professional duty to sev-

eral, often conflicting, parties—to science, to the primacy of the individual patient, to the society at large, and, importantly though not always explicitly, to his or her self protection. AIDS has challenged the relative priorities among these values; self-protection, for example, has become an unprecedented concern in the course of clinical practice. And scientific procedures in the selection of therapies have come into conflict with patients' needs. Nursing, too, is undergoing stresses due to AIDS, significantly at a moment when the profession appears demoralized and its membership in decline. Yet, in its responses to AIDS, the nursing profession has new opportunities to reestablish caring values as the central force in its mission.

The articles in these two supplements illuminate the social responses to these and other tensions dramatized by AIDS. And they suggest possible directions for cultural change as we confront AIDS in the future. Social responses have, over the past seven years, ranged from denial to heroic action, from apathy to creativity, from withdrawal to activism, and from resurgent racism to promotion of a shared national identity. The future cultural effects of an epidemic can only be anticipated by understanding the present context—the existing norms, social structures, and social relationships—that shape a society.

Though our focus is on the United States, this double supplement begins with the case of sub-Saharan Africa. The African example exhibits in bold relief the multiple dimensions of cultural and social change that can be affected and accelerated by AIDS. The rest of the articles center on the United States.

We first examine some of social relationships and behaviors strongly influenced by AIDS—relationships within the family, among adolescents, and among intravenous drug users. Our authors then explore the implications of AIDS for the regulatory process, and for the rights and protections of individuals. We also suggest that certain obligations and reciprocities are influenced by an epidemic, such as the concept of reproductive freedom, and for the donation of blood. We then turn to the provision of health care services from medical professionals, the nursing profession, and volunteers, all profoundly affected by AIDS. And finally, we examine the epidemic's extraordinary impact on our cultural vision, as represented in the arts and in various forms of popular entertainment.

AIDS is reshaping many other dimensions of social and institutional

life beyond those we could discuss here. It is affecting the attitudes and behavior of single women and homosexuals as they try to protect themselves from risk. It is restructuring many other social dynamics in the gay community, highlighting the tensions among voluntary associations in that community of whether to emphasize service delivery to people with HIV disease, to undertake radical political action to influence government policies on AIDS, or to press for broad gay rights encompassing full health care and social justice. It is changing the practices of many institutions—prisons, the military, and schools—as they try to contain the incidence of disease within their domains. It is challenging professional associations in health and social fields to devise informed and humane approaches to AIDS research and policy that full memberships will accept, and it is prompting political parties, above all the Democratic Party and its Rainbow Coalition, to forge workable planks on AIDS education, treatment, and approaches to cure. And it may change, perhaps in drastic ways, the policies of insurance companies, immigration authorities, employers, and, especially, public health departments. Black and Hispanic communities are struggling over the appropriate roles key institutions—particularly kin networks and the church—are to play in checking the disproportionate spread of HIV among minority groups and in meeting the needs of those who have contracted AIDS.

Exposing fundamental tensions and value conflicts, AIDS and its consequences will force our society to reexamine its collective identity, reassess its policies, and redefine its goals. Clearly, however, societies have choices. The long-term effect of AIDS on our norms, values, institutions, and cultural understandings can be devastating or enlightening, brutalizing or liberating. This disease of society can foster frustration or open new social options. It may, in the future, be a fount of creativity or it may be a source of despair. The choice is ours.

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