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AIDS AND THE HEALTH CRISIS OF THE U.S. URBAN POOR; THE PERSPECTIVE OF CRITICAL MEDICAL ANTHROPOLOGY

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Abstract—The social identity of HIV/AIDS in the U.S. has been shaped, for the most part, by two factors, the prevailing configuration of social relations across class, racial, gender, and sexual orientation, on the one hand, and the prevailing array of public health, especially epidemiological, categories of disease transmission, on the other. Focusing on the AIDS epidemic among inner city people of color, this paper challenges the distortions wrought in our understanding from both of these factors and instead develops an alternative perspective for AIDS research among medical anthropologists and health social scientists generally.

Key words—AIDS, critical medical anthropology, inner city health, epidemiology

In some ways it is reasonable and useful to describe the U.S. as constituting (at least) two separate if intertwined societies: people of the inner city and everyone else. While poverty is by no means confined to the inner city, and neither are all oppressed ethnic minorities or people of color, the intersection of urban poverty and socially devalued ethnicity (especially being African-American and Latino, and in some parts of the country Native American and Asian as well) have proven to be a particularly unhealthy combination. Not only does it often appear as though the U.S. has more-or-less turned its back on the inner city [1]—a lesson brought home with furious intensity in the spring of 1992 in the Los Angeles inner city uprising—but the consequences of such abandonment are seemingly uncontainable. One of these consequences is the rampant spread of AIDS in many U.S. inner city areas. Almost half of people in the U.S. who have been diagnosed as having AIDS are African-Americans and Latinos from impoverished urban neighborhoods. This paper examines AIDS within the context of health and social issues facing the urban poor and attempts to locate this crisis in terms of the class, ethnic, and gender relations that define American society. AIDS is understood in this paper as both a health crisis and a cultural crisis, both of which are rooted ultimately in social conditions and social relations. While understanding the way AIDS in the inner city has been constructed as a public health concern is an objective of this paper, a larger goal is to move beyond both Geertzian interpretation of cultural construction and epidemiological analysis of disease toward the political economic contextualization of AIDS.

The paper begins with the presentation of a framework for grounding political economic analysis in medical anthropology by reflecting on a parallel but earlier development in cultural anthropology. This discussion suggests the importance of reinserting AIDS into the encompassing inner city landscape of health and social conditions from which it was extracted for purposes of public health intervention. Failure to analyze AIDS in context has contributed to the emergence of a set of conceptual categories that warrant re-examination in light of ethnographic findings by anthropologists recruited to the fight against AIDS. Reconsideration of inner city AIDS in terms of its social dimensions allows the development, in the final section of this paper, of an alternative critical medical anthropology perspective.

A CONCEPTUAL FRAMEWORK FOR THE ANTHROPOLOGY OF AIDS AMONG THE URBAN POOR

Anthropological involvement in health research among the inner city poor has been growing steadily in recent years [2, 3]. This development is emblematic of a significant redirection in anthropological focus and is reflective of a broader turn toward the study of American society by North American anthropologists. Having overcome the traditional anthropological "suspicion . . . of trying to understand one's own society" [4, p. 3], medical anthropologists have encountered a problem that has beset the discipline at several fateful junctures in its history. On several past occasions, as they have moved into the study of new social fields characterized by patterns of social relationship unseen in previous research, anthropologists' conceptual tools have been stretched beyond utility, producing intellectual turmoil and leading, in time, to a reconceptualization of basic frames of explanation. This appears to be happening again with the AIDS crisis.

An understanding of this process can be gained by examining briefly an earlier and by no means unrelated conceptual shift that occurred among cultural anthropologists as they moved from the study of small scale, subsistence communities to the investigation of peasant populations. As Roseberry comments,

> We can see in this ... literature the recognition of a crisis of anthropological theory and method, a recognition that the methods for the study of primitives did not serve those studying peasants in 'complex societies.' ... Peasants were, quite simply, not isolated from wider historical process ... How were we to understand these anthropological subjects in terms of the world-historical process through which they emerged or by means of which they maintained themselves without simplistically reducing the dynamics of their communities to the dynamics of world history? What did the anthropological perspective mean when the assumptions of holism were so clearly inadequate? [5, pp. 146–147].

One of the most successful early efforts to directly confront and address these issues in peasant research was the book *The People of Puerto Rico* [6]. Based on a series of local community studies carried out in different regions of the Island by Julian Steward's students, the book attempted to describe and analyze each local community, fit these communities together by examining the larger economic and historial processes that shaped their development, and finally, locate social developments in Puerto Rico in terms of "processes of proletarianization as these have developed throughout the world" [6, p. 505]. The end result of this project was a significant rethinking of peasant communities, which, through the ongoing work of some of the participants in the Puerto Rico project [e.g. 7, 8], has led to fundamental changes in anthropological thinking generally, including the emergence of a political economic orientation in anthropology and a reconceptualization of all ethnographic cases in light of intertwined political and economic "processes that transcend separable cases, moving through and beyond them and transforming them as they proceed" [7, p. 17]. Remarks Appadurai,

> As we drop our anthropological blinders, and as we sharpen our ethnohistorial tools, we are discovering that pristine Punan of the interior of Borneo were probably a specialized adaptation of the larger Dayak communities, serving a specialized function in the world trade in Borneo forest products ...; that the San of South Africa have been involved in a complex symbiosis with other groups for a very long time ...; that groups in Melanesia have been trading goods across very long distances for a long time, trade that reflects complex regional relations of supply and demand ...; that African 'tribes' have been reconstituting and deconstructing essential structural principles at their 'interior frontiers' for a very long time ... [9, p. 37]

As medical anthropologists address health conditions in the inner city, they too experience a crisis of theory and method, and increasingly, feel the need to develop new conceptual tools. This crisis is magnified by the sudden appearance of HIV/AIDS as a serious health problem among the U.S. inner city poor. Although first described and still a major cause of suffering and death among middle class, white gay men, AIDS has come to be recognized as a world health problem and a special problem among the urban poor. The outstanding features of AIDS in the inner city are suggested in the following passage:

> In kindergarten this year, my 6 year old son has been learning the Pledge of Allegiance. Recently, as he proudly recited it at the dinner table, the thought came to mind to insert the words 'and AIDS' after liberty and justice in the final sentence. But the truth is that just as liberty and justice are not equally distributed to all, neither is AIDS. For those who have the least liberty and justice have the most AIDS and vice versa. And it is no coincidence that this is so ... As Ira Harrison has quipped: 'AIDS—poverty strikes again.' And behind poverty in this country, behind the unequal distribution of liberty and justice lies the issue of race. And behind the issue of race, as W.E.B. Du Bois [10, p. v], the renowned Black sociologist and author of *The Souls of Black Folk*, so forcefully wrote 'lies a greater problem which both obscures and implements it: and that is the fact that so many civilized persons are willing to live in comfort even if the price of this is poverty, ignorance and disease of the majority of their fellowmen' [11, p. 89].

This comment suggests the importance of closely examining the U.S. AIDS crisis in terms of social class and ethnic relations, and, as indicated below, in terms of gender politics as well. Yet, as Ortner [12, p. 164], argues, "The first thing that strikes an anthropologist reading the ethnographic literature on America, written by both sociologists and anthropologists, is the centrality of 'class' in sociological research and its marginality in anthropological studies." Moreover, she [12, p. 166] reports that anthropological ethnographies of U.S. society focus on the "minutiae of everyday life" while exhibiting a "tendency to avoid almost any kind of macrosociological analysis, let alone making class a central category of research." Indeed she suggests [12, p. 166], the chronic tendency of urban ethnography has been " to 'ethnicize' the groups under study, to treat them as so many isolated and exotic tribes," rather than to recognize their interconnections in light of transcendent processes and overarching structures.

Reversing this more general trend in anthropology generally was one of the driving forces motivating the writing of *Europe and the People Without History*, Eric Wolf's seminal account of the broad historical patterns of political economic relationship between so-called core and peripheral areas of the world economic system. As Wolf has argued, the adoption of ethnography—the observation of social processes in natural contexts—as the defining hallmark of anthropological research had both beneficial and problematic consequences. While revealing "hitherto unsuspected connections among sets of social activities and cultural forms," it nonetheless "lulled its users into a false confidence" about the nature of social behavior [7, p. 13]. Increasingly, human groupings came to be seen and understood as concrete, independent wholes when they were, in fact, like peasants, part and parcel of larger social units brought into being and shaped continually by wider fields of power. Unfortunately, these wider fields are not always clearly observable 'on the ground,' especially not by anthropologists who have been trained to avoid seeing them because they were defined as being beyond the pale of anthropological concern. Indeed, as Wolf [13] noted in his Distinguished Lecture to the 88th meeting of the American Anthropological Association, the very term 'power' has tended historically to make anthropologists uncomfortable.

It is in light of Wolf's challenge to avoid exoticizing the people anthropologists study by focusing on relationships of power and broader nets of interconnection that we turn to an examination of the issue of AIDS in the inner city. Without doubt, the study of AIDS has taken anthropologists into a new domain of human biocultural experience. Consequently, Herdt [14, p. 3] stresses, AIDS "is not only affecting how we live and organize society but how we in anthropology and the social sciences must analyze that reality." These changes mandate a careful consideration of the concepts we employ as we study the AIDS crisis. As Wolf [13, p. 587] indicated in the lecture mentioned above, "We need to be professionally suspicious of our categories and models; we should be aware of their historical and cultural contingencies . . ." Among the inner city poor, the beginning point for re-examining the concepts mobilized by the public health system in responding to AIDS lies in situating this disease in terms of the broader configuation of health and social conditions that structures the epidemic.

CONTEXTUALIZING INNER CITY AIDS: FROM EPIDEMIC TO SYNDEMIC

AIDS was a profoundly unexpected disease, "a startling discontinuity with the past" [15, p. 1] As McCombie [16, p. 10] suggests, global public health efforts that predate the beginning of the AIDS epidemic, such as the smallpox eradication program, "reinforced the notion that mortality from infectious disease was a thing of the past." Consequently, whatever the actual health needs of the heterogeneous U.S. population, the primary concerns of the health care system were the so-called Western diseases, that is, chronic health problems, such as cancer and cerebrovascular problems, of a developed nation with an aging population [17]. Comments Brandt:

> The United States has relatively little recent experience dealing with health crises . . . We had come to believe that the problem of infectious, epidemic diseases had passed—a topic of concern only to the developing world and historians [18, p. 367].

However, as a result of AIDS and widespread drug use as well, the term epidemic has reentered popular vocabulary in recent years. It is evident that low-income, marginalized areas of U.S. cities have been rocked by an explosive chain-reaction of interconnected epidemics.

Many definitions of the term epidemic exists. Marks and Beatty [19], in their history of the subject, adopt a broad approach and include both communicable and noncommunicable diseases that affect many persons at one time. Epidemics (from *epi* or 'in' and *demos* 'the people') are conceptually linked to other terms in the 'demic' family, including 'endemics' (from *en* or 'on'), which are non-explosive, entrenched diseases of everyday life in particular communities, and 'pandemics' (from *pan* or 'all of') which are epidemics on an enlarged, perhaps, global scale.

None of these concepts, however, quite captures the contemporary inner city health crisis, which is characterized by a set of closely interrelated endemic and epidemic conditions, all of which are strongly influenced by a broader set of political–economic and social factors, including high rates of unemployment, poverty, homelessness and residential overcrowding, substandard nutrition, environmental toxins and related environmental health risks, infrastructural deterioration and loss of quality housing stock, forced geographic mobility, family breakup and disruption of social support networks, youth gang and drug-related violence, and health care inequality [1, 20]. As a result, as McCord and Freeman [21] have observed, men in Bangladesh have a higher probability of survival after age 35 than men in Harlem. More generally, "the death rate in blacks is higher than in whites, and for many causes of death mortality differentials are increasing rather than decreasing" [22, p. 1238]. However, these differences cannot be understood only in terms of racial inequalities, there are significant class factors involved as well. The vast majority of urban-dwelling African-Americans, as well as Latinos, "are members of the low paid, poorly educated working class that have higher morbidity and mortality rates than high-earning, better educated people" [22, p. 1240]. Indeed, these mortality differentials are directly tied to the widening wealth and income differentials between the upper and lower classes of U.S. society.

Consequently, rather than treating AIDS in isolation as a new epidemic with unique features, this paper understands AIDS in terms of the broader inner-city health crisis. I have suggested the term *syndemic* [23] to refer to the set of synergistic or intertwined and mutual enhancing health and social problems facing the urban poor. Developing this concept necessitates a closer examination of health in the inner city.

A profile of the syndemic

Urban minority populations suffer from disproportionately high rates of preventable infant mortality and low birthweight, diabetes, hypertension, cirrhosis, tuberculoses, substance abuse, human immunodeficiency disease, and sexually transmitted diseases [24–26]. For many health indicators, these differences are striking. Infant mortality, which is often used in epidemiology as a general reflection of the health of a population, provides a disturbing example. Infant mortality among inner city African-Americans and Puerto Ricans has been called America's shameful little secret [27]. In 1987, the Children's Defense Fund announced that a child born in Costa Rica had a better chance of surviving beyond its first birthday than an African-American child born in Washington, DC [28]. This pattern is not limited to the nation's capitol. Overall,

> . . . African-American children are twice as likely to be born prematurely, die during the first year of life, suffer low birthweight, have mothers who receive late or no prenatal care, be born to teenage or unmarried parent, be unemployed as teenagers, have unemployed parents, and live in substandard housing. Furthermore, African-American children are three times more likely than whites to be poor, having their mothers die in childbirth, live in a female-headed family, be in foster care, and be placed in an educable mentally-retarded class [29, p. 153]

In some inner city neighborhoods of Hartford, where I have been involved in health social science research for the last 10 years, the rate of infant morality has been found to be between 29–31 per 1000 live births, more than three times the state average [30]. Similarly, in 1985 Boston experienced a 32% increase in infant mortality, with African-American infants dying at two and a half times the rate of white infants. Rising infant mortality in Boston as elsewhere has been linked to a sharp increase in the percentage of low birthweight babies, which in turn is seen as a product of "worsening housing conditions, nutrition and access to medical care" among inner city ethnic minorities [31, p. 1]. Although these "contributing variables act additively or synergistically," household income stands as the single best indicator of an infant's vulnerability, with poor familes having infant mortality rates that are one and a half to three times higher than wealthier families [32, p. 374].

Class disparities in mortality rates are not limited to infancy, substantial differences also have been found among older children. For example, children from inner city poor familes are more likely to die from respiratory diseases or in fires, than children from wealthier surburban families. Inadequately heated and ventilated apartments also contribute to death at an early age for poor urban children. Hunger and poor nutrition are additional factors. As Fitchen indicates

> That malnutrition and hunger exist in the contemporary United States seems unbelievable to people in other nations who assume that Americans can have whatever they want in life. Even within the United States, most people are not aware of domestic hunger or else believe that government programs and volunteer efforts must surely be taking care of hunger that does exist here [33, p. 309].

However, several studies have shown that a significant link exists between hunger, malnutrition, and inner city poverty, especially among ethnic minorities. A study by the Hispanic Health Council of 315 primarily minority households (39% African-American, 56% with elementary school aged children in eight Hartford neighborhoods found that 41.3% reported experiencing hunger during the previous 12 months (based on having positive answers to at least 5 of 8 questions on a hunger scale) and an additional 35.4% experienced food shortages that put them at risk of hunger (based on having a positive answer to at least one question on the hunger scale) [34]. It should be noted that the 1990 census (as did the 1980 census) found Hartford to be among the 10 poorest cities (of over 100,000 population) in the country (as measured by percentage of people living in poverty). Over 27% of the city's residents fell below the federal poverty line, compared to a Connecticut statewide rate of just under 7% according to the census [35]. Hartford, however, is not unique. Research conducted through the Harvard School of Public Health found that federal cuts in food assistance programs have contributed to significant drops in the number of children receiving free and reduced-price school lunches, producing growing reports of hunger and malnutrition from pediatricians in cities around the country [36]. The study, for example, found reports of marasmus (protein-calorie deficiency) and kwashiorkor (protein deficiency) in Chicago.

Cardiovascular disease commonly has been portrayed as primarily a consequence of either genetic predisposition or 'life-style choice,' including such factors as personal eating or exercise habits. As Crawford [37, p. 75] suggests, "Americans have . . . been exposed to a virtual media and professional blitz for a particular model of health promotion: one that emphasizes lifestyle change and individual responsibility." Often these portrayals have had the ring of victim-blaming, implying that individuals personally select their 'lifestyle' from a range of equally accessible options [38]. As a consequence, even at the popular level, health comes to be defined "in terms of self-control and a set of related concepts that include self-discipline, self-denial, and will power" [37, p. 66]. Research by David Barker and his colleagues on cardiovascular disease suggests the folly in this line of thinking. These researchers show that the lower the birthweight of a newborn or body weight of a one-year old infant, the greater the level of risk for developing heart disease or stroke in adulthood. Low birthweight babies, they report, have higher blood pressure and higher concentrations of the clotting factors fibrinogen and factor VII as well as low-density liproprotein (LDL) cholesterol as adults, factors that are associated with susceptibility for cardiovascular disease. Numerous attempts have been made to explain excessive levels of premature morbidity and mortality from cardiovascular diseases, especially heart diseases, stroke, and hypertension. Some have attempted to explain this pattern in terms of racial-genetic predisposition. Research by Barker and others [e.g. 39], however, reveals the likely relationship of these diseases to the larger syndemic health crises and thus to poverty and social inequality.

Alcohol-related problems have been found to be especially common among Latinos, particularly Mexican-American and Puerto Rican men. A study in the San Francisco Bay area, for example, found that 35% of Latino men reported at least one alcohol-related health or social problem compared to 26% of white men [40]. A study of drinking patterns among Puerto Rican men in Hartford found that, compared to a national sample of men, they were much more likely to report health problems associated with drinking, acting belligerently under the influence, having a friend or spouse complain about their drinking, having alcohol-related problems with the police, and engaging in binge-drinking [41]. Similarly, studies of inner city African-Americans have found they experience higher than average rates of physiological complications, such as esophageal cancer and cirrhosis mortality, related to long-term heavy alcohol consumption [42–45]. While both Latino and African-American cultures include strong proscriptions on alcohol consumption (in certain contexts, for certain social subgroups, or in relationship to particular religious belief systems), inner city areas are populated by people who embrace a range of values and social practices related to drinking [43, 46, 47]. Although abstinence is notably high among particular social groupings in the inner city, drinking-related problems are comparatively high for both African-Americans and Latinos. As Herd indicates with specific reference to African-Americans,

> Medical problems associated with heavy drinking have increased very dramatically in the black population. Rates of acute and chronic alcohol-related diseases among blacks, which were formerly lower than or similar to whites, have in the post war years increased to almost epidemic proportions. Currently, blacks are at extremely high risk for morbidity and mortality for acute and chronic alcohol-related diseases such as alcohol fatty liver, hepatitis, liver cirrhosis, and esophageal cancer [48, p. 309].

The association between drug use and deteriorated inner city areas has been discussed in the social science literature since the days of the Chicago School of Sociology [49, 50]. More recently, several large- and small-scale epidemiological studies have collected data on drug-related incidence, prevalence, morbidity and morality among inner city ethnic minorities. The findings of these studies have been summarized by Andrea Kopstein and Patrice Roth in a report for the National Institute on Drug Abuse (NIDA). These researchers note that while the National Household Survey on Drug Abuse indicates a decline in current illicit drug use nationally, "Minorities, particularly blacks and Hispanics, are more likely to reside in central city areas and may therefore be *more at risk* for drug abuse and ultimately more at risk for the negative social and health consequences associated with drug abuse" than the general U.S. population [51, pp. 1–2]. Specifically, the National Household Survey shows that among adults over 35 years of age, African-American men are the population subgroup most likely to report illicit drug use at least once in their lives, in the past year, and in the past month. Thirty-seven percent of African-American men in this age group report lifetime use, compared to 25% of white men. For example, the prevalence of drug use in the month prior to the interview was 2% of white men compared to 5% for African-American men. An examination of individual drug prevalence patterns also confirms the high level of risk among ethnic minority groups. For cocaine use, Hispanic youth aged 12–17 have higher prevalence rates than African-American or white youth, while African-Americans have the highest cocaine prevalence rates among adults over 35 years of age. Regarding heroin use, 2.3% of African-Americans, 1.1% of Hispanics, and 0.8% of whites have ever been users. Data from NIDA's Drug Abuse Warning Network (DAWN), a national system for monitoring the medical consequences of drug abuse as reported by participating hospital emergency rooms and medical examiner offices, show a similar pattern. According to 1989 data from the DAWN system, African-American patients were the most likely group to mention use of an illicit drug in conjunction with their emergency room visit. All of these data suggest that directly and indirectly drug abuse disproportionately affects inner-city ethnic minority populations. Importantly, despite this fact, Kopstein and Roth [51, p. 51] note that "blacks presenting with a drug abuse problem at the emergency rooms in the DAWN system were more likely than whites to be treated and released. Whites, on the other hand were more likely to be admitted to the hospital."

Additionally, both African-Americans and Latinos have been found to be overrepresented among the large number of injection drug users (IDU's) in U.S. urban areas [52]. David Musto, whose book *The American Disease* [53] is a classic in the drug field, has assembled data to suggest a steady rise in the number of IDU's from the 1970s on. He estimates that the number of heroin injectors soared from 50,000 to at least a half-million between 1960 and 1970. By 1987, the National Association of State Alcohol and Drug Abuse Directors, Inc. (NASADAD) concluded that there were about 1.5 million IDU's in the U.S. based on aggregated data from state alcohol and drug agencies [reported in 26]. The level of minority involvement in injection drug use is seen by examining New York City data, in that New York is a national center of drug injection and has the highest number of IDU's in the country. Friedman *et al.*, [54], using New York State Division of Substance Abuse Services admissions data, estimate that the ethnic composition of injection drug users in New York City is 38% African-American, 38% Latino, and 23% white, while the city as a whole is 52% white, 24% African-American and 20% Latino.

These data suggest that under conditions of discrimination, poverty, deprivation, unemployment, and frustrated expectations, mood altering drugs found an open market in inner city areas [1]. As Hanson [55, p. 3] comments

> Many of the minority newcomers [to urban areas] became victims of unemployment, poverty, and racial discrimination . . . Is it surprising that they sometimes coped with this situation by turning to drugs?

This response to oppressive conditions was facilitated by the ready availability of drugs in ghetto and barrio neighborhoods, a consequence of Mafia targeting of these areas for drug distribution. As Waldorf [56] observes, "Heroin is seemingly everywhere in Black and Puerto Rican ghettos and young people are aware of it from an early age." To these youth, drugs offer insulation from the outside world allowing users to

> feel that their harsh and hostile environment cannot penetrate their lives. They escape from their problems, other people, and feel better [57, p. 89].

For inner city residents, drug involvement can come to seem like the only available path, a natural life development, as expressed by one 22 year-old addict from Miami:

> You grow up in a place where everything is a real mess. Your father's a thief, your mother's a whore, your kid sister gets herself some new clothes by fucking the landlord's son, your brother's in the joint, your boyfriend gets shot tryin' to pull down a store, and everybody else around you is either smokin' dope, shooting stuff, taking pills, stealing with both hands, or workin' on their backs, or all of the above. All of a sudden you find that you're sweet sixteen and you're doin' the same things . . . It all came on kind of naturally [quoted in 58, p. 162].

In this way, drug use and drug injection became widespread among urban minority youth in the 1950s and has continued its prevalence every since [59–60].

The transmission of AIDS, of course, has been closely linked to drug injection [61–66]. Among drug injectors with AIDS nationally, 79.2% are African-American or Latino [67]. In New York City, there was a threefold increase in overall mortality and morbidity among IDU's in treatment between 1984 and 1987. While rates of hospitalization in this population rose by 40% for AIDS between 1986 and 1987, they rose by over 300% for tuberculosis and 100% for endocarditis [68]. Among women, 51% of all U.S. AIDS cases are African-American, and another 20% are Latina [67]. Among children, over 75% of AIDS cases are among ethnic minorities. The incidence of heterosexually acquired AIDS is almost 10 times greater for African-Americans and four times greater for Latinos than for whites [69]. Similarly, "[a] disproportionate share of the burden of adolescent AIDS cases is borne by minority youth" [70, p. 160].

To date there have been about 250,000 diagnosed cases of AIDS in the U.S. Of these, 30% are African-Americans and 17% are Latinos [71]. While these two ethnic groups comprise about 28% of the U.S. population, they account for 47% of AIDS cases. Importantly, the median survival time of individuals diagnosed with AIDS varies by ethnicity. In Connecticut, for example, the median survival in months is 11.2 for whites compared to 7.7 for African-Americans and 10.2 for Latinos [72], reflecting the broader differences in the general health and access to health services of these populations.

Since the mid-1980s, there has been a dramatic rise in the incidence of syphilis in the U.S., "attributable to a very steep rise in infection among black men and women" [69, p. 63]. While rates of infection dropped below 5000 cases per 100,000 population for white men in 1985 and continued to decline through 1988, for African-American men the rate began climbing in 1985 and by 1988 was about 17,000 cases per 100,000 population. Among women, in 1988 there were about 2000 and 13,000 cases per 100,000 for white and African-Americans respectively. By 1991, 85% of primary and secondary syphilis cases recorded in the U.S. were among African-Americans [73]. In part, this sharp increase has been linked to sex for drugs or money exchanges associated with cocaine use. Blood test data show that low income, urban residence, and lack of education are all associated with positive blood results for syphilis. Rates of gonorrhea infection also show marked racial differences, and these differences have widened noticeably since 1984 when the incidence among African-Americans began a sizeable increase. By 1991, of the 544,057 cases of gonorrhea reported to the Centers for Disease Control, 82% were among African-Africans [73]. Beginning in 1984, another sexually transmitted disease, chancroid, which produces open lesions and has been associated with HIV transmission in parts of Africa, began to appear in a number of U.S. inner cities. The total number of chancroid cases reported in the U.S. rose from 665 in 1984 to 4714 by 1989 [69]. Similarly, African-American women report 1.8 times the rate of pelvic inflammatory disease as do white women, while herpes simplex virus type 2 is 3.4 times higher in African-Americans, hepatitis B is 4.6 times higher, and cervical cancer with a suspected STD etiology is 2.3 times more common among African-Americans than whites [74].

As this epidemiologic overview suggests, the diseases and conditions that comprise the inner city syndemic are closely intertwined. Poverty contributes to poor nutrition and susceptibility to infection. Poor nutrition, chronic stress, and prior disease produce a compromised immune system, increasing susceptibility to new infection. A range of socio-economic problems and stressors increase the likelihood of substance abuse and exposure to HIV. Substance abuse contributes to increased risk for exposure to an STD, which can, in turn, be a co-factor in HIV infection. HIV further damages the immune system, increasing susceptibility to a host of other diseases. In this way, HIV increases susceptibility to tuberculosis;

however, there is growing evidence that the tuberculosis bacterium, in turn, can activate latent HIV.

An overview of the grave nature of the health crisis of the inner city poor suggests that problem-specific, short-term health projects, the kind that time-limited, soft-money funding commonly are designed to launch, are short-sighted and ill conceived. Rather, there is a critical need for longer-term, more comprehensive, systemic public health efforts that address the root causes of the crisis, causes that lie in the oppressive structuring of class, ethnic, sexual orientation, and gender relations in U.S. society. Additionally, locating and reconceptualizing AIDS within the broader syndemic that plagues the inner city poor, helps to demystify the rapid spread of the disease in marginalized populations. In this context, *AIDS itself emerges as an opportunistic disease*, a disease of compromised health and social conditions, a disease of poverty. It is for this reason that it is important to examine the social origins of disease and ill health, whatever the immediate causes (e.g. particular pathogens) of specific health problems. In the case of AIDS, conceptually isolating this disease from its wider health environment has resulted in the epidemiological construction of 'risk groups' and 'risk behaviors' which, rather than unhealthy living and working conditions, discrimination, racism, homophobia and related issues, have become the primary focus of public health efforts. Lost in this effort, is an understanding of AIDS as a disease that is spreading under particular historic and political conditions [75]. Instead an approach has been adopted that has "skewed the choice of models and hypotheses, determined which data were excluded from consideration . . ., and offered scientific justification for popular prejudice . . ." [76, p. 50].

FUZZY CONCEPTUAL CATEGORIES IN THE AIDS FIELD

The conceptual skewing alluded to by Oppenheimer has its roots in the fact that epidemiologists, like other scientists, are "cultural actors, prone to the blind spots and folk theories of their own society" [14, p. 7]. Because the first few cases in New York and Los Angeles were among self-identified gay men, the initial etiological questions generated by the public health system had to do with whether there was something peculiar about the biology or social behavior of gay men that was causing this new disease. Soon other groups of people were found to be contracting the disease, leading to the creation of the risk group 4*H Club*: homosexuals, hemophiliacs, Haitians, and heroin users. As this heterogeneous listing suggests, from the beginning of the epidemic, there has been an effort to divide people into distinct social categories. While the idea of risk group has been strongly challenged, and the emphasis in recent years has been on risk behaviors, there remains the sense that discrete and bounded categories of people exist that are at special risk and in need of special prevention efforts, including, if necessary, isolation from the 'mainstream' population. Indeed, the language of prevention often has implied that the primary motivation for targeting the epidemic among so-called high risk groups is to avoid the spread of AIDS into the 'mainstream' (i.e. white heterosexuals who are neither prostitutes or injection drug users).

The preeminent categories of AIDS risk and transmission in the U.S., which show up in the regular Centers for Disease Control and Prevention surveillance reports on the epidemic, and the reports of city and state health departments around the country, include:

homosexual/bisexual
intravenous drug use
sex partner of an IV drug user

While from a distance, these terms seem to be meaningful and to label real types of people or at least types of behavior, a closer examination shows the fuzziness and constructed character of these epidemiological categories. Often, these constructed 'risk groups' have little correspondence with the active social identities and social locations of those at high risk for HIV infection. As Kane and Mason [77, p. 220] note, "The static and fragmented sense of the social dimension of HIV risk conveyed by risk group categories is inevitably challenged by ethnography." Ethnography also reveals the problem of attempting to use the categories as the basis for directing prevention efforts.

Firstly, what is a homosexual? Do homosexuals constitute a group? a subculture? In what sense is this a discrete entity or natural category? For example, in much of Latin America and among Latinos in the U.S., a differentiation is made between *activos* and *pasivos*, the former being men who insert during anal intercourse and the latter being those who receive [78, 79]. Unlike among white gay men in the U.S., these appear to be somewhat distinct and enduring sexual identities rather than interchangeable sexual positions. Importantly, *activos* do not consider themselves to be homosexuals but they do consider *pasivos* to be homosexuals. Writing of Mexico, Carrier notes that males who play the insertive role

> are not stigmatized as 'homosexual' . . . The masculine self-image of Mexican males is thus not threatened by their homosexual behavior as long as the appropriate role is played and they also have sexual relations with women. Males playing this role are referred to as *mayates*: and may be called *chichifo* if they habitually do so for money. Although involved in bisexual behavior, they consider themselves to be heterosexual [80, p. 134].

Unlike in the U.S. generally, the key defining issue in homosexuality is not who you do it with but what you do with them. Additionally, Carrier maintains that

> at any given age, more sexually active single males in Mexico have had sexual intercourse with both genders than have Anglo-American males. The Kinsey . . . data suggest that about 15% of single sexually active Anglo-American males

> between 15 and 25 have mixed sexual histories. The percentage of Mexican males with mixed histories may be as high as 30 or more for the same age group [80, p. 135].

These patterns are not limited to Mexico, but are found as well in the barrio neighborhoods of the U.S. inner city. A study of Mexican-Americans in California reports that "even though immigrant Mexican male patterns of sexual behavior are somewhat modified by new and quite different sociocultural factors, their homosexual behaviors in California continue to be mainly patterned on their prior sexual experiences in Mexico. As a result of selective acculturation by individuals of Mexican origin to mainstream Anglo-American patterns of sexual behavior, however, considerable behavior variation exists among Mexican-American males involved in homosexual behavior" [81, p. 252].

We have encounted this same 'problem' of diversity in developing AIDS prevention targeted to the inner city gay Latino population of Hartford, CT. In recruiting an outreach worker for the Latino Gay Men's Health Project, we found that it was difficult to identify a Latino gay or bisexual man with any prior experience in AIDS prevention, reflecting the failure of training programs to reach this population. The individual who ultimately was hired brought a substantial background in AIDS outreach. However, it soon became evident that as a transvestite his primary outreach contacts were confined to one sector of the gay/bisexual community and it was difficult for him to recruit from other sectors of the complex and diverse Latino gay/bisexual population. Activities and approaches that were acceptable for one sector of this multifarious 'group' were inappropriate and uncomfortable for another. Some participants, for example, complained about the lack of a 'serious attitude' toward AIDS prevention among those they identified as the 'drag queens' in the group.

Consequently, despite being lumped together by the homophobia of the dominant society, it is evident that men who have sex with men do not constitute one or even two distinct social groups, rather they comprise a broad range of individuals and include those organized into several different (in part overlapping, in part mutually exclusive) activity/identity oriented subgroups and those who do not identify with any specific subgroup or embrace a homosexual identity. Failure to recognize this diversity stems from the historic biomedical construction of homosexuality as a fixed inverted behavioral pattern rooted in genetic make-up, hormonal malfunctions, or specific developmental psychodynamics and family patterns. In AIDS research and prevention, this essentialist view of homosexuality often has "blinded researchers [and providers] to the diversity of behavioral patterns within the gay community" [82, p. 193].

IV drug user is another problematic epidemiological category for several reasons. First, not all people who inject illicit drugs inject them into their veins, that is, not all drug injectors are IV drug injectors. Consequently, despite its wide use in the literature, the label IV drug user increasingly is being replaced by the term injection drug user (IDU). Even the drugs that people inject vary considerably. For example, some individuals have been found to be alcohol injectors. This practice, though apparently limited, is legal, although it is no less risky in terms of HIV transmission than illicit drug injection. Second, to what degree are drug injectors a discrete group? To a large extent, the construction of drug injectors as a distinct, coherent, and socially isolated group has been achieved through the development of a professional discourse on the 'drug subculture'. A broad literature on this subculture existed prior to the 1980s and it has been expanded considerably since then because of AIDS. For example, Fiddle [83, p. 4] comments: "addicts share a ... culture with its own language," while Freudenberg [84, p. 1128] writes that "[d]rug using behavior is deeply rooted in the drug subculture." On the positive side, the subculture perspective has been offered as an alternative to psychologistic understandings of injection drug user behavior. Note Friedman and his co-workers,

> In contrast to views that see IV drug use as simply a matter of individual pathology, it is more fruitful to describe IV drug users as constituting a 'subculture' as this term has been used within sociological and anthropological research ... This calls our attention to the structured sets of values, roles, and status allocations that exist among IV drug users ... From the perspective of its members, participating in the subculture is a meaningful activity that provides desired rewards, rather than psychopathology, an 'escape from reality,' or an 'illness' [85, p. 385].

Although contributors to the drug subculture literature recognize that there are regional and ethnic variations, they often write as though it is nonetheless possible to analyze IDUs as constituting a single, subculturally unified group. The existence of a distinct subculture among IDUs has been dated in the drug literature to the 1930s and is attributed, at least by some researchers, to the passage of the Harrison Act in 1914, which began the process of criminalizing drug use in the U.S. As a result, drug users came to "perceive themselves as culturally and socially detached from the life style and everyday preoccupations of members of the conventional world" [86, p. 128] and to associate more or less exclusively with other drug users [87].

Drug user vernacular is said to perform several significant functions in maintaining the subculture, including setting its social boundaries, labeling in-group experiences so that they might serve as bonding mechanisms, shaping members' identities, and allowing access to drugs and protection from the police. Argues Iglehart [88, p. 111], a shared drug-related language is used in "informational exchanges ... and as a manipulative tool to insulate and protect the users within his world and from the larger society outside."

Beyond discussions of drug language, the substance abuse subculture literature includes descriptions of group rituals for drug injection (e.g. 'booting,' the process of drawing blood into the needle while shooting up), behavioral expectations in several socially constructed subcultural scenes (e.g. rules for appropriate behavior in shooting galleries and drug copping areas), subculturally patterned social interaction and recognized social roles (e.g. social control activities by the houseman at a shooting gallery), life coping strategies (e.g. pooling resources to purchase drugs, diverse hustling schemes, techniques for hiding drugs to avoid police detection), and group specific values (e.g. respect shown to long time drug injectors), in short, an authentic cultural florescence. Pivotal to this subcultural system, needle sharing has been described as a core rite of intensification, "a symbol of social bonding among people who otherwise have little occasion to trust one another" as Conviser and Rutledge put it [89, p. 45], while "tracks" (visual evidence of needle-inflicted damage to veins) are described as proud badges of group membership.

Further, Inciardi [58] argues that violence is an integral component of the drug subculture and one that does not necessarily stem from the fact that drug possession and use are illegal. He cites a number of contexts in the subculture in which violence is proscribed: "territorial disputes between rival drug dealers; assaults and homicides committed within dealing and trafficking hierarchies as means of enforcing normative codes; robberies of drug dealers, often followed by unusually violent retaliations; elimination of informers; punishment for selling adulterated, phony, or otherwise 'bad' drugs; punishment for failing to pay one's debts; and general disputes over drugs or drug paraphernalia" [58, p. 137–138]. AIDS and the fear of using infected needles, he asserts, have added a new context for the expression of violence among drug users.

A major implication of the drug subculture literature is that injection drug users are so marginalized and estranged from the mainstream world that ethnic identity or other social roles are of minimal salience to them and, by extension, may not be of particular relevance to AIDS prevention efforts developed in the inner city for hardcore drug users. From this view, what matters most to the IDU is his/her next 'fix' and hence the cultural mechanisms that facilitate access to drugs are more meaningful and valued than ethnic heritage or other cultural identities such as kinship.

However, there are reasons to be cautious in adopting a subcultural model for understanding IDUs [90]. First, it is far from clear that they possess a long-standing, homogeneous, or well articulated subculture that is particularly distinct from broader cultural practices. According to Page [91], injection drug use has a relatively short history; group lore is not well developed; injection vernacular, though real and important, is characterized by considerable geographic variability; standardization of shooting practices is unlikely given geographic variation in drugs of choice; and drug use patterns are subject to rapid shifts, including adoption of non-injection patterns of drug consumption when injectable drugs are in short supply, available drugs are of particularly poor quality, or in response to health education efforts. A comparison between injection drug users in Miami and Hartford, in fact shows that there exists considerable variation in drug use practices, drugs of choice, needle practices, injection locations, level of sexual risk, and sociodemographic characteristics of drug injectors [92]. For example, while 76% of the IDUs recruited through inner city street outreach in Hartford reported at least daily drug injection, in Miami only one-third reported this level of injection frequency. Frequency of heroin use was found to be particularly important in differentiating Hartford and Miami injectors. Thus, while 69% of Hartford IDUs reported daily injection of heroin, this was true for only 19.5% of their Miami counterparts. Even within ethnic groups, diversity is considerable across geographic areas. An analysis of drug use and AIDS risk among Puerto Rican IDUs in eight U.S. cities found that crack was used in much greater frequency in Miami and Harlem than in the other six cities; while the inhalation of heroin was fairly common among Puerto Rican IDUs in Newark, this practice was rare in some other cities, especially Miami; speedball (a mixture of heroin and cocaine) was quite commonly injected in Hartford but unusual in Chicago; and while injected cocaine was the drug of choice in Philadelphia, and injected heroin filled this bill in Jersey City, in Hartford, both drugs injected alone and in combination, were found to be the norm [92]. This inter-city variation in drug use patterns reflects even wider behavioral differences associated with the routes of consumption and biochemical effects of specific drugs as well as the cultural construction of these effects. Considerable variation also exists within individual cities. In a survey using a random sample of persons with AIDS in New Jersey, IDUs were found to have varied life-styles, rather than to be participants in a single subculture [93].

Additionally, Bovelle and Taylor [94, p. 178] point out that while IDUs make use of a *drug argot*, many users express their "connection with mainstream culture by their ability to shift easily in and out of standard English when expediency demanded . . . " In fact, drug users, for the most part, have not developed a unique idiom. Rather, much of what has been identified as drug language has its origin in working class Black English. As Inglehart [88, p. 112] recognizes, the "[t]erminology and metaphorical imagery used by addicts are often drawn from black slang, and reflect Afro-American cultural values as expressed in dynamic, performance-oriented speech." While Latino drug users in U.S. inner city areas have been heavily influenced by African-American cultural and linguistic patterns as well, they tend also to draw on their Latino subculture as a linguistic and cultural source. Additionally, the language of both African-American and Latino drug users has been heavily influenced by the drug treatment 'subculture' especially the 12-step self-help movement but other treatment modalities as well.

Further, closer investigation has shown that the primary reason that most injection drug users share needles is not ritual expression or social bonding but survival-oriented pragmatism [95]. For example, in their study of male prostitute injection drug users in San Francisco, Waldorf and co-workers [96] found that the primary reason for sharing was lack of needles rather than a symbolic importance placed on the act of sharing. Additionally, many drug injectors have been found to try hard to avoid developing tracks so that they will not be identifiable as a drug user [76]. 'Passing' as a non-user, by painstakingly avoiding fitting any of the reigning drug user appearance or behavioral stereotypes, is a survival strategy adopted by some IDUs. This gambit, which has been reported by a number of drug users interviewed in our Street Knowledge Study in Hartford, involves limiting participation in drug-oriented social scenes to the minimum necessary to secure drugs, a behavioral pattern that constrains the development of a drug subculture.

In sum, while it is not incorrect to talk of a drug subculture, in doing so, it is important to avoid reifying and exoticizing this phenomenon while undervaluing other identities and cultural influences on IDUs, including the pull of ethnic identification, attachment to local communities, and involvement in kin networks. The Heroin Lifestyle Study of African American IDU men, for instance, identified many "long-time, serious heroin users" who nonetheless were "still active in their communities".

> A common bond among these men was minority group status in a society perceived by many to be racist. This ingroup experience of being Black and poor was reflected repeatedly in the comments of study participants. For example, in response to the question, how do you spend your day, one man responded: 'I listen to records ... things like that, watch T.V. I enjoy doing what anybody else would do. No different, I'm Black and I'm poor' [55, p. 6].

Also, existing research points to important differences among IDUs across ethnic groups. In terms of life experience, psychological impairment, and drug use, a number of differences have been noted [97]. For example, a comparison of Chicano and Anglo IDUs by Anglin and co-workers [98] found that the former tend to traverse a shorter road to drug injection that includes consumption of a narrower variety of drugs than the latter.

Moreover, the notion of a subculture of injection drug use can be problematic if it suggests that subcultural norms and values independently generate and sustain risk behavior [76]. As indicated, needle sharing tends to be produced by lack of access to needles not by subcultural values about the social bonding achieved by sharing. The critical issue is the social location of injection drug users as social outcasts (e.g. the ban on the use of federal funds for needle exchange) and not IDU subculture *per se*.

Finally, there is the category, sex partner of an injection drug user. As Glick Schiller [99, p. 243] points out, unlike members of the dominant society, IDUs commonly are "described as having 'sex partners' rather than lovers or spouses". One of the common conceptual leaps that occurs with this term is the assumption that it refers to women who are partners of male drug users with little thought given to the possibility of men who do not use drugs being in relationships with women who do. Also, as Kane [100] has emphasized, being the sex partner of a drug injector is not a natural category, it is not a social group, nor is it necessarily part of an individual's identity. Indeed, many people are sex partners of injection drug users and do not know it. Others may suspect but fear knowing the full truth. Needless to say, this makes prevention efforts targeted to individuals at risk in this way very difficult. As Herdt [14, p. 13] has written: "Though the notion of sexual partner may seem obvious, it varies across cultures and is probably the source of significant error in research design. Whether a partnership is sexual and/or social, culturally approved or disapproved, voluntary or coercive, is of real import ... "

In sum then, we see the degree to which epidemiology, in responding to AIDS, has constructed rather than discovered relevant social categories and the extent to which there is a "lack of correspondence between ... categories and the social reality to which these categories are meant to refer" [100, p. 1049]. As Stone emphasizes

> risk factors and designations of high-risk groups do not grow immediately and automatically out of epidemiological research. They are created in a social context that involves judgement, persuasion, bargaining and political maneuvering [101, pp. 91–92].

Unfortunately, one of the primary consequences of the association in the public's mind of these so-called risk groups with AIDS is that most people have been allowed to feel that they are not at risk, when in fact they may be. Observes Glick Schiller,

> In 1989 the Presidential Commission on the Human Immunodeficiency Virus Epidemic recommended that 'people who fall into any (high risk) categories should seek testing and counseling services from their physician or public health agency, regardless of presence or absence of symptoms'. The logical result of such advice was that if you did not see yourself as gay, as an IV drug user, or as a sex partner of an IV drug user, you did not think of yourself as being at risk for AIDS [99, p. 245].

A number of serious consequences flow from the social and epidemiological construction of AIDS risk groups. These include: (1) perpetuating popular misunderstanding of who is at risk for AIDS and how they are at risk; (2) mistargeting of health education efforts; (3) spreading of the disease because people miscalculate their personal level of risk; (4) stigmatizing, silencing, and abusing individuals with AIDS; (5) dividing communities and thereby reducing their ability to participate collectively in building unified and effective responses to the epidemic; (6) reinforcing social divisions that block politically conscious class formation among the poor and working classes; (7) increasing the mistreatment of socially stigmatized groups; and (8) concentrating public health resources specifically on AIDS while comparatively ignoring the syndemic and social nature of AIDS in the inner city [99].

From the perspective of critical medical anthropology, avoiding these problems requires a reconsideration in light of three important *social dimensions* of AIDS, its: *social construction*, *social transmission*, and *social location*.

THE SOCIAL DIMENSIONS OF AIDS

Like nineteenth-century cholera, AIDS is accurately described as a disease of society in the most profound sense [102]. This is true because of three social dimensions of AIDS that have helped to shape the challenge the epidemic presents for doing useful work in medical anthropology in the inner city.

AIDS as a social construction

AIDS is socially constructed, in the sense that its impact as an arena of focused human experience is shaped by social definitions, social values, and social relationships. For example, there has been the protracted discussion at the Centers for Disease Control and Prevention over the definition of AIDS: should AIDS be defined in terms of a blood test showing the presence of HIV antibodies (i.e. immune system response to infection with the virus) combined with the development at least one so-called opportunistic disease (proving a deterioration of bodily functioning) from an approved list of identified AIDS-related diseases, or should it be defined in terms of blood test results plus a specified rate of a special type of white blood cell (CD4 type leukocytes) per unit of blood, given the tendency of the virus to target, penetrate, and progressively destroy these cells. While the latter option has won out, either way, of course , the AIDS diagnosis is a socially constructed label. AIDS is present only when those with authority to define disease say so. As Treichler [103] has suggested, the situation is reminiscent of an apocyphal story from baseball: Three empires are talking. The first empire says: I call 'em as I sees' em. The second empire says: I calls 'em as they are. And the third empire, the one who perhaps best understands the social nature of the game, says: They ain't nothin till I calls 'em. In AIDS, the latter condition reigns but not without challenge.

For example at the beginning of the epidemic, AIDS, or GRID (gay-related immunodeficiency) as it was then called, was biomedically constructed exclusively as a disease of gay men. Consequently, the appearance of AIDS-like symptoms ('gay cancer,' 'gay pneumonia') among inner-city children did not lead to a diagnosis of AIDS. In December 1981, when Arye Rubinstein, chief of Albert Einstein's medical college Division of Allergy and Immunology submitted a paper to the annual conference of the American Academy of Pediatrics suggesting that the African-American children that he was treating in the Bronx were suffering from the same disease as immunodeficient gay men, he was rebuffed.

> Such thinking ... was simply too far fetched for a scientific community that, when it thought about gay cancer and gay pneumonia at all, was quite happy to keep the problem just that: gay. The academy would not accept Rubinstein's abstract for presentation at the conference, and among immunologists, word quietly circulated that [Rubinstein] had gone a little batty [104, p. 104].

The same pattern occurred among inner city drug injectors who presented immunodeficiency disorders in the early 1980s. Consistently, health officials "reported them as being homosexual, being strangely reluctant to shed the notion that this was a gay disease; all these junkies would somehow turn out to be gay in the end, they said" [104, p. 106].

Similarly, ever since AIDS came to be seen as a disease transmitted through the sharing of drug injection equipment, there are indications that many people in the inner city had died of HIV-related causes even though they were never diagnosed as having AIDS. For example, Commissioner of Health for New York City, Joseph, reported:

> During the last five years, we have seen a dramatic increase in the numbers of deaths of IV drug abusers ... They have been dying from TB, pneumonia, and other conditions that could very well be complications of AIDS-related immunosuppression *not identified as CDC-defined AIDS* ... If we adjust our surveillance for this increase in deaths among IV drug addicts, the absolute number of AIDS-related ... deaths in the City would be as much *as 50% higher than is currently reported* (emphasis added) [105, p. 163].

Indeed, the redefinition of AIDS that has recently occurred followed on the heels of a protracted debate about the failure of the CDC-definition to include opportunistic vaginal and pelvic infections that are peculiar to women, and are disproportionately common among inner city women who have died in increasing numbers from immunodeficiency conditions in recent years.

Understanding the social construction of AIDS, in short, is critical to fighting AIDS in the inner city. However, because it "accords social class (in the form of class-linked power differentials) a central role in the study of social relations of sickness and healing" [106, p. 29], it is sometimes assumed that critical medical anthropology is only concerned with macrolevel phenomena and overlooks the importance of culture as a signifying system used by people to construct a meaningful social world. Following the approach of Roseberry [107], however, it is possible to sidestep the traditional materialist/idealist antinomy in anthropological theory building by viewing social construction itself as a material social process. The objective of this approach is to understand cultural categories "not simply as socially constituted but as socially constituting" [107, p. 28], that is, not just as products or fixed metaphoric, symbolic, or evaluative expressions of a given culture (i.e. cultural texts to be read or interpreted) but as part of the flow of ongoing politically and economically influenced cultural production. This emphasis on creation draws attention to the context of cultural production, including raising questions about who is involved in the productive process, who controls or shapes the direction of cultural production, and who benefits thereof, as well as what is the historic and socio-political location of this process. In Mintz's [8, p. 157] apt phrase, "Where does the locus of meaning reside?" In other words,

> If culture is text, it is not everyone's text. Beyond the obvious fact that it means different things to different people or different sorts of people, we must ask who is (or are) doing the writing [107, p. 24].

This discussion focuses attention on the ways in which the construction of AIDS as a meaningful cultural category proceeds within social fields of power. Whether it be the development of disease definitions, creation of AIDS-related knowledge about the immune system, the construction of 'risk groups', the defining of 'risky settings' (e.g. gay bath houses, ghettos, shooting galleries), the labeling of 'risk behavior' (e.g. promiscuity, prostitution), or the setting of parameters on AIDS education (e.g. the ban on portraying homosexuality in a positive light in AIDS projects supported with federal dollars), the social construction of AIDS occurs in a world of contested interests and hierarchical relations.

Further, attention is drawn to the historic impact of particular meaningful constructs as they gain acceptance and are transmitted socially as the lens through which aspects of the world are known and experienced. Once a social construction like AIDS becomes established (i.e. becomes part of either the dominant/hegemonic culture or a sub-ordinate/counterhegemonic culture), it acts as a material force in shaping subsequent social behavior and relationships, including helping to set the parameters of later social contestations. The rise to prominence of particular configurations and their influences on social action can only be understood therefore by linking cultural construction to the structure of social relationship. For, in addition to endowing the world with meaning and order, culture "perpetuates and legitimates power" [108. p. 166].

It merits stressing that this does not mean that the social understandings packed into AIDS as a cultural concept are products of social forces alone. As a materialist perspective, Critical Medical Anthropology begins with the assumption that HIV has an independent physical existence (that is, independent of its meaningful construction in one or another cultural system, including that of immunology or biomedicine generally), and that characteristics and organic effects of the virus impose themselves on human experience. Experience of the virus, in short, is shaped, in part, by its biotic qualities. Treichler has identified a continuum of approaches to understanding the relationship between culture and biology in AIDS as follows:

> First, the virus is a stable, discoverable entity in nature whose reality is certified and accurately represented by scientific research; a high degree of correspondence is assumed between reality and biomedical models. Second, the virus is a stable, discoverable entity in nature but is assigned different names and meanings within the signifying systems of different cultures; all are equally valid though not all are equally correct. Third, our knowledge of the virus and other natural phenomena is inevitably mediated through our symbolic construction of them; biomedicine is only one among many, but one that currently has privileged status [103, p. 67].

At either end of this epistemological and ontological continuum are two additional approaches. The *mechanical materialist* view understands HIV as a discrete and knowable part of physical reality that cultures merely label, while the *radical idealist* approach portrays HIV as a fully human construction, an abstraction from a whirling buzzing world that is not directly knowable but must be responded to by an encultured being. In Treichler's [103, p. 68] view, conventional medical anthropologists have tended to opt for the middle ground: "Most seem more comfortable with the notion of a single, stable, underlying biological reality to which different cultures assign different meanings than with the view that everything we know about reality is ultimately a cultural construction."

The Critical Medical Anthropology perspective differs from both of these alternatives because it argues that even if it is assumed that HIV is a part of nature, it need not be seen as having an existence that is necessarily independent from human activity and culture, including political economy, because nature need not be understood from an ahistoric naturalistic perspective. From this standpoint, it is readily seen that nature is shaped by society no less than society is shaped by its encounter with nature [108]. As we engage the so-called natural world, we confront ourselves through the imprint of past human interactions with physical reality. For example, it has been suggested that both the evolution of HIV from a simian virus into a species (or, in light of the existence of HIV-1 and HIV-2, a set of species) adapted to human hosts as well as the initial spread of the virus among people in Africa were consequences of the polio vaccination campaign conducted in the Congo during the 1950s (on the grounds that oral polio vaccine was prepared from the kidneys of African green monkeys). While this particular connection has been disputed by vaccine researchers [109], it suggests one of the many ways human actions historically have played a significant role in shaping the physical world including human biology. Writes Crosby,

> On the pampa, Iberian horses and cattle have driven back the guanaco and rhea; in North America, speakers of Indo-European languages have overwhelmed speakers of Algonkin and Muskhogean and other Amerindian languages; in the antipodes, the dandelions and house cats of the Old World have marched forward, and kangaroo grass and kiwis have retreated [110, p. 7].

These changes, components of European colonial expansion, Crosby labels *ecological imperialism*. In examples like this, we see that nature is not as 'natural' as we sometimes like to imagine. Rather, to a considerable degree, it is a product of human labor, although often not the intended or desired product of that labor.

The development of malaria as a major source of human morbidity and mortality worldwide presents another example well known to anthropologists. The Anopheles mosquito that serves as vector for the parasite that causes malaria was greatly influenced by human environmental reshaping for purposes of food cultivation, a development that reflected and expressed significant changes in the human social relationships and polity associated with production of a surplus and food storage. Cultivation created sunlit pools of stagnant water favored by Anopheles mosquitos for breeding while storage of a food surplus allowed the concentration of a large number of human victims in settled villages. During this process, there is little doubt that the mosquito changed to facilitate more effective exploitation of human created environments for breeding and humans as a major source of the blood needed for reproduction. As this example suggests, nature does not exist *apriori* to and separate from humans, nor, by extension, does HIV. If, as is now widely believed by virologists, HIV-1 and HIV-2 had their origins as benign simian retroviruses (SIV_{cpz} and SIV_{smm} respectively), the successful cross-species transmission and subsequent worldwide spread in the new human host undoubtedly was significantly influenced by human social activity, ways of life, and patterns of interrelationship, including, again, powerful forces of a political economic nature.

This argument can be made most clearly if we move beyond the U.S. inner city to consideration of AIDS in Africa, given that Africa commonly is proposed as the site of origin of HIV and simultaneously, as the 'dark continent' of European imagination, has long served the West as a trope for nature, at once wild, unexplored and threatening [111, 112]. Whatever the origin of HIV, an issue mired in controversy because under conditions of oppression "the question of origin becomes confused with the idea of responsibility " [16, p. 15], AIDS is widely spread in several parts of Africa. Some would see this as a consequence of the virus having existed longer in Africa than elsewhere. And yet, understanding the distribution of AIDS on the African continent requires a consideration of political economic factors, including colonial and post-colonial factors. For example, writing of Southern Africa, Baldo and Cabral argue:

> The most important historical structural processes concerning HIV in Southern Africa are the LIW [Low Intensity Wars] and the disruption of the economy, particularly the rural economy. Various population groups are forced into continuous movements, including displacement flight from the war affected areas, regular armies and groups of bandits, rural populations moving to towns (joining the poverty and marginality circle including prostitution and street children) and rural populations moving near army barracks for trading [113, p. 40].

In this instance, the effort by South Africa to maintain its internal system of exploitation through Apartheid and its regional dominance by promoting low intensity wars of destabilization against its neighboring countries produced social conditions that contribute significantly to the opportunities for human infection. Other, yet related, political economic factors also have been identified. With reference to Zaire, for example, Schoepf comments:

> Disease epidemics generally erupt in times of crisis, and AIDS is no exception. Zaire, like most other sub-Saharan nations and much of the Third World, is in the throes of economic turmoil. Propelled by declining terms of trade and burdensome debt service, the contradictions of distorted neocolonial economies with rapid class formation have created what appears to be a permanent, deepening crisis . . . In Zaire, as elsewhere in the region, economic crisis and the structure of employment inherited from the colonial period shape the current configuration, contributing to the feminization of poverty and consequently to the spread of AIDS [e.g. through prostitution or multiple partner sexual relationships associated with smuggling networks developed to contend with the worsening economic conditions] [114, p. 262].

As these two examples show, while the human immunodeficiency virus has a material existence independent of social factors, its role and importance as a source of morbidity and mortality among humans cannot be understood in isolation from political economy. Contrary to the arguments of some critiques of Critical Medical Anthropology [e.g. 115], placing emphasis on the social origins of disease does not constitute a denial of the biotic aspects of pathogens, hosts, and environments. Rather, it is an affirmation of the critical importance of adopting a holistic and historically informed biosocial approach to health.

Social transmission of AIDS

A second way in which AIDS is a social disease is that it is spread through social behaviors, especially intimate behaviors like a sexual contact and injection drug use. For this reason, it is tempting to think of AIDS as an easily preventable disease: people need merely avoid identified risk behaviors and no one will become infected. This simplistic line of thinking about human behavior leads easily to victim-blaming, because individuals who become infected can be said to be responsible for putting themselves at risk. Importantly, the ability of individuals to adopt known AIDS prevention strategies is to no small measure socially determined. Research on AIDS risk, for example, unveils its close connection to issues of power in interpersonal relations. Illustrative of this point are the following comments of inner city Puerto Rican women participants in a community focus group discussion on AIDS conducted by the Hispanic Health Council in Hartford. Discussing the issue of encouraging a partner to use a condom, one woman stated:

> If he's a violent guy, she's exposing herself to violence, because she is implying that he's cheating on her or because she's implying that she might have gone out with somebody. Or he might reject having any sexual activity. Some of them would just walk away. They would just get up and walk away. Either they'd try to persuade her not to use condoms and if she insists, he'd walk away [78, p. 96].

Commenting on her own situation, another focus group participant noted,

> I know that the first time I was so afraid I said you'd better use them. He was kind of upset, you know, because of the fact that I did not believe him, but I had to think about myself. He used them in the beginning, but afterward he just didn't. I was kind of worried, and now the fact that I find out that he's still using drugs and things like that, it scares me, and I think, you know, should I go for a test or what should I do [78, p. 96].

As both of these examples indicate, sexual politics can be a significant determinant of AIDS risk [116, 117, but also see 118]. Notes Sibthrope [119, p. 208], "Safer sex is unsafe if it has the potential to challenge a relationship with a significant partner . . ." Moreover, prevention education (e.g. emphasis on monogamy and condom use) can overlook the fact that under certain circumstances, especially those where limited options prevail and individuals must make the best of what is available, it is possible for "the benefits of taking ... risk [to] outweigh the advantages to avoiding it" [120, p. 597]. This applies not only to gender relations, but to other types of emotionally and materially supportive social relations as well. While known to be highly risky, injecting drugs in a shooting gallery, for example confers definite benefits (e.g. access to needles, access to water, protection from police surveillance, help in case of a drug overdose, potential access to drugs). Similarly, sharing drug injection equipment can be seen as a form of 'life insurance' among people with scarce resources if it helps to maintain a relationship with someone who can be called on in time of need [120]. Consequently, the social transmission of AIDS must be understood in light of the cultural and political economic nature of specific social relationships among the urban poor. No less than cultural concepts, even intimate social relations are generated, enacted, and revised in contexts of social inequality.

The social location of AIDS

Finally, AIDS is a disease of society in the sense that the disease spreads, as Bateson and Goldsby [121] suggest, along the fault lines of society. In the U.S. especially, AIDS is disproportionately a disease of the dispossessed, a disease of the socially condemned and denigrated, a disease of social outcasts and a disease of the poor. Yet, as Fee and Kreiger emphasize:

> The epidemiological categories of 'risk groups' that are firmly established in the infectious and chronic disease models have ... tended to mask the class basis of many health issues. AIDS and HIV-related diseases are no exceptions. Official AIDS statistics, for example, report cases classified by age, gender, race/ethnicity, and mode of transmission and do not provide any information on poverty or social class ... The invisibility of class in the official data mirrors the invisibility of class in public understanding and public policy [122, p. 337–338].

Yet, class plays no small role in determining exposure to HIV. Summarizing data on HIV seroprevalence for newborns in New York City, Novick *et al.*, [123, p. 1749] note that the areas of the city with the highest levels of infection are poor inner city neighborhoods, where low income ethnic minorities constitute a substantial portion of the population. These are the same neighborhoods that have suffered the highest rates of AIDS-related deaths. Yadira Davila, a drug addict from the lower East Side of New York describes the impact of the AIDS epidemic on her neighborhood in the following words,

> Everybody is dead. The lower East Side is almost entirely empty. The only people left are the crackheads. Everybody at the Essex Street market are gone. Before we would pass by and it would be crowded. Everybody selling this and that. Now everything is empty [124, p. 46].

Roderick Wallace [1] has analyzed the social distribution of AIDS in New York in terms of the social disorganization of poor neighborhoods caused by changes in social policy, such as withdrawal of essential municipal services like fire protection, implemented with the intention of lowering population densities and achieving planned population shrinkage in targeted areas. After service withdrawal by the City Planning Commission and other agencies, Wallace has documented a mass migration of refugees from burning areas into nearby neighborhoods, which themselves become overcrowded and are targeted for service reduction and subsequent burnout and migration. In these areas undergoing urban desertification, social networks and other forms of support are severely disrupted. These changes are associated with heightened rates of substance use and HIV infection. At the heart of one of the most devastated urban zones studied by Wallace, a section of the South-Central Bronx, 25% of emergency room patients in the local hospital now test positive for HIV infection. Wallace [1, p. 811] concludes that social policies, which are fairly direct expressions of social relations among contending social groups, propelled the urban environmental changes that resulted in skyrocketing HIV infection and death.

While hiding the role of class factors in the spread of AIDS, epidemiological categories have been mobilized to divide off some groups and individuals for derogatory social labeling and physical suffering. Central to the epidemiological picture of AIDS in the U.S. has been the high prevalence of infection in so-called "hidden populations" [125], that is, groups that are not well known because their social activities generally are staged outside the view of mainstream institutions and agencies of social control. Epidemiological categories reinforce the concerns of those who seek to expand the power of institutions of social control over such populations. Consequently, AIDS involves two epidemics in one, a health epidemic and an epidemic of accusation and condemnation against the afflicted [126]. Hence the countering slogan of AIDS activists: "Fight AIDS not those with AIDS."

Following Arras [127], it perhaps is useful to differentiate 'democratic' from 'undemocratic' diseases. In the former (e.g. influenza), disease is transmitted easily and widely across class, racial, and ethnic lines, making it difficult to stigmatize and lay blame for illness on less empowered groups. In undemocratic diseases, marginalized groups are disproportionately affected. As the foregoing discussion makes clear, the "undemocratic nature of the AIDS epidemic is not the inevitable result of an encounter with infectious disease" [128, p. 324], rather it is the unfortunately but inevitable result of encounter with morbid social conditions and oppressive social relations. Consequently, "examination of the spread of AIDS cannot be disentwined from the examination of more general and underlying political, social, economic and geographic structural factors within which disease transmission is embedded" [129, p. 1160]. Such examination, an objective of Critical Medical Anthropology in the AIDS epidemic, holds potential for suggesting the types of changes in the quality of living and working conditions in the inner city that are necessary for a significant reduction in AIDS transmission.

CONCLUSION

In this paper, I have tried to illustrate some of the ways in which AIDS, as part of the inner city syndemic, has acutely challenged research in health social science and medical anthropology. Further, I have suggested a framework that is conscious of the political economic construction, transmission, and location of AIDS as a way to respond to this challenge. An even larger challenge facing health social scientists lies in translating our research findings, rapidly and usefully, into AIDS prevention, support and treatment. Our primary task involves designing research that matters, research that makes a difference. In a time of crisis, we must be as concerned about the applications of our research as we are about the elegance or creativity of our design, as sure that what we find may help save lives or give comfort as it will lead to any publications or presentations. Over 10 years into the AIDS crisis, we are in much need of taking stock of just how useful our work in AIDS has been. If, as Socrates suggested, a life unexamined is not worth living, then it can be said that research that is not at all relevant to furthering life in a time of crisis may not be worth doing [130].

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Black-White Disparities in HIV/AIDS: The Role of Drug Policy and the Corrections System

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Abstract: African Americans in the United States are disproportionately affected by HIV/AIDS. We focus in this paper on the structural and contextual sources of HIV/AIDS risk, and suggest that among the most important of these sources are drug policy and the corrections system. In particular, high rates of exposure to the corrections system (including incarceration, probation, and parole) spurred in large part by federal and state governments' self-styled war on drugs in the United States, have disproportionately affected African Americans. We review a wide range of research literature to suggest how exposure to the corrections system may affect the HIV/AIDS related risks of drug users in general, and the disproportionate HIV risk faced by African Americans in particular. We then discuss the implications of the information reviewed for structural interventions to address African American HIV-related risk. Future research must further our understanding of the relations among drug policy, corrections, and race-based disparities in HIV/AIDS.

Key words: HIV/AIDS, race disparities, structural interventions, drug use, drug policy, criminal justice, corrections, probation, parole, incarceration.

African Americans in the United States are disproportionately affected by HIV/AIDS, with the rate of AIDS for African Americans nine times that of Whites.[1] As a growing number of researchers emphasize the need to examine and address the structural and contextual sources of HIV/AIDS risk, we suggest in this paper that among the most important contextual factors associated with these disparities are drug policy and the corrections system. In particular, high rates of exposure to the corrections system (including incarceration, probation, and parole) spurred in large part by the "war on drugs" being carried out by both federal and local governments in the United States, have disproportionately affected African Americans. We review a wide range of research literature to suggest how this, in turn, may affect the HIV/AIDS-related risks of African Americans. We then discuss the implications of the information reviewed for interventions to address that risk.

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Black-White disparities in HIV/AIDS. While African Americans make up only 13% of the U.S. population, they represent 39% of all AIDS cases reported in the U.S. through 2002.[1] Furthermore, the proportion of AIDS cases accounted for by African Americans has steadily and markedly increased over time: of the more than 42,000 new cases reported in 2002, 50% were African American, an overall rate that was almost 11 times greater than the rate for Whites in that year.[1] In the same year, African Americans constituted almost two-thirds of all AIDS cases in women and two-thirds of all pediatric AIDS cases.[1] These trends are likely to continue, or even worsen: African Americans accounted for 54% of the new HIV diagnoses reported in the United States in 2002.[1] Through 2001, 56% of all HIV diagnoses among 13–24 year olds were in African Americans.[2]

Sexual contact is the most common route of HIV infection among African Americans. Among the African Americans living with HIV/AIDS at the end of 2003, 75% of women and 22% of men reported acquiring the virus through heterosexual contact; 47% of men reported being infected through male-to-male sexual contact; 22% and 23% of men and women, respectively, reported acquiring HIV through injection drug use.[3] Still, injection drug use is more frequently the source of AIDS among African Americans than among Whites. While injection drug use accounted for 9% of cumulative AIDS cases in White men through 2003, it accounted for 32% of such cases in African American men.[3] In a recent study investigating HIV diagnoses among injection drug users in 25 states with HIV surveillance, researchers found that Blacks continue to be disproportionately represented among diagnosed injection drug use-related HIV cases. Among women, African Americans represented 66% of all injection drug use-related HIV cases, while among men, African Americans represented 64% of all such cases.[3] Other recent studies confirm that African American injection drug users (IDUs) are more likely to be HIV-infected than their White counterparts. Kral and colleagues found that 12.5% of African American injectors but only 2.8% of White injectors tested HIV positive.[4] Similarly, Day found that African American IDUs were four times as likely to have AIDS as their White counterparts.[5]

To what can these disparities be attributed? Explanations for HIV/AIDS often focus on individual risk behaviors, with Black-White disparities in HIV/AIDS viewed as the result of race differences in risk behaviors related to drug use or sex. Yet in general, African Americans report less risky drug use and sexual behaviors than their White counterparts. In terms of drug use, White adolescents are more likely to use illicit drugs than their African American counterparts,[6] and to initiate both illicit and non-illicit (alcohol, tobacco) drug use at younger ages.[6–10] Relative to White adults in 2002, African American adults reported less lifetime and past year use of illicit drugs other than marijuana (24.9% vs. 33.0% and 7.3% vs. 8.2%, respectively) and only slightly more use in the past month (3.8% vs. 3.5%).[11] Furthermore, in a study of currently non-injecting heroine users, including individuals who had, in the past, frequently, infrequently and never injected drugs, Neaigus and colleagues found that African Americans were underrepresented in the group of those with an injection history.[12] Similarly, in a study of risk behaviors of female jail detainees, rates of reported needle sharing were much higher among non-Hispanic Whites than among either African American or Hispanic women.[13] Examination of sexual risk reveals that, as a group, African Americans also do not appear to be engaging in riskier sexual behavior than their White counterparts. Though African American youth do report more sexual behavior earlier than White youth,[14] consistent use of a reliable means of contraception has been more strongly associated with African American than White youth;[15] reported condom use is higher among Blacks than among other racial and ethnic groups.[14, 16–18]

More promising for understanding race differences in HIV/AIDS than explanations based on individual risk behaviors are structural explanations, which focus on the social and contextual factors that determine health. While high rates of HIV/AIDS among African Americans have been attributed to a variety of structural factors (such as poverty,[19–21] homelessness,[22–23] community disintegration,[24] access to sexually transmitted disease services and discrimination and racism[25–29]) arguably one of the most pronounced relevant features of the social context of the past several decades is the disproportionately high rate of incarceration among African Americans.[25]

Incarceration, drug policy, and African Americans. Over the past decade, the number of individuals in U.S. prisons and jails has increased dramatically. Nearly 1.4 million people were incarcerated in U.S. federal or state adult prison systems, and an additional 700,000 were residing in jails at the close of 2003.[30] This growth was especially magnified in the African American community: the rate of current incarceration among African American men went from 1 in 30 individuals to 1 in 15 between 1984 and 1997.[31] The U.S. distinguishes itself not only in its scale of punishment but also in its degree of racial disparity across all levels of the corrections system. Consider these statistics from 2003: in 2003, Blacks were 5 times more likely than Whites to have been to jail;[30] 39% of local jail inmates were Black;[30] 44% of the prisoners under federal or state jurisdiction were African Americans;[32] the rate of sentenced male prisoners under the jurisdiction of state and federal correctional authorities per 100,000 residents was 465 for Whites and 3,405 for Blacks.[33] As of 1997, an African American male was estimated to have a 1 in 4 likelihood of going to prison in his lifetime, compared with a chance of 1 in 23 for a White male.[34] These racial disparities are magnified among young men: in 2003, 12.8% of all Black males aged 25 to 29 years were in prison or jail, compared with just 1.6% of White males of the same age;[30] similarly, in 1999, 40% of all the juveniles in public and private residential custody facilities, and 52% of those in such facilities for drug offenses, were Black.[31] Finally, while women are incarcerated at lower rates than men, a racial disparity also exists between African American and White women. Black females were 5 times more likely than White females to be in prison in 2003.[32]

Growth of the incarcerated population, as well as the racially disparate form that it has taken, relates in large part to U.S. drug policy. U.S. policies towards drug offenses have become increasingly punitive since the 1980s. Measures such as mandatory minimum sentences, penalty enhancements for the sale and use of drugs in certain areas (drug free zones), disparities in the penalties associated with possession of crack and powder cocaine, and restrictions on syringe availability are examples of policies that increase the frequency of arrest and incarceration of drug offenders.[35] Between 1980 and 1995, the number of drug offenders in state prison increased by more than 1000%, accounting for 1 out of every 16 inmates in 1980, but 1 out of every 4 in 1995.[36] In the same time period, drug offenders represented 50% of the growth in state prison populations, and more than 80% of the total growth in the federal inmate population.[36] These increases in drug-related incarceration were not distributed equally between African Americans and Whites. While the number of White state prison inmates sentenced for drug offenses increased 306% between 1985 and 1995, the number of African American state prison inmates sentenced for drug offenses increased 707% in the same time period.[37] The increase in the number of drug offenders in state prisons accounted for 42% of the total increase for African Americans, but only 26% of the total increase for Whites.[38] Among federal prisoners, African American men account for 34% of those incarcerated on non-drug offenses, but 42% of those incarcerated on drug offenses.[33]

The tripling of the female incarcerated population between 1980 and 1990 is similarly related to drug policy.[39] The number of women arrested for drug offenses increased by 89% from 1982 to 1991,[40] and sentencing of drug offenders accounted for 55% of the increase in the female prison population between 1986 and 1991.[39] What is true for men is true for women as well: incarceration rates have increased more rapidly among African American women than among White women, resulting in a growing race disparity in women's incarceration rates.

Incarceration and HIV risk. Whatever the explanations for race disparities in incarceration, it is reasonable to hypothesize that incarceration affects the HIV/AIDS risk of individuals with a history of incarceration. First, the prison environment itself may be a high-risk setting for the transmission of HIV/AIDS due to both the prevalence of HIV among inmate populations and the high-risk activities that occur inside the prison walls. In 2002, the known cases of HIV, as a proportion of the total custody population in state and federal prisons, varied across the nation from 0.2% to 7.5% with an average across prisons of 1.9%.[41] In 1997, 20% to 26% of all people living with HIV in the U.S. were incarcerated at some point during the year.[42] The exact magnitude of sexual risk behaviors occurring in prison is difficult to ascertain given the unreliability of official prison sexual assault records, the social pressures that inhibit men's willingness to report same-sex behavior, the differences in sample size and populations that are studied, and the variety of ways in which researchers define sexual activity.[43–44] While several studies estimate that about 20% of men experience some form of sexual contact while incarcerated, others have reported much higher and much lower rates.[43–47] Whatever the rate may be, the majority of these sexual activities are likely to be unsafe due to the dearth of condoms in prisons. Injection drug use also occurs in prison and is associated with increased HIV risk;[47–51] tattooing may be an additional risk factor.[52] Using HIV testing to investigate HIV transmission within U.S. jails or prisons, some studies have found no strong evidence of intraprison spread of HIV,[53–54] while Mutter and colleagues found that 3% of a sample of individuals continuously incarcerated since 1977 had seroconverted to HIV-positive status.[55] In a more recent study, Krebs and Simmons[56] found that, among a sample of 5,265 inmates, the intraprison HIV transmission rate was 0.63% and HIV transmission while in prison largely occurred through sex with another man. In general, studies suggest that while sex and drug use decrease overall among the incarcerated, they are conducted in a riskier manner inside prison than outside.[57–58]

Though it is difficult to assess whether African Americans have a greater risk of HIV transmission while in prison than Whites, some studies indicate that their risk behavior while in prison differs little from that of Whites.[57, 59] This suggests that any association between incarceration and Black-White disparities in HIV/AIDS that relates to prison as a risk environment results from the greater likelihood that African Americans will be exposed to this environment and not to any differences in risk behavior while incarcerated.

In addition to any risk associated with prison itself, it is important to consider the consequences of incarceration for the lives of released inmates. In particular, incarceration affects social networks and family relationships, economic vulnerability, and access to social and risk reduction services. Before elaborating on these, two caveats are worth noting. First, the literature about the consequences of incarceration does not generally examine how the race of the ex-prisoner shapes the challenges that he or she faces upon re-entry. While there is research that specifically explores the effect of incarceration on African Americans, especially as it relates to social and family networks,[25, 60–61] these studies do not always include analysis by race. Second, clearly many of the issues faced after incarceration (e.g. weak social networks, economic insecurity, uncertain access to safe housing and health care) may have been obstacles faced before incarceration. The point here is not that these factors are necessarily novel, but that they are intensified by the stigma, disconnection, and legal consequences of incarceration.

With regard to the relationships among incarceration, network stability, and HIV risk, Hoffman and colleagues found that individuals in networks with higher rates of turnover (more new members entering the network and more members leaving) were more likely than others to engage in HIV-risk behaviors, even after controlling for other behavioral and socio-demographic risk factors.[60] Arrest and incarceration may contribute to network disruption and consequently to increased HIV risk for African American drug users.[60–62] Incarceration may also destabilize sexual and family relationships. Rates of divorce are higher in marriages where one of the partners is incarcerated.[63] Upon imprisonment of their male partners, women often find new male partners to replace them.[64] Thus, men leaving prisons may not have stable relationships to which they can return. This situation may be worsened by the reduced earning potential of ex-prisoners and the fact that stigma associated with incarceration may make them less attractive as potential spouses.[65]

The economic security of released inmates is also affected by their criminal history. Researchers debate the exact effect of incarceration on future employment:[66] some studies show that ex-offender status has no effect on gaining employment,[67] perhaps partly due to the limited employment histories of many ex-inmates prior to incarceration.[68] (It should be noted, however, that others suggest that many inmates were productive members of their communities prior to incarceration.[69–70])

Incarceration reduces individual earning potential in a number of ways. Prison vocational and job readiness programs, though showing some success in helping inmates to secure work upon release, are not available to all prisoners and often lack the post-release support and follow-up necessary to be truly effective.[71] Employers also are reluctant to hire people with criminal records. A survey published in 1996 found that 65% of all employers would not knowingly hire an ex-offender.[72] In many fields, including law, real estate, medicine, nursing, physical therapy and education, employers are actually prohibited from hiring people with criminal records.[71] Time spent incarcerated is time spent networking with other criminals, not legal employers. Upon release, the ex-prisoner may have more and stronger relationships with people who earn money illegally than with people who run legitimate businesses.[65] It appears that, "as time spent in prison increases, the likelihood of participating in the legal economy decreases [p. 32]."[71]

While ex-prisoners' ability to find work is impaired, it is also difficult for them to benefit from public income maintenance and health programs until they can secure a job. The Personal Responsibility and Work Opportunity Reconciliation Act of 1996 stipulates that "persons convicted of a state or federal felony offense involving the use or sale of drugs are subject to a lifetime ban on receiving cash assistance and food stamps [p. 1]."[73] While states have some discretion in enforcing the ban, 17 states have introduced no nuance and entirely deny people benefits on this basis.[74] Former inmates who are disabled or have chronic health conditions can get medical care through the Medicaid program, but it can take government agencies up to 45 days to approve Medicaid applications and only some states provide coverage to people with pending applications.[75] A lack of identification among ex-prisoners can also make acquiring public assistance problematic.[71, 75]

Economic instability and diminished social ties have serious implications for the housing options of former prisoners.[76] All states offer transitional housing programs (e.g., halfway houses, sober houses, residential substance abuse treatment) to help prisoners re-enter the community. However, the number of individuals being released from incarceration far outnumbers the capacity of these programs; they are able to serve only a fraction of the re-entry population and are often restricted to certain types of offenders.[71] Whether they are released directly from jail or prison or re-enter society via a transitional housing program, it can be very difficult for ex-offenders, most with little or no money, to find housing.[71] Private housing is often unavailable because ex-offenders often lack the funds to provide a security deposit or solid credit history.[77] Public housing may also be inaccessible due to long waiting lists, project policies that ban tenants with criminal histories, and/or federal laws that "deny [government-funded] housing to individuals who have engaged in certain criminal activities [p. 35],"[71] namely drug and sex offenses.[76] Furthermore, many may no longer have any connections with people in the community on whom they can rely. Transitional housing programs created specifically for people who are coming out of prison may direct them to single room occupancy (SRO) hotels that have sub-standard living conditions where residents may easily re-enter a life of crime.[77] One newly released prisoner with a history of drug abuse commented, "When you go to a hotel, you're walking right into a relapse [p. 8]."[78]

These long-term consequences of incarceration may affect individual HIV risk. Lack of income can affect the ability to negotiate condom use[79] and retention in drug treatment,[80] factors that are in turn associated with HIV risk. Bluthenthal and colleagues found that 60% of baseline Supplemental Security Income (SSI) recipients in a San Francisco study of more than 1,200 IDUs lost their SSI benefits when rules were changed to disallow Social Security Administration (SSA) disability based on alcoholism or drug addiction.[81] Injection drug users who lost benefits were more likely than those who retained benefits to participate in illegal activities, share syringes, and inject drugs. They conclude that policies denying income support to IDUs increased their risk for HIV infection. Economic instability may also lead individuals, especially women, but also men,[82] to engage in survival sex, a potential risk factor for HIV.[83] Homeless individuals have been shown to have a high frequency of substance use[84] and risky drug use behaviors in terms of frequency, injection in riskier locations, and poorer needle hygiene.[85] Furthermore, while individuals in drug treatment are at lower risk for HIV than are out-of-treatment users,[86–91] former inmates' access to drug treatment services is generally limited by their lack of financial resources. In all of these ways, incarceration may affect HIV risk. In summary, the extent to which African Americans are disproportionately likely to be incarcerated relative to Whites may help explain race disparities in HIV/AIDS.

Probation, parole, and HIV risk. Do probation and parole moderate or increase the effects of incarceration on HIV/AIDS risk in drug users? Together, these forms of community supervision represent the most widespread alternative to incarceration programs in the country and in any given state. Probation refers to a sentence ordered by a judge, usually instead of, but sometimes in addition to, time in jail. It allows the convicted person to live in the community for a specified period of time, usually under the supervision of a probation officer, depending on the circumstances and the seriousness of the crime. During 2003, more than 2.2 million adults nationwide entered probation supervision.[92] In December 2003, just over 4 million people were on probation in the U.S.; women made up 23% of these and Blacks made up 30%.[92] Drug law violations make up the single largest offense committed by probationers, accounting for one-fourth of probationer offenses.[92]

Parole is the conditional release of a prison inmate after he or she has served part of his or her sentence, allowing the inmate to live in the community under supervision during the parole period. The decision to grant parole is the responsibility, in a majority of states, of a parole board or commission, and is made only after time has been served. At the end of 2003, 774,588 adults in the United States were on parole, with over 492,000 of those entering parole during that year.[92] Women made up 13% of these parolees and Blacks 41%.[92] People who had committed drug-related offenses accounted for 40% of those released on parole in 2002.

As alternatives to incarceration, probation and parole may moderate the impact of confinement by reducing the time an individual spends incarcerated. However, when released to these programs, the vast majority of individuals are subject to active and continued supervision by the criminal justice system. More than three-fourths of probationers are required to report regularly to a probation authority either in person, or by mail or phone, and over 80% of parolees must maintain regular contact with a paroling agency.[92] In addition to this regular contact, most people in such programs are required to meet certain conditions (such as refraining from drug use or association with former friends) while on parole or probation, violations of which can send them back to prison, even when no new crime has been committed.[71] To the extent that our current parole supervision system actually increases rather than reduces recidivism,[93] parole and probation may exacerbate the consequences of incarceration for the lives of drug users, and any accompanying race disparities in HIV/AIDS.

Few studies have specifically examined the HIV risks associated with people on parole and probation. A 2004 descriptive study of 200 people on parole and probation in New York City found that all of the women and 92% of the men had ever been tested for HIV.[47] Seventeen percent of the women and 12% of the men who were tested were HIV-positive. The study also found that HIV knowledge was high, largely due to HIV education in drug programs and prison, although there were significant gaps. Still, in spite of this HIV knowledge and regular testing, many of the subjects reported histories of engaging in high-risk drug use and sexual behaviors. The authors also interviewed parole and probation staff and found they had insufficient training and education about HIV services. The high caseloads and public safety demands of their jobs forced staff to consider HIV prevention as a secondary concern. The study concludes that "more knowledge is needed about the factors that affect the initiation and persistence of drug and sex related risk behaviors among offenders being supervised in the community [p. 382]." It seems clear, however, that it will take more than individual-based educational interventions to address the drug and sex-related risks of those on parole and probation.

There are at least two factors relating to probation and parole that may affect HIV-related risk among drug users: the conditions under which probation and parole are granted and the power vested in probation and parole officers to enforce these conditions. One of the standard conditions of release on probation or parole is to follow all federal, state and local laws,[94] including those that criminalize the use and possession of drugs. To enforce this, and other conditions of release, probation and parole officers are granted wide-ranging powers, such that probationers and parolees are treated differently from regular citizens[95] and parole officers can conduct warrantless searches without parolees' consent.[96] This has meant that individuals under the supervision of the probation and parole systems are essentially under constant surveillance and subject to search of their home or person at any time. Research has demonstrated that, at least for those who do end up using drugs, this surveillance, real or threatened, can negatively affect the risk reduction activities of probationers and parolees. For example, in research conducted among California injection drug users, Human Rights Watch found that the fear of violating probation or parole was cited by many as a deterrent to using syringe exchange programs.[97] Research also suggests that after their release, many incarcerated individuals with a drug use history will return to drug use [98] although those who enter drug treatment programs may be more successful in delaying the return while they are in the program.[99–101]

As previously mentioned, inmates may be prohibited from interacting with their former friends and other members of their social networks upon release.[71] While this may reduce the likelihood that they will return to old drug-using and criminal networks, it may also leave them isolated and without social support, or force them to identify new networks, possibly among those whom they met while incarcerated.[102] It is an empirical question, then, whether this condition of release will reduce any

HIV-related risk associated with their former networks or exacerbate the network disruption and isolation associated with incarceration and any subsequent HIV-related risk.

In general, studies with parolees and probationers confirm that they face many of the difficulties, described previously, that are confronted by those who are re-entering society after incarceration.[101,103–104] What is less clear is whether probation and parole, in and of themselves, add or ease the burdens associated with re-entry. There is some reason to suggest, as discussed above, that the surveillance and other conditions associated with parole and probation may affect re-entry. Furthermore, research suggests that among some inmates, community supervision, and the conditions that come with it, are viewed as putting them at greater risk for re-incarceration to such a degree that they choose to serve a full term in prison and be released at the end of their sentence with no strings attached.[105] In their literature review, Wood and May cite two studies done in the 1990s that found about 30% of nonviolent offenders chose prison time over intensive supervision probation.[105] Their own research found this to be particularly true for African Americans and drug offenders.[105]

In summary, few studies relating to incarceration, parole, or probation explicitly consider the implications of these components of the corrections system for HIV risk in drug users, or race disparities with respect to this risk. However, existing research, discussed above, does provide strong rationale for further exploring the connections among the corrections system (including incarceration, probation, and parole), HIV, and race.

Structural Interventions for Reducing Race Disparities in HIV/AIDS

To the extent that incarceration, associated community re-entry, and potential subsequent supervision under parole and probation, do contribute to HIV risk among drug users in general and race disparities in HIV/AIDS in particular, then interventions that address these factors may reduce HIV risk and race disparities. One group of such interventions are those aimed at delivering HIV prevention messages within the corrections system to those under its jurisdiction, run either by corrections personnel themselves or by others under contract with the system.[106–107] This would include such things as programs to promote HIV risk awareness among prison inmates and efforts to work with probation and parole officers to link their clients with prevention programs.

More important still are structural interventions, which can take a number of forms, including:

- *Interventions aimed at reducing the likelihood of involvement with the corrections system.* To the extent that U.S. drug policy has been associated with increased incarceration and other forms of criminal justice supervision, reform of drug policy would constitute a major HIV prevention intervention of this type. Examples of such reform can be found throughout the country: in 1997, New Mexico established a statewide needle exchange program (Senate Bill 220); in 1999, Connecticut increased the amount of syringes that can be purchased at a pharmacy without a prescription (House Bill (HB) 7501); in 2001, Indiana eliminated mandatory minimum sentences for certain nonviolent drug offenders and reformed its *Drug-Free Zone* law (HB1892).[108] Other efforts aimed at providing substance abuse treatment and reducing the likelihood of initiation of drug use or entrance into the drug trade would also serve this purpose.

- *Interventions aimed at reducing the risks associated with incarceration and supervision.* Efforts to initiate harm reduction programs within the prisons, such as providing condoms and clean syringes to inmates, would be interventions of this type, as would the provision of a broad array of drug treatment options, including pharmacological interventions (e.g., methadone and buprenorphine detoxification programs) within the prison. Prison needle exchange programs have successfully reduced risk behavior and HIV transmission, without endangering staff or prisoner safety or increasing drug use, in Switzerland, Germany, Spain, Moldova, Kyrgyzstan, and Belarus.[109] As more is known about the risks associated with probation and parole, it may become clear what modifications of these systems would reduce HIV-related risks.
- *Interventions aimed at easing the burden of re-entry.* Interventions of this type might include such initiatives as intensive case management programs that help link former inmates to existing services. But they also include efforts to expand the services available to inmates and others under the supervision of the corrections system, such as special employment or housing programs.[66–67, 71, 76–77, 93, 98, 103, 110–111] In addition, reforms in welfare policy that, for example, would end restrictions on access to income maintenance and benefit programs among those convicted of drug-related crimes would also be interventions of this type.[73, 108]

These are just a few examples of structural interventions that have the potential to address the HIV risk associated with involvement in the corrections system. To the extent that African Americans are disproportionately exposed to this system, and the subsequent risk it represents, such interventions have the potential to reduce racial disparities in HIV as well.

Directions for Future Research

While we have cited much research with implications for the relationship of the corrections system to HIV risk, particularly among drug users and as it relates to racial disparities in HIV/AIDS, there is much more work that needs to be done. This includes research relating to the criminal justice system as a factor in HIV risk, the HIV-related effects of ongoing and potential future reforms of the criminal justice system, and the ways that drug and welfare policies are associated with HIV risk and the criminal justice system.

- *The corrections system as a determinant of HIV risk.* Not enough is known about how, specifically, the corrections system operates as a determinant of HIV risk. It seems clear that prison itself is a risk environment, although there is more to know about the extent and nature of risky behaviors that occur behind bars. Even less well understood however, is how other forms of criminal justice supervision, such as those represented by probation and parole or other alternatives to incarceration, shape (for better or for worse) HIV risk. Furthermore, in this review we have focused primarily on research relating to the impact of the corrections system on the HIV risk of individuals. It is important both to recognize and to better understand the multifarious effects of this system, for its consequences extend well beyond individuals. When large numbers of a population are removed from their homes and communities, and others are constantly moving back and forth between institutionalization and independent living, it also affects their partners, families, social networks, neighborhoods, and entire communities.[25] In short, one need not be a drug user or a former inmate to be put at risk for HIV by the corrections system. Finally, we have focused attention on the corrections system from the perspective of those who are placed under its jurisdiction, but it is also necessary to develop a better understanding of the imperatives, policies, regulations, procedures, and norms that structure this system, particularly as they shape the way it addresses drug use, drug users, and HIV-related risk. Such an understanding will make it possible to develop more effective structural interventions to address HIV risk.

- *HIV-related effects of reforms in the corrections system.* While we have suggested here that reform of the corrections system can constitute an HIV prevention intervention, there are other, more common bases on which reform of the criminal justice system have been justified and implemented. Indeed, numerous states and locales are implementing criminal justice reforms to address such things as the economic and human costs of incarceration. Research is needed to examine the effects of these reforms on HIV risk and other related health outcomes.
- *Drug and welfare policy and HIV-related risk.* It is clear that drug policy in the U.S. has contributed significantly to increased exposure of individuals to the corrections system over the last two decades. This, in turn, suggests that drug policy reform represents a potential intervention for addressing associated HIV risks. However, there are numerous components of drug policy, including such things as mandatory minimum sentences, penalty enhancements for the sale and use of drugs in certain areas (drug free zones), disparities in the penalties associated with possession of crack and powder cocaine, and restrictions on syringe availability. Research can identify whether some of these components of drug policy are more important than others in promoting increased vulnerability to the corrections system, in general, and the disproportionate vulnerability of African Americans in particular. This, in turn, would suggest whether some drug policy reforms ought to be higher priorities than others. Similarly, it is likely that various components of welfare policy that restrict access to benefits and programs for those convicted of drug-related felonies and that exclude addiction to alcohol and substances from definitions of disability exacerbate the problems of community re-entry. The extent of these effects and the particular ways that they relate to HIV risk are important topics for further research.

Given the significance of incarceration, probation and parole in the lives of drug users, it is important to understand their potential HIV-related effects better. Research examining these effects must be especially attentive to analyzing whether they vary and are moderated by race. To the extent that African Americans, both drug users and non-drug users, are more likely to be under the jurisdiction of these institutions, they are more likely than Whites to feel their effects. Also important is the question of whether the HIV-related effects of exposure to the corrections system vary by race and, if so, in what ways. For example, it seems likely, given the high degree of residential segregation in urban neighborhoods that the effect of the corrections system on African Americans outside that system is greater than it is on Whites.[25]

Questions of the role of the corrections system in promoting Black-White disparities in HIV/AIDS extend well beyond the particularities of HIV. Ultimately, they lead us to confront the question of the relationships among incarceration, race, public safety and public health more generally, and to ask whether current approaches to public safety seek to protect the safety of some at the expense of the health of others.

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Picture a Coalition

GREGG BORDOWITZ

As a twenty-three-year-old faggot, I get no affirmation from my culture. I see issues that affect my life—the issues raised by AIDS—being considered in ways that will probably end my life. For this reason I think that if there is to be a movement that will shift the discussion of AIDS away from the moralizing, punitive attitude that has characterized this country's policy, it will be built out of an emergent popular culture, one that affirms the lives of those affected. It will be a counterculture that will grow out of a broad-based mobilization to end the global epidemic.

There are already moves to contain this growing activism. Threats of mass mandatory HIV antibody testing and quarantine are written in banner headlines. Certain individuals and groups have already been subject to such assaults—within those institutions where surveillance is most easily enforced. This is not even to mention the discrimination people living with AIDS (PLWAs) have faced in all aspects of social life. The first targets of repression are, as always, the most disenfranchised. Thus, New York City's health commissioner Stephen Joseph has recently called for consideration of "mandatory AIDS testing [*sic*] for prostitutes and sex and drug offenders, as well as a heavy crackdown on all forms of prostitution."[1]

What purpose will enforced testing serve? Test results will establish much more than the extent to which a population has been exposed to a virus. Their

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[1] Ronald Sullivan, "AIDS Test Is Weighed in Sex Cases," *New York Times*, November 21, 1987, p. B30.

On December 10, 1987, members of the Metropolitan Health Association, an affinity group of gay AIDS activists, staged a peaceful sit-in at the office of Health Commissioner Stephen Joseph to protest what MHA member David Harris called "Joseph's malign neglect of widespread explicit educational efforts to stem the course of AIDS in favor of punitive measures scapegoating the most vulnerable and disenfranchised members of society." Their list of demands included "an end to Dr. Joseph's flailing about on the AIDS issue. Long-term planning is needed today to prepare for an excess of 100,000 New Yorkers who will have AIDS and AIDS-related illnesses by 1991. There is no time for false posturing on testing in an attempt to appear tough on the problem, while doing far too little to create workable solutions." Eight MHA members were arrested after Joseph refused to state publicly that he would reconsider his position.

Testing the Limits: New York. 1987.

purpose is to identify an entire social group on the basis of the presence of antibodies. A whole new class of people will be designated as seropositives. The limits of the AIDS community will be established.

What is really being tested? The limits of control that can be exerted over our bodies. The limits of constraint that can be placed on our actions.

We are being tested. The Reagan Administration spends funds for costly, inefficient testing programs instead of for medical research, preventive education, and health care. This misuse of our tax dollars and neglect of our real needs tests the limits of our tolerance. It tests the limits of our will to fight back.

We in the communities affected by this epidemic will not stand for further intrusion into our already disempowered lives. Through direct action we will wrest control of the public discussion of AIDS. Through direct action we will make known the demands of the sick. Through direct action we will establish a national health care policy in the interests of people living with AIDS.

Drastic measures are being adopted. Activists are taking to the streets, making demands on their elected officials. Activists are providing alternative health care, educating their communities, researching alternative treatments. Activists are producing alternative media.

When circumstances require that drastic measures be adopted, independent media activists assume a central role. This role is twofold: to assist other activists in clarifying their positions and goals, and to represent those positions and goals to the world. Adopting the agenda of AIDS activists, media activists make armed propaganda.[2]

Video activists are everywhere met with the same challenges. We must call into question the established structures of the media. We must create new ways to make and distribute media. We must work toward participatory forms of representation that incorporate people into the communication process.

In the AIDS crisis, all of this must be done in order to facilitate moves toward the treatment and cure of AIDS and ARC, the distribution of preventive education materials, and the protection of civil rights. Video activists must clarify

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[2] "The guerrilla expresses him or herself basically through armed activities, even if sometimes he or she uses other means of communication with people, like papers, pamphlets, radio messages, interference on radio and TV stations. . . . Armed propaganda takes on special importance . . . when it is a question of clarifying for the people, in periods when drastic measures must be adopted, positions whose goals are not sufficiently clear and which, thus, are difficult for the working-class mind to understand" (Actas Tupamaras, "Tactics of the Urban Guerrilla" [1971], quoted in Armand Mattelart, "For a Class and Group Analysis of Popular Communication Practices," in Seth Siegelaub and Armand Mattelart, eds., *Communication and Class Struggle, Liberation, Socialism,* New York, International General, 1983, vol. 2, p. 20). Although the above quotation evidences voluntarist tendencies of revolutionary media theory regarding the "working-class mind," it adequately describes the radical potential of alternative media in times of struggle.

A war is being fought over our bodies. Thus, through civil disobedience we will use our bodies as means of contention. Continuing government inaction necessitates militancy. Even armed resistance may become necessary in response to widespread manditory testing and/or quarantine.

situations, render relations, picture possibilities for the emerging AIDS movement.

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In the spring of 1987 the Testing the Limits Collective, comprised of lesbians, gays, and straights, formed to document emerging forms of activism arising out of people's responses to government inaction in the global AIDS epidemic. The founding members of the collective, Sandra Elgear, Robyn Hutt, Hilery Joy Kipnis, David Meieran, and myself, are all activists who view our documentary work as organizing work. The productive capacity and efficacy of the collective's project depends on establishing and maintaining links with protest-oriented groups and support organizations in the communities affected by AIDS.

Most of the members of the collective are participating members of ACT UP (AIDS Coalition to Unleash Power), "a diverse, nonpartisan group united in anger and committed to direct action to end the global AIDS epidemic." ACT UP's first action was staged on Wall Street in March 1987 to protest the unavailability of promising drug treatments and the announcement by Borroughs-Wellcome that they would charge each patient up to $13,000 per year for AZT. Immediately following the action, at which seventeen people were arrested, the Food and Drug Administration announced plans to cut two years off the drug approval process. Media attention began to focus on drug treatment issues, and film of ACT UP's Wall Street demonstration became stock footage in subsequent reporting.

After this initial demonstration, ACT UP grew to be a core group of over 200 people. It coordinated the following actions in 1987:

—April 15th: A demonstration at the Main Post Office in New York City protesting the lack of tax dollars earmarked for AIDS research.

—June 1st: ACT UP joined other national activist organizations in civil disobedience at the White House. Washington police wore yellow rubber gloves as they arrested sixty-four people. Later that day, ACT UP demonstrated at the Third International Conference on AIDS. The civil disobedience garnered extensive international media attention. The second demonstration forced many public officials to break their seven-year silence.

—June 30th: A rally and civil disobedience in Federal Plaza, New York City, to protest mandatory testing, immigration policy, and the negligence of the federal, state, and local governments. Thirty-three people were arrested.

—July 21st: A four-day, around-the-clock protest at Memorial Sloan-Kettering Hospital, one of the four AIDS Treatment Evaluation Units (ATEUs) in New York funded by the National Institutes of Health (NIH). ACT UP called for the NIH to conduct more clinical trials on promising drugs other than AZT and to increase the number of PLWAs in these trials. As a result of this demonstration, ACT UP established an ongoing dialogue with all four ATEUs in New York City.

—August 4th: ACT UP quickly mobilized 100 people to protest Northwest Orient Airlines for refusing passage to PLWAs. In response to the demonstration and to law suits brought in conjunction with the Lambda Legal Defense League and the National Gay Rights Advocates, Northwest issued a policy statement that PLWAs will now be permitted to fly on the airline.

—September 9th: A demonstration at the National Press Building in Washington, D.C., where the Presidential Commission on the HIV Epidemic was meeting for the first time. Several ACT UP members testified before the commission. In addition, ACT UP formed a subcommittee that continues to supply certain commission appointees with accurate and thorough information.

—September 22nd: ACT UP sponsored a community forum consisting of a twenty-member roundtable discussion about the possibilities for coordinated actions focused on issues of education, civil liberties, and health care.[3]

Through participation in ACT UP at every level of its process, the Testing the Limits Collective has been able to document each of these events, resulting in material that was, in effect, produced by the entire membership of ACT UP. As a member of both the video collective and the activist organization, it was important to me to be able to integrate my participation into a single practice. Thus, within ACT UP, I insisted that my work as a documentarian be recognized as itself a form of activism. Such recognition is hard-won. Activist groups generally consider only the dominant media, to which they have a fundamentally contradictory relationship: seeing it as the enemy and at the same time seeking legitimation from it. Discussions of the media are often bogged down in such petty issues as how to write a good press release or how to get the organization two minutes coverage on local news broadcasts.[4] An activist group that expends too much of its energy on the presentation of its image before the dominant media only gives the impression that it is more interested in publicity than in achieving its goals through direct action.

Within ACT UP, Testing the Limits had to earn its support. We were initially regarded as hobbyists, just as we are by the mainstream media: we cannot get press passes and the network musclemen physically cast us aside because we don't have broadcast-level equipment. One of our tasks was therefore to educate the group about the importance of alternative media. We had to introduce and reintroduce ourselves as independent documentarians within the group. We arranged screenings to show people what we were doing. We had constantly to announce our intentions and explain our activities.

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[3] All information taken from an ACT UP pamphlet.

[4] See Dee Dee Halleck, "A Few Arguments for the Appropriation of Television," *High Performance,* no. 37 (1987), pp. 38–44.

Through this process, it became clear that the production of documentary overlaps with the efforts of political organizing. In order to tear down the structures that house the "public discussion" of AIDS, we have to build alternative structures, structures that can generate and foster an affirmative culture for people living with AIDS.

As a member of ACT UP's Outreach Committee, I worked with others to establish relations with other AIDS activist and support groups. Such networking had also become the focus of Testing the Limits's project while documenting a teach-in, hosted by the *Village Voice*, at which many community representatives and groups were present. The collective also independently interviewed these organizations' members, including Suki Ports of the Minority Task Force on AIDS, Mitchell Karp of the Human Rights Commission's AIDS Discrimination Unit, and Yolanda Serrano of ADAPT (Association for Drug Abuse Prevention and Treatment).

The collective's videotaping coincided with and contributed to the work of the Outreach Committee in seeking to build a coalition between groups. In coorganizing the ACT UP-sponsored community forum in September 1987, I was able to get the participation of many of the community representatives with whom the collective had already worked. The community forum then generated still more documentary material, which was edited by Jean Carlomusto, producer of Gay Men's Health Crisis's cable program *Living with AIDS,* into a half-hour show broadcast on the program the following week.

All the material the collective produced within the first three months after its formation was compiled into a six-minute tape. Entitled *Testing the Limits*, the tape is a fast-paced trailer that serves as a short catalogue of resistance to government policy.[5] It draws on the experiences of people from many communities affected by the AIDS crisis. Taped in various social spaces around New York, people are shown in meeting halls, churches, parks, homes, in the studio, at rallies, demonstrations, forums.

Testing the Limits is scripted to the song "Living in Wartime" written by Michael Callen, a person living with AIDS and founding member of the PWA Coalition, and performed by the group Low Life.

> This is the time for doubting,
> To stop and wonder why.
> This is the time for shouting
> I don't believe the lies.
> One way or another
> No one will be spared.

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[5] The pilot was first described as a "catalogue of resistance" by Mark Dion. The designation is appropriate because the pilot tape is an "index" to the kinds of direct action being taken as well as to the documentary material that constitutes the tape.

Call out to my brothers
Doesn't anybody care?

We are living,
We are living in wartime.[6]

This song was used as a vehicle to organize information and propel the viewer through the material. "Living in Wartime" figures far more significantly in the tape than merely as a sound track. Both lyrics and melody are used as a formal, rhetorical structure that narrativizes the roughly compiled material within the tape. The song functions to organize the dense arrangement of information, shaping it into a work of propaganda. This tape is an attempt to use the music television form—a commodity form—as a form of truly popular culture. We appropriated some of the tropes of MTV to deploy them as agit-prop.

The six-minute tape was used effectively as a VCR organizing tool, screened in galleries, at meetings, fundraisers, and on cable TV. It was also screened at the lesbian and gay film festivals in San Francisco, Chicago, and New York. In addition, it functioned as a pilot for the collective's future documentary projects.

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Testing the Limits, the pilot tape, would become a model for a twenty-eight minute video called *Testing the Limits: New York.* Like the pilot, this tape is a catalogue of resistance drawn from the nearly 100 hours of video the collective had produced. The collective made the decision to edit the material according to voice, as opposed to image. We wanted to listen to what people had to say about themselves and their situations.

Statements by activists from many communities were roughly ordered according to three areas of concern in the AIDS crisis: civil liberties, education, and health care. The script was divided into three sections according to these categories, recognizing that each of the categories would be triangulated around every issue, within each section. The collective discussed the many varied points of view expressed in the material and arrived at editing decisions through a loose consensus process. We arranged and rearranged clusters of material according to the particular relation of each of the members to the issues. Our task was complicated, sometimes painful, as our decisions had to be mediated by the multiplicity of social relations in play.

This collective process resulted in a number of awkward juxtapositions

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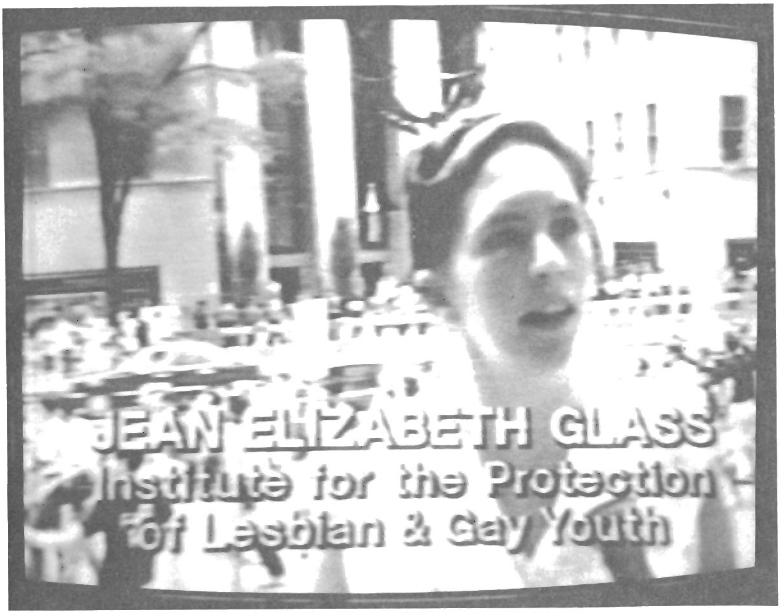
[6] "Living in Wartime," music and lyrics by Michael Callen, performed by Low Life, © Tops and Bottoms, Inc., BMI.



Testing the Limits: New York. 1987.

Jean Elizabeth Glass [a client of the Hetrick-Martin Institute, formerly the Institute for the Protection of Lesbian and Gay Youth]: "What's happening now in New York City is unthinkable: AIDS is now the leading cause of death for young men from the ages of eighteen to forty-four. Eighteen years old! That means they're contracting AIDS when? When they're fourteen? thirteen? fifteen? We're not educating these kids. AIDS is the leading cause of death in New York City in women twenty-six to thirty-seven. They caught it when? When they were eighteen? nineteen? They're not being educated. Obviously 'just say no' doesn't work for pregnancy. It doesn't work for veneral diseases like syphilis or gonorrhea. It's not going to work for AIDS.

One of the things that IPLGY does is tell kids the truth, and it's one of the few places that they get the truth. They're not getting it in the schools, they're not getting it in their homes, and they're not getting it on the street. At the institute, they at least have a shot to come in and ask very serious questions. Do I get AIDS if someone spits one me? Do I get AIDS if I have anal intercourse? Can I get AIDS from sucking my lover off? IPLGY uses terms that the kids understand. If you say 'anal intercourse,' they look at you like . . . 'what?' At least it's one place where you can come out and say 'fucking and sucking without a condom can give you AIDS.' The kids understand it and they respect it."

within the tape. One of the most jarring occurred in the section on education, in which a statement by Ruth Rodriguez of the Hispanic AIDS Forum was followed by a statement by Denise Ribble of the Community Health Project. Speaking in Spanish (subtitled in English), Rodriguez delivers an impassioned speech to members of her own community on issues of Latino representation and self-determination. Immediately following, Ribble describes the use of dental dams in lesbian safe sex practices. The conflict of the two segments involves more than the obvious. Rodriguez directly addresses the camera with a sense of rage. Then, relaxed in her clinical setting and clearly talking about something she enjoys, Ribble presents to the camera a piece of green latex, her "Christmas version" of the dental dam.

It is difficult to articulate what disturbed us about this juxtaposition. To my mind, we were confronted by our own internalized homophobia. We didn't think that a description of lesbian sexual practices should follow a statement about the cultural exclusion of the Latino community. We were afraid to risk offending the Latino community, assuming that that community would not view the issues as of equivalent importance.

This evidenced a historically specific discursive formation. For the sake of countering prevalent assumptions, such as "AIDS is a gay disease," many activists will deny that their sexual orientation is associated with their AIDS activism. This is counterbalanced by others who stress the problems the epidemic has posed for certain gay people to such an extent that they exclude recognition of the problems for anyone else. Regardless of intention, I think the collective, at times, recapitulated the homophobia exemplified by the former tendency. I think we experienced our own internalized AIDS-related homophobia. But there's no such thing as a thought crime. Editing occasioned a process that enabled us to work through some of the specular relations implicit in AIDS work. For me, each image that raised issues of sexuality was charged with questions about my own sexual orientation. Thus, I was forced to view issues of race, gender, and class as they figure in relation to gay sexual politics.

The juxtaposition between Ruth Rodriguez's statement and Denise Ribble's description did not seem to make sense at all, even though we had arrived at it through a reasoned process. In fact, what *does* make sense in the AIDS crisis would, in other circumstances, seem a non sequitur. The current situation involves a collision of issues that had existed before the epidemic. The response to the epidemic has thus enabled a number of groups to understand social injustices as systemic biases within society that affect all subaltern groups differently. For this reason, the experience of various issues by diverse groups must be rendered in terms of the common situation. Further, this compilation of experiences must be shown to result in a sense of shared goals.

In the end, we didn't retain the Rodriguez-Ribble juxtaposition. Other combinations of material seemed to approximate the historical conditions more accurately, according to the consensus of the collective. The entire section on

Ruth Rodriguez [Hispanic AIDS Forum]: "Our community needs education on the prevention of AIDS. That information has not reached us precisely because those who are in charge of protecting our rights, historically, have not done so and will not do so unless we take control and demand our rights for ourselves."

Denise Ribble [Community Health Project]: "For women, oral sex obviously constitutes a large part of what's going on. So we recommend dental dams. This is a dental dam. This is my Christmas version. A dental dam is a barrier between the virus and your body."

education became a collage in which issues of cultural sensitivity are formally anchored by Denise Ribble's safe sex instructions. These instructions are edited to intervene at regular intervals that determine the pace of what would otherwise seem arbitrary in the arrangement of material in the section. We arrived at this formal solution in view of our historical situation: experiences were grounded in a presentation of the principles of safe sex practices.

Editing decisions show the rough composition of issues that are the AIDS crisis, triangulated around civil liberties, education, and health care. This multiplicity is rendered—as voiced—by members of the affected communities. Concerns specific to each community are roughly juxtaposed. The single most important objective is to affirm the lives of people living with AIDS and the social relations these lives include. Finally, it is necessary to show courses of action that will bring about positive change. Protest and resistance must be militantly advocated.

Testing the Limits: New York is punctuated with powerful images of protest, explicitly intended to present direct action as the means to change. References to the print media and network television are occasionally introduced to situate the issues polemically in relation to the so-called public discussion of AIDS. The use of music serves a similar purpose, attempting to ground the tape in genuinely popular cultural production.

"Living in Wartime," the song used for the pilot, opened and closed the twenty-eight minute tape.

> They try to break our spirits.
> They try to keep us in our place.
> They do it to the women
> And the poor of every race.
> We face a common enemy,
> Bigotry and greed.
> But if we fight together
> We will find the strength we need.
>
> We are living,
> We are living in wartime.[7]

A section of the rap called "Respect Yourself," produced by the Philadelphia AIDS Task Force, was used in a transition between the section on civil liberties and that on education. The transition is a quick paced, diced selection of urban images contrasted with images of protest. Scripted with a simple theme of "movement" in mind, it is roughly edited to the rap beat.

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[7] *Ibid.*

Be you a butcher, a baker, a candlestick maker,
AIDS don't care about the color of your skin.
You gotta keep your body strong.
Respect yourself and you will live long.[8]

The only other scored transition occurs between the sections on education and health care. A portion of the Romanovsky and Philips song "Homophobia" is played under a series of images about "touch." Shots of the Washington police wearing rubber gloves at a civil disobedience are paired with images of activists joining hands at the ACT UP civil disobedience at Federal Plaza in New York.

Now AIDS has claimed so many lives
And still there is no cure,
And if they don't spend more on research
It will keep on killing more.
Because it's called a gay disease
It's easy to ignore,
Which sounds a lot like blatant homophobia to me.[9]

Songs can succinctly render complex concerns in ways that are extremely accessible; music-making is central to building a popular culture. As we scripted sections of the tape to this music, it became clear that the collective's activity is part of an emerging cultural project.

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The agenda of this project compels the video activist to organize the screening and distribution of material. People must be able to see themselves making history. People living with AIDS must be able to see themselves not as victims, but as self-empowered activists. In view of this agenda, distribution plans have to be fundamentally pragmatic: Generate as much material as possible. Show this material in as many forms and as many places as possible. Utilize every possible resource. Work by any means necessary.

The Testing the Limits collective has addressed issues of distribution by organizing its production as a self-generating process. The twenty-eight minute documentary is the "public image" for the work of the collective. As such, it is made to appeal to a wide audience. It has been screened in Los Angeles at the American Film Institute and in New York at both the New Museum of Contemporary Art and Global Village. Appropriate for broadcast, it is a means to

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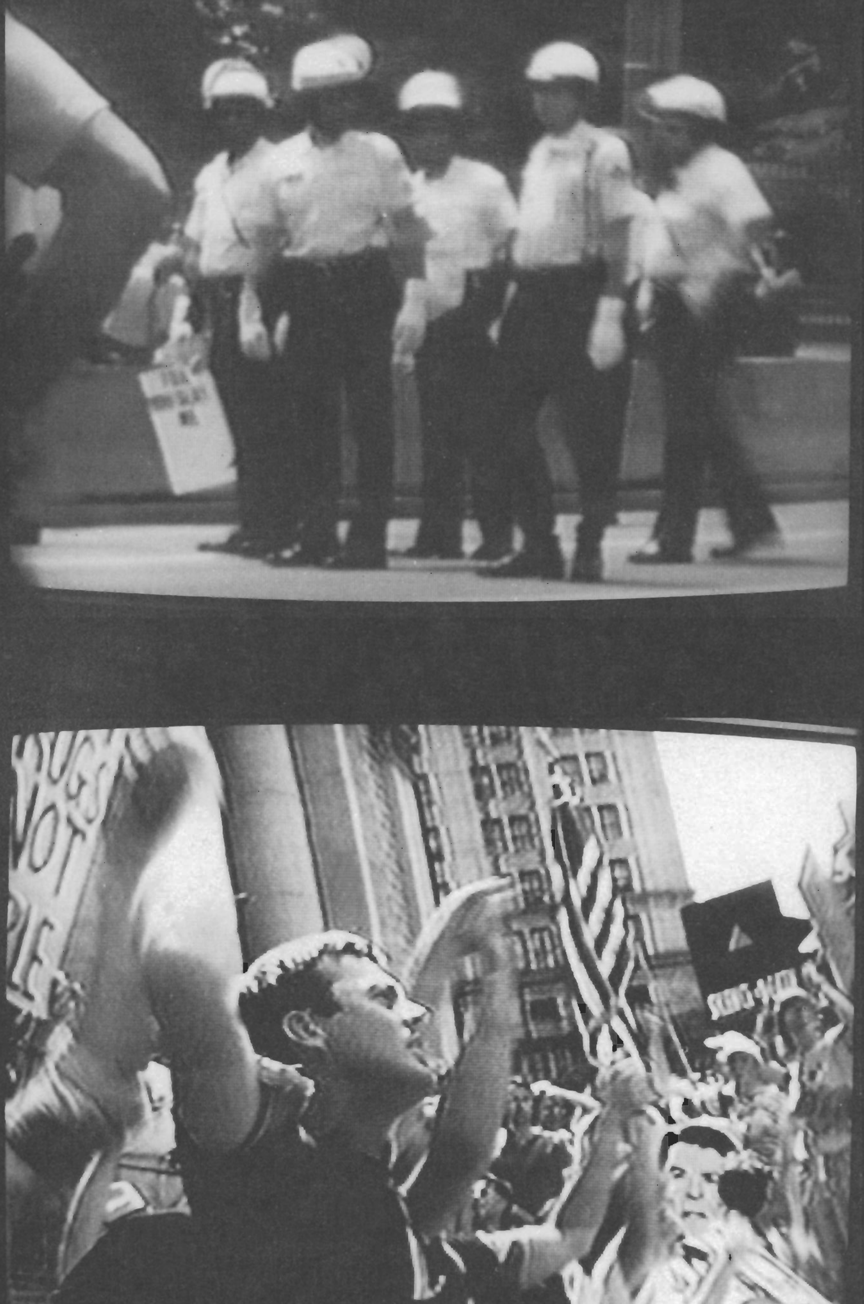
[8] "Respect Yourself," produced by Philadelphia Community Health Alternatives, Black and White Men Together, with the assistance of the US Conference of Mayors.

[9] "Homophobia," music and lyrics by Romanovsky and Philips, © 1985 Romanovsky and Philips. Thanks for their continuing commitment to lesbian and gay activism.



Testing the Limits: New York. 1987.

recognition and funding. More importantly, it provides an impetus to the community-based advocacy work in which the collective is engaged. Our material can be disseminated through local distribution, presented anywhere a screening is possible. The collective has a policy of sharing material with anyone in the movement. Aside from the local VCR circuit, material is fed to public access programs such as *Living with AIDS,* mentioned above, and *Out in the Eighties,* a gay cable TV show. It is possible to set up screenings anywhere. Some groups have organized screenings in parking lots, running tapes off the cigarette lighter of a station wagon, propping the TV on the tailgate.[10]

Imagine a screening. In a local community center a consumer VCR deck and a TV set sit on a table. Representatives from the various communities affected by AIDS sit in front of the TV. They watch a video composed of interviews with each of them. They see themselves pictured in relation to one another as they sit next to one another.

Consider this screening. It presents both means and ends for the video AIDS activist. The AIDS movement, like other radical movements, creates itself as it attempts to represent itself. Video puts into play the means of recognizing one's place within the movement in relation to that of others in the movement. Video has the potential to render the concerted efforts—as yet unimagined—between groups. The most significant challenge to the movement is coalition building, because the AIDS epidemic has engendered a community of people who cannot afford *not* to recognize themselves as a community and to act as one.

The AIDS epidemic has caused us to change our behavior. It has shaped our social relations as it has changed our views of ourselves. This became apparent to me recently, after coming out to my family. I realized that I had come out as a member of two disenfranchised groups. I am a member of the gay community and a member of the AIDS community. Furthermore, I am a gay member of the AIDS community, a community that some would establish by force, for no other end but containment, toward no other end but repression, with no other end but our deaths—a community that must, instead, establish *itself* in the face of this containment and repression. We must proudly identify ourselves as a coalition.

Picture a coalition of people refusing to be victims.

Picture a coalition of people distributing condoms and clean works.

Picture a coalition of people having safe sex and shooting up with clean works.

Picture a coalition of people staging a die-in in front of City Hall or the White House until massive funds for AIDS are released.

Picture a coalition of people getting arrested for blocking traffic during rush hour as they stand in the middle of Times Square kissing one another.

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[10] See Halleck, p. 40.

Picture a coalition of people occupying abandoned buildings, demanding that they be made into hospices for people living with AIDS.

Picture a coalition of people chanting "Money for AIDS, not for war" as they surround and quarantine the Pentagon.

The government and the medical establishment denounce as "immoral" the people who get sick and the people they hope will get sick. They worry about themselves, their children, and the "innocent victims." They predict the kinds of people who get AIDS, the numbers of people infected, the numbers of deaths that will occur. But they are doing next to nothing to cure the sick and prevent the spread of AIDS.

People are asking, "If they won't do anything now, when will they?" "If they won't do anything for those who are sick now, for whom will they?"

Getting no answers, people are mobilizing.

Getting no answers, a movement is emerging.

Picture a coalition of people who *will* end this epidemic.

some transitions in the history of AIDS treatment activism

from therapeutic utopianism to pragmatic praxis

Mark Harrington

This paper focuses on the evolution of AIDS treatment activism in America, and particularly in New York City, where the American epidemic has its epicentre, and where treatment activism originated.

I would like to dedicate this essay to Vito Russo, who was both a cultural and a political activist, whose life work, *The Celluloid Closet*, has recently been released as a film.

the outbreak of AIDS treatment activism

A number of unique historical circumstances contributed to the outbreak of AIDS treatment activism in New York City with the foundation of ACT UP/New York in March 1987.

Before the outbreak of AIDS in 1981, there was an innate American sense of entitlement to certain rights. Middle class gay men certainly felt entitled to these as well. Being middle class, they had not known deprivation. Being gay in the 1970s, many of them felt liberation had been won. Being men, many enjoyed relative economic and social privileges. AIDS undermined these entitlements and revealed that the ostensible liberation of the 1970s was incomplete.

For forty years Americans had lived inside the 'antibiotic bubble', when it was believed that infectious diseases were on the wane and that antibiotic chemotherapy could quickly be developed for new and emerging infections (as occurred with Legionnaire's disease in the 1970s).

There had been almost two decades of gay and lesbian political mobilization, following the civil rights model, and many experienced gay and lesbian activists were able to join a new movement focusing on AIDS.

There had been six years of ground-breaking AIDS activism, including the foundation and growth of service-providing agencies such as Gay Men's Health Crisis (GMHC) in 1981, the invention and dissemination of safer sex practices, starting with Richard Berkowitz, Michael Callen and Joe Sonnabend's *How to Have Sex in an Epidemic* in 1982; the establishment of the People with AIDS (PWA) self-empowerment movement, including its Denver Principles, released in 1983. The Denver Principles maintained that people with AIDS have the right to participate in every decision-making body affecting people with AIDS (PWAs). ACT UP would set out to turn the Denver Principles into reality within the research world.

The introduction of the HIV antibody test in 1985, and its widespread use by people to determine their serostatus, (who didn't yet know how many antibody-positive persons progressed to AIDS), created a population of thousands of anxious but still healthy individuals who might be able to mobilize around AIDS if there were any reason to do so.

New York City was the epicentre of the AIDS epidemic in the United States. By 1987 over 7,000 cases of AIDS had been reported, half had died, and between 200,000–400,000 were believed to be HIV-positive.

The rapid development and FDA approval of AZT in March 1987 created a new climate of hope about the prospects for treating AIDS, combined with outrage over AZT's $10,000 a year price. Hope and outrage made an inflammatory combination.

Finally, Larry Kramer was in between plays.

the outbreak of AIDS treatment activism (1987–89)

In March 1987, just around the time AZT was licensed, Larry Kramer gave a speech at the Lesbian & Gay Community Center in New York, which led to the formation of ACT UP/New York. Larry said 'power means the willingness to accept responsibility', and those words had a major impact on our initial activism.

ACT UP was devoted to 'direct action to end the AIDS crisis' – and our definition of direct action was an experimental, improvisatory one. Initially, we tried a range of scattershot tactics, without any overall strategy. Large planned demonstrations and smaller spontaneous ones ('zaps') were mounted to problematize AIDS as a public issue, enhance gay and lesbian visibility and vilify political adversaries. Among the elements and targets of ACT UP's initial activism were zaps and demonstrations about gay visibility, AIDS discrimination, drug companies, political leaders, the media, other AIDS organizations. Larry's motto 'drugs into bodies' was often chanted, but there was little organized activism directed towards achieving that goal.

ACT UPs spread like wildfire around the United States. Particularly important chapters were formed in Boston, Chicago, Los Angeles, San Francisco and Washington, D.C. ACT UP drew people into an exciting cultural and political ferment, with a new sense of community, collective power and joy. This went hand-in-hand with a good deal of intolerance to outside figures, including other AIDS organizations.

ACT UP was like a religious movement in the following ways. Our prophet was Larry Kramer. People with AIDS were saints and preachers while alive (Michael Callen, Vito Russo, Ray Navarro) and martyrs after they died. We had conversion experiences (joining ACT UP, going to civil disobedience training) and could achieve spiritual liberation by joining the community, ACT UP, which viewed itself as the elect. Demonstrating and getting arrested were like initiation rites (baptism). We had separate congregations (affinity groups) which competed to carry out the most radical demonstrations. We had our iconography ('SILENCE=DEATH', Gran Fury, Art Positive, 'THE AIDS CRISIS IS NOT OVER', 'READ MY LIPS', 'THE GOVERNMENT HAS BLOOD ON ITS HANDS'). We demonized our enemies (Ronald Reagan, Ed Koch, Stephen Joseph, Anthony Fauci, Ellen Cooper). Even our enemies could be redeemed if they 'converted'; Ellen Cooper went from being an 'ice maiden' to 'Joan of Arc', according to Larry Kramer, who also elevated Anthony Fauci from 'murderer' to 'hero'. Politicians, unlike scientists, were never redeemed. We regarded other AIDS organizations, such as GMHC, with suspicion and sometimes denunciation, as assimilationist sell-outs or as moderates too prone to compromise. The congregation of the elect met each Monday night at the Centre and later at Cooper Union. We read our credo at the start of each meeting: 'ACT UP is a diverse, non-partisan coalition of individuals united in anger and committed to direct action to end the AIDS crisis . . .' and we had our 'Amen!' chant, 'ACT UP! Fight Back! Fight AIDS!' We had our communion, 'drugs into bodies'. We had our messianic hopes: the cure was possible, it was just around the corner, we had to work incessantly to make it come *faster*. As Larry Kramer exhorted us in spring 1990, 'WE MUST MAKE TOMORROW HAPPEN TODAY.'

In the late 1980s, we were in the grip of a therapeutic utopianism in which it did not feel naive to believe that a cure was imminent and, together, we could make it appear.

unleashing power: developing a strategic focus on treatment research (1988–1990)

At the same time, some of us were beginning to develop a more long-term, strategic focus on treatment research, developing a unique form of direct action: treatment activism. Treatment activism would inevitably change the kind of work ACT UP did, but initially this wasn't apparent, because we were still on the outside of the research world. Later, after we'd broken into that world and began to carry responsibilities there, conflicts would arise about whether treatment activism was a legitimate form of direct action at all. ACT UP adapted many activist practices from past movements, and invented still more; treatment activism was an ACT UP invention, without precedent in the civil rights, feminist or gay rights struggles activism.

Some implicit strategies informed my own initial work with ACT UP's Treatment + Data (T+D) Committee in 1988–89. In college, I had studied critical theory, where I had been struck by Michel Foucault's emphasis on two themes. First, that in political activism, it is necessary to master the language of your adversaries and use it to advance your own ends. This we did with medical jargon surrounding clinical trials, drug development and FDA regulation. Second, the necessity to mobilize on a number of fronts and advance whenever a position gives way. We couldn't know in advance which front would give way. Once we had gained a strategic position, we needed to continue occupying it. The work, as we learned, goes on for years. We didn't know, initially, that our campaigns against the US Food & Drug Administration (FDA) and the National Institutes of Health (NIH) would be so successful. Looking back, however, it is obvious that those tactical 'victories' meant we'd have to spend years solidifying the reforms we worked for and overseeing the design, conduct and analysis of clinical trials.

We started out with a number of 'drugs into bodies' access zaps. For example, in the summer of 1988, Peter Staley led an occupation of Kowa, a Japanese shoe importer, which also made dextran sulfate. Kowa was refusing to sell dextran sulfate to Americans with AIDS who flew to Japan to get the drug. The zap was a success, and Kowa relented, but the drug didn't work and ultimately people stopped using it. We weren't very sophisticated yet about *which* drugs we wanted to put into *whose* bodies, and why.

Another concurrent campaign was also led by Peter Staley, organized around trying to lower the price of AZT. This involved over a year of demonstrations, occupation of Burroughs-Wellcome headquarters and the New York Stock Exchange, along with pressure from other sources such as Congress and the press. Ultimately the company buckled and the price of AZT was lowered by 40 per cent. Note, however, that it wasn't ACT UP alone, as we liked to think at the time, but rather ACT UP together with the Waxman Committee in Congress, editorials in *The New York Times* and elsewhere, which worked to induce Burroughs-Wellcome to lower the price.

A third access campaign involved DHPG (ganciclovir), which was still not licensed in 1989, although it was already the standard of care for CMV retinitis. Without DHPG, people with AIDS were going blind. This was the first campaign in which we really did our homework. We demonstrated at the FDA, got the press on the story, and secured an alliance with Anthony Fauci of the NIH to demand widespread access to and early approval of DHPG. Access was granted in March 1989, and full FDA approval followed in June. The DHPG example led directly to the proposals ACT UP put forth that summer for a 'parallel track' for access to new AIDS drugs while they continued to be studied in trials.

Parallel Track, which resulted in the distribution of ddI to nearly 27,000 people with AIDS between 1989 and 1991, was really the product of several converging forces – our FDA demonstration, the deregulatory, pro-drug company agenda of President Bush and his administration, and the experience of the DHPG fiasco.

At the time, we were thrilled that so many PWAS were getting ddI, but we were taking an enormous risk. ddI killed some people from pancreatitis, and could have killed many more, had it been more toxic. It wasn't until 1992 that the drug showed any clinical benefit in controlled trials, and not until 1995 (with the release of ACTG 175) that ddI emerged as a superior first-line antiviral to AZT. Thousands of people could have benefited from this knowledge years earlier if activists had focused their energy on answers as well as on access. With ddI, we were lucky. Some commentators felt, however, that AIDS activists were being used by industry to put a human face on drug deregulation. Ultimately Parallel Track paved the way for Accelerated Approval, an FDA procedure adopted in 1992, under which drugs could be approved for treating AIDS if they demonstrated beneficial effects on a surrogate marker such as CD4 counts or viral load. With Accelerated Approval, even less would be known when drugs were licensed, and there were no strong guarantees that appropriate post-marketing studies would ever be carried out.

After we succeeded in making the FDA more flexible and responsive to the needs of PWAS, we turned our attention to the agency which conducts the great bulk of clinical trials of AIDS drugs, the National Institutes of Health (NIH), the logical next step after FDA. After exposure to the philosophy of Dr Joseph Sonnabend and the Community Research Initiative (CRI), which helped to develop aerosolized pentamidine for PCP prophylaxis, we were concerned that NIH was not conducting enough studies of prophylaxis and treatment for the opportunistic infections. We had a massive demonstration at NIH on 21 May 1990. This was the last time ACT UP conducted a truly unified treatment activist demonstration – for it succeeded in achieving our goals, and by doing so, drew some of us into long-term engagement within the NIH and its AIDS Clinical Trials Group (ACTG). By drawing some of us in, however, others were left out, and tactical conflicts arose over whose style of activism was more legitimate.

Within the ACTG, activists created structures for ongoing community involvement in and power over AIDS treatment research. Activists from around the country, representing a diverse array of communities, sat on all research committees, helping to design protocols and work out problems at trial sites. Pressure from activists and from liberal Congressmen such as Henry Waxman of Los Angeles and Ted Weiss of New York resulted in a whole host of new opportunistic infection (OI) treatment and prevention studies being undertaken. Within a few years a whole new generation of OI drugs had been tested, approved and marketed. Among these anti-OI drugs were aerosolized pentamidine, azithromycin, clarithromycin, fluconazole, foscarnet, ganciclovir (oral and intravenous), itraconazole and rifabutin. The standard of care for HIV disease and AIDS changed radically between 1987 and 1993, and part of this was due to the involvement of treatment activists.

At the same time, progress in treating HIV itself remained agonizingly slow.

despair, dissent & dissolution (1990–93)

After 1990, T+D's tactical successes and its commitment to seeing them through created ideological and tactical stress within ACT UP. We'd won more power within research than other groups within ACT UP had won in other areas, so where was the cure? The inside/outside strategy (demonstrations followed by meetings) began to be questioned. Demonstrations and zaps against drug companies stopped working; both the media and the industry were bored by them. They became expected, a sort of 'dog bites man' story.

Some activists felt that T+D's focus on treatment research distracted from struggles against racism, sexism, homophobia, and capitalism. ACT UP became a victim of its very success, drawing in a multitude of activists whose primary focus was not AIDS.

A relentless tide of death carried away some of the movement's most beloved, charismatic and inspiring leaders and members. AIDS was clearly not yet the 'chronic, manageable disease' we'd hoped in 1987–89 that it might rapidly become.

Some ACT UP factions wanted to disengage from research meetings and did not want to work with other community groups and activists. The Women's Caucus, for example (largely a group of seronegative white lesbians) interrupted conferences to protest two studies, ACTG 076 and ACTG 175. Rather than propose improvements to those trials, they wanted to 'stop 076' and 'stop 175'. If they had been successful, two of the most dramatic discoveries of the 1990s would never have occurred. Activists can impede research as well as improve it.

By 1991, it seemed we were spending more time fighting other ACT UP members than fighting AIDS. In January 1992, the core of T+D left ACT UP to form TAG, the Treatment Action Group, so that we could focus all our energy on treatment activism.

regrouping, reform & pragmatic rationalism (1993–96)

Initially, it was not clear whether TAG would focus on old-style direct action or new-style treatment activism. Peter Staley dropped a giant condom on Senator Jesse Helms' house. The neighbours were annoyed, but the national media ignored the event and Helms, needless to say, didn't stop his homophobic legislative manoeuvrings. We carried out several drug company zaps against Astra, Dai-Ichi and Roche, but the drug companies didn't budge. It seemed like the old kinds of AIDS activism weren't working.

So we became a think-tank. In spring 1992, TAG commissioned Gregg Gonsalves and me to review the 3,000 AIDS research grants funded by the National Institutes of Health (NIH). We found that no one was overseeing the $800 million AIDS research effort, and that eighteen different institutes were each spending their AIDS money however they wanted. Money, time and lives were being wasted. Our report, released at Amsterdam in July 1992, led to Congressional reforms signed into law by President Clinton in June 1993. For the first time, a powerful Office of AIDS Research (OAR) at NIH would coordinate the AIDS research effort and control the AIDS research budget. Implementing these reforms would take years.

Also in 1993 came what was perhaps the most demoralizing moment in AIDS research, at the Berlin AIDS conference, when the Concorde investigators revealed that early AZT didn't prolong life, and when the investigators of ACTG 155 lied about their study results, claiming that AZT/ddc was superior to AZT when in fact combination therapy, in that study, proved worse. At Berlin, several activists from TAG and GMHC confronted Margaret Fischl, the lead investigator of ACTG 155, calling her analysis 'intent-to-cheat'. For the first time, activists were beginning to demand more stringent studies which would yield more unambiguous results, and scientists were defending studies too small and poorly designed to give PWAS clear guidance about treatment decisions.

Over the next years, some treatment activists began to demand larger, better-controlled studies, carried out in populations at all stages of HIV disease, to determine rapidly whether new anti-HIV drugs were safe and effective. After five years of nucleoside analogue research, we still did not know when people should start therapy, or with what regimen.

In 1994 TAG instigated a nationwide furor by calling on FDA not to grant accelerated approval to Roche's protease inhibitor, saquinavir, until adequate post-marketing studies were underway. Saquinavir had at that point been studied in only 200 patients for six months, and looked, judging by surrogate marker data, to be nearly as ineffective as ddc. TAG was widely attacked for our proposal for a large simple trial which would enroll people with advanced, middle and early disease, and determine within one year whether or not saquinavir added appreciably to the standard of care. Despite the furor, drug companies began to listen. Roche doubled the size of its two pivotal studies. Abbott adopted TAG's proposal for a 'standard of care' control arm, allowing patients in a study of its new protease inhibitor, ritonavir, to take any of the approved antivirals, and proved within six months that ritonavir could half the rate of progression and death in people with under 100 CD4 cells. This led to immediate full approval for ritonavir, based on clear clinical data, a first since the original AZT approval in 1987.

TAG was also working on other aspects of AIDS research. In 1995, the Office of AIDS Research commissioned an expert external scientific evaluation of the entire NIH AIDS research effort, which by now had swelled to $1.3 billion at twenty-four NIH institutes. TAG members and other treatment activists participated in this year-long review, which resulted in a set of recommendations for sweeping reform across the entire NIH AIDS research effort. TAG will spend the next few years seeking to implement these reforms, as well as defending the OAR and the AIDS research budget in Congress.

Treatment activists have won many victories which have extended health and life for thousands of people with HIV, but we have had virtually no impact on AIDS in the developing world, where 80 per cent of the cases occur, and the ultimate goals of a cure and a vaccine remain elusive.

future prospects and provisional principles for treatment activists

AIDS treatment activism is unlike other social change movements because our adversaries are biological as well as social, political, economic and cultural.

- Activists must be flexible tactically but stubborn strategically.
- We must master and appropriate the jargon of science.
- Citizens must have power in setting research priorities and running research programs.
- Activists must, like scientists, 'listen to the data' and change course when new findings make it necessary. Goals and tactics which worked in 1989 will not work in 1996.

- Activists must not only abandon, but actively repudiate, activist dogmas which have become outdated or refuted by new research. Treatment activists must not expect more from science than it can deliver. Science is not magic.
- Clinical studies can be rigorous and answer important questions while remaining flexible, humane, and incorporating the best current standard of care.
- Activists need allies among scientists, the press and in government in order to prevail.
- Unreflective activism can impede scientific progress.
- Activist formations must change along with scientific or historical changes; ACT UP had its time and served a valuable purpose; now there is a need for new formations.
- Activists need a proactive program of policy changes, especially for times when (as in the UK currently) a Conservative government may be about to be replaced by a progressive one.

Some people believe that, with the development of the protease inhibitors, we may be at a turning point in the AIDS epidemic. Is this so? Possibly, from a scientific standpoint. From a public health standpoint, probably not. The drugs won't reach enough people to dent the AIDS toll worldwide in this decade, although they may affect progression and mortality rates in the developed world. Even where people can access these drugs, which we still don't know how to use, the emergence of viral resistance to them is virtually inevitable. They're unduly expensive and their side effects are daunting. No one knows how long the antiviral effect will last.

Ultimately, we'll need immunological interventions as well as antiviral drugs to keep infected people healthy, and we'll need a vaccine to keep the uninfected from infection. These goals are still far off. Even if we're not at the beginning of the end of the AIDS pandemic, however, at least we may be nearing the end of the beginning.

questions for activists / questions about activism

Last year I called Larry Kramer for a peace talk. We haven't spoken for several years. I asked him how his lover was, how his dog was, how his T-cells were. We started talking about whether or not we were at a turning-point in the epidemic, and if so what to do. 'But where are the soldiers?' sighed Larry.

I thought about it. Are activists really like soldiers, where all you have to do is point them in some direction and say, 'Go!'? Even if they were, where *would* we tell them to go, and what to do?

Activists aren't like soldiers. They're a self-selected group of people who feel a calling to do something to intervene. Activism encompasses a complex variety of phenomena: the mobilization of individuals into new formations centred on some common danger or issue; creating or redefining communities of those affected, individual and community rites of identification, mobilization, activation, intervention and reflection. Each stage in this process poses issues and conflicts for individuals and 'the movement' – issues about unity and diversity, tolerance and cohesion, strategy and tactics, negotiation and resistance, evaluation and stagnation, utopianism and pragmatism, messianism and utilitarianism, all before a background of a constantly changing historical context. So in conclusion I'll pose a series of questions for which there are no unequivocal answers.

What is activism? Who defines it? Are some kinds of activist praxis more authentic than others? Who are activists? Where do we get our legitimacy? Are we elected? Not usually. Sometimes we're hired by community-based organizations which derive their support from community members or foundations; other times we're self-selected volunteers. Other questions proliferate: Are activists 'right' because we 'represent' the 'authentic' community? What if activists disagree? Why do we so often disagree? Why are our civil wars so fratricidal?

Are activist interventions 'experiments' or heroic 'battles' with victories and defeats, heroes and martyrs? If activist interventions are experiments, who interprets the data, and how do you correct course?

Why do some activist subcultures outlive their usefulness and become cults wedded to narrow dogmatic practices? Why are activists so insistent on ideological purity, and so intolerant of differences of opinion?

When and why can activists make tactical alliances with other activists or with sometime adversaries (such as scientists, NIH, press, drug companies, Congress)? What is the difference between compromise and co-optation?

Can prevention activism learn from treatment activism, and vice versa?

Is a treatment (and/or a prevention) activism possible in developing or authoritarian countries?

Information is the very lifeblood of AIDS treatment activism. How can the information pools be broadened, diversified and made more accessible?

Why is there so little effective international mobilization to make AIDS drugs more broadly available throughout the world?

movements, markets and the mainstream

gay activism and assimilation in the age of AIDS

Joshua Oppenheimer

Since the early 1990s, there has been a spectacular decline in American grassroots AIDS and queer activism. And yet, gay men are currently experiencing no respite in the devastation wreaked by the health crisis and at the same time are weathering a massive backlash led by religious zealots and social conservatives. If the struggle against prejudice for the basic prevention, treatment, and civil rights needs of gay men confronting AIDS is a matter of survival, it is also a matter of survival to examine why the grassroots movements which initiated and led that struggle have all but disappeared. With this, we must also examine what political structures (lobbies, charities, and so forth) have replaced grassroots organizations, how these non-grassroots institutions have altered the conditions and goals of AIDS and gay activism, and which social processes and policies reinforce – and foster quiet acceptance of – these transitions.

As scientists develop promising new anti-viral treatments,[1] we are potentially living through a critical moment in the epidemic's history. I would argue that, in the US at least, a concerted, grassroots politics could re-focus gay and lesbian community priorities on the fight for equitable distribution of HIV treatments, and could challenge the counter-productive Centers for Disease Control 'prevention' campaigns which still advocate abstinence and

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Diminished worlds? The geography of everyday life with HIV/AIDS

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This paper examines the impact of HIV/AIDS upon the geography of everyday life using insights gained from an ethnographic study of nine men with symptomatic HIV and AIDS in Los Angeles. Variations among respondents and their immediate environments produce different experiences following diagnosis. Despite these variations, there exist some striking similarities in the impact of the illness. These similarities are conceptualized using a stage model to illustrate the changing effect of the illness upon the geographical dimensions of respondents' lives. Respondents' lives were fundamentally altered by HIV/AIDS, but not all changes were detrimental. The complex nature of the illness engenders a series of both positive and negative shifts in well-being, which, in turn, produces expansion as well as decline of people's daily worlds. Copyright © 1996 Elsevier Science Ltd

Keywords: HIV/AIDS, daily geography, social networks

Introduction

Living with HIV/AIDS on a daily basis is a complex and difficult task. The lowering of the body's immune system leaves a person vulnerable to a wide range of opportunistic illnesses that would pose little or no threat under normal circumstances. The shock of diagnosis, and the subsequent strain of living with a terminal illness can also induce psychological problems that may interfere with an individual's daily life. In addition, people with HIV/AIDS have to endure the widely reported social responses of discrimination and neglect. Despite these challenges to the individual's well-being, it cannot be assumed that life with HIV/AIDS consists solely of deterioration and demise. In fact, the temptation to equate diagnosis with death threats to obscure what may be many years of fruitful, it problematic, existence. It may also cause us to overlook the wide spectrum of assistance that people require following diagnosis.

Alongside concerns about the significance of life following diagnosis is the realization that people's experiences with HIV/AIDS will vary. This is particularly true as more cases of HIV/AIDS emerge among people of different sexual orientation, race, ethnicity, class, religion and age. But even with a relatively small, homogenous population, the precise nature of medical symptoms, psychological impacts and social responses, is hard to calculate, as is the ability of a given individual to deal with them. Although similarities undoubtedly exist, factors such as personality, the reactions of friends and family, the nature of the surrounding community and the availability of proximate services may have a profound effect upon individual experience.

The variations in people's abilities to deal with HIV/AIDS raise important questions about why they occur and, subsequently, the differential implications they are likely to hold for those living with HIV/AIDS. Although a large body of literature currently exists on this general topic, very little research has explicitly considered the geographical dimensions of living with HIV/AIDS. It is my contention that space is a vital component in any attempt to comprehend the changes that take place in life following diagnosis. First, the particular space or place in which the person with HIV/AIDS exists is an important determinant of both the reaction he/she can expect to experience from others, and the resources available to assist with the emotional and material challenges that may arise. Second, the physical, psychological and social challenges that appear as a result of HIV/AIDS may affect the space that surrounds the individual. If a person is unable to leave home either because he/she is physically unwell or fears the reactions that he or she may encounter outside, that person's day-to-day world is consequently *diminished* and he/she is unable to access the surrounding community and its resources. Indeed, given the debilitating nature of HIV/AIDS, and the level of public anxiety surrounding the illness, one might expect worlds to be diminished following an HIV diagnosis.

This paper reports on a pilot study designed to explore the geographical dimensions of life with HIV/AIDS. The central questions posed in the study were: what effect does an HIV diagnosis and the subsequent onset of AIDS have upon the geographical dimensions of an individual's day-to-day life, and what factors combine to influence the magnitude of this impact for different individuals? The study comprised a series of detailed interviews with nine men contacted through the Necessities of Life food-bank operated by AIDS Project Los Angeles (APLA) between February and June of 1994. I look first at current geographical research on HIV/AIDS, as well as analogous geographical research, which provides an important foundation for this work. Following this, the research methodology is outlined in detail. The results of the study are then presented in two sections. The first examines those factors that exert a significant influence on the nature of life following diagnosis. The second develops a space/time model of post-diagnosis life. Given the limited size of the study sample, the conclusion is used both to summarize the current research and to offer future directions for inquiry.

Geography and HIV/AIDS

The geographies of HIV/AIDS

In recent years, geographers have begun to make contributions to an understanding of the AIDS epidemic. These have primarily taken the form of efforts to map the origin of the HIV virus and its diffusion at global, national and local levels (e.g. Shannon *et al.*, 1990; Smallman-Raynor *et al.*, 1992; Gould, 1993). While these contributions are valuable, an exclusive focus upon the spatial diffusion of the virus as *the* geography of AIDS may have deleterious consequences for the way in which we conceptualize people living with HIV/AIDS. As Michael Brown has recently argued with reference to gay men's experience with HIV/AIDS, geographers' preoccupation with the spatial diffusion of the virus threatens to reduce gay men's bodies to biological hosts, subject of interest only to the extent that they are able to transport HIV across space (1995, p. 163). He emphasizes the need for an awareness that:

> [t]here can be many ways of knowing what AIDS is . . . We should be critically aware, therefore, that there can also be many geographies to know through this crisis, and their implications, must be perpetually interrogated. (1995, p. 179).

Clearly, the mapping of the virus remains important, but it provides only a single, and necessarily partial, geography of AIDS. Alternative geographies are being written, such as Brown's (1994, 1995) study of Vancouver's AIDS politics; the critique of spatial science by Newman (1990) and Watts *et al.* (1990); Geltmaker's (1992) analysis of AIDS activism in Los Angeles; and Sloane's (1993) commentary on the AIDS memorial quilt. But they are regrettably few and far between. One area that geographers have yet to explore, and where their expertise may be beneficial, is the experience of people *following* diagnosis with HIV.

The appearance of HIV, the progression to AIDS, and the manifold complications that accompany these events undoubtedly affect the geography of people's daily lives. Hence, we may be able to augment an overall understanding of the illness by illustrating the nature and extent of this impact. Ellis provides an example of this in his study of the migration patterns of people with HIV/AIDS (Ellis, 1993). His research suggests that interstate migrants with AIDS may move either for access to improved health care and social services, and/or for access to family support, a finding that has a variety of implications for the effective provision of services to people with HIV/AIDS and for familial relationships. In addition, research on the experience of people following diagnosis with HIV/AIDS may provide a further illustration of the way in which health status is the product of more than health care alone, a theme that has received considerable attention in recent discussions about the evolving structure of 'medical geography' (Kearns, 1993, 1994; Dorn and Laws, 1994; Hayes *et al.*, 1994).

While geographical studies focusing upon the experience of people with HIV/AIDS are limited, other work within the discipline offers useful bases for the research conducted here. Specifically, the issue of social networks and daily paths may provide an important tool to comprehend the geographies of people living with HIV/AIDS. Of particular relevance may be the experiences of marginalized groups such as homeless people and people with mental illness. A cautionary note must be issued, however. While comparison between the experiences of people with HIV/AIDS and those of other groups is possible, it must be remembered that HIV/AIDS remains a potentially fatal and highly stigmatized condition. Three interrelated dimensions of the illness are especially pertinent to this discussion. These are: the *physical impacts* associated with declining immunity and the appearance of opportunistic infection

(Redfield and Burke, 1988; Bartlett and Finkbeiner, 1991; AMFAR, 1994); the *psychological changes* brought about by diagnosis and the subsequent burden of uncertainty, disability and death (Oberhofer-Dane, 1989; Weitz, 1989; Duffy, 1994; Schwartzberg, 1994);[1] and the *social responses* associated with the negative public reaction and discrimination that continue to surround the illness (Herek and Glunt, 1988; Hunter and Rubenstein, 1992).

Social networks and daily paths

A social network may be defined as a time–space map recording a set of repeated social interactions, and social network analysis provides an ability to record shifts occurring in the geography of an everyday environment (Fischer, 1977; Rowles, 1978; Rowe and Wolch, 1990; Wallace, 1991, 1993). On any given day, the sum of these social encounters constitutes a *daily path*. Over longer periods of time, daily experiences combine to produce a cumulative *life path*, which simultaneously represents both end-result and context of our actions (Pred, 1985).

For individuals, the discontinuities induced by the appearance of HIV/AIDS may produce a fundamental renegotiation of the people and places that constitute daily life. Elsewhere, geographers have examined the impact of extraordinary and traumatic events upon the structure of individuals' social networks. For example, studies have documented the shifting and sometimes delicate methods used by people to deal with life on the streets (Hopper *et al.*, 1985; Dear and Takahashi, 1992; Wolch and Dear, 1993). Similar research has also been undertaken for the community-based mentally ill (Froland *et al.*, 1979; Kearns *et al.*, 1987; Laws and Dear, 1988), and, more recently, for women living with multiple sclerosis (Dyck, 1995). In this study, a focus upon social networks and daily paths allows an investigation of the way in which the appearance of HIV/AIDS forces individuals to adapt to the changing dimensions of their daily lives. In some instances, the shift might be an acute one brought about by the onset of an opportunistic infection. In others, it might be one of a series of more subtle and incremental changes caused by dwindling financial resources or more frequent medical appointments.

In addition to simply recording change in individuals' daily geographies, emphasis must also be placed upon the underlying etiology of those shifts. Within geography, a far more critical interrogation of the relationship between social process and spatial structure in recent years has produced greater recognition of the role that space plays in representing and sustaining existing social norms. At the level of the individual, such recognition has translated into an appreciation of the way in which the daily geographies of 'marginal' groups embody and reproduce the conditions of their subordination. Such groups have included women (McDowell, 1983; Monk, 1992); the mentally ill (Dear and Wolch, 1987; Smith and Giggs, 1988); the physically disabled (Hahn, 1988; Golledge, 1993); the homeless (Rowe and Wolch, 1990; Wolch and Dear, 1993); gay men and lesbians (Knopp, 1992; Valentine, 1993a); and gypsies (Sibley, 1992). These and other studies illustrate the ways in which group members are constrained within and by the social space around them, and, importantly, the ways in which individuals seeks to challenge the accepted configurations of the spaces of everyday life (Rose, 1993). For people with HIV/AIDS, a similar focus may help to indicate the extent to which limitations placed upon an individual's daily world are the products not of HIV/AIDS in isolation, but rather emerge from, and are mediated through, the surrounding social environment.

One instance of social-spatial constraint may be *community opposition* to service-dependent populations (Dear *et al.*, 1994). The force of community resistance is an important determinant of the extent to which 'deviant' groups are accepted into, or excluded from, community space (Takahashi, 1992). The appearance and proliferation of HIV/AIDS has created a new and rapidly expanding service-dependent cohort with an arguably unique and highly stigmatized social identity (Brandt, 1988; Rogers and Ginzberg, 1989). Yet, the generally low levels of community acceptability conceal significant variations in public attitudes, suggesting that particular locations within a city, region or country are likely to exhibit different reactions towards people with HIV/AIDS (Takahashi, 1992; also McCaig *et al.*, 1991). The nature of this reaction will, in turn, influence the level of resources made available by the community and the ease with which people with HIV/AIDS are able to utilize community space, directly affecting the morphology of their day-to-day lives.

Study design

Framework for analysis

A preliminary heuristic was devised to conceptualize those factors that influence individual experiences with HIV/AIDS. The heuristic drew primarily from two sources. First, studies documenting the experience of people with HIV/AIDS and their care-givers provided insight on the difficulties commonly faced following diagnosis (e.g. Wolcott *et al.*, 1986; Adelman, 1989; Lang, 1991; Catania *et al.*, 1992; Bechtel and Swartzberg, 1993; Schwartzberg, 1994). Second, research on the daily geographies of marginal and/or service-dependent populations within

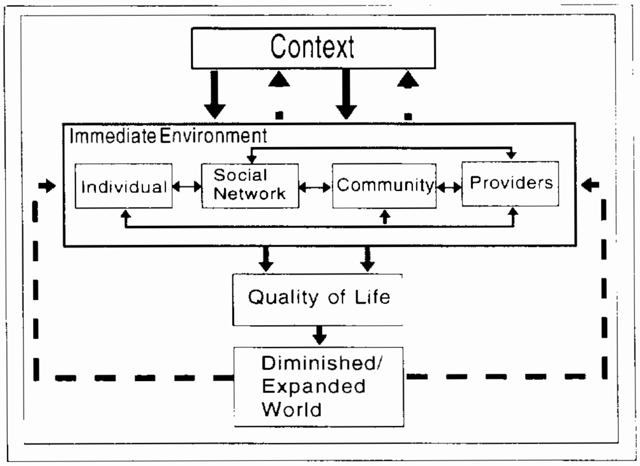


Figure 1. Dimensions of life following an HIV diagnosis.

geography offered useful parallels (particularly Laws and Dear, 1988; Rowe and Wolch, 1990; Valentine, 1993a,b).

Figure 1 illustrates the heuristic graphically. Outcomes are influenced by five broad dimensions: the *individual's* physical health, psychological well-being and socio-demographic profile; the informal *social network* comprising friends and family; the availability of medical, welfare and voluntary/non-profit *service providers*; the attitudes and resources of the *surrounding community*; and the influence of the *broader social context*. The first four of these dimensions interact over fairly short spans of time and space—the immediate environment. They are influenced by, and exist within, a fifth dimension (social context) mediated through such institutions as the state, the legal system and the media. For each individual, the interplay of these five dimensions affects the immediate quality of life and, in turn, exerts influence upon the size and shape of the individual's daily world. The balance of these five dimensions could change quite substantively over time. Since HIV/AIDS affects people differently, time elapsed since diagnosis can be used descriptively to gauge the rate of change in an individual's health and daily world, but not normatively to indicate what health status or size of daily environment should be (Small, 1993). As a result, the framework uses chronological time to gauge changes occurring in the size and shape of the individual's live space, with the understanding that time elapsed since diagnosis is not itself a reliable predictor of change.

Methodology

To investigate the utility of this preliminary heuristic, a pilot study was undertaken, comprised of a series of nine detailed interviews with male clients of AIDS Project Los Angeles (APLA) living with either symptomatic HIV or AIDS. Clients were contacted through the 'Necessities of Life Program,' a food-bank where approximately one-third of the agency's 4000 clients receive a weekly supply of groceries and household items. Since clients must be considered low-income to qualify for this program, the population from which interviewees were recruited did not present the full spectrum of people registered with the agency.

After receiving the program manager's permission to conduct the study, several men were invited to participate in an interview about the extent to which their lives had changed since HIV diagnosis. Following the initial contact on site, interview times and locations were scheduled. The interviews were informal in nature, but based upon a semi-structured questionnaire that was used only as a guideline for each interview. In addition to basic personal information about the respondent (health status, socio-demographics, etc.), the questionnaire placed emphasis primarily upon recording any transformation in daily patterns of activity following an HIV diagnosis with specific reference to the role of the five dimensions identified in *Figure 1*. Once an initial draft of the questionnaire was completed, it was pre-tested. This pre-test generated useful input on the wording of items, and several questions concerning daily experience were added to improve the overall effectiveness of the instrument.

All of the men approached consented to an interview, and seven interviews were conducted during February and March 1994. Although the majority of the questions developed prior to the interviews were relevant, respondents were encouraged to talk freely about what was important to them. Following completion of the interviews, the tapes were transcribed producing approximately 150 pages of single-space typescript. An initial analysis of the transcripts prompted a further revision of the questionnaire, placing more emphasis upon the impact of medication and adding items dealing explicitly with sexual activity. In early May, two more clients of the food-bank were interviewed, producing an additional 40 pages of typescript.

Respondents were selected without prior knowledge of their specific diagnosis (i.e. whether they had symptomatic HIV or AIDS). However, an attempt was made to visually gauge their health status (based on the presence of symptoms such as skin discoloration, persistent coughing, noticeable weight loss and poor mobility). Ultimately, interviews were conducted with five men with symptomatic HIV and four with AIDS. All but one of the respondents were gay. Age and race/ethnicity were considered during the selection procedure, since it was anticipated that these characteristics would influence individual experience following diagnosis. As a result, two of the participants were Latino, three were African American, and four were Anglo. Four were in their 30s, four in their 40s, and one in his 50s. *Table 1* contains brief profiles of each of the individuals involved. All names have been altered to protect confidentiality.

Analysis of the transcripts proceeded by coding the men's responses to identify a wide variety of similarities and differences in individual experience and to determine, where possible, a series of factors responsible for these experiences [see Lofland and Lofland (1995) on such coding procedures]. During coding, particular emphasis was placed upon the following: any change in the structure of everyday life noted by respondents; the extent to which respondents thought these changes were attributable to the appearance of HIV/AIDS; the way in which any changes in individuals' lives were reflected in, and mediated through, the changing morphology of their daily paths; and the point in time when such changes occurred. The analysis produced two distinct but related sets of findings. The first focuses upon the five dimensions presented in the heuristic (*Figure 1*) and their influence upon life following diagnosis. The second set of findings was less expected. Despite the different experiences reported by the men, the common threads running through their accounts support what is essentially a model of life with HIV/AIDS for respondents. I shall now examine both themes in turn.

Dimensions of life following diagnosis

The individual

The physical health of individuals following diagnosis is naturally a major determinant of their experiences with HIV/AIDS. Although the nature of these experiences may be unique, some generalizations concerning respondents' experiences are nevertheless possible, suggesting that the illness imposes significant, even severe, constraints on the geographical extent of an individual's daily world. Despite his positive attitude, Carlos made it clear that HIV has reduced his daily path:

> I have slow days when I know that perhaps it's best if I read a book and watch TV and don't go out and wash the car, and do not go out and do gardening, and do not go out walking. There are days when I know it's best if I just enrich my mind.

Other respondents provided similar examples of the ways in which their movement had been impeded. For Bill, the onset of myopathy[2] has meant periods of time when any movement of his arms and legs has been painful. When asked whether getting around was a problem, he replied:

> There's good days and there's bad days. Sometimes [I] don't feel good, my legs are hurting too much, or my arms are hurting too much, or my stomach's bleeding. There's just a lot of things.

Where physical deterioration occurs, the immediate functional constraints may be exacerbated for some respondents by a loss of confidence in their ability to get around. Discussing his daily activities, Jeff commented:

> I isolate myself. If I have to go somewhere, I think like a little old lady. I go in the middle of the day, and I don't go out after dark. See, what's so scary [is] you can get diseases from other people that they won't get. It scares me when I'm on a bus, if a woman coughs, I automatically think I'm gonna come down with something.

Aside from physical health, the psychological strength of respondents is also important, since it affects the extent to which a person will be able to cope with the trauma of diagnosis and other emotional challenges. During interviews, respondents were asked to elaborate on their attitude toward life with HIV/AIDS. All respondents suggested that maintaining a positive attitude was of crucial importance. Indeed, there was a strong consensus that the psychological and the physical, mind and body, were inextricably linked. However, despite its obvious value, a positive attitude is not always easy to maintain. The initial trauma of diagnosis, physical deterioration, concerns about dependency, and a variety of other issues may do much to weaken psychological resolve. Where this occurs, the psychological challenges may impose their own spatial constraints upon the individual's daily environment. Carlos explains why he chose not to leave his home for several months after he was diagnosed with HIV:

> It was my internal problem. I felt 'Oh, God! How can I face the joy of riding in a beautiful old

Table 1. Respondent profiles

Carlos is 44 years old. He was diagnosed in August of 1992 but says that, to date, he has had very few problems with illness, aside from an initial outbreak of herpes and occasional bouts of fatigue. He lives with a long-term friend. Both of them have had very good jobs, and although currently unemployed, Carlos says that he has several long-standing offers of employment. Many of his friends from the 'old days' have died of AIDS, but he says that he currently has a strong group of companions. Carlos admits that the HIV diagnosis has changed things, placing his life 'on hold', and he wishes that he could be independent again.

George is 53 years old. He was diagnosed about 3 years ago but claims to have known that something was wrong at least 6 years prior to that. He is a little unclear about his current health status, but he says that he has had hepatitis. In addition to HIV, he also has problems with alcoholism. George currently lives in a Section 8 (state-subsidized) apartment complex. He believes that several other tenants are also positive, because he has seen them at APLA.

Jeff is 31 years old. Diagnosed in 1990, he has since had hepatitis and an outbreak of herpes. He is unclear about his health status and has not had a blood test since July of 1993. He says that he often feels lethargic and disoriented and finds it very hard to concentrate. His memory has deteriorated, and his eyesight has worsened. He continued to work after diagnosis, until the hepatitis forced him to stop. Jeff seems very isolated. Circumstances mean that he has very few friends and no confidant to lean on when times are bad. His family has been of little help to him.

Mike is 37 years old. He was diagnosed in late 1985 and considers himself to be someone with 'full-blown' AIDS because his T-cell count is below 200 and he is currently suffering from Kaposi's Sarcoma (KS). He has just moved to a Section 8 apartment and lives there with a roommate. He has not worked since 1992. The visibility of the KS has increased the amount of time Mike spends at home. Overall, Mike thinks little has changed in his life. He says that he does not feel constrained presently, except by the visibility of the KS. He has a car, so he can get around during the day, and he is determined to keep working on his art, so that he will have established himself if a cure is ever found.

Gary is 39 years old. Diagnosed in early 1990, he says he had a good idea that something was wrong before that. He admits that he had been having unprotected sex, and that he has also been an IV drug user. He lives alone in a one-room apartment. He has had two bouts of pneumonia (PCP) and is just recovering from the second. He claims to have a good employment background and is currently enrolled in a college course. Since the pneumonia returned, he has had to drop out of school but is determined to return. Gary suggests that his life has changed fundamentally. He has found out a great deal more about himself and feels that he is a much better person mentally, even if he has deteriorated physically.

Bill is 36 years old. He was diagnosed at the end of 1984 and is currently on the boundary between symptomatic HIV and AIDS. He lives with a long-term companion in a two-bedroom duplex. He has not worked for some time but has been involved in voluntary work. Bill concedes that life has changed significantly. He has had to learn to become more dependent on others, something that he finds hard to do. He also wishes he could get out much more than he is currently able. Despite this current weakness, Bill is determined to get on with life and has a good understanding of what is needed to cope with the illness, both in terms of his internal mind-set and the resources available around him.

Alvaro is 38 years old. He says that he was diagnosed in 1987 but that his illness is currently classified as HIV, despite the fact that his T-cell count is only 26. He is generally optimistic about his health. He lives in a one-room apartment, where he has been since he broke up with his lover. He worked regularly several years ago but suffered a serious back injury that forced him to quit. The majority of his time recently has been spent caring for friends with AIDS. He also helps to run a support group for gay Hispanic men. Since diagnosis, Alvaro feels he has become much more conscious of his health and the things that are important to him. He would like a long-term companion and is sure that HIV has been responsible for his not finding a partner.

Ray is 46 years old. He was diagnosed in 1991 during a stay in hospital and is currently classified as having symptomatic HIV. He lives in a Section 8 apartment. Prior to that he spent time living in an AIDS hospice. Ray is a devout Buddhist, and because of his faith, he believes that he will be able to overcome the illness. He is very optimistic about life. Buddhism also provides him with a busy social calendar. He helps to run a Buddhist support group for gay men with HIV/AIDS. In general, he believes that people diagnosed with HIV must take control of their lives. They should not allow themselves to be swayed by prejudice or by the advice of doctors and other service agents who do not fully understand the needs of people with HIV/AIDS.

Steve is Anglo, gay and 46 years old. He tested positive for HIV in 1990. He says that he felt something was wrong for several years prior to that but was too afraid to test. A bronchial problem he had about 2 years ago responded to a treatment for PCP pneumonia, so he is considered to have AIDS. Steve lives with a companion in a Section 8 apartment. He was an alcoholic over a decade ago, and he believes that the psychological strength he developed overcoming the alcoholism is of great help when dealing with HIV. He admits that the illness has done much to sap the energy he once had. Despite this lack of energy, Steve tries to undertake occasional work to help pay the bills. It also gives him an opportunity to meet old friends.

> convertible on a lovely day, or going out and doing something fun with this death sentence hanging over me?' It was overwhelming for a long time, and I chose to deal with it by staying in familiar surroundings.

Reactions of this nature were common following diagnosis, producing severe discontinuities in both daily path and social network. However, not all psychological changes reported were detrimental. The men reported that being diagnosed had also forced several more substantive, positive changes in their psychological make-up. In particular, emphasis was placed upon the importance of living life to the full and not taking things for granted. Steve captured many respondents' feelings when he suggested:

> You don't take things for granted as much. You appreciate the little things more, and you learn not

> to sweat the big things. I feel like I'm more involved in the immediate present than having any long-term goals, and that's something that everyone could avail themselves of.

Such sentiments are perhaps common to individuals confronted with a debilitating illness or any other challenge to an established pattern of existence (e.g. Snyder and Ford, 1987), but their importance should not be underestimated. A positive attitudinal shift of this nature may spur individuals to challenge those factors that conspire to diminish their daily worlds. Mike explained that the shock of diagnosis followed by the death of his lover in 1985 had prompted him to move to L.A. and begin a bachelor's degree in art:

> 'Well, what do I really want to do?' . . . I'd always wanted to go to art school, so it sorta prioritized my goals . . . I thought that's what I wanna do, so I'm gonna do it.

Social networks

A strong social network was also important in respondents' daily lives. Live-in companions were of particular importance, since they provided someone with whom to share fears and concerns, as well as assistance of a more practical nature. The ending of a long-term relationship clearly had a substantial impact upon the dimensions of Gary's day-to-day life:

> Sometimes I think I spend too much time in the apartment. A lot of my not getting out is because of the situation with my friend. Before he left, we'd make a point to get out, and when we were in, it was just different. Being in with someone you want to be with; the whole experience of being home was different.

His companion's absence reduces the variety of activities that occur within Gary's daily path, causing him to spend more time at home even when he is feeling well enough to go out. Concomitantly, the absence also works to devalue the subjective sense of place that Gary had attached to his home-base, where he now spends the majority of his time.

HIV-positive friends were also important, since they provided a sense of camaraderie that could not be obtained elsewhere. For Jeff, the absence of these types of friends is apparent when he says:

> I would like to have more friends, but people that are in the same boat . . . maybe they've been through what I'm going through, and can tell me that it's just a phase.

For Alvaro and Ray among others, participation in support groups for people with HIV/AIDS has allowed them to develop friendships with others living with HIV/AIDS. Aside from the knowledge and support available, interaction with other members of the group helped to maintain a variety of destinations within respondents' daily geographies. When asked about his day-to-day activities, Ray explained:

> Tuesday night I had an activity. There's always an activity going on in the organization if you want to go, and they're always at 7 p.m. during the week . . . If there's anybody going, they'll come and get me, but I normally try to take responsibility and go on my own.

Supportive family members were important sources of both material and emotional assistance for some respondents. However, when families were unable or unwilling to deal with the news of diagnosis, they could also exert a significantly negative influence on people. Jeff recalled his mother's reaction to the diagnosis: 'My mom was very cruel to me on the phone when I first told her, cos she told me, she said, "Well, you better start saving money to pay for your funeral."'

Fortunately, the lack of support provided by Jeff's parents contrasts markedly with the assistance offered by an aunt who lives nearby. Of all people, she appears to play a central role in sustaining a variety of activities for Jeff beyond the confines of his one-room apartment. She recently helped him to move apartments, often takes him out in the car, and invites him over to her house on occasion to spend time with other members of the family.

Service agencies

Service agencies played a very significant role in day-to-day life. Use of medical services was naturally important, and, in particular, medication was a major influence on many respondents' daily activities. Using anti-viral drugs such as AZT, ddI or ddC[3] or undergoing treatment for a variety of opportunistic infections often had very real detrimental impacts for respondents, and several commented that the medication was often worse than the illness it was designed to prevent! Side-effects ranged from feelings of nausea, inability to sleep, neurotic behavior and loss of sensory perception, to more serious problems like the high levels of toxicity produced in the user's blood and bone marrow. Such side-effects have consequences for both the quality and spatial extent of participant's lives. Carlos explains the difficulties he encountered attempting to drive to his doctor's office whilst on AZT:

> [A]t the corner of Sunset and Rodeo, I sat through three red lights, the traffic around me just seemed to be a big blur. The light would turn green, and I would look to the left and to the right, and the next thing I know, the light would change to amber and red. A lady got out of her car, came over and

> knocked on the window. She said 'you'd better go home, you don't look well.'

Steve offered another example of the influence of medication upon daily activities when he described the impact of the antibiotic he had been using to counter a parasitic infection.

> That antibiotic has been really rough to deal with, and that's why I knew this month when I had some catering work to do that I couldn't do it . . . I would have to cancel all the work, and I've really been in a financial deficit in the last few months.

In these and other instances, medication, rather than an illness, was responsible for diminishing the spatial extent of respondents' daily lives.

Non-profit agencies also played a significant role in respondents' day-to-day lives, acting as vital sources of in-kind income, financial aid, services and referral. In addition, they provided important environments in which friends and acquaintances could be met and made. As Jeff suggested:

> I love going to APLA, not just to pick up my groceries, but to get out and talk to some people, to meet some people, and to listen to what other people are saying . . . just get out, y'know.

A final point about service agencies in general also relates to the issue of place. Medical caregivers, social services and non-profit agencies play important roles in all respondents' daily lives, at some level helping them to cope physically, psychologically and materially with HIV/AIDS. Yet, as has been suggested for other service-dependent populations, the relationship that an individual has with the various helping agencies is often complex and at times arduous (e.g. Reich and Wolch, 1988). Establishing and maintaining access to range of needed resources requires substantial physical and emotional stamina and may come to dominate an individual's daily path. Ray captures the full-time nature of self-maintenance when he states:

> During the daytime, whether it's going to the doctor's, whether it's going to the therapist's, or the herbologist's, that's my job. From the time I get up and leave this room, that's my job from 9 until 6. I'm taking care of my life.

The community

Respondents lived in a total of five different geographical communities within the Los Angeles area (Hollywood, Mid-Wilshire, Mount Washington, Silverlake and West Hollywood). Experience of formal opposition towards people with HIV/AIDS was, for the most part, nonexistent in these west-side and inner-city neighborhoods. At an informal level, however, anxiety about community reaction had an important impact on some of the men. Jeff recounted one experience:

> I was waiting for the bus to stop, and I reached for the metal pole that you hold onto and I missed . . . this girl saw me, and I thought to myself 'she knows' and that's scary to me; I don't know how I would react if I was out in public and people could tell.

When rejection did occur, it was often very hard to deal with. This was particularly true for the single gay men in search of a partner. Alvaro spoke about his attempts to date men when he revealed his HIV status: 'I told him I'm HIV positive, and you can see the change; he never called me back; I saw him another day in the bar, and he act like he don't know me.' The difficulties involved in finding a significant other following diagnosis further illustrates the importance of having an established partner. The absence of a regular partner may also make it hard to fulfil one's sexual desires. Ray's situation reveals how this may represent yet another constraint on post-diagnosis life:

> I still want to live, I still want to have sex because I am a sexual being, a sexual person, I have those desires. At first, I was denying it, y'know, I was dying inside, I was up here masturbating and watching movies and all that stuff, and I thought 'Oh, God, I can't do this.'

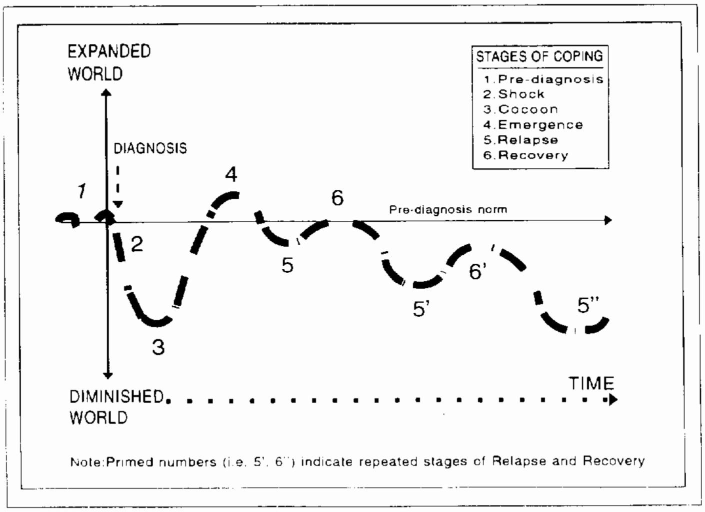
When rejection does occur, therefore, a troubling consequence may be an increasing reluctance to reveal one's HIV status to prospective partners. Although he expresses no desire to harm anyone, Alvaro has begun to think twice about discussing the illness:

> Sometimes you like the person and you don't wanna tell them because [you] don't know his reaction. This is really hard because . . . I feel like a liar [but] I understand now why people don't want to know. Your life's changed when you know you're HIV.

Social context

In addition to the individual and factors constituting his immediate environment, the broader social context was considered because everyday relationships take place within a wider setting comprised of manifold components, such as prevailing public policy and cultural traditions. There was a relative lack of response to questions concerning contextual influences. This may have been a product of the interview format used, since questions relating to contextual influences came at the conclusion of the interviews, by which time people's interest may have waned. In any event, two factors were commonly identified: government and religion.

Questions concerning the government's role in mediating the impact of HIV/AIDS generated the



Note:Primed numbers (i.e. 5', 6'') indicate repeated stages of Relapse and Recovery

Figure 2. Dynamics of the life course following diagnosis.

most response overall from the men. Respondents were often critical, primarily because they felt that the government had little interest in the well-being of the gay community. While some interviewees did mention a growing optimism brought about by the advent of the Clinton administration, they also thought that the increased attention given to people with HIV/AIDS in recent years has been partly due to the changing demographics of the impacted population and the realization that AIDS is not simply a 'gay disease'.

Respondents also identified ways in which government policy affected them at the level of the everyday. Access to welfare constituted a notable influence on quality of life. Many of the respondents suggested that government benefits were barely enough to survive on. For some, casual/part-time employment or an employed lover/companion provided important supplemental support. Access to Section 8 housing was also an important influence, since the federally subsidized program requires households to pay no more than 30% of their net income toward rent. Carlos also felt that regulations regarding earned income while receiving government benefits prevented him from returning to work:

> If I go ahead and take a full-time job, what happens if I have a horrible relapse? How do I pay for the hospital? How do I pay for the medications? Even in this bad economy, I could get a job, the problem is that I would lose every benefit.

Surprisingly, none of the men mentioned the impact of local government agencies, even though the city of West Hollywood and the Los Angeles County Board of Supervisors have been important influences upon the local response to HIV/AIDS (Geltmaker, 1992). This absence may have been due to a tendency to think primarily in terms of *negative* influences upon daily life. The generally supportive local environment and the broad range of nearby services (whether state-funded or not) may have made the role of local government seem less significant to the men.

Religion appears to have affected people in two ways. First, Mike and Jeff felt that religious beliefs have made both homosexuality and HIV/AIDS largely unacceptable in their families' eyes. This fact has seriously strained the relationship that each man has with his family, exacting both emotional and material tolls. A second and more positive impact of religion comes from Ray, whose Buddhist faith provides him with a unique perspective on HIV. His belief that he has the ability within him to reverse the progression of the illness has served thus far as a vital psychological boost. At the same time, Buddhism has also helped him to view death in a far less threatening light.

Dynamics of the life path following diagnosis: the ebb and flow of life with HIV/AIDS

This analysis suggests that a variety of dimensions combines to influence individual experience following an HIV diagnosis. However, some important similarities appeared among respondents' experiences. The strength of these similarities is such that it is possible to conceptualize life after a diagnosis as a series of loosely defined stages that occur both through time and space (*Figure 2*). The vertical axis in *Figure 2* indicates the spatial extent of the person's world, with the mid-point intended to represent a pre-diagnosis norm. The horizontal axis indicates time since diagnosis.

From diagnosis onwards, the model suggests that a series of stages, which I term *shock, cocoon, emergence, relapse* and *recovery*, can be used to characterize respondents' daily lives. Before respondents' experiences are examined in greater detail, two caveats should be issued. First, it is important to note that this study focuses upon individual experience in a community setting, and not with the permanent hospitalization that may ensue should an individuals' health continue to deteriorate. Second, the stages should not be treated as fixed or immutable, since individual experience will vary, sometimes significantly. In some instance, stages may overlap. For example, during the onset of, or recovery from, an opportunistic infection, it may be difficult to identify a specific turning point. A more accurate metaphor may be that of an ebb and flow, where the good days slowly being to outnumber the bad, and vice versa. In addition, some people may not experience all stages. For example, individuals who experience a particularly pronounced decline in health may never recover. Others who fail to exhibit any symptoms over long periods of time may find the initial trauma following diagnosis is succeeded by a prolonged period of emergence largely untroubled by physical decline. The order of the stages may also vary. For people diagnosed as a result of a marked decline in physical health, the shock and subsequent withdrawal may occur concurrently with a period of relapse and recovery. For others who are psychologically resilient, and particularly those who remain asymptomatic for longer periods, post-diagnosis isolation and withdrawal may not appear until after a marked physical or mental deterioration.

The variations in individual experience highlight the danger of attempting to 'fit' people's experiences to a model. At the outset, I had no intention of creating such a model. I envisioned that, over time, the evolving medical and social dimensions of the illness would affect respondents differently. This expectation did not prepare me for the similarities that appear to exist between respondents' experiences in dealing with HIV/AIDS. The interdependence between the general and the specific is important in an understanding of respondents' lives following diagnosis and can be captured if we regard *Figure 2* not as a teleological progression towards a fixed end-stage, but rather as one possible configuration of the stages or trends that constitute life following diagnosis. In this sense, the model is a loose-fitting template illustrating a series of stages or trends common to most respondents, rather than an overly deterministic representation of the men's diminishing worlds. The template also illustrates the spatially and temporally dynamic nature of life following diagnosis. At the same time, the heuristic framework displayed in *Figure 1* remains useful as a way of understanding more about the precise nature of individual experience with HIV/AIDS, since the magnitude, rate and order of change in a person's everyday world are collectively influenced by the five dimensions identified therein.

Pre-diagnosis

The pre-diagnosis stage is important for two reasons. First, it provides some understanding of the preconditions that influence an individual's ability to deal with the onset of HIV. Carlos, for example, had spent some time helping a neighbor come to terms with breast cancer. This experience helped him when he found out he was HIV-positive because 'I took some of that strength she had, and applied it to my own situation.' The fact that some respondents had overcome earlier traumatic experiences did not imply that they were untroubled by diagnosis, but it did allow them to pass through the initial order more rapidly than others.

A second feature of the pre-diagnosis period concerns the impact of not knowing whether one is HIV-positive or not. Steve explained that it had been several years before he had finally tested because he had been afraid to know. The dread of illness took a demonstrable psychological toll upon Steve. It may also have been detrimental physically because he spent 3 years without the potential benefits of medical care. In addition, Steve's anxiety had a measurable impact on his daily path. When discussing his ties to immediate family members, he stated:

> The period of time prior to testing, I used to spend a lot of time with them, because I was in that state of fear. So when I had a free day, I would go out and visit, because in the back of my mind I was thinking about how long I was going to be around . . .

Shock

Not surprisingly, the shock of diagnosis was often severe. As Carlos reveals:

> I feel that I have a good foundation, and that mentally I have a lot to hold onto . . . [but] I was torn loose from my moorings, I was just floating. This is an horrendous shock that will literally cut you off at the ankles.

For many respondents, diagnosis brought with it an expectation that death was both inevitable and imminent. Ray, who had attended a counselling session at L.A. Shanti not long after his diagnosis, reported that the first response of everyone in the group had been that they feared they were going to die.[4] For those people who possessed a better understanding of the implications of diagnosis, or had no immediate symptoms, it was possible to cushion the blow of diagnosis, but it was significant nonetheless. Even for Gary, who was fairly sure he would test positive, diagnosis was traumatic because he finally had it in writing and: 'it was certain then. I had to deal with that reality.'

Regardless of variations in magnitude and timing, there is a sense that diagnosis provides a catalyst to separate individuals from established patterns of existence and initiates a relative decline in the extent of their daily worlds.

Cocoon

After the initial period of shock, respondents appear to have entered a third stage, best described as 'cocoon'. In each case, the men began a period of relative isolation and withdrawal, both social and geographical. In this respect, Carlos was typical:

> There was a big gap in my life from the time I found out in August of '92 to the spring of '93. I didn't leave this house unless it was for a medical appointment. I didn't want to see the outside world.

This stage also appears to be characterized by a diminution of interpersonal space as people severed ties with others. For some, separation may have been the result of an irrational fear of infecting others. This feeling of contamination was commented on by several of the men, including Gary, who ventured:

> At first, I didn't want to be near people because of [the illness]. I'd see a little kid, cos there's children in my family, I didn't want to pick up babies so I distanced myself. I just felt like I shouldn't be around people. It really messed with my head.

The cocoon period may also contain a renegotiation of personal space. If diagnosis was accompanied or followed immediately by illness, respondents were forced to deal with functional and possibly aesthetic change in their bodies.

During the cocoon stage, the negative psychological impact of illness is at its greatest. Withdrawal often represented a method of dealing with the news of diagnosis. As Bill explained: 'you isolate yourself, and you try to reevaluate what you did wrong or where you don't want to go, or be ostracized, or be stared at. [It's] a whole mental trip.' Yet withdrawal is also potentially harmful. Closing in on oneself meant that the assistance that would otherwise have been available from friends, family and counsellors was forfeited. As Carlos ventured:

> [It's] completely against my personal philosophy to reach out for help . . . and so that's why I created this shell, this isolation . . . I did not reach out for help, and that's the one thing I would change, I should have gone immediately [for counselling], that's one thing that any person should get.

A final theme of this stage, which provides a link to the next, is that despite the depression and anger, it is also a time for reflection and thought. As I mentioned the impact of diagnosis upon respondents' attitudes towards life was not always negative. Respondents frequently suggested that they felt diagnosis had given their lives a deeper meaning and a much clearer sense of purpose. Significant similarities existed among their introspective experiences. Individuals ventured that they had become better people; that they felt better; that they realized the importance of friends; and that they knew what they had to do. The mixture of emotions is captured by Gary: 'I know what I'm out here for now, I really do . . . it really helped me a lot, it's just a shame that it took [diagnosis] to knock me upside the head.'

Emergence

For respondents, the process of introspection presages the beginnings of a fourth stage. I have termed this stage 'emergence' because there appears to be an identifiable point at which withdrawal and reflection are assigned lesser roles, and life assumes new meaning, with significant consequences for respondents' daily geographies. Often, the presence of a catalyst for this transition is apparent. For Bill, it was volunteering at an agency helping other people with HIV and AIDS:

> I came down sick first. It takes some time before you finally move beyond that, [but] suddenly you're coping. I don't know, it's like a shell broke or something when I went to do volunteer work . . . all this old stuff fell by the wayside.

This experience can be placed alongside several others, all suggesting an extremely rapid reversal. HIV/AIDS, by necessity, remains important and periodically rises to prominence, but the illness is increasingly absorbed as an additional, albeit problematic, part of daily life. Although descriptions of the changes people had experienced were analogous, exactly when they took place varied considerably. Bill suggested that his period of isolation had lasted for about 3½ years; Ray felt it had taken about 2 years of his life to come to terms with HIV/AIDS; but Carlos' and Gary's withdrawal had been closer to the 12-month mark. Jeff was still dealing with the fact of diagnosis several years after the initial diagnosis.

Regardless of the exact duration of withdrawal, coming to terms with the illness appears to be concurrent with and responsible for a relative increase in levels of activity, and an expansion of the space in which individuals exist. Carlos explained:

> I just decided I was going to get over myself. I said 'I'm not going to die, I've got a life left in me.' After that, I was dying to get out. I was at museums, I was at the supermarket. Wherever there were people, I wanted to be.

Carlos' eagerness to leave the private space of home for more public spaces indicates also a growth in his interpersonal environment. This was generally true among all those who had overcome the initial trauma of diagnosis. Many of the activities people were engaged in (volunteering, attending college, bodybuilding, and so on) involved contact with a variety of different people. At a more personal level, the ability to resolve the psychological trauma of diagnosis suggests that the men are able to *re-inhabit* the space of the body. With emergence, individuals appear to possess the strength of mind to reassess the body, not as an object of fear and loathing, but as an essential part of their being—a space that must be re-inhabited and cared for if they are to successfully cope with the illness.

Despite the relative expansion of people's life worlds, this fourth stage is not without constraint. In all lives, the impetus to maintain a busy schedule (something that appears to be an integral part of emergence) was tempered to some extent by poor physical health and/or a lack of available income. Moreover, the emphasis on psychological recovery during this stage does not imply a complete recovery. Overall improvement may be substantial, but it does not remove the cyclical pattern of highs and lows that overlay daily life. Almost everyone reported variations in their psychological well-being on a fairly regular basis, often centered around issues of dependency, instances of negative social reaction, or concerns about the future. Despite these caveats, the fourth stage is essentially about the re-creation of daily life; about coming to terms with illness, and displacing it from a position of pre-eminence in daily life. Here people's worlds are not diminished, but expanded.

Relapse

The optimistic expansion in daily life achieved in the fourth stage cannot be maintained indefinitely. A fifth stage represents a step back from the progress made in dealing with HIV/AIDS; that is, a relapse. I have less direct evidence of this stage, in part because fewer interviewees had experienced it, but it appears to be characterized by a substantial decline in health, often a result of contracting an opportunistic infection. In such instances, both physical changes and the associated impact upon respondents' confidence may challenge the existing spatial dimensions of daily life. Gary, recovering from a second bout of PCP pneumonia at the time of the interview, said that he had been increasingly reluctant to travel too far from his home, because he was unable to rely on his health: 'I'm afraid to get out there. Like last night, I got caught out, and it was getting dark, and the cold air; the congestion started getting in my lungs so fast I got scared, y'know.' At an interpersonal level, contacts may also be increasingly difficult to maintain due to the reduced level of activity. Gary had stopped attending college in recent months, so that one sphere of his existing social network is, at least temporarily, removed.

Coping with a decline in health may be especially problematic when the deterioration has a noticeable aesthetic impact. In such cases, individuals may be unable to face others, or indeed, to deal with the now visibly-marked spaces of their bodies. Mike provides the clearest example of how visible decline impacted his daily world. Both Kaposi's Sarcoma (KS)[5] and chemotherapy had a serious impact on his physical health and curtailed his activities. Moreover, the purple skin discoloration typical of KS has made it difficult to ignore the presence of illness. This has had a marked effect upon Mike's daily geography; he admits that it has prevented him from leaving the apartment. When asked about his social life, for example, he commented:

> I never went out to gay bars that much, but now I don't go at all. They're very physically oriented; if you're the perfect person they're okay . . . well, I don't feel like the perfect person anymore, at least not outwardly.

Symptoms, particularly when visible, represent direct challenges to the individual's control over the personal space of the body. Bill was attempting to come to terms with such a challenge at the time of the interview. Myopathy has made it difficult for him to walk or leave the house. Aside from these physical constraints, the progression of the illness imposed an identity upon Bill that he is unwilling to assume—that of the invalid or, in his terms, 'cripple'. The growing divergence between Bill's image of his ideal self and the corporeal entity that he must inhabit on a daily bais has done much to lower his spirits in recent months.

Recovery

Although the precise timing may vary, a period of relapse is followed by one of three eventualities: death, permanent hospitalization, or relative recovery. Given my focus upon life with HIV/AIDS in a community setting, I concentrate solely on the advent of a relative recovery. The limited sample size means that this final stage is based for the most part on my informed speculation, but several of the respondents' experiences suggest that recovery from illness will allow the continuation of life within a community setting as well as a relative expansion of daily geographies. Indeed, continuing medical advances may make the cycle of relapse and recovery something that is played out several times prior to permanent hospitalization or death. Over time, of course, the decline in health is likely to become steadily worse, as the peaks of recovery become less pronounced, the troughs of relapse more so. For the person coping with HIV/AIDS, the cycles of relapse and recovery necessitate an ability to *negotiate a deal* with one's body; in other words, to come to terms with the deterioration of the corporeal self.

Among respondents, Gary has already had two bouts of PCP pneumonia, completing one cycle of relapse and recovery. Mike could also be considered to be at the beginning of a recovery, since the discoloration caused by the KS is beginning to clear. In each case, an individual's daily environment tends to expand and contract in tandem with the fluctuations in health. Asked whether he thought his world had diminished in recent months, Bill said simply: 'sure, it's a smaller world, but it'll get bigger again.' Interpersonally, the trends may prove a little more complex. It is possible that interactions remain relatively constant; however, long periods of caring for someone may induce 'emotional burnout' among friends and family who serve as informal caregivers (Adelman, 1989; Wolcott *et al.*, 1986).

Conclusion

> I got a lot of calls from all over the country when I was first diagnosed. Then, as time went by, it slackened off. Then, it got to the point when nobody was calling. It was like they were saying goodbye to me, but what about me? I'm not dead. (Jeff).

This paper has been concerned with understanding what happens to a person's world following HIV diagnosis. During the early stages of the research project, I constantly encountered reports documenting the physical deterioration, emotional trauma, social ostracism and eventual death faced by people with HIV/AIDS. As a result, my initial expectation for the study was that it would serve to illustrate the increasingly problematic nature of day-to-day existence, a central component of which would be the diminishing geographic dimensions of daily life. To a certain extent, this initial expectation was met during the interviews conducted with the nine men who participated in this study. HIV/AIDS clearly had begun to take heavy physical and emotional tolls upon each of them. People that they did and did not know had reacted unpleasantly toward them. News of diagnosis had forced each of them to struggle with the fact of their own mortality. Their lives and life paths had been fundamentally altered by the presence of HIV/AIDS. Yet collectively, these phenomena represent only part of the respondents' experiences with HIV/AIDS. They illustrate the different forms of adversity associated with the illness, but they do not reveal how the men attempt to respond to these challenges, and, in so doing, reinvent the dimensions of their daily lives.

What is perhaps so striking about the experiences of the men in this study is the degree to which they are able to incorporate the cataclysmic health events produced by HIV/AIDS and other negative events associated with the illness without surrendering their sense of control over the structure and spatial dimensions of their day-to-day lives. Clearly, the adjustments required to deal with HIV/AIDS take time. To varying degrees, each of the men has learnt to respond to problems as (and when) they arise and, when necessary, to modify his daily routines accordingly. In some instances, such modifications may be temporary, such as cancelling a planned activity due to lack of physical energy. Other changes may be more permanent, such as accepting a growing dependence on the assistance of others.

During the course of their daily lives, respondents draw upon a variety of resources to cope with the challenges associated with HIV/AIDS. These include not only medical care, but also the material and emotional support provided by the service agencies that constitute a vital part of their formal social network, and the family members and friends who comprise their informal networks. These resources also include respondents' own physical strength and psychological reserve. Among the men, the level of available resources varied, and over time each of them has had to contend with changes in his ability to respond to the illness, some of which have been positive (e.g. learning to deal emotionally with the news of diagnosis or meeting HIV-positive friends), while others have been more detrimental (e.g. dwindling financial resources or the side-effects of medication).

Although the men's experiences differ, it is clear that life with HIV/AIDS is *not* a straightforward process of decline and death. HIV/AIDS remains a terminal condition; its presence continues to imply that death will occur prematurely. Yet to varying degrees, respondents have moved beyond the initial trauma of diagnosis. In so doing, they have found ways to accept the changes that their bodies are experiencing, to acknowledge, or in some cases ignore, the growing uncertainty about the future, to negotiate the shifting dimensions of daily life. At certain times, and in certain places, the impact of HIV/AIDS has overwhelmed each of the men, forcing them to relinquish elements of their daily routines. Yet respondents work to overcome these restrictions on their daily activities, using substitution (e.g. volunteer work to replace paid employment) where possible, and reinvention (i.e. adjusting their routine to accommodate unavoidable change) where necessary. It is true that their worlds have been diminished in certain ways. To some extent, this is inevitable. It is also true, however, that the men spend much of their time living with, and not dying from, HIV/AIDS.

In closing, the methodology and size of this study place obvious constraints upon my ability to speak about people with HIV/AIDS in general, but it nevertheless provides a revealing, and at times surprising, account of several people's experience. The strong similarities and obvious differences that were identified among interviewees may also help to guide future investigation. The most obvious question concerns the extent to which interviewees' experiences compare with the experiences of others. How do these gay men's experiences differ from those of straight men and women, of lesbians, of gay men in other, often less hospitable locations? Although I have warned against sweeping assertions concerning people's ability to deal with the illness, the average heterosexual man may have less experience and less knowledge about HIV/AIDS that his gay counterpart. To what extent will this deficit work to intensify the shock and withdrawal that appear to characterize life immediately following diagnosis? Women's experiences may exhibit both similarities and differences with those presented here. Social sanctions surrounding female sexuality, the relative lack of services oriented to the needs of women with HIV/AIDS, and the generally resource-poor environments confronting poor women of color are just three of the factors that might further problematize daily life.

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Notes

[1] Much of our understanding about dealing with mortality stems from the work of Kübler-Ross on the stages of death and dying (Kübler-Ross, 1969). She has also written specifically about the challenge of dealing with HIV/AIDS (Kübler-Ross, 1987; see also Nuland, 1993).

[2] Myopathy is a condition producing severe pain and inflammation in the individual's thigh and shoulder muscles. It can be produced as a side-effect of some anti-viral medications.

[3] AZT (zidovudine), ddI (didanosine) and ddC (dideoxycytidine) are commonly use anti-viral medications. They are all anti-HIV nucleoside analogues and are presumed to inhibit HIV through termination of the viral DNA chain.

[4] Shanti is a service organization for the terminally ill that was founded in San Francisco and later developed a range of programs specifically for people with HIV/AIDS.

[5] Kaposi's Sarcoma (KS) is the most commonly diagnosed malignancy among people with HIV/AIDS. KS most commonly affects the skin but can also attack lymph nodes, oral cavity and gastointestinal tract.

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