What’s Housing Got to Do with It?

Mindy Thompson Fullilove, MD and Robert E. Fullilove, EdD

Two parallel realities—neighborhoods dying and neighborhoods being reborn—have characterized the AIDS epidemic in the United States. The devastating spread of HIV infection has been felt with equal force in the bluest areas of some of America’s urban centers and in the most sparkling havens of gay culture. AIDS and urban destabilization have spun together over the past twenty years, during a period when civil rights, women’s rights, and gay rights movements have simultaneously experienced invigorating successes and crushing defeats.

Housing Deconstruction

Those living within the American system of poverty have depended on three factors to maintain their tenuous existence. First, the poor depended on the existence of stable housing relatively close to work. Second, they depended on resource exchange within their social network. Simply put, what they could not buy they obtained through borrowing, bartering, or knowing someone who “caught stuff as it fell off the truck.” Finally, they relied on the availability of the unskilled jobs. Such jobs did not pay sufficiently for people to escape poverty, but they did, typically, permit families to eat and survive.

Yet stability is not necessarily part of the “America way.” Our culture celebrates the “new,” the “modern,” and the “young.” Our industry, unhampered by demand to make things that last, actually makes products that will wear out quickly or that can simply be thrown away after a single use. Just as last year’s coat is thrown out in favor of a new model, so houses and even communities are abandoned for “better” places. The ghost towns of the old west stand as bleak monuments to our national wish to move on.

This spirit of disposability—of planned obsolescence—has influenced our urban planning efforts. The Central Ward of Newark, once a bustling, if poor, black ghetto, was razed by bulldozer to make way for “urban renewal.” For twenty years, this so-called “renewal” consisted of acres of rumble-strewn land. Slowly, a medical school, a community college and other official buildings replaced the homes where people had lived. In order to make way for the “new,” a community was destroyed, and its people scattered to the surrounding neighborhoods.

With the destruction of the disposable ghettos and the scattering of their residents, the fragile social networks of the poor were decimated. No longer could Joe borrow a cup of sugar from Sadie next door. No longer could Aunt Millie watch the children from her window. Without the sugar, Joe can’t bake a cake. Without Aunt Millie watching, children are more likely to misbehave.

Concomitantly, automation and mechanization have all but eliminated unskilled jobs; new jobs, created by automation or to serve the information and service sectors of the economy, demand a high level of proficiency in math, reading, and computer skills. Yet inner-city residents are unlikely to have these skills. In fact, most inner-city residents, even those who have graduated from high school, are “functionally illiterate,” that is, unable to read or write beyond the fourth grade level.

Thus, the American system of poverty—depending on stable communities, social networks, and unskilled jobs—has been thrown into disarray. In this context, the incidence of diseases of poverty—syphilis, gonorrhea, and tuberculosis—has grown at frightening rates. Infant and maternal mortality rates rival those of developing countries. HIV disease joins, and synergistically adds to, the ills caused by the collapse of poor neighborhoods.

Housing Reconstruction

The death rattle of neighborhoods presents one part of the recent history of urban areas. The other part of that history has been the discovery that cities of all sizes offer a different way of life from that which exists in the suburbs or the country. People who sought an urban life found that many of the forsaken buildings had charm and character, and that, because they were unwanted, they were cheap. The new urbanities—who were not minority, who were not poor (though not necessarily rich), who were from somewhere else—reclaimed neighborhoods from blight. With freedom, cash, and enthusiasm, the newcomers built communities with bright houses, good coffee shops, well-lit bookstores, and places to meet.

Houses hold the family, link families together, form communities, and are, therefore, the physical structure of survival.

Following the growth of the gay liberation movement, an important facet of urban reconstruction was provided by the development of gay communities. The “gay community” created a new organization of social life for gay men and lesbians. The secretive, closeted networks that had characterized gay life before the Stonewall riot in New York City were reorganized in larger, freer networks, concerned with defining every aspect of daily life from politics to sexuality. These communities reconstructed their physical, social, and psychological environment, creating a powerful, and rapidly evolving lifestyle. There is no doubt that during this time, the redefinition of gay sexuality was accompanied by the rapid dissemination of sexually transmitted diseases, eventually including AIDS. There is also little doubt that the cohesive community that had been able to liberate its sexuality was also able to define a new—and relatively disease-free—eroticism.

The creation of a sense of forward momentum is perhaps the most profound feature of successful reconstruction. Reconstruction, as it recreates the environment, is marked by a series of ventures, from housing to business to social activity. As these succeed, they build a track record of competence, encouraging participants to try even larger and more important undertakings. Conversely, community deconstruction leads rapidly to community immobilization and paralysis. Though social change itself is intimately tied to disease—destabilization resulting from social change can create conditions that facilitate disease—the capacity to respond to illness is linked to a community’s ability to respond to new challenges and new needs. Communities in the process of reconstruction have the forward momentum with which to halt the spread of disease; communities paralyzed by disintegration do not.

Coalition Politics

Coalition is an important political strategy for minority groups because coalition can influence the political will. Coalition

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politics, particularly between gay activist organizations, and the public health and AIDS research communities, have been important to the advances in the fight against AIDS. This coalition is fundamentally challenged by what many have called "the changing face of AIDS," that is, the growing number of minorities, intravenous drug users, children, and women who are ill with HIV disease. Staggering inequalities in education, power, and resources, and differences in language exist to separate the groups. Gay men appear to be organized and to have personal resources. Scientists and public health officials appear to have access to the resources of the research community. People of color appear to have nothing. Yet all of this is, perhaps, illusion.

In major urban areas, the gay community—with as many as half its members infected with AIDS—faces biological destruction unless added resources can help it survive this crisis. Scientists and public health officials fight a constant battle against AIDS discrimination within the health establishment. Communities of color are weakened, but have resources of patience, nurture, and rage that have ensured centuries of survival under oppressive conditions.

What do these disparate groups have in common? They share the urgent commitment to control the spread of HIV, to limit the effects of illness among the infected, to save those who are dying. Despite a history of marked differences that have continued into present, the potential future of these communities is all too similar. For the gay community, a biological bulldozer could wreak devastating havoc equal to forces of destruction that have demolished the inner city. For the health community, it is clear that AIDS is but a symptom of the vulnerability of the human organism. If we cannot unite to limit the spread of disease, then disease—if not this one, then the next one—may eventually engulf the planet.

What's Housing Got to Do with It?

Houses are fundamental representations of civilization. Houses hold the family, link families together, form communities, and are, therefore, the physical structure of survival. The house-by-house destruction of a community is enfeebling; it breeds disease. More importantly, house-by-house destruction can be caused by a bulldozer or a microorganism.

Limiting the spread of AIDS is a house-to-house project. In some neighborhoods, we must rebuild houses and give the homeless shelter. In other neighborhoods, we must visit the sick and make sure the grass is cut. The San Francisco AIDS Foundation suggested that a vacuum cleaner could fight AIDS. Indeed, services that help people maintain their lives in their homes are basic to survival.

Part of what is needed is the recognition of the common elements that bind us all together in our battle against this disease. Coalitions succeed best when their members are focused on what they have in common and learn to accept their differences. Gay men and inner city intravenous drug users ostensibly exist at opposite ends of the human behavioral continuum, but, faced as they both are with a pressing crisis, they must find a common cause. Perhaps it is this house-to-house preservation of our communities that can unite us in the future.

Mindy Thompson Fullilove, MD, and Robert E. Fullilove, EdD—at the HIV Center for Clinical and Behavioral Studies of the N.Y. State Psychiatric Institute and Columbia University—research the excess risk of contracting HIV among Blacks and Latinos in the U.S.

References

To see a slide show on Harlem and the Mazeway Disintegration, please write to the NIMH/NIDA, Anke E. Erhardt, PhD, Principal Investigator.

Request for Submissions and Comments
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Community and Mental Health

The destruction of "community" occurs when a neighborhood is bulldozed to make way for urban development, but it also occurs when people leave families and neighborhoods of origin because of conflict, for example, when parents and friends reject gay children. In both cases, living through this kind of disruptive change has psychological consequences for individuals, as well as sociological consequences for neighborhoods, and the ramifications for individuals may continue long after "community" is restored.

What are the psychological effects of forced migration, of being uprooted from family and community, whether as a result of urban development or emotional conflict? The gay experience serves as one example. Gay men and lesbians may successfully integrate themselves into urban gay life, but they may be less successful in distancing themselves from the responses of those closest to them who reject them and their expressions of sexuality. For gay people who have grown up in a homophobic society, this lack of acceptance—exemplified by the need to hide true feelings from families, colleagues, and neighbors—challenges feelings of self-worth, self-confidence, and community. The constant sense that one is bucking the system by being different, and needing to hide while wanting desperately to "fit in," can lead to psychological, if not behavioral, isolation, substance abuse, and the spread of HIV.

The isolation and fractured social support following the dissolution of communities, whether due to the effects of poor urban planning or homophobia, can indirectly lead to HIV-related risk behaviors. For those without a reference group, a "family" of caring others who provide a context in which an individual can feel supported and valued, alienation can result. Individuals may strive to develop new reference groups and instead find the exquisite loneliness of the crowd, and seek solace in drugs, alcohol, or multiple, fleeting sexual contacts. These experiences, while providing a momentary sense of belonging and being valued, may actually stimulate interpersonal problems as short-term relationships end and result in repeated experiences of abandonment and rejection.

Despite these obstacles, thousands of gay men and lesbians have developed long-term relationships, recreated community, and fostered non-traditional extended families. But it has been their recognition that "community" is crucial as a bulwark against the spread of both physical and emotional disease that has preserved urban reconstruction successes and thousands of lives threatened by HIV disease. In evaluating the significance of community deconstruction, whether it involves people of color or gay men and lesbians, practitioners need to consider direct psychological ramifications as well as sociological, economic, and political ones.

—James W. Dilley, MD, Director, UCSF AIDS Health Project


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References

To see a slide show on Harlem and the Mazeway Disintegration, please write to authors, c/o HIV Center, 722 West 168th Street, New York, New York 10032.

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Studying AIDS in Hidden Populations

Benjamin P. Bowser, PhD

We do not live in an ideal society, but if we did, government would take an active role in educating people about HIV infection, and the public would respond by ceasing high-risk activities, and there would be a clear understanding of who was at greatest risk for infection and how to effectively reach and educate these subpopulations. "Ideal" is not too far from the condition necessary to conduct survey research that will result in representative and valid population samples. For such sampling, populations of interest must be clearly defined, fully accessible, and accurately enumerated. For a brief time in the 1920s and 1930s, when survey methods were being developed in the United States, society seemed to look like this. We were a nation of small towns where it was thought that everyone belonged to a nuclear family. Households and families were one-in-the-same, and each had an address. The basic conditions for getting a random, and presumably, representative sample still existed for household-based populations and social groups with definite memberships. But increasingly, critical subpopulations are neither well-defined, accessible, nor self-identified.

Of course, we do not live in an ideal society. The American small towns, the "Yankee Cities" and "Middletowns," have been transformed into the central cities, suburbs, and distant suburbs of large metropolitan areas. We live in a mass society which is united primarily in its public institutions—our educational and political systems—and the mass media. The movement toward a mass society is paralleled by fragmentation in our private lives in which our closest relationships are not only defined by the older divisions of race, class, gender, but also by the new dimensions of generational cohorts, sexual orientation, political consciousness, and occupational and professional identities. In the real society, information at the official and public levels does not automatically pass into the many rapidly changing and increasing private worlds that now make up this nation.

AIDS and Private Lives

We define people who are at a risk of being infected with HIV by their public identities—they are gays or bisexuals, intravenous drug users, and now possibly crack and cocaine users and dealers. Yet, for many it is their private behaviors, often not reflected in their self-selected public identities, that put them at risk for HIV infection. For example, there are men who view themselves as heterosexuals, but who engage in occasional sex with men. There are Latino and Asian homosexuals who are "closeted" because of extreme homophobia in their own cultural communities and therefore not accessible. Thus, if AIDS prevention messages are effective, they will have to be received by those whose private risks are masked by their public identities.

When we look more closely at private behaviors, it is erroneous to view all gays, bisexuals, injection drug users, and crack users as having the same risk of becoming infected with HIV. There are people within these groups who do practice safer sex and who properly clean their needles. There are injection drug users who are successful in the "straight" world and who do not associate with or see themselves as drug addicts. Among these people, there are those who have taken AIDS prevention messages to heart and who practice safer sex and injection techniques. There are also those, however, who have heard the message and still take extraordinary risks of being infected with the AIDS virus. What do we call these hidden populations and how do we gain access to them?

Defining Hidden Populations

In real society, high-risk-takers, both within and outside of statistical high-risk groups, have several things in common. First, they are neither clearly defined nor do they necessarily define themselves as risk-takers. Since we can neither conveniently enumerate nor find them, we cannot directly sample them according to ideal survey conventions. Second, all of these groups, regardless of their AIDS risk, are negatively viewed by the general public. With the exception of self-identified gay and bisexual men, all of these men and women are underground and live in hidden and private worlds. Third, risk for HIV infection may not have the same salience to groups of people whose private lives are filled with other, more immediate risks—being shot, beaten, or made destitute. And, finally, we have yet to define and study the circumstances and potential for effective AIDS prevention among people whose ability to take precautions against HIV infection may be subject to someone else's control: women, known as "toss-ups," who exchange sex for crack in crack houses, prostitutes who accept money or drugs for sex, and others who are sexually abused.

These private worlds, which are hard to define and access, do not represent new conditions. Among Afro-Americans, W.E.B. Du Bois wrote of "roving men and women" and of "worthless" individuals in Philadelphia's Seventh Ward in 1898. E. Franklin Frazier wrote about the circumstance of "Negro" migrants from the South as they entered "Cities of Destruction" in the 1930s. Terry Williams revisits these issues today.  

What is new is that those populations exist in large numbers, are ever more permanent, and are experiencing a profound separation from conventional society. HIV has clustered in pockets within these hidden worlds. What is crucial is that, as evident in a basic tenet of epidemiology, we are not completely and effectively separated from each other by class, race, and locational barriers. Thus HIV threatens not only the high-risk takers within hidden communities, but ultimately everyone else in American society, medically, ethically, and economically.

The Research Challenge

The ability to reach hidden high-risk populations is often compromised by the limits of conventional research methodologies and the related necessity to get projects funded. The threat posed by HIV, however, mandates that we refuse to compromise. It is necessary to develop and test new research strategies that are more attuned to the complexities and diversity of current communities, to both their public identities and hidden populations.

Hidden populations have to be accessed by convenience samples, "snowball" techniques, and systematic social network referrals. The MIRA "Crack Users Survey" was enhanced by focus groups of teen crack users who shared their knowledge and provided culturally appropriate terminology. The use of community outreach workers and service providers who are trusted members of the "hidden" populations is very important. A key to quality research within the hard-to-access populations is employing the people who already have access and acceptance. They can then be trained as interviewers. Finally, participant observation and other ethnographic techniques are also critical tools not simply for generating insight for survey questions, but as always to understand the social context of hidden AIDS risk behaviors. Ultimately, the AIDS prevention message may have to enter hidden worlds in the same way researchers do, through unorthodox strategies and trusted intermediaries.

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References

Response of Community Organizations to AIDS. Hunter College (AIDS Education and Prevention, Winter 1989).

A study of 28 community organizations in a primarily minority neighborhood in New York City found that more than half had undertaken AIDS activities in their work, 44 percent planned future AIDS programs, and 30 percent had no plans to do AIDS work.

Researchers collected data during interviews with 28 leaders or activists representing organizations—including advocacy groups, multi-service agencies, educational institutions, and church groups—based in a neighborhood whose population of 54 percent Latino and 17 percent Black residents had a disproportionately high incidence of HIV infection. Over the past two years, 76 percent of the organizations had addressed issues related to drug use and 72 percent had worked on issues related to sexuality, teenage pregnancy, or family planning.

Groups likely to be involved in HIV-related work were those that had "multiple missions," and those that had experience with either drug use issues or sexuality issues. Organizations that were actively involved in AIDS work were much more likely to serve a large constituency of Black people. Leaders of organizations not involved in AIDS prevention work cited a lack of financial resources, space, and personnel needed for such work, the demands of their existing missions, and political opposition.

The authors conclude that many community-based organizations, often with little outside help, have undertaken some AIDS-related activities, and that in Black and Latino communities, AIDS is only one of many community stresses and so must be integrated into broader community goals.


Black Americans do not have the same level of access to health care as Whites, and when Blacks do gain access, they are less likely than Whites to receive certain surgical and other therapies. In a review of studies for a variety of illnesses, Blacks had differing and often greater health care needs than Whites.

One survey showed that Black men with heart attacks were only half as likely to receive angiography (radiographic representation of the heart's blood vessels) and only one-third as likely to undergo bypass surgery as their White counterparts. Another study showed that doctors recommended surgery more often for White than for Black patients, and that among those for whom surgery was recommended, White patients were more likely to have the surgery performed.

A survey of patients with end-stage kidney disease found that patients treated at institutions located in high-income areas and serving predominantly White populations were almost twice as likely to receive transplants as patients treated at institutions located in low-income areas and serving Black populations. In a telephone survey, Black subjects were more likely than White subjects to respond that their physicians did not inquire sufficiently about pain, did not tell them how long it would take medication to work, and did not discuss test and examination results.

The Council on Ethical and Judicial Affairs suggests that income, education, socioeconomic differences, and subconscious bias account for disparities. To respond to racial disparities, they recommend: insurance reform nationwide to improve access to health care; exploration of racial issues by physicians and the medical profession to foster awareness of the issues involved; and development of practice parameters by professional associations.

Effectiveness of Low-Dose ZDV. Reports of two studies: University of Washington School of Medicine, University of California San Diego School of Medicine, University of Southern California School of Medicine, Harvard Medical School, National Institute of Allergy and Infectious Diseases, and the Research Triangle Institute; and the National Institute for Allergy and Infectious Diseases AIDS Clinical Trials Group, including 32 research institutions. (The New England Journal of Medicine, October 11, 1990).

Two important studies have confirmed earlier data that lower doses of zidovudine (ZDV; AZT) are as effective and less toxic than higher doses that were originally recommended. In the first report, a pilot study, a daily dose as low as 300 milligrams was as effective as doses of 600 milligrams and 1,500 milligrams.

This study included 67 subjects with ARC, all of whom had T-helper cell counts between 200 and 500 at the beginning of treatment. Twenty-eight received 300 milligrams, 24 received 600 milligrams, and 15 received 1,500 milligrams. The study ran for 12 weeks, and was followed by an elective extension period. About half the subjects in each group also received acyclovir. The subjects, almost all of whom were gay men, had a mean age of 36.

Individuals who received the lowest dose of ZDV reported the greatest increase in T-helper cell levels and the greatest weight gain. The proportion of subjects whose antigen or plasma virus levels declined and the median decrease in antigen levels were similar at all three doses, and of seven subjects who developed AIDS, an equal proportion came from each of the three groups. Toxicity was most common in the highest dose group.

In the second study, two groups of 262 subjects (with histories of Pneumocystis carinii pneumonia) each received either 1.5, 500 milligrams or 600 milligrams of ZDV daily. Thirty-four percent of the subjects receiving the lower dose and 27 percent receiving the higher dose survived two years into the study (a statistically significant difference). Toxicity, including anemia and low white cell count, was significantly lower in the 600 milligram group.

Next Month

The World Health Organization acknowledged the rapidly increasing proportion of women with HIV by designating as the theme of World AIDS Day (December 1), Women and AIDS. In the December issue of FOCUS, Denice J.D. Benson, MFCC, at the AIDS Health Project, and Catherine Maier, PhD cand., at the San Francisco AIDS Foundation, examine the psychosocial issues of women with HIV disease. Acknowledging the varying situations women face, they highlight those women living in areas of high HIV prevalence where incidence among women is relatively low.

Also in the December issue, Helen Schietinger, RN, MFCC, of the World Health Organization in Geneva, examines the epidemiology of AIDS among women worldwide and the specific concerns of some of these populations.