

AIDS in Rural America: Research and Educational Issues

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Estimates of the incidence rate of HIV/AIDS indicate that the number of AIDS cases is continuing to grow (CDC, 1990). Currently, 1 million persons are infected with HIV and it is predicted that during 1990 the number of newly diagnosed AIDS cases will be 52,000-57,000. This count is expected to continue increasing to 61,000-98,000 AIDS cases during 1993.

As the number of AIDS cases continues to rise, the disease is beginning to appear in rural areas of the country (Young, BA; 1988). As of January 1990, there was a total of 117,781 cases of AIDS; 17,512 cases were in non-metropolitan areas (CDC, 1990). Recent evidence shows that there was a 31% increase in diagnosed AIDS cases in areas with populations under 100,000 (CDC, 1990). AIDS is no longer a disease isolated to the urban epicenters, e.g., New York, Los Angeles, and San Francisco.

This analysis attempts to identify the implications of the growing AIDS caseloads in rural areas. It attempts to serve as an overview of the increasing AIDS problem in rural America. Theories on the growing number of rural AIDS cases will be presented. Second, obstacles to adequate patient care will be discussed. Finally, important research and educational issues as a result of the rural AIDS caseload will be introduced.

AIDS cases increasing in rural areas

Along with the 31% increase in diagnosed cases of AIDS in cities with populations under 100,000, there have been other increases in areas outside major cities. Table 1 indicates that areas outside large population centers have seen the greatest increases in diagnosed cases of AIDS (CDC, 1990).

There are several possible explanations for the rising number of AIDS cases in the rural areas of the country. One such explanation is what has been labeled the "Return of the Native" theory (Verghese, Berk, and Sarubbi, 1989). This theory postulates that patients identified as HIV+ in a rural Tennessee community had been made aware of their HIV status in an urban epicenter. The typical patients seen by this Tennessee practice were homosexual white men who had moved away from their homes for social or economic opportunities that a city could provide. Furthermore, the HIV infection, when determinable, was contracted in the urban area. These patients, upon recognizing the seriousness of their disease, returned to their homes. Fortunately, in most cases the family and community provided essential support to the patient throughout the disease. This is a tendency that was not predicted, given rural Southern attitudes.

A second explanation for the increasing rural AIDS caseloads relates to risk behavior in homosexual men. The increasing rate of HIV infection among homosexual men has started to slow in New York, San Francisco, and Los Angeles (CDC, 1990). These populations have witnessed the effects of HIV/AIDS for some time. They have also had access to prevention programs, e.g., programs that attempt to change high-risk sexual behaviors of homosexual men which are efficient means of transmitting the virus, such as unprotected anal intercourse.

Recent evidence indicates that homosexual men in rural areas are not changing their sexual practices. One study focused on the sexual practices of homosexual men, comparing high AIDS prevalence areas with low AIDS prevalence areas (St. Lawrence, et al., 1989). The results, summarized in Table 2, indicate that men in high AIDS prevalence areas were more likely to participate in low-risk behaviors and had unprotected anal intercourse less frequently than homosexual men in smaller cities. Furthermore, the most common sexual practice among homosexual men in low AIDS prevalence areas was anal intercourse without a condom.

A second study found similar results (Kelly, et al., 1990). This analysis focused on homosexual men in small Southern cities with a low prevalence of AIDS. Twenty-five percent of the respondents to the questionnaire had unprotected anal intercourse as the insertive partner within the last two months; another 23% had been the receptive partner. Thirty-five percent had been the insertive partner in unprotected oral intercourse where fluid was exchanged, while 29% had been the receptive partner. These behaviors are greater than those reported for homosexual men in some of the large AIDS epicenters.

While these behaviors influence the number of AIDS cases in these areas, no conclusive studies have been carried out linking these particular behaviors with the number of AIDS cases in the area. That is to say, it is not known if the men in these particular studies are actually responsible, either directly or indirectly, for the AIDS cases in the surrounding rural community.

AIDS is also transmitted through high-risk behaviors associated with intravenous drug use. AIDS cases associated with heterosexual IV drug use have continued to increase over the past year (CDC, 1990). While no specific information is available about the rates of IV drug use in rural areas, drug abuse does exist and is responsible for AIDS cases in various rural areas.

In 1988, the CDC broke down AIDS cases into urban (Metropolitan Statistical Areas) and rural cases (Young, BA; 1988). When looking at the modes of transmission in these two groups the rural data provided interesting results (see Table 3). According to the data, heterosexual IV drug abusers made up a greater percentage of the AIDS cases in rural areas than in urban areas.

A recent analysis of AIDS case trends in Georgia found similar results (Starrberg, 1990). The number of cases in Georgia has tripled in the last three years. During 1989, the incidence of AIDS cases in rural areas and small cities was equal to the incidence rate in Atlanta. Health officials of the state indicate that "the 'significant epidemic' now emerging in central and southeastern Georgia is being fueled primarily by drug abuse and heterosexual transmission of the virus from male drug abusers to their female sexual partners." (Starrberg, 1990)

Perhaps the most recent study focusing on IV drug users is being carried out in Arizona, by the Southwest Border Rural Health Research Center. Their three-year study is examining the behaviors,

attitudes, and practices of local, Hispanic IV drug users and the effectiveness of specified HIV risk reduction interventions (Erickson and Estrada, 1990). Initial analysis has focused on obtaining the current level of knowledge, IV drug habits, and sexual practices of the identified sample. The initial results indicate that the sample had adequate knowledge of high-risk drug and sexual practices. However, that knowledge did not encourage low-risk behavior. For example, the sample respondents, when they did clean their needles, tended to use only water. They had multiple sex partners and condom use was infrequent (Erickson and Estrada, 1990).

While AIDS is a growing problem in the traditional risk groups found in rural areas, i.e., homosexual men and IV drug users, other groups limited to rural areas are experiencing the AIDS epidemic as well. Migrant and seasonal farmworkers are becoming infected with the virus. One of the first seroprevalence studies completed using a migrant population collected 426 blood samples. Out of those blood samples, 11 (2.6%) were HIV+. According to the results, the prevalence rates for Black migrant and seasonal farmers were fairly high for this one clinic in North Carolina, but nonetheless consistent with other reports focusing on racial and ethnic differences in those who are at risk of getting AIDS (CDC, 1988).

A very important factor in this group of rural individuals with AIDS is their knowledge about the disease and their overall health status. While no specific evidence is available quantifying the AIDS risk knowledge, attitudes and behaviors of these special populations, there has been some information focusing on the prevalence of, and level of knowledge about, sexually transmitted diseases (STDs). The prevalence of STDs is high in migrant farmworkers.

The high prevalence of STDs in migrant farmworkers usually is attributed to inadequate health knowledge, poor accessibility to health care, mobile life style, limited case finding follow-up due to rapid mobility, the asymptomatic period of syphilis and gonorrhea during which the infection may unknowingly be transmitted to others, lack of condoms when needed, language barriers with health care personnel, and variation among ethnic populations in definitions and myths of health and illness (Smith, 1988).

These same characteristics will also influence the incidence rate of AIDS in this population.

A final reason for the increasing rates of AIDS in rural areas is associated with the changing course of the disease. AIDS was, at one time, immediately life-threatening. Over the years of the epidemic, new treatments have been developed which are being used effectively for both opportunistic infections and the HIV (Smith, 1990). AIDS is becoming a chronic disease and is being treated as such. In order to keep the costs associated with AIDS care to a minimum while maintaining an adequate level of care for the varying needs of these patients, a continuum of care combining outpatient, inpatient, and home care is being developed in parts of the country (Smith, 1990). Tertiary care centers are no longer the only place to receive treatment, so patients will increasingly rely on community resources, including rural resources.

Obstacles to AIDS treatment in rural areas

The number of AIDS cases in rural areas is growing and will continue to do so. However, the growth in available health care for people with AIDS in rural areas is not growing at a parallel rate. In fact, despite the increasing availability of services to treat AIDS patients, these treatments do not always find their way into the rural community.

First, access to rural health services, in general, is decreasing. Findings from the Joint Task Force of the National Association of Community Health Centers and the National Rural Health Association indicate that public funding for rural health care compares unfavorably to urban and suburban areas. Farm closures, unemployment, loss of insurance, and inability to pay for health services are straining persons living in rural areas. Rural hospitals are closing, while physicians and nurses are in short supply (NACHC & NRHA, 1989).

AIDS is taxing the health care system to the extent that rural area health care services, which are already strained, may not be able to meet the needs of AIDS patients. According to the NACHC and NRHA report, "Very little has been said concerning rural responses to AIDS patients, and few rural areas possess the coordinated patient care system necessary to meet this challenge. Fewer still have the resources to actually create such a local system." (NACHC & NRHA, 1989)

Second is the lack of personnel available to care for AIDS patients. This is a problem that is not unique to rural areas. There are many possible reasons for personnel not wanting to care for AIDS patients. Information overload, inadequate reimbursement, fear of infection, fear of loss of other patients, institutional pressure, burnout, dislike of homosexuals, and dislike of drug users are all possible reasons why physicians may not provide compassionate, nonjudgmental care for patients with AIDS (Smith, 1990).

Coupling the inadequacies of the rural health care system with the lack of devoted personnel caring for AIDS patients leads to a bleak picture regarding the AIDS patient's ability to receive treatment. However, rural physicians may feel a greater responsibility to care for persons with AIDS than their urban counterparts. When physician attitudes about AIDS are broken down into MSA vs. non-MSA there is a slight difference (Rizzo, Marder, and Willke, 1990). Table 4 indicates that 76.5% of physicians in non-MSAs agree that physicians are obligated to treat HIV patients, while 72.6% and 74.1% of the physicians in MSAs with populations over 1 million and under 1 million, respectively, feel the same way. Unfortunately, only 35% of the physicians in non-MSAs have treated an HIV+ patient (Rizzo, Marder, and Willke, 1990).

Finally, there are several characteristics of rural communities themselves that may affect the treatment of AIDS patients. Kathleen Rounds focuses on structural factors, like the lack of services and the geographic isolation of some patients, and the confidentiality issue (Rounds, 1988). There is a fear within any community, including a rural community, to disclose a seropositive HIV status, largely because of the environment of the rural community. According to Kathleen Rounds, "Fear, intolerance, and stigma are not problems unique to rural areas. However, given the lack of confidentiality and the homogeneous nature of most rural communities, these attitudes are much more pronounced and their impact more strongly felt (Rounds, 1988)." In addition, Nieto summarized eight different characteristics of a rural community; all of which have an affect on the treatment of HIV/AIDS in a community. They are:

1. large and highly interactive nuclear and extended family configurations;
 2. concern about family privacy, honor, morality, and moral standing in the eyes of others;
 3. narrowly defined *declared* values and norms;
 4. efficient informal community information networks;
 5. self-sufficiency, self-reliance, and resourcefulness as values;
 6. suspicion of "outsiders";
 7. intolerance of "deviant" sexual orientations and practices; and
 8. a sense of invulnerability relative to urban or "big city" problems.
- (Nieto, 1989)

These characteristics help form the attitudes rural individuals have regarding AIDS.

Unfortunately, the attitudes and knowledge about AIDS in the rural community are not the same as national attitudes and knowledge. A recent analysis of attitudes and knowledge about AIDS and homosexuality was carried out in Kentucky (Dhooper and Royse, 1989). The results found the respondents less knowledgeable about AIDS and less tolerant of AIDS victims and homosexuality than respondents to two other national polls.

The characteristics and attitudes of rural communities make it difficult for patients to gain the adequate support needed to combat the psychosocial consequences of the disease. The necessary social support networks that have been created in response to AIDS in the urban areas of the country are not found in the rural setting. Rural AIDS patients and homosexuals are forced to rely on the existing support networks they have in their communities, because there is not a large, visible homosexual community to depend on, and because the mental health professionals who help these individuals may not have an adequate understanding of issues encompassing homosexuality (D'Augelli and Hart, 1987). Unfortunately, this existing network may not be able to cope with AIDS or homosexuality. For example, a homosexual man, living in a rural community where his primary support network is heterosexual, may be afraid to reveal his HIV status and his sexual orientation because that network may exclude him at a time when support is most needed.

Improving the obstacles to patient care

So far this analysis has focused on the growing problem of AIDS in the rural setting and the characteristics of the rural health system which fail to provide the necessary AIDS services. However, there are important ways to help reduce the risk of certain populations becoming infected. Education is currently the only means of preventing HIV infection. Obviously, educational efforts should not be limited to large metropolitan areas. In fact, heterosexual IV drug users, homosexual men, and migrant workers found in rural areas should receive culturally appropriate education.

Before educational efforts can be entirely effective it is necessary to specifically identify why these rural communities are being affected by the AIDS virus. In other words, what factors are causing these groups to be susceptible to HIV infection? Homosexual men in rural areas currently make up a smaller proportion of the rural AIDS caseload, when compared to their urban counterparts. Given this pattern of distribution, rural homosexual men may perceive themselves as being at lower risk for infection. In light of this, is this a contributing factor to homosexual men less consistently practicing safe sex? And if so, how can this be counteracted? So far, the disease has not affected the rural homosexual community to the extent that the urban homosexual community has been affected, but given the persistence of high-risk behaviors, AIDS poses a serious threat to the rural homosexual population. Attempts need to be made at determining the extent of this threat.

Rural IV drug users are also important to think about when considering interventions targeted at reducing the prevalence of AIDS. Why is this transmission route greater in rural areas than urban areas? Perhaps urban IV drug users are receiving adequate education to help prevent the spread of HIV infection. IV drug treatment centers and community health centers may not be available for rural IV drug users. Finally, questions regarding rural drug use are: how pervasive is drug use in rural areas and why?

Finally, the migrant population needs to be studied. An assessment of AIDS attitudes and knowledge of migrant farmworkers needs to be carried out. While some evidence exists about the knowledge of STDs in this community, there is no comparable evidence regarding AIDS. In addition,

information regarding sexual activity and IV drug use would assist in understanding the current high-risk behaviors in which this population might participate. Once knowledge, behaviors and attitudes have been assessed, specific educational designs can be implemented to reduce the potential increase of AIDS cases in migrant communities.

Other issues may influence the pattern of AIDS in rural areas. For example, rural and urban prisons may affect a community's overall AIDS caseload. Do HIV-infected prisoners, once released, return to rural areas and have they received adequate education regarding HIV transmission? What is the prevalence of HIV infection in rural prisons, and how does this affect community attitudes about AIDS? Is it possible that teenagers run away from rural communities to urban areas where they may find themselves involved with drug and/or prostitution rings, and eventually return with the HIV virus?

Efforts at preventing HIV, do not, however, address the problem of care for patients already infected with the AIDS virus. Some of the obstacles mentioned above are a compilation of problems associated with the overall delivery of health services in rural areas. These obstacles will only be eliminated through improvements in rural health services. However, there are some important ways to bridge the health care gap for patients with AIDS in rural areas and improve the care they receive.

Health care professionals, particularly physicians and nurses, should not only receive education about AIDS, but should be informed about the special populations affected by AIDS. Because the percentage of overall AIDS cases in rural communities remains small in comparison to urban areas, the demand for services is not as great as in the urban epicenters where the AIDS epidemic is prevalent. Furthermore, there is no feasible way to develop the type of services that are found in urban centers. Educating rural health professionals about the specific needs of AIDS patients fills in a portion of the gap between rural and urban treatment.

Educating health care professionals also improves the attitudes these professionals have regarding AIDS and this, in turn, may influence the attitudes of the community. Educating rural nurses about AIDS and homosexuality has been successful. A recent workshop held for rural nurses resulted in

an increase in positive attitudes about AIDS and homosexuality, as well as a decrease in the level of fear of caring for AIDS patients (Young, Koch, Preston, 1989). Such workshops should also address IV drug users and migrant farm workers, and should be given to other health care personnel, like doctors and other allied health care professionals.

Services to rural AIDS patients can be enhanced in other ways. Coordinating services through case management is one way to improve the delivery of care to patients in rural areas. Case management attempts to identify health care needs and match those needs with services that can be supplied in the community, thus increasing the time the patient remains in the community (Mor, Piette, Fleishman, 1989).

Utilizing existing rural support structures for persons with AIDS (PWAs) and their families is an appropriate and logical next step. However, the attitudes that some communities have regarding AIDS and deviant behavior must be improved. The rural PWA may be categorized as being morally reprehensible and in clear violation of family and community norms (Nieto, 1989). Religious institutions and informal informational networks are important in the formulation of attitudes and values within the rural community (Rounds, 1988). Because of their importance in the rural community, these institutions may serve as a route through which education about AIDS can promote some attitudinal changes.

AIDS has started to affect the rural communities across the country, and people in rural areas with HIV/AIDS have the same health care needs as those in the urban epicenters of the AIDS epidemic. Unfortunately, this population is easily overlooked, because it is not as visible and may even be denied in certain rural communities. Implementing sound HIV/AIDS education, prevention programs, and policies will enable rural areas of the country to prepare for and/or prevent the problems of an increasing AIDS caseload, including service delivery problems.

This analysis has identified key issues that need further analysis. So far, some important issues have been specified that can help policymakers understand the implications of the increasing

rural AIDS caseload. However, it is essential to clarify some of the more uncertain issues presented. This, in turn, can improve the specificity with which rural AIDS policy is designed.

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Table 1

Population characteristics of reported AIDS cases with percent change in cases by year of report and year of diagnosis - United States, 1988 and 1989

| | 1989 Cases | 1988 Cases | % Change | |
|---|------------|------------|----------------|-----------------|
| | | | Reported Cases | Diagnosed Cases |
| Population size of metropolitan area | | | | |
| < 100,000 | 2,799 | 2,067 | 35% | 31% |
| 100,000-499,999 | 3,758 | 2,853 | 32% | 39% |
| 500,000-999,999 | 3,958 | 3,661 | 8% | 29% |
| >1,000,000 | 24,713 | 23,615 | 5% | 8% |

Source: CDC, *JAMA*, March 2, 1990, p. 1191.

Table 2

Percent distribution of sexual activities practiced by 290 gay men in 2-month period in high- and low-prevalence areas

| Activity | High-Prevalence Area (%) | Low-Prevalence Area (%) |
|-----------------------------------|--------------------------|-------------------------|
| Anal intercourse without a condom | 13.0 | 35.4 |
| Oral intercourse without a condom | 11.4 | 19.7 |
| Oral-anal contact | 14.6 | 8.7 |
| Mutual masturbation, no insertion | 38.2 | 15.0 |
| Body rubbing, no insertion | 13.0 | 7.0 |
| Anal intercourse, condom used | 9.8 | 14.2 |

Source: St. Lawrence, et al., *Public Health Reports*, July/August 1989, p. 394.

Table 3

Percent distribution of transmission modes in urban and rural areas

| Mode of Transmission | Urban (%) | Rural (%) |
|--------------------------|-----------|-----------|
| Homosexual-Bisexual Male | 64.7 | 47.1 |
| IVDA Heterosexual | 18.0 | 25.9 |
| IVDA Homosexual | 7.2 | 9.6 |
| Adult Hemophiliac | .8 | 2.7 |
| Heterosexual Contact | 4.1 | 4.0 |
| Adult Transfusion | 2.2 | 5.9 |
| Adult Undetermined | 3.0 | 4.7 |

Source: Young BA, *Healthcare Forum Journal*, July/August 1988, p. 12.

Table 4

Physician attitudes toward treating HIV-seropositive patients by area size, 1988

| | Number of Physicians | Agree (%) | Disagree (%) | Not sure (%) |
|-----------------|----------------------|-----------|--------------|--------------|
| Area size | | | | |
| SMA, >1 million | 1,400 | 72.6 | 21.8 | 5.6 |
| SMA, <1 million | 1,010 | 74.1 | 20.5 | 5.4 |
| Non-SMA | 474 | 76.5 | 18.2 | 5.4 |

Source: Rizzo, et al., *Medical Care*, Vol. 28, No. 3, p. 256.