

**HIV/AIDS IN THE RURAL UNITED STATES:
EPIDEMIOLOGY AND HEALTH SERVICES DELIVERY**

by

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ABSTRACT

Objective: This integrated research review addresses two major literature domains: i.) epidemiology of rural Human Immunodeficiency Virus/Acquired Immune Deficiency Syndrome (HIV/AIDS) and ii.) organization, financing and delivery of health services for rural HIV/AIDS patients.

Data Sources: The abstracting, indexing services, and bibliographies searched were as follows: AIDSLINE, CINAHL, HEALTH, Index to Health Information, RICHS, National Directory of AIDS Care, the AIDS Information Sourcebook, the AIDS Bibliography Series.

Study Selection: An assessment of the rigor of each literature piece was based upon a scoring of research design, sample design, measurement and statistical analyses.

Data Extraction: The quality of the literature was reflected in a score indicating the scientific rigor of each investigation. An annotation form served as the guideline for data extraction. The form was used by multiple raters and called for independent observations.

Data Synthesis and Conclusions: Overall, these literatures are very young. However, certain important implications arise from our review. Epidemiological evidence indicates that there has been a dramatic increase in the relative proportion of rural HIV/AIDS incident cases over the past five years. Explanations of the rural increase focus on injection drug use, heterosexual behavior, and sexually transmitted disease levels. Dramatically elevated rates of infection in rural black women are indicated. Rural areas experience a higher level of in-migration than out-migration of HIV/AIDS infected individuals. The health services literature suggests: i.) rural providers and institutions have limited resources and little experience with

HIV/AIDS patients, and ii.) a few states and rural communities have developed AIDS networks and integrated case management systems.

INTRODUCTION

HIV infected individuals in rural areas face many of the same problems in access to health services that other rural residents do. Furthermore, the unique nature of this infection compounds them. Difficulty in rural health services delivery arise from fundamental issues of demand and supply, fragile economic infrastructure and underinsurance. Rural areas are also characterized by high percentages of Blacks, Native Americans and impoverished who require relatively high levels of care complicated by geographic barriers. The availability of health care facilities and personnel for rural residents is also significant.

Most of the vast literature on HIV (Human Immunodeficiency Virus) and AIDS (Acquired Immunodeficiency Syndrome) has focused on metropolitan epicenters where the majority of cases has occurred. Yet even in the early years, when it was viewed as a big-city phenomenon, there was never a scientific foundation for believing the epidemic would bypass rural America. A small number of investigators recognized this and their findings have been accumulating since the late 1980s.

Now, with HIV/AIDS cases increasing at a faster rate in rural areas than large urban ones, we provide a comprehensive and critical review of this immature but growing literature. We concentrate on the epidemiology of rural HIV/AIDS and the availability and adequacy of health services for rural patients.

METHOD OF REVIEW

Several abstracting, indexing services and bibliographies were searched for relevant articles. Specifically, AIDSLINE, CINAHL, HEALTH, Index to Health Information, RICHHS, National Directory of AIDS Care, the AIDS Information Sourcebook and the AIDS Bibliography Series supported the identification of literature.

We located 70 articles assessing the quality of research design, sample design, measurement and statistical analysis of each. Many were review articles. Within the analysis and interpretation stage, the literature was described and evaluated.

THE EPIDEMIOLOGY OF RURAL HIV/AIDS

The AIDS virus has established itself within rural populations. While rural AIDS incidence is still low compared to urban, it has been rising considerably faster since 1988-89 ¹. From 1991 to 1992, non-metropolitan AIDS cases increased 9.4 percent, while cases in metropolitan statistical areas (MSA) of 50,000 to 500,000 increased 3.3 percent, and cases in MSA's above 500,000 increased 3.1 percent ². Rural HIV/AIDS is distributed unevenly, with 30 percent of cases concentrated in the South Atlantic states ³. Rural HIV/AIDS rates are particularly high among black women, adolescents, Native Americans and migrant workers. Rural HIV/AIDS patients are more likely to be female, heterosexual, non-white and young ^{4,5}.

Intravenous drug use and heterosexual contact are emerging as important modes of transmission. Individuals infected in urban locales who migrate to rural areas account for a substantial number of local cases.

Incidence and Prevalence of Infection:

While growing proportions of HIV and AIDS cases are documented outside large cities, the original epicenters, the numbers are still small⁶. Rural HIV seroprevalence rates reported a range from 0.05 to 5.0 per 100,000³. U.S. urban rates are 10.0 per 100,000 for metropolitan areas of 50,000 to 500,000, and 25.8 per 100,000 for areas larger than 500,000³.

In California, general population surveillance found that HIV seroprevalence in rural counties nearly doubled between 1988 and 1991, rising to 5.0 per 100,000 from 2.6 per 100,000⁴. Various studies have found particularly high HIV/AIDS rates among rural women, homosexuals, and adolescents.

Rural Women:

Adult and adolescent women represent a growing proportion of HIV/AIDS cases in both urban and rural communities of the United States^{7,8}.

Like urbanites, most rural women with HIV/AIDS are black. Nationally, 72 percent of women diagnosed with AIDS from 1986 to 1990 were black or Hispanic⁷. In Georgia, the proportions of black women with HIV/AIDS were 76 percent in metropolitan Atlanta and 74 percent elsewhere⁵. California surveillance from 1988 to 1991 revealed an HIV seroprevalence rate of 43.4 per 10,000 among rural blacks of childbearing age, compared to 5.63 per 10,000 for Hispanic and 4.7 per 10,000 for white women⁴. In several studies of Florida prenatal clinics, 8.3 percent of non-Haitian black women were determined to be HIV seropositive^{9,10,11}. Even after controlling for IV- drug use, infection rates for rural black women have been reported at levels 20 times higher than for white women⁵. Tests for maternal HIV antibodies in 1.6 million newborns in 1989 found that black women had infection rates up to 35 times higher than white

women in nine urban and rural states ^{12, 9, 11, 8}.

High rates have been reported for Native American women too. Samples from 58 Indian Health Service clinics in several Western states revealed HIV seroprevalence of 11 per 10,000, a rate four to eight times higher than that for all women in the same states. (Socio-economic status may be a confounding factor). Unlike general rural urban population comparisons, rural American Indian and Native Alaska females have HIV infection rates comparable to their urban counterparts ¹³.

Homosexual/Bisexual Males:

Examination of the distribution of AIDS among homosexual/bisexual men in the United States demonstrates that AIDS incidence has risen since identification of the first cases ¹⁴. The greatest number of and highest percentage increase in homosexual/bisexual cases have been in the southern United States especially the South Atlantic, East South Central, and West South Central Census Bureau Divisions. Overall, the increase has been much less rapid in metropolitan relative to non-metropolitan areas. In fact, it is suggested that a plateau has been achieved in metropolitan locales over 1,000,000 population. In comparison, in population areas of fewer than 1,000,000 and in rural areas incidence has increased positively and linearly through 1989. Differences in therapy, migration, reporting practices and high risk sexual behavior are considered responsible for the urban /rural contrast ¹⁵.

Adolescents:

High levels of HIV seroprevalence have been noted in rural adolescents ¹⁶. Testing from 1988 to 1990 in rural Mississippi yielded a seroprevalence rate of 4.0 per 1,000 among 9,855 adolescents treated for sexually transmitted disease ¹⁷. The rate for females nearly equaled that

of males, and the rate for adolescents from counties with populations below 25,000 was equivalent to that of counties over 100,000. Black adolescents had rates 3.5 times higher than whites.

Regional variation:

HIV and AIDS appear to vary across rural regions. Numerous researchers have identified particularly high infection rates in the South, notably among women, adolescents and homosexual/bisexual men.

Investigations of 1,082 prenatal clinic patients in rural Florida found an HIV seroprevalence rate of 5.1 percent^{9,10,11}. In one rural South Carolina hospital, 22 percent of 1,365 newborn cord blood samples drawn over one year were HIV-positive¹⁸.

Among 137,209 students, across the United States aged 16 to 21 entering the Job Corps program for disadvantaged youth from 1987 through 1990, the highest rural seroprevalence rates were in the Southeast, while the highest urban rates were in the Northeast¹⁹. Other investigators have uncovered remarkably high HIV seroprevalence among disadvantaged adolescents in the Southwest¹⁶.

And for male homosexual/bisexual non-intravenous drug users, the greatest recent increase in HIV/AIDS has been in the South Atlantic, East South Central and West South Central Census Bureau divisions³.

Rural HIV Transmission:

Explanations for the regional variation in rural HIV/AIDS cases center on differences in IV drug use, sexual behavior and levels of sexually transmitted diseases²⁰.

A distinguishing feature of the rural HIV/AIDS population has been that it includes a

substantial number of individuals not infected locally. More recently this group, largely composed of homosexual men, is being replaced by a locally infected population more likely to be female and heterosexual. While there has not been sufficient study of rural HIV transmission to definitively state the relative importance of various infection routes it is apparent that intravenous drug use and heterosexual contact are becoming important modes of rural transmission²⁰.

Urban-Rural Migration:

The phenomenon of HIV/AIDS patient migration is only now undergoing descriptive study making explanations of migration behavior theoretical at best.

Several reports indicate that migration of infected individuals accounts for a substantial portion of rural HIV/AIDS cases. In eastern North Carolina, the majority of HIV/AIDS cases had moved from urban locations, such as New York²¹. In another study, 62 percent of HIV-positive University of North Carolina outpatients had previously lived outside the state. Of these, 20 percent were diagnosed and another 17 percent believed they were infected before migrating²². It has been estimated that 69 percent of the AIDS patients and 55 to 65 percent of HIV-related care provided at University of Iowa health centers is to patients who had migrated to Iowa^{23,24}.

Based on available evidence, it seems that more HIV positive patients move into than out of rural areas. The literature indicates that 18 to 50 percent of urban incident cases move to rural sites, while only 8 percent of those diagnosed in rural areas leave^{3,25,26,27}. Patients moving to rural areas are often at advanced stages of HIV infection²⁵.

Although the relationship between diagnosis and migration is not well understood, the migration pattern appears largely a coming home phenomenon. Eighty-three percent of

HIV/AIDS patients moving to North Carolina did so for family support ²². A study of West Virginia HIV/AIDS patients identified many homosexual expatriates of the state returning after diagnosis in large metropolitan areas ²⁸. Fifty percent of HIV/AIDS patients in a rural Washington community had been diagnosed elsewhere and were all previous residents of the community ²⁹.

North Carolina rural patients who acquired their infections locally were more likely than urban infected migrants to be female, heterosexual, non-white and young ²¹.

Intravenous drug use and heterosexual contact:

Census data suggest that intravenous drug use is particularly important to non-metropolitan HIV transmission, particularly in the Northeast, South and West Census Regions ³⁰. California AIDS surveillance from 1985 to 1991 found that rural patients were significantly more likely than urban to be heterosexuals, females and adolescents ⁴.

Over half (56%) of women diagnosed with AIDS at the Duke Infectious Disease Clinic were from rural communities. Twenty-five percent were tested due to an infected sexual partner, and 13 percent because of personal IV drug use ³¹. A rural South Carolina investigation found that 20 percent of the sex- and needle-sharing partners of HIV-infected individuals were infected ³². Among Florida rural prenatal patients, HIV infection was more likely in those who were younger when they became sexually active, had two or more sexual partners, and had had sex with a high-risk partner ^{9,10,11}.

Certainly, IV drug use is a major contributor to the distribution of HIV infection in women, but there may be regional variation, as yet unexplained. A California study found that rural women were more likely than urban women to be infected through IV drug use ³³. But

among Georgia women, IV drug use accounted for fifty-eight percent in urban and rural areas. Black women accounted for 86-87 percent of non-metropolitan and metropolitan IV drug-related cases ⁵.

Crack cocaine usage:

In studies of rural Florida prenatal clinic patients, 33 percent of crack cocaine users tested HIV-positive ^{9,10,11}. Rural women who engage in sex to obtain crack cocaine are becoming infected with HIV and syphilis at a faster rate than the same urban population ³⁴. This is despite the fact that there is little difference between the two groups in the implied likelihood of HIV infection -- they are similar in AIDS-related knowledge, and high-risk drug and sexual behaviors.

Sexually transmitted disease:

Associations have been noted between HIV infection and sexually transmitted diseases in rural populations. A seroprevalence assessment of 1,309 hospital patients in rural Georgia, found a majority of those testing HIV-positive also positive for at least one sexually transmitted disease ³⁵. Another Georgia study found an important proportion of HIV-positive IV-drug users were infected with syphilis ³⁶. Syphilis infection has been associated with HIV infection among rural prenatal patients in Florida ^{9,10,11}. And a study of 198 migrant farmworkers in rural South Carolina found 13 percent positive for HIV and 16 percent positive for syphilis ³⁷.

AIDS-related knowledge and AIDS- preventive behavior:

Rural homosexual/bisexual men appear to have been slower to adopt the changes in sexual behavior credited with slowing HIV transmission in New York, San Francisco and Los Angeles. High-risk sexual behavior is considerably more common among homosexual/bisexual men in the smaller cities and rural areas of the South than in large metropolitan epicenters ^{38,15}. High risk

AIDS-related behavior also characterizes the Native American population. A comparison of AIDS-related knowledge, attitudes, and behaviors across Native American, black, and Hispanic populations identified 7 percent of American Indians, 4 percent of blacks and 2 percent of Hispanics as high risk. American Indians at risk for HIV/AIDS infection were typically sexually active young males with high levels of drug and alcohol use ³⁹. Furthermore, American Indian and black adolescents are more likely than whites to have low levels of AIDS-related knowledge and negative attitudes about people with AIDS ⁴⁰. And among South Carolina migrant farm workers, 13 percent of whom were positive for HIV, 46 percent reported not using condoms ³⁷.

Some community-based survey research finds rural adolescents to be more AIDS knowledgeable than urban youth; other reports are contradictory ^{41,42,43}. Behavioral findings indicate that rural relative to urban adolescents engage in either similar or lower levels of AIDS-preventive behavior ^{42,43}.

Diagnosis:

Rural HIV/AIDS cases frequently are diagnosed after presentation for another reason. A pair of studies in the Carolinas report that women are commonly diagnosed in the course of obstetrical and gynecological care ^{18,8}. Among the 158 women with HIV infection followed at the Duke Infectious Disease Clinic, 36 percent were diagnosed during prenatal care, 25 percent due to an awareness of an infected sexual partner, 14 percent because of an AIDS-indicator condition, and 13 percent because of IV drug use ⁸.

A Georgia study found that IV-drug users were typically diagnosed as HIV-positive after seeking care for syphilitic symptoms ³⁶.

RURAL HIV/AIDS SERVICES

Health care for AIDS patients and HIV-infected individuals differs markedly across rural and urban areas and between rural communities⁴⁴. Empirical research on the structure, financing and delivery of rural HIV/AIDS services is even more limited than the epidemiological literature. However, several literature reviews, case studies and field surveys offer useful insight into rural HIV/AIDS care.

Resource Limitations - Facilities, Services, and Health Personnel:

With some exceptions, the more rural an area is, the fewer basic health resources are available; specialty care services are rarer still. For HIV/AIDS patients, this is obviously problematic⁴⁵. One survey found rural hospitals fell significantly below urban ones in providing services and facilities essential for comprehensive AIDS care⁴⁶. Rural isolation restricts HIV/AIDS patients' access to primary care, consultation services, diagnostic testing, early drug treatment, laboratory follow-up, experimental drug trials, social, mental health, formal home care, case management programs, and other support services^{44,47,48,46,49,50,51,52}. Patients in rural areas near urban centers may obtain adequate care given transportation, but in more remote areas, especially in frontier regions, distance can pose an insurmountable barrier. One comparison of urban and rural women with AIDS in Georgia found that those in metropolitan Atlanta had significantly longer median survival times than those elsewhere in the state⁵.

The clearest challenge to rural HIV/AIDS care is that rural communities generally suffer from resource limitations accompanying low population density. Specifically, deficits in primary and acute care, and specialty physicians contribute to the challenge of rural AIDS care. The trend toward rural hospital closures and declining rural admissions are additional factors to consider.

Also, many rural areas have weak economies marked by high unemployment and poverty. Rural Americans are less likely than urban to have health insurance, public (i.e., Medicaid) or private⁵³. Rural hospital administrators are acutely aware of the financial impact that even a single uninsured AIDS patient could have on small facilities^{54,55}. Some administrators plan to simply transfer anyone diagnosed with AIDS to a major metropolitan hospital⁵⁵.

The government response to HIV/AIDS has done little to correct difficulties inherent to rural areas. Funding for HIV/AIDS services from state and federal sources has gone primarily to urban areas, where incidence is higher⁵⁶. The epidemiological evidence, however, indicates that rural needs are becoming increasingly urgent. Not only is incidence rising, but many of the patients migrating into rural areas arrive in advanced stages of AIDS, having already failed various treatment alternatives.

Organizational development:

Concerns about HIV/AIDS policies and educational interventions at rural hospitals have been raised. A survey of 558 nonfederal acute care general hospitals found that 76.1 percent of small rural hospitals (100 or fewer beds) had adopted written HIV/AIDS policies, compared to 90 percent of large urban hospitals (250 or more beds)⁵⁷. Of 108 hospitals studied in eight frontier states, 39 percent had experience with HIV infected patients and only 36 percent had policies⁵⁴. Examination of HIV/AIDS professional education in 244 rural hospitals, found that while most required basic training, only superficial attention to diagnostic, treatment, psychosocial, ethical and economic issues was given⁵⁸.

Provider inexperience:

Because HIV infection is still uncommon to rural areas, providers often lack diagnostic

experience. In a two-year seroprevalence study one-third of rural patients identified as HIV positive (in a primary care practice) had not been previously diagnosed by their primary care provider ³¹. Another seroprevalence study of 1,309 hospital patients in rural Georgia found that the majority of those infected had not been identified earlier ³⁵.

Lack of familiarity with AIDS may engender negative attitudes. One study determined that nurses in rural hospitals were more fearful of contagion and more willing to isolate AIDS patients than urban nurses ⁵⁷. Importantly, differences between rural and urban nurses diminished when number of interactions with AIDS patients was controlled for ⁵⁹. One observation suggested that rural perioperative nurses are more comfortable and sympathetic with AIDS patients than urban ⁶⁰.

Provider and community attitudes:

Several authors report prejudice among rural health care professionals against HIV/AIDS patients ^{61,59,62,49,63}. There is no literature examining the impact on quality of care. There are no urban/rural comparisons of provider prejudice nor contrasts of AIDS-related prejudice with that of other morbidities. Specifically, in a Georgia survey, 64 percent of rural physicians believed they had a right to refuse care to and eighty-seven percent reported a dislike of treating AIDS patients ⁶⁴.

Negative rural beliefs about AIDS-related sexual and drug use behavior have been described ⁶¹. One investigation found such attitudes contributed to a hesitancy among rural nurses to provide care ⁶⁵. Strained relations between heterosexuals and homosexuals in rural communities can affect willingness to provide and seek care ⁶². Confidentiality is a major concern for patients in small communities, where private details often must be shared with

professionals who are also acquaintances. Rounds, Galinsky and Stevens report that telephone communication is a feasible alternative for rural HIV/AIDS patients seeking social support ⁶⁶.

PROPOSED SOLUTIONS

Aside from directing more health care resources to rural areas, the research suggests the importance of enhanced coordination of care and professional education. One promising initiative is case management, where a patient care network is overseen by a coordinator of physicians, social workers and other health and human service providers. A study of patients at home with advanced AIDS-defining illnesses, found that availability of a case manager determined treatment success ⁶⁷. A case management program for Native Americans greatly improved accessibility and quality of HIV/AIDS services ⁶⁸. In addition, a rural Tennessee outpatient center has demonstrated a high level of comprehensive HIV/AIDS care through an integrated case management approach ⁶⁹.

Some authors call for broader cooperative efforts between urban centers and rural communities ⁶². Chase and Dodson report that a coalition-based linkage of state, and local organizations could maximize cost-effectiveness ⁵⁰.

Several investigations emphasize education for nurses and primary care physicians. In one study, rural nurses exposed to a comprehensive educational program were less fearful of and more willing to care for AIDS patients ⁷⁰. Some rural physicians desire special training to better manage their HIV/AIDS cases ⁴⁹. Finally, one proposal would establish a telephone hot line for rural providers seeking clinical information and referral sources ⁷¹.

CONCLUSION

Several years ago, some authors were asserting a dearth of non-urban HIV/AIDS research^{72,6}. Today, the rural HIV/AIDS literature remains small. However, it is growing and does hold important implications for public health authorities, providers, policymakers and researchers. HIV/AIDS cases are increasing at a faster rate in non-metropolitan areas than in large urban settings, but these less-populated regions are often ill-equipped to care for patients. Moreover, those at greatest risk are typically minorities who already face financial and cultural barriers to health care. In particular, this synthesis suggests:

- *) HIV is spreading faster among rural than urban women. Rural female adolescents have a seroprevalence rate nearly equal that of males.

- *) Particularly high HIV/AIDS rates have been noted among certain rural minority groups. The majority of rural female cases are black, with some research indicating seroprevalence rates up to 35 times those of white women. Reported seroprevalence in rural Native American women is comparable to that of urban.

- *) An important portion of rural HIV/AIDS cases migrated from urban areas, often arriving at advanced stages of the disease.

- *) The largest concentration of rural cases is in the Southeast.

- *) IV-drug use and heterosexual contact are important modes of HIV transmission in rural communities.

- *) Some rural groups, especially homosexual/bisexual men in the South, continue to engage in high-risk behavior to a greater degree than their urban counterparts.

*) Rural resource inadequacies restrict HIV/AIDS care. The problem is compounded by inexperience among rural health professionals and fragmentation of care.

In many cases the literature raises more questions than it answers. Why, for instance, is HIV spreading faster among rural crack-using women than urban when their knowledge and behaviors are similar, and urban women actually have more sex partners³⁴?

It should be noted that the little research that has been conducted has focused on specific populations and regions. The literature is so limited, that this review, based on an extensive search of indexing services and bibliographies, recovered fewer than 100 articles, many of them outdated. Rigorous empirical research is rare. Seroprevalence rates are drawn from convenience samples, and while providing early evidence of the importance of a problem, selection bias is a concern. There has been no large-scale investigation of HIV/AIDS incidence and prevalence in the general rural population, though the Ryan White Comprehensive AIDS Resources Emergency Act of 1990 required one. Such an effort should focus on variations among risk groups, as well as among different types of rural communities and regions of the nation.

Additional research is needed on rural HIV/AIDS health services delivery and costs. There have been several regional surveys of hospitals and providers, but the literature largely is based on case studies and anecdotes. A systematic evaluation of rural innovations, such as AIDS networks and integrated case management systems, would be useful.

HIV/AIDS is a serious public health problem for rural areas, and it is worsening. More substantively comprehensive, and methodologically rigorous epidemiological and health services research is needed to prepare an adequate response.

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