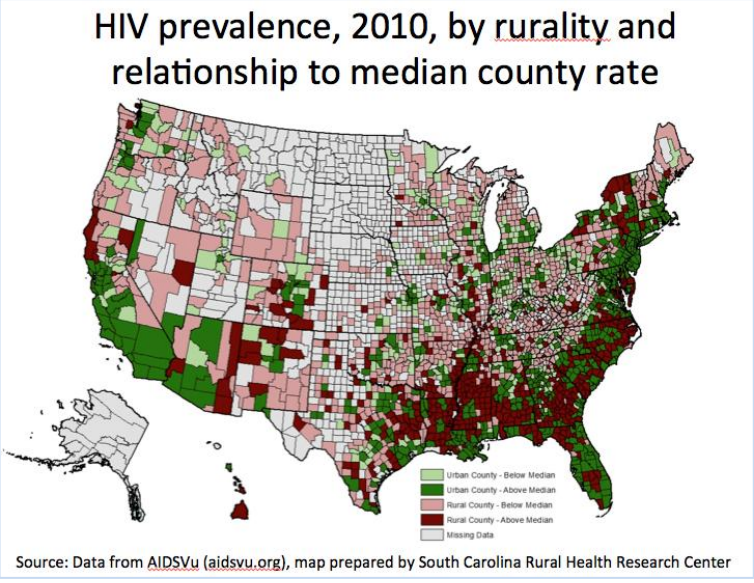
HIV/AIDS in Rural America:
Disproportionate Impact on minority and Multicultural Populations

Human Immunodeficiency Virus (HIV) disease is a communicable disease that can spread from one person to another through sexual contact, injection drug use, transfusion of blood/blood products or accidental needle stick. The virus can also be transmitted from an infected mother to her child during pregnancy via placenta, during labor via vaginal secretions or after delivery via breast milk. HIV reduces the number of CD4 lymphocyte cells in the blood, which the body needs to fight infections. A decline in body's immunity predisposes HIV-infected individuals to a number of other infections. When the level of CD4 cells in the blood drops below 200 cells per cubic millimeter of blood, the person with HIV infection has progressed to AIDS (Acquired Immune Deficiency Syndrome). The person is also diagnosed with AIDS if he/she has developed one or more opportunistic infections, regardless of the CD4 count. Left untreated, HIV almost universally results in AIDS and persons diagnosed with AIDS typically survive about 3 years without any treatment.

HIV cannot be cured, but it can be managed with appropriate medication, reducing the degree to which the individual suffers from complications or risks spreading the disease to others. When an HIV positive person does not know he or she is infected, or does not adhere to regular treatment, both complication rates and infection rates can increase. HIV is of particular concern to rural America because lack of resources can lead to gaps in detection of the infection and in treatment maintenance. Further, traditional norms and conservative values in rural areas often translate into high prevalence of HIV-related stigma and low rates of disclosure resulting in reluctance to come forward for HIV screening and treatment among rural individuals.

Epidemiology of HIV/AIDS



Approximately 1.2 million persons are estimated to have HIV, of whom about 898,000 have been diagnosed, with the remainder unaware of their condition.[1] Even though the HIV epidemic is still predominantly located in major urban areas, trends over the years suggest an increasing impact of the disease on women, minorities, older adults, rural residents, and those living in the South. Most persons in the US with diagnosed HIV reside in urban areas, 82.5% in metropolitan statistical areas (MSAs) with a population of ≥500,000, and 10.3% in MSAs with population between 50,000 and 499,999.[2] About 6.2% of HIV positive persons live in nonmetropolitan areas (counties with no urban area of 50,000 or more residents).[2] Similar patterns were observed for AIDS incidence in 2011 and AIDS prevalence at

the end of 2010, with 7.5% of new AIDS cases and 6.1% of existing cases, respectively, living in nonmetropolitan areas.[2]

While the sparse population of many rural counties leads to low numbers of persons with HIV, the proportion of the population affected can be as high in rural as in urban counties.[3] The geographic distribution of HIV rates across rural and urban counties in the US is graphically illustrated in the map above.

The Centers for Disease Control and Prevention (CDC) reports that since the early 1990s, 5% to 8% of the new AIDS cases each year have been diagnosed among those who live in non-metropolitan areas.[2] Of concern, rural men and women aged 15-44 are less likely to have been tested for HIV in the past year, including testing as part of routine blood donation, despite having similar risk patterns for sexual activity and drug use.[4] While male-to-male sexual contact accounts for the majority of new cases in all areas, the proportion attributable to heterosexual activity and drug use is higher in rural than in metropolitan counties.[2]

As shown in the map above, rural counties in the South and Southwest have high rates of persons living with HIV. While urban HIV rates in 2010 were highest in large metropolitan areas in the Northeast, HIV rates in smaller metropolitan and rural areas were highest in the South.[2] Inadequately treated, HIV can progress to AIDS. A study by the Rural Center for AIDS/STD prevention (2011) noted an increasing incidence of new cases and deaths from AIDS in the South.[5] The prevalence rate of adults and adolescents living with AIDS in non-metropolitan areas is 99.5 per 100,000 people in the South.[2]

In rural America, African-American men and women account for 50% of the AIDS cases, whites 38%, Latinos 10%, and American Indians and Alaska Natives 2%.[2].The disparity is greatest for African-Americans and Latinos living in the rural South and rural Northeast, with young African-American women being the fastest growing group infected with HIV through heterosexual exposure.[6] Minority status is associated with social determinants that can trigger higher rates of HIV/AIDS, such as a lack of educational opportunities, poor economic position, poor access to healthcare, higher susceptibility to other forms of STDs, and living in a neighborhood prone to crack cocaine use and prostitution.[6] Studies have reported that low-income African- American women were more likely than their urban counterparts to not use condoms, not have HIV prevention counseling during pregnancy, and not worry about HIV.[6]

HIV/AIDS among rural migrant workers and recent immigrants is another concern, especially along the U.S.-Mexico border and many parts of the South.[7] The at-risk population includes documented and undocumented individuals who work in agriculture or other industries, as well as truck drivers who cross the border from Mexico and travel throughout the country.[8] Access to care may only be through federally qualified Community and Migrant Health Centers and because of the mobility of this group, traditional prevention and surveillance may be challenging.
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The National Institute on Aging reports a growing number of older people living with HIV/AIDS.[9] Almost one-fourth of all people with HIV/AIDS in this country are aged 50 and older, due to increasing survival after diagnosis as well as newly diagnosed cases.[9] The elderly generally perceive themselves to be at less risk and are less aware of how HIV/AIDS is spread.[9] However, 17.2% of the estimated 50,199 new HIV cases diagnosed in 2011 occurred in persons aged 50 and older.[9] Medicare now covers testing for HIV and other sexually transmitted diseases as a preventive service, at no cost to the beneficiary. During 2011 and 2012, 66,000 beneficiaries sought HIV testing.[10]

There are challenges in assessing the "true" impact of HIV on rural areas. One difficulty is the lack of consistency in defining "rural" areas. In addition, there might be discrepancies in reported and actual data for two main reasons: (1) persons diagnosed in urban areas may migrate to rural areas after HIV diagnosis; and (2) those diagnosed in rural areas may not provide their rural hometown address to avoid stigma[5].

Complexities of the HIV/AIDS in Rural America

Persons living with HIV/AIDS (PLWHA) who reside in rural areas face unique challenges. At the personal level, rural residents are less likely to have health insurance and may feel less able to conceal their HIV status within small communities. At the community level, problems include distance to care, lack of health care facilities and health care providers with HIV/AIDS expertise, limited availability of supportive or ancillary services, stigma and discrimination, and limited educational and economic infrastructure.[11]

The high cost of HIV care may be difficult to manage for rural residents. The average annual cost of antiretroviral therapy is approximately $9,000 to $12,000; costs can be even higher for those with lower CD4 counts.[12] Rural residents are less likely to have adequate insurance coverage compared to their urban peers.[5] Many without coverage either defer medical care or seek care in settings such as emergency rooms, which are not set up to provide continuity of care. While implementation of the Affordable Care Act may increase the ability of some rural residents to pay for care, long term effects remain to be determined. Limited state participation in Medicaid expansion suggests that many PLWHA will continue to lack financial coverage for their care. This is particularly true in the South, where many rural PLWHA reside.

Programs such as Medicaid and the Ryan White Comprehensive AIDS Resources Emergency Act (hereon, the CARE Act) provide medical care and coverage for AIDS drugs for qualifying patients. Both programs have income eligibility requirements and, in the case of the CARE Act, waiting lists exist to get HIV drugs. [13]

Early start and continuation of HIV care is critical in maintaining optimal viral suppression, necessary for decreased transmissibility of the virus and reduction in HIV-related morbidity and mortality. Practitioners need to be knowledgeable both in the complex regimen associated with HIV and with techniques for motivating patients to continue with treatment. While Ryan White providers can provide with both disease expertise and financial support for PLWHA, these providers are disproportionately located in urban communities. As consequence of gaps in care, only one in five PLWHA receives care that results in an undetectable viral load, the desired outcome for disease management.[14]. Inadequately treated rural patients not only are at increased risk of disease progression due to lack of HIV care and treatment, but may also serve as sources for HIV transmission to others.

HIV Policy Recommendations

The NRHA recognizes that HIV control efforts must transcend geographic borders and must cover the full spectrum of prevention, detection of new cases, and treatment for all persons living with HIV/AIDS in order to achieve the goals of the National HIV/AIDS Strategy. As noted earlier, the bulk of prevention efforts have been in urban epicenters. It is imperative to expand the focus to rural America which is increasingly being affected by the HIV epidemic.

The NRHA recommends the following strategies in the context of the HIV epidemic affecting rural America:

Prevention:

- Identify the needs and available resources of each rural community to plan an effective strategy for the community in focus since strategies that address HIV in rural areas are not a one-size-fits-all solution.
- Distribute educational materials to key places such as beauty shops, barber shops, bowling allies, restaurants, grain elevators, community centers, etc. to help raise HIV/AIDS awareness in rural communities.

Detection:

- Enhance efforts to screen for HIV in the rural South by establishing and maintaining screening facilities to encourage individuals who would be otherwise reluctant to or would not be able to travel to urban sites for HIV screening.
- Target high risk populations such as adolescents, women, minorities, lesbian-gay-bisexual-transgender (LGBT) communities, older adults, and prison inmates by employing outreach workers/ community health workers who can encourage residents in rural communities to get screened.

Treatment

- Provide training and financial support to outreach workers who can link PLWHA to health care facilities.
- Strengthen efforts to increase linkages with health care services, especially among those who receive their diagnosis in a community setting such as mobile screening units, community-based HIV/AIDS service organizations, or university campuses.
- Provide transportation by offering reimbursement of costs, having a viable transportation option such as a clinic van, or improving public transport infrastructure that would enable PLWHA to come for their regular HIV care.
- Train rural health care workforce including physicians on HIV specific issues and their management as well as cultural competency, especially for those who work with multicultural or multiracial patient populations.
- Increase the number of Ryan White medical providers in rural counties or offer incentives for HIV specialists who deliver their services to rural communities.
- Employ innovative service delivery strategies to offer patient-centered comprehensive medical care through telemedicine for consultation with urban HIV specialists as well as supportive or ancillary services.

Development and coordination

- Increase advocacy efforts in rural communities by collaborative efforts with multiple stakeholders such as faith-based organizations.
- Identify a central depository for rural data on HIV/AIDS such as epidemiological reports, model programs, policies, and continuing education.
- Increase funding to safety net providers (Ryan White medical providers and providers accepting Medicaid) for rural PLWHA.
- Urge the Centers for Medicare and Medicaid Services to “risk-adjust” Medicare capitation payments and require states to adjust Medicaid capitation payments for services delivered to PLWHA.

Summary

Despite intense public health efforts, HIV/AIDS epidemic poses significant challenges in rural America and especially the rural South. Contextual factors unique to rural residence create additional barrier to accessing and utilizing appropriate care for PLWHA. Early diagnosis and consistent engagement in HIV care is critical to the successful management of HIV disease both at individual as well as population level. It is imperative to take aggressive efforts in rural communities including policy level strategies.

End Notes:

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