National Rural Health Association

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

Epidemiology of AIDS in Rural America

Human Immunodeficiency Virus (HIV) is an infection, which can lead to Acquired Immune Deficiency Syndrome (AIDS). There currently are an estimated 800,000 to 900,000 People Living with AIDS or PLWA in the United States, with an estimated 40,000 new infections each year.[1] In 2001, 7.6 percent of reported AIDS cases were from rural areas (i.e., non-Metropolitan Statistical Areas),[2] a rise from the 6 percent overall figure since the epidemic's start. Further, statistics show troubling patterns in the epidemic's uneven and potentially debilitating impact on specific rural regions in America, most notably:

- Southern states' burden of HIV/AIDS is heavy compared to other rural regions. The South has over half of rural AIDS cases but comprises just 35 percent of the U.S. population.[3] In 1996, 59.6 percent of rural cases were Southern. In 2001, 70 percent were from the south.[4] In 1999, the South represented 76 percent of rural female AIDS cases.
- Minority and multicultural populations comprise most cases of HIV/AIDS.
- In nearly every rural region of the nation, African American and Hispanic AIDS cases are disproportionately greater compared to their representation in the local general population. To illustrate, African American and Hispanic individuals each comprise 1 percent of rural residents in the Northeast but are, respectively, 25 percent and 20 percent of the region's cases.
- As with cases overall, over half of rural AIDS cases are among men who have sex with men or MSM, according to 2001 data. Another 20 percent are injection drug users. Heterosexual contact represented 20 percent of male AIDS cases in 1999.[5]
- Women comprised 21.6 percent of rural AIDS cases in 1999, and cases are predominately minority women. Rural female cases are more likely attributed to heterosexual transmission from a man at risk for HIV, rather than an injection drug user.[6] This is a shift away from the former predominant means of transmission: injection drug use. In the U.S., from 1985 to 1999, the overall proportion of female AIDS cases more than tripled, from 7 percent to 25 percent. There are wide variations across regions of the country.

HIV/AIDS among migrant workers and recent immigrants is another concern, especially in rural areas along the U.S.-Mexico border and many parts of the South. The population at risk includes both 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. 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.

Complexities of the Epidemic

HIV/AIDS care and prevention activities are especially difficult in rural America. A 2000 report from State AIDS directors[7] outlines a number of issues, which are also often cited in other studies. They include:

- Long travel distances to access services.
- Inadequate supply of health care providers with HIV/AIDS expertise. Rural individuals with HIV are less likely to see providers experienced in HIV care.[8] In 1997, rural patients were far less likely to be on combination antiretroviral regimens as compared to urban patients: 57percent versus 73percent.
- Lack of available medical facilities.
- Limited social services and client support, such as helping clients obtain care and adhere to complex drug regimens.
- Concerns over confidentiality and stigma keep people from getting tested for HIV or seeking care if infected. An estimated one-third of the people living with HIV disease, around 180,000 to 280,000 people, do not know they are infected, according to CDC.[9]
- Scant substance abuse treatment services make untreated addiction a barrier to dealing with one's HIV disease.

Rural regions and minority populations in particular are most affected by fragile economic infrastructures: under-funded rural health and social services programs, high levels of poverty, geographic challenges and a higher proportion of people who lack health insurance.

Economics of HIV Disease

The U.S. has a patchwork of private and public payers of care. There are an estimated 40 million Americans without insurance and an additional 70 million or more who have inadequate coverage.[10] Rural residents in particular are less likely to have insurance. Many without coverage either defer medical care or seek care in the public sector in such settings as emergency rooms, which are not set up to provide continuity of care. Data suggest that the high cost of HIV care is more difficult to manage for rural residents.

For example, the average annual cost of antiretroviral therapy is approximately $9,000 to $12,000 and even higher for less healthy individuals, as measured by lower CD4 counts.[11] HIV's heaviest impact is on minority and poor individuals and is compounded for rural areas, where 14 percent of residents are at or below the federal poverty level as compared to 11 percent for urban areas. Insur-ance coverage is thus more likely to be through public sources such as Medicaid or, lacking other funding, state/local sources. These are costs unlikely to be borne with ease by rural providers. With the growing number of states experiencing budgetary pressures, there is a risk that Medicaid benefits and services will be further cut.

Programs like Medicaid and the Ryan White CARE Act provide medical care and coverage for AIDS drugs for qualifying patients. They have income eligibility requirements and, in the case of the CARE Act, waiting lists exist to get AIDS drugs. Some of the services essential to securing improved health and well-being are not paid for.[12]

Rural Prevention Challenges

A 1999 CDC-authored article observes that the bulk of prevention efforts have been in urban epicenters.[13] That same article recommends adoption of an array of prevention interventions, stating: "It is only by attending to the mix and interaction of all the relevant factors that the spread of HIV can be successfully curtailed in any setting, regardless of its urban or rural setting." It is difficult to measure how prevention programs in rural areas are addressing HIV given the variations across rural sites as well as the difficulty of measuring something that does not happen (i.e., not getting infected and thus not becoming a statistic).

One CDC study suggests that many rural citizens acquire HIV from urban contacts. Therefore, prevention efforts must transcend geographic borders in order to be effective.

Since AIDS has been so closely associated with urban areas rural residents perceive a lower HIV risk. However, this perception of low risk can result in individuals engaging in riskier behaviors. In one study, African American women from rural Missouri were about twice as likely to perceive little HIV risk for themselves, as compared to urban women. This included lower use of condoms and failure to receive HIV counseling and testing during last pregnancy.[14]

Policy Recommendations

Prevention

The NRHA affirms that education is fundamental to the prevention, control, and treatment of HIV/AIDS. In this effort, the NRHA acknowledges that minority, multicultural, and special populations present particular challenges to such educational efforts and, accordingly, will focus attention on the needs of these constituents residing in rural communities. The NRHA supports:

- *Targeting Populations at High-risk.* Target prevention efforts to areas and populations hit hardest, including the rural South; population groups with the highest numbers/rates (particularly African Americans and other minority populations); risk categories comprising the largest and/or increasing proportion of cases.
- *Prevention in Care Settings.* Expand and encourage AIDS prevention education in primary care settings as providers come into contact with individuals who may not know their HIV status.
- *Prevention Materials.* Develop prevention materials that specifically target rural communities' values and beliefs. Make these materials available where people with high risk behaviors will access them, such as beauty shops, barber shops, bowling allies, restaurants, grain elevators, community centers, etc. Identify a central depository for rural information (data) about HIV/AIDS for epidemiological reports, model programs, policies, and continuing education.

Barriers to HIV Care

- *Expand Rural Efforts to Identify and Link Persons With HIV Into Care.* Federal funding and program efforts should be expanded in rural areas to help more individuals learn their HIV status. Data and monitoring of the disease in rural areas must be conducted for surveillance issues.
- *Enhance Training of Rural Providers in HIV Care.* Federal efforts should be expanded to train more rural providers in conducting HIV care, making referrals to HIV specialists, and/or consulting with HIV experts in working with clients with HIV.
- *Implement Cultural Sensitivity Training for Providers.* The training programs must have a comprehensive program for cultural competency and sensitivity training for rural providers who will work with multicultural individuals with HIV.
- *Service Delivery Innovations.* Federal efforts should continue to identify, and fund, HIV/AIDS care services that address care challenges facing rural individuals with HIV and those prior to becoming symptomatic. These include, for example, expansion of the CARE Act and community/migrant health center services to provide HIV care in rural setting and supportive services to enhance access to care such as transportation.

Targeting of Resources

- *Reimbursement of Care Costs.* The NRHA continues to strongly support access to essential health care resources for all Americans, regardless of socioeconomic status, ethnicity, diagnosis or place of residence. This must include access to the currently expensive and clinically appropriate treatment essential for the preservation of the health and life of HIV/AIDS patients. Implementation requires many actions by many interests, including development of appropriate risk or alternative payment adjustment among risk-bearing payers. The NRHA urges the Centers for Medicare and Medicaid Services to "risk adjust" or otherwise adjust Medicare capitation payments and require states to adjust Medicaid capitation payments.
- *Expand funding for the Ryan White CARE Act and work to increase participation among rural citizens*.

Leadership and Policy

Despite decades of public information efforts, HIV/AIDS continues to be stigmatized and carry a heavy social burden. Persons with HIV may face consequences when confidentiality about their infection status is breached. Examples include loss of insurance, family and work supports, employment, and housing. These fears preclude some from learning their HIV status or even getting into care once they do find out. Legal protections have been instituted in many areas, but these challenges remain. Recommendation to confront ongoing stigma and discrimination is as follows:

• *Minority and Multicultural Community Leadership Against Stigma, Discrimination, and Supporting HIV Prevention/Care.* Rural community leaders, particularly in minority and multicultural communities, can play a positive role in educating people that they should learn their HIV status, get treatment if infected, and support family and friends living with HIV disease.

End Notes

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Contributing Authors

Debra M. Phillips, M.D., Professor, Family and Community Medicine, Southern Illinois University School of Medicine, Quincy Family Medicine Practice, dphillips@siumed.edu

Esther Forti, Ph.D., R.N., Associate Professor and Director, South Carolina Geriatric Education Center, Associate Director, Center on Aging, Medical University of South Carolina, fortie@musc.edu

Jeffrey J. Guidry, PhD., Associate Professor, Department of Kinesiology, Texas A&M University, School of Rural Public Health, j-guidry@hlkn.tamu.edu

Alan Gambrell, WordPortfolio, Inc., gambrell@aol.com

Angeline Bushy, Ph.D., R.N., F.A.A.N., Bert Fish Endowed Chair, School of Nursing, College of Health and Public Affairs, University of Central Florida, abushy@pegasus.cc.ucf.edu

Kim Byas, Sr., M.P.H., C.H.E., Region 5 Representative, American Hospital Association, kbyas@aha.org

David Berry, Dr.P.H., M.S.P.H., Professor, Health Policy & Management, South Texas Center for Rural Public Health, deberry@srph.tamu.edu

www.NRHArural.org

Headquarters Office
One West Armour Blvd., Suite 203
Kansas City, MO 64111
816/756-3140

Government Affairs/Policy Office
1307 Duke St
Alexandria, VA 22314
703/519-7910