



Stigma

Entry and Retention

Transportation

Substance Abuse

NEW STRATEGIES for RURAL CARE

For people in urban America, rural life can be hard to imagine. What is a quick walk around the block for milk in New York City can be a 15-mile drive in many parts of the country. A short ride to the doctor's office in Los Angeles can be a round trip that takes an entire day for people in small towns, assuming that they have a car—and a doctor.

A W.K. Kellogg Foundation study revealed that misconceptions and contradictory views about rural America are widespread:

[R]ural life represents traditional American values but is behind the times; rural life is more relaxed and slower than city life, but harder and more grueling; rural life is friendly, but intolerant of outsiders and differences; and rural life is richer in community life, but epitomized by individuals struggling independently to make ends meet.¹

Beyond the clichés is a rural America that is unique, diverse, complex—and too often fraught with health disparities. Of 41 million uninsured Americans, about 20 percent are rural residents. Nearly one-half of rural residents suffer from a major chronic illness, yet rural residents average fewer medical appointments than people in urban areas.^{5,6} Health care provider shortages in rural areas extend to most medical disciplines, including dentistry.^{7,8,9} Even when services are available, people face distance- and time-related barriers to accessing care.

DID YOU KNOW?

Only 10 percent of physicians practice in rural America, although 22 percent of Americans live there.²

Rural people living with HIV/AIDS are less likely than their urban counterparts to receive highly active antiretroviral therapy, or HAART, and 66 percent of rural residents on HAART travel to urban areas to receive care.³

Rural Americans are more likely than non-rural Americans to live below the Federal Poverty Level.⁴



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Barriers to HIV/AIDS care in rural America are many. Finding specialists can be difficult. Just 10 percent of physicians practice in rural areas, whereas 22 percent of Americans live there. The lack of public transportation and long travel times to medical appointments pose additional problems. But for rural Americans living with HIV/AIDS, stigma may be the single greatest deterrent to testing and treatment. In this issue of *HRSA CARE Action*, you will read about a woman who stayed out of care for more than a decade because of negative attitudes towards HIV in her community. Sadly, her story is not unique.

Yet, the picture is changing for many other rural Americans living with HIV/AIDS, thanks to ground-breaking health care delivery systems. Through Internet-based interventions, telemedicine, and Webcasts, rural providers are now able to reach clients more effectively and to communicate with HIV specialists in urban areas. In doing so, rural providers are better equipped than ever to deliver high-quality, comprehensive services to the people who need it most.

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Cover: An HIV-positive client in rural Washington State.
Page 5: A road block in rural Mississippi.
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Additional copies are available from the HRSA Information Center, 888.ASK.HRSA, and may be downloaded at www.hab.hrsa.gov.

This publication lists non-Federal resources to provide additional information to consumers. The views and content in those resources have not been formally approved by the U.S. Department of Health and Human Services (HHS). Listing of the resources is not an endorsement by HHS or its components.

These structural issues have a detrimental impact on the health of rural Americans. People living with HIV/AIDS (PLWHA) in rural areas report crippling levels of stigma. And comorbidity rates for HIV and addiction and mental illnesses are high. These circumstances, among others, foster the spread of HIV infection and make treating HIV/AIDS more difficult.

SURVEILLANCE DATA

About 1 in 5 Americans—or 65 million people—live in rural areas, classified as “nonmetropolitan regions of the U.S. with <50,000 people” by the U.S. Office of Management and Budget (OMB).^{10,11}

AIDS Prevalence. In rural areas, more than 51,000 cumulative AIDS cases had been reported among adults and adolescents by December 31, 2006.¹²

AIDS Rate. In 2006, the AIDS rate per 100,000 adults and adolescents was 6.4 in nonmetropolitan America compared with 19.3 in metropolitan statistical areas (MSAs)* with more than 500,000 people.¹³ The AIDS rate in the rural South at 9.8 per 100,000 is the highest in rural America, followed by the rural Northeast (7.1), the West (3.4), and the Midwest (2.8).¹⁴

Race/Ethnicity. African-Americans represent only 8.5 percent of the rural population in the United States but account for 50 percent of all rural AIDS cases.^{15,16} In the Northeast, African-Americans and Latinos each represent 1 percent of the rural population but 25 percent and 20 percent of AIDS cases, respectively.¹⁷

Region. The South now accounts for 67 percent of all AIDS cases among rural populations.¹⁸ This large share is attributable to the disproportionate impact of HIV on racial and ethnic minorities and to the fact that 90 percent of rural African-Americans live in the South.^{19,20}

Age and Gender. The age at diagnosis and gender of PLWHA does not vary significantly among urban, suburban, and rural areas.²¹

*MSAs are geographic entities defined by OMB for use by Federal statistical agencies in collecting, tabulating, and publishing data.

RURAL CHALLENGES to CARE DELIVERY

Whether in the Nation’s largest city or smallest community, providers of HIV/AIDS care have much in common. They know that comprehensive care is critical and are committed to providing essential support services that make engagement and retention in care possible. They value cultural competency and confidentiality, and they are committed to quality and to working with other organizations to create a holistic approach to the needs of clients.

Although providers everywhere may share a strategic vision, living in a rural area can create unique challenges to addressing HIV/AIDS. Perhaps none of those issues is more significant than stigma.

Stigma

“If you haven’t lived in this area, it’s difficult to fathom the fear people have of others finding out they have this disease,” says Sister Betty Ann McDermott of Sacred Heart Southern Missions AIDS Ministry in Walls, Mississippi.

The ministry serves PLWHA and their families in nine northern Mississippi counties. Four of the counties fall within the Ryan White HIV/AIDS Program Part A Memphis Transitional Grant Area (TGA).

Last year, Sacred Heart reached 130 people living with or affected by HIV/AIDS by offering such services

as rental and utility assistance, a thrift store, HIV education, advocacy, food pantry, pastoral counseling, and transportation as well as referrals to and linkages with providers of other services. Sacred Heart’s AIDS Ministry services are funded through a mixture of Ryan White Part A and non-Ryan White monies. Where Sacred Heart serves, the issue of stigma is so pervasive that it is a constant concern. According to Sister Betty Ann:

I have seen deathbed confessions to a spouse or partner who then has to deal with the loss that comes with death and also the new knowledge that the loss is due to AIDS. It also brings the simultaneous realization that they, too, may be infected with HIV. It adds to the psychosocial complexity of providing needed information, care, and comfort. It makes denial seem like a more appealing option.

Sacred Heart Southern Missions can mitigate some of the impact of stigma for its clients. First—and perhaps most important—Sister Betty Ann explains, the organization is not “branded with HIV disease” because it offers a broad range of services, of which the AIDS Ministry is only one part. “People know we’re associated with Sacred Heart but not the AIDS Ministry, so [they] don’t suspect it if we come to someone’s house to talk to them or pick them up,” she says.

REPORTED AIDS CASES AND RATES, ADULTS AND ADOLESCENTS, THROUGH 2006

MSA Population	Number	Rate/100,000 Population	Cumulative Cases Through 2006
>500,000	30,607	19.3	807,912
50,000–500,000	4,239	9.2	88,041
<50,000 (nonmetropolitan)	2,696	6.4	51,146

Source: Centers for Disease Control and Prevention. *HIV/AIDS in urban and nonurban areas*. n.d. Available at: www.cdc.gov/hiv/topics/surveillance/resources/slides/urban-nonurban/slides/urban-nonurban.pdf

Similarly, the AIDS Ministry's office is located within the social services and volunteer office, and all personnel are identified as part of Sacred Heart Southern Missions, not the AIDS Ministry. This simple practice gives people the sense of privacy and anonymity they so deeply value. In addition, Sister Betty Ann provides client and community education about HIV to help diminish stigma associated with the virus and to encourage people to enter care.

Sacred Heart serves the southern edge of the Memphis TGA. Across the Mississippi River, in the TGA's westernmost area, is Crittenden County, Arkansas, home to the federally funded East Arkansas Family Health Center, a Ryan White Part C grantee. Like all Community Health Centers under the Federal 330 program, the center provides an array of primary health care services. Thus, PLWHA who seek care are not assumed to have AIDS simply because of their association with the facility.

"We work hard on confidentiality, and to be safe, we talk to clients in private rooms. All file cabinets are locked, and because we're under the umbrella of a large health center, it helps make patients feel safe," explains Cherry Whitehead-Thompson, HIV/AIDS program manager at East Arkansas Family Health.

Many organizations serving PLWHA in rural areas take additional steps to help people cope with stigma. Staff participation in cultural sensitivity training can create a better understanding of consumer perspectives. It also can provide practical, hands-on approaches to help consumers deal with the impact of stigma.

Over the years, the National Minority AIDS Council has offered a variety of successful training through a technical assistance cooperative agreement with the HIV/AIDS Bureau. Since inception, the program has addressed barriers to accessing HIV/AIDS care related to stigma (see http://careacttarget.org/links.asp#CulturalCompetency_Stigma). But training shouldn't stop with staff. Nancy Young, program director at Special Health Resources for Texas (SHRT) in Longview, Texas, notes that "all clients undergo patient education to help reduce and overcome stigma as well as increase understanding of its effects."

Over the past decade, technology has become a powerful force in the delivery of health care in rural areas. Telemedicine is now a familiar practice, and in 2005, the Health Resources and Services Administration (HRSA) administered 159 telemedicine projects, of which 92 totaled more than \$34.5 million each.

Internet and e-mail technology can also be used to help meet consumers' other needs. For example, in addition to providing rural PLWHA with a host of information about living with HIV/AIDS successfully, the virtual world can help ease the isolation that is so often a result of stigma. Unfortunately, many underserved and impoverished PLWHA lack computer literacy as well as computer access. For those who have access, however, services such as bulletin boards and chat rooms can help replace isolation and loneliness with community and support.

Entry and Retention in Care

Early diagnosis of HIV among PLWHA in rural areas remains all too uncommon. Rural residents are less likely than urban residents to be tested for HIV because of limited access to testing services, stigma, or underestimated risk of infection.^{22,23} They may also have poorer access to prevention information.

It is hard to contemplate a meaningful solution to this problem without greater access to lifelong comprehensive health care, which, by definition, includes preventive health care. The U.S. Department of Health and Human Services support for health centers in rural areas is an important ingredient for achieving this goal. (For more information, see www.hhs.gov/news/factsheet/rural/html.)

➔ HEALTH CARE PROVIDER SHORTAGES

in rural areas extend to most medical disciplines, including dentistry. Yet even when services are available, people face distance- and time-related barriers to accessing care.

In the absence of broad access to prevention information and testing, rural providers have taken creative steps to reach out. For example, the Wyoming Rural AIDS Prevention Project piloted a peer-led, Internet-based intervention for rural men who have sex with men (MSM) whereby two MSM (one HIV positive and one HIV negative) discuss HIV prevention strategies in online communities. Results show an increase in knowledge, safer sex practices, and self-efficacy among respondents.²⁴

Unfortunately, the pathway to better health for many PLWHA is not cleared by early diagnosis alone. Illustrating this point is the story that Tarsha Taylor, a case manager for the Mississippi Department of Health, tells about one of her clients.

We recently had a woman who was referred to us. She did not know very much about the disease. Her knowledge, attitudes, and behaviors indicated that she was newly diagnosed. In actuality, we discovered that this woman had been diagnosed in 1996. Stigma had kept her out of the system. Once we learned that she had lived with the disease for that amount of time, it explained why her medications were not working.

Transportation

When traditional social networks (e.g., church and civic organizations) are closed to people in rural areas

because of discrimination and stigma, providers must work harder to locate and keep clients in care. Intensive case management is essential, as are language and cultural skills and follow-up after missed appointments. But those skills and services mean little if the patient cannot get to the doctor.

Transportation is undoubtedly at or near the top of the list of intractable barriers to care in rural America. Not only is there a lack of public transportation in rural areas, but geographical isolation, rugged topography, and long distances between towns can result in extensive travel to medical and social services.²⁵

For some rural PLWHA, the long distance to a provider is unavoidable, whereas for others, the lack of anonymity in their own small town may discourage them from seeking services locally.²⁶ The distance between HIV providers and rural residents not only is a deterrent for consumers but also can hinder prevention efforts on the part of providers.²⁷ Economic factors also may play a role: Consumers may be unable to take time off from work to travel long distances to appointments, their health may not permit such extended travel, or the cost of travel may be too high.^{28,29}

Providers throughout rural areas of the United States have used their determination and ingenuity to bridge the transportation gulf. Much can be learned from their interventions.





IMPROVING CAPACITY: TIPS FROM THE FIELD



Recruit Interns from a Local University

Sacred Heart recruits from the University of Tennessee to help increase capacity.

Find Experts

At SHRT, a specialist makes monthly visits to assist SHRT's team and provide education. Taking specialists to a rural health setting is an allowable use of funds under Ryan White Parts A–D.

Use Telemedicine

Many rural organizations now use Webcasts or video conferencing between rural providers and an HIV specialist (who is often based in an urban area).

Get Others on Board

Partnering with local organizations can help increase engagement and retention in care. Sharing protocols can increase synergy and strengthen clients' safety net.

Continue Education

Contacting National Quality Centers can help with technical assistance and training and improve quality management.

Apply Screening and Training Tools

Several tools, such as the Substance Abuse and Mental Illness Symptoms Screener (SAMISS), may assist providers. This tool takes approximately 15 minutes to administer and has been shown to be effective in frontline screening. The SAMISS can be downloaded in both English and Spanish and accessed at www.dshs.state.tx.us/hivstd/qm/documents.shtm. HRSA's *HIV/AIDS in Rural Areas: Lessons for Successful Service Delivery* discusses replicable models to increase quality and access to care. Hard copies can be requested at www.ask.hrsa.gov/detail.cfm?PubID=HAB00284.

- ▶ **Sacred Heart Southern Missions AIDS Ministry** uses private cars driven by three employees and two volunteers to transport patients. Drivers must sign confidentiality forms, and driver's insurance is covered by Sacred Heart. "Many patients are multiply diagnosed," explains Sister Betty Ann. "If they need medical transportation, even if it isn't for HIV, we'll take them because we're all they have."
- ▶ **The East Arkansas Family Health Center** provides gas reimbursement to consumers for traveling to HIV-related medical appointments. The organization also has a prepaid account with cab companies in West Memphis.
- ▶ **SHRT** has an eight-passenger van, which was purchased as part of the Special Projects of National Significance Oral Health Initiative to assist in bringing patients from their 23-county, entirely rural service area to appointments. The organization also hired a full-time transportation aide using funds from its SPNS grant.
- ▶ **The Mississippi State Department of Health Mobile Medical Clinic** travels to rural areas to reach out to people at highest risk for HIV. Program managers are careful to avoid HIV-specific branding by making no mention of HIV on the van and offering a number of health services unrelated to HIV, such as blood pressure and cholesterol screenings and tests for glucose levels and syphilis. With assistance from private partners, the van has also offered papanicolaou (PAP) tests, clinical breast exams, gonorrhea and chlamydia screenings, digital rectal exams, and prostate-specific antigen (PSA) exams.^{30,31}

Substance Abuse

Rates of methamphetamine (known as "meth"), oxycodone (OxyContin, Percocet), and alcohol abuse are higher in rural America than in urban regions. Rural youth ages 18 to 25 are more likely than their urban counterparts to have used meth or oxycodone. Eighth graders in small towns are 104 percent more likely to use meth than are those in large urban areas.³²

Substance use contributes to poor treatment adherence, missed appointments, and the inability to stay in treatment over time. Moreover, it severely inhibits

the capacity to rebuild one's health and may lead to risky behaviors, such as unprotected sex. Meth use, in particular, has been associated with increased HIV risk due to side effects such as increased sexual arousal and decreased inhibition and judgment.³³

Services for substance abuse prevention and treatment are scarce in rural areas. "[Available resources] for treatment centers, law enforcement, and prevention programs are stretched thin over sparsely populated regions. Rural residents frequently must travel great distances and wait for months to be treated at the few, widely spaced and understaffed hospitals and health facilities available to them."³⁴ In fact, rural residents average between 13 and 30 miles to a substance abuse treatment facility (and longer distances in frontier areas), whereas 49 percent of urban residents live within 1 mile of a treatment facility.³⁵

Difficulties in addressing substance abuse in rural areas, however, go beyond a lack of treatment. Rural residents are more likely to be referred to substance abuse treatment by the criminal justice system than by health care systems or through self-referral.³⁶ Even where help is available, the stigma associated with drug abuse treatment can discourage people from seeking treatment in their home community.³⁷

To help counter substance use, the East Arkansas Family Health Center provides educational outreach in addition to HIV testing. "We will do outreach at churches, community venues, and we'll go to public housing," explains Whitehead-Thompson, but "we really need more residential substance abuse treatment options. When someone is ready for help, we need to be able to put them in a place where they can be treated and get help. . . . It affects our success rate not having more residential substance abuse treatment in rural areas."

One way of more effectively linking people with addiction issues to treatment services is through better screening. Whitehead-Thompson says, "When we encounter people at intake, we'll ask them about substance use as part of our psychosocial screening. We offer available resources for substance abuse treatment, and if they're willing to go, we'll provide transportation or vouchers." Similarly, SHRT's Young notes, "We screen all HIV patients through our HIV Early Intervention (HEI) Substance Abuse Program. We have HEI case managers who specialize in substance abuse issues at our offices. They offer group and individual counseling."

Provider partnerships with other area organizations serving PLWHA can also help increase success rates. The Healthy Relationship Intervention, for example, is a behavioral intervention program involving a partnership of the Jefferson Comprehensive Care System in rural Pine Bluff, Arkansas, with the Arkansas Department of Corrections, the Arkansas State Health Department, and addiction treatment and recovery centers. The organizations work together to identify and bring PLWHA engaging in high-risk sexual behaviors and drug use into treatment. Participants reported decreased risk activities and increased disclosure of HIV status.³⁸

CONCLUSION

The challenges facing PLWHA in rural America are enormous. Like PLWHA everywhere, they need community and support, which are difficult to find where stigma is pervasive. PLWHA need opportunities for drug treatment and comprehensive health care, but these services may be elusive in rural settings. Rural providers face barriers, too, in expanding service area coverage or service offerings in an environment of "do more with less."

Courageous PLWHA and extraordinarily committed organizations are wrestling with these and other challenges. Addressing HIV/AIDS requires health care interventions and social, cultural, and educational interventions. Where this approach is not in play, HIV incidence and AIDS morbidity are apt to increase. Where this approach is in place, infections are prevented, PLWHA become healthier, and they contribute to building healthier communities.

➔ ONLINE RESOURCES

National Rural Health Association:
www.ruralhealthweb.org

National AIDS Education and Training Center:
www.aidsetc.org

Technical Assistance, Resources, Guidance, Education, and Training (TARGET) Center: www.careacttarget.org

Rural Health, Open Door Forum: www.cms.hhs.gov/OpenDoorForums/24-ODF-RuralHealth.asp

Centers for Medicare and Medicaid Services, Rural Health Center: www.cms.hhs.gov/center/rural.asp



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