In the late 1980s, the “second wave” of the AIDS epidemic included a growing number of HIV-infected people who sought care in semi-rural and rural areas. Between 1988 and 1989, the total of newly reported AIDS cases in these areas increased by more than 30 percent compared to only 8 percent for the whole United States.

Services for this growing population of HIV-infected people lag well behind urban-based services. Clinical experience gained in urban settings is easily communicated to more isolated practitioners—typically through journal articles and conferences. But, urban models for the delivery of care are more difficult to transfer to an isolated setting.

San Francisco’s AIDS response has been cited as a model for cost-effective and compassionate care. This response has been dependent on characteristics unique to cities in general, and to San Francisco in particular. Direct access to tertiary care facilities (hospitals), and large federal grants have supported the urban response to AIDS. In San Francisco, this effort has been further aided by the cooperative efforts of an outspoken, politically astute gay and lesbian community and a tolerant, concerned general population.

In contrast, rural and semi-rural areas experience unique barriers to the creation of HIV services. Local customs and prejudices accentuate the AIDS stigma, acting as a deterrent to the development and open provision of HIV care. A high percentage of indigent patients often burdens poorly funded public health clinics. The distribution of federal HIV funds has focused on urban “epicenters” rather than addressing the needs of the underserved in rural areas. Long distances between clinics impede access to local primary care. Even longer distances limit access to tertiary care centers and, therefore, to experimental therapies. Information and education about all therapeutic options, including support groups and alternative treatments, are less available.

These barriers represent a new challenge to the national AIDS response. A centralized, urban-based approach has failed to support the development of rural and semi-rural services. Two contrasting solutions are available: the creation of regional HIV centers designed to receive the influx of rural and semi-rural patients; or the decentralization of HIV primary care with the dedicated support of established HIV centers.

The North Coast region of California—including the semi-rural and rural areas of Sonoma, Mendocino, and Lake counties—has pursued the path of decentralization. Like San Francisco, the North Coast has a visible and involved gay and lesbian community. But, like other semi-rural and rural areas, the North Coast has had limited resources to develop this response. As such, it offers a parallel to San Francisco’s urban model, and an example of the possibilities and limitations for HIV-related care in non-urban settings.

The North Coast Experience

Because of its proximity to an urban area with a high concentration of HIV disease, the North Coast has an uncommonly high AIDS incidence for a rural or semi-rural area. Sonoma County has consistently ranked among the top four in AIDS incidence of California’s 58 counties. Mendocino has the ninth highest incidence, placing it ahead of all other rural counties. Lake County, ranking twentieth, is also one of the highest among rural
Editorial: In the Country
Robert Marks, Editor

The AIDS epidemic in the United States and other developed nations is unquestionably an urban phenomenon. The size of urban populations, the concentration of people with HIV disease in many cities, and the more tolerant attitudes of city dwellers toward sexuality and drug use have contributed to the faster spread of HIV infection in these areas.

But the epidemiological data cited by Scott Eberle in this month’s FOCUS are a caution against the belief that urban conditions are necessary for the virus to spread. The explosion of HIV disease in the rural U.S. confirms that infectious disease is limited by neither geography nor demographics.

In order to respond to this situation, policy makers and practitioners must analyze the differences between urban and rural HIV disease manifestation and medical and mental health service delivery. The fundamental question Eberle poses is how can successful urban models be used to inform rural service delivery in places like the north coast of California, and how can these models be efficiently transferred? In what ways must urban programs be changed to meet the specific needs of rural populations, rural patterns of living, and rural medical and financial resources? How should services be disseminated: from regional centers or by individual practitioners throughout rural areas?

The Urban Practitioner’s Role

For the majority of urban providers, this analysis may seem to be of little practical significance. The country is far away: “A nice place to visit, but I wouldn’t want to live there.” Learning about the rural epidemic, however, is important first because it reminds us that the epidemic expresses itself differently in different areas, and second because it suggests that urban solutions are not the only remedies, nor are they always the most appropriate.

But academic interest ends where professional responsibility begins. This is not a call for urban practitioners to move to the country to dispense their city medicine. Instead it is a challenge to all of us to acknowledge the widening course of the epidemic, to consider the city lessons that might be relevant to country populations, to be available for consultation to help transfer appropriate technology and approaches, and to be open to the ways in which urban responses may need to be modified to suit rural needs.

The urban epidemic is now in the country. Counties in rural areas are now home to many of the major cities of our nation, as well as the people in those cities. As the rural demographics of HIV disease reflect the demographics of HIV disease in surrounding urban areas, it is no surprise that on the North Coast most HIV transmission has resulted from unprotected sex between men.

With limited HIV-dedicated funds, the North Coast region has been forced to integrate its HIV-related care directly into pre-existing services. The region’s unique strengths—a relatively visible and involved gay and lesbian community and a relatively tolerant general community that is concerned about the overall impact of AIDS—have played key roles in developing this integrated approach. This has evolved through four major stages: individual, agency, community, and regional.

In the early 1980s, one physician was identified as the local “AIDS doctor,” providing over half of Sonoma County’s HIV care. In a similar way, individuals whose lives were touched by the epidemic voluntarily provided much of the hands-on home care.

As the burden of HIV-related care increased, and individual responses were strained, an agency response developed. The lone AIDS doctor was hired to form the county’s HIV Clinic and the volunteer response coalesced to form Face to Face, a non-profit agency providing practical and emotional HIV support.

The successful development of centralized agencies allowed other health care groups to remain minimally involved. But, by 1988, this agency response reached a breaking point. The crisis was exemplified by the county hospital’s experience. By the year’s end, its cumulative total of HIV-related admissions had reached 356, compared to a combined total of 61 admissions at five other private hospitals.

The county then sought to develop a community-wide response. Existing agencies—particularly the HIV Clinic and Face to Face—were conceived as central hubs that would provide initial evaluations, referrals, consultations, and educational outreach. The result was that rather than being overwhelmed by the growing primary care burden, these central agencies instead encouraged the involvement of private physicians, social workers, therapists, nurses, and volunteers.

The move toward a community-wide effort has had three major by-products: the Primary Care Referral system, the Case
Management Network, and the Sonoma County Psychotherapists’ HIV Network. The Primary Care Referral System currently includes over 60 private physicians and 39 county hospital resident physicians.

The Case Management Network is comprised of HIV case managers from 17 different agencies, including Face to Face. The Psychotherapists’ Network offers sliding scale services from 30 private therapists to augment county mental health services.

All three programs depend on a three-pronged approach; the provision of education and consultation by HIV specialists; the management of more difficult cases by a core group of competent primary care doctors, case managers, and therapists and the gradual education of new participants. A comprehensive set of HIV primary care protocols, updated annually, are particularly important in supporting the work of physicians. Educational materials are also being developed for case managers.

Lacking the centralized resources of Sonoma, Mendocino and Lake responses have evolved more slowly, but have been aided by the Sonoma County experience. Sonoma County’s regional outreach was prompted by the federal government’s AIDS Education and Training Center program, which assigned the responsibility of practitioner education for the North Coast to a Sonoma County faculty.

In 1991, the HIV Clinic’s staff began monthly satellite clinics in Mendocino and Lake counties, providing educational and consultative services in these more rural settings. Rather than assuming primary care, these regional visits sought to support the involvement of local physicians and ancillary services. In 1992, a similar outreach program began in southern Humboldt County.

A Centralized Approach

The spread of AIDS to rural and semirural areas prompts a choice between two models of health care delivery: the development of regional AIDS centers or the decentralization of primary care. While both of these approaches deserve attention, the North Coast experience with decentralization offers a model for reconciling pre-existing centralized services with a gradually decentralizing epidemic.

The main advantage of centralization is that regional AIDS centers can offer a consistent standard of care in areas surrounding regional hubs. Four problems, however, may interfere with the success of regional centers. First, quality of care in more isolated communities would remain dependent on referrals from less experienced physicians. At the same time, shifting care to regional centers would encourage outlying physicians to remain ignorant of HIV-related issues. Regional centers may run into the same problems faced by single disease facilities for tuberculosis and mental health; in a study of such facilities, David Rothman and Eileen Tynan concluded that specialization leads to segregation, which enhances stigmatization and social distance, and decreases freedom of choice for patients. Finally, centralized inpatient services discourage the creation of needed outpatient, home care, and case management services.

Decentralization

In contrast to this centralized approach, a move toward community-based HIV primary care in semi-rural and rural areas has important benefits. Increased awareness and familiarity with AIDS among local health professionals improves both early detection of HIV disease and prevention education for the uninfected. The decentralization of primary care disperses the emotional burden of HIV care and prevents provider burnout. Similarly, it relieves the economic burden of AIDS, currently borne disproportionately by public hospitals and clinics. Finally, as the response broadens, each community is better able to tap potential sources of voluntarism.

The greatest barrier to decentralization is that it initially requires the involvement of less experienced physicians. But this is balanced by the fact it provides a mechanism for training front-line practitioners who would otherwise be unable to offer competent care to rural communities with no access to centralized regional services.

In 1988, more than 500 North Coast physicians responded to a questionnaire identifying the key barriers to a decentralized response. These included: the lack of
HIV-related experience, the need for continuing education and consultative support, poor reimbursement for time-consuming work, fear of being labeled as an “AIDS practitioner,” fear of transmission, and dislike of gay men or injection drug users. Several published studies have confirmed these findings.

Overcoming Barriers to Decentralization

The North Coast model addresses many of these concerns. Periodic visits by HIV specialists and daily phone access to specialists between visits support inexperienced and isolated primary care physicians. These consultations provide patient evaluation, physician education, and quality assurance. By supporting the voluntary participation of multiple practitioners, this model also minimizes the burden on a single physician in a community, avoiding the “AIDS doctor” label and distributing the financial burden of AIDS care more evenly.

The dislike of gay men and injection drug users is a more difficult barrier to overcome, particularly in isolated rural communities. Sonoma County, and to a lesser extent Mendocino and Lake counties, have benefited from the work of the lesbian and gay community and its sympathetic allies, particularly because their participation has challenged assumptions and fears about treating gay men. A similar partnership is beginning to develop in support of injection drug users and their access to HIV care.

Communities without a visible and vocal HIV-infected population will be hindered in this ability to challenge the perception that AIDS is “somebody else’s problem.” Outreach from a “regional center” can aid the stabilization and growth of a rural AIDS advocacy group. This consultative and educational outreach is particularly effective when it supports, rather than replaces, local primary care.

In the absence of this regional alliance, local HIV services are left to struggle against overwhelming barriers. If decentralization fails, the default solution is the current system of centralized, urban-based services. The isolated HIV-infected person is left to choose between either substandard local care, long commutes to urban centers, or permanent migration.

Conclusion

Health care in the semi-rural and rural U.S., as in other underserved areas, has reached a state of financial crisis, and this lack of money is the greatest single barrier to the development of adequate rural services. The North Coast has faced this challenge by maximizing limited resources through a decentralized model of care. Rather than assuming sole responsibility for the burgeoning case load, centralized HIV specialty services have encouraged and supported broad-based community involvement by physicians, nurses, social workers, therapists and volunteers. This integrated, community-based model offers some hope of bridging existing service gaps.

Even so, the model’s success begs a larger solution. Much like the North Coast’s centralized HIV services have supported the rural provision of primary care, a national health program is needed to support local HIV services in all areas—be they urban, semi-rural or rural.

Clearinghouse: Rural AIDS

References


Resource Centers

The federal government has established AIDS Education and Training Centers (ETC) in 17 regions throughout the United States. ETCs, staffed by faculties including health and mental health professionals, provide services such as telephone consultation, post-graduate education, and information bulletins. Two regional ETCs—in California and Colorado—are specifically designated as addressing the needs of rural practitioners.
HIV-Related Challenges for the Rural Therapist

Alan Drucker, MD

The most obvious differences between rural and urban communities are size and economic base. While rural communities have fewer people than cities and traditionally have relied on agriculture rather than industry, however, it is the social, political, and moral beliefs of rural residents that influence the emotional consequences of HIV disease in these areas.

HIV-related emotional support is complicated by the psychological landscape of rural communities and the obstacles these communities face in delivering mental health care. Significant characteristics of rural communities that are related to HIV disease are traditional political and moral values, isolation, and a lack of HIV-related supportive resources. This article explores these factors and suggests approaches practitioners should take to address them.

Complicating Factors
“Traditional values” shape standards of conduct in rural communities. Consequently, rural communities tend to be more politically and morally conservative than cities. Attitudes toward those with HIV disease and about common behaviors that transmit the virus result in the severe stigmatization of HIV-infected people.

Rural communities also tend to be less private than metropolitan areas. This often leads to positive attributes such as altruism, shared pride, and empathy. But for those who are considered, or consider themselves, to be “foreigners,” nonconformity may lead to discrimination, abandonment, and feelings of alienation. This means that, for people with HIV disease in rural areas, self-esteem and identity are especially influenced by the degree of acceptance or rejection by the community.

The interaction of these factors—rural conservatism and a lack of privacy—leads to physical and emotional isolation. In cities, people with HIV disease often experience the isolation of the crowd—the sense that they are alone despite the fact that they are surrounded by others in similar circumstances. In rural areas, isolation is intensified by the absence of others with whom to share the experience of HIV disease. This response is exacerbated by the scarcity of HIV-related medical and psychosocial resources in rural areas.

Other factors compound these problems. Rural areas have higher rates than urban areas of substance abuse. Substance abuse in turn aggravates pre-existing mental illness and further leads to impairment in judgment. These conditions increase the likelihood of HIV transmission through needle sharing and unsafe sexual encounters while intoxicated. This is of particular significance with respect to rural adolescents, who may not receive more appropriate care.
HIV prevention education or emotional support in politically and morally conservative rural areas.

Finally, rural communities have been traditionally underserved by mental health providers, and the demand for services exceeds the capacity of available clinicians. These communities have limited resources that further result in unavailable or inaccessible mental health services, increased cost for services, and added stress on those who require and provide such services. In addition, many practitioners have neither experience nor training in the management of HIV-related mental health issues, community awareness and concern about AIDS is limited, and community leaders rarely publicly support HIV-related funding that might remedy this situation.

**Mental Health Approaches**

Any approach to providing HIV-related mental health care in rural communities must address the pronounced impact of fear, prejudice, and rejection on HIV-infected people and their families. While it is unrealistic to expect rapid changes in the conservative and insular nature of many rural communities, effective mental health interventions can focus on creating supportive environments and identifying resources for people with HIV disease.

The typical urban response to HIV-related emotional issues is referral to group therapy and support groups. In rural areas, where HIV prevalence is low, mental health practitioners must rely more often on individual therapy to meet the needs of those affected by HIV disease. Rural therapists may also be more likely than urban therapists to serve as allies, advocates, advisors, case managers, and friends to their clients. These roles challenge traditional doctor-patient boundaries and may require greater time commitments. There are currently few alternatives to this expanded role, but therapists who are keenly aware of their own limits may be able to respond without succumbing to burn-out.

Some practitioners are introducing innovative approaches to providing emotional support without increasing the burden on themselves. A few rural areas are using telephone support groups to overcome distance, and reduce feelings of isolation, enhance coping skills, and provide social support. In other communities, clients use computers with modems to establish “on-line” support groups and to disseminate resource referrals and treatment information.

Many rural communities are forming consortia or networks to share scarce resources among nearby rural communities. While a single community or county may be unable to afford hiring a therapist to meet the needs of its HIV-infected population and their families, two or more communities or counties may be able to hire and share a therapist to treat their combined case loads. This plan is not limited in use to mental health services. It could apply to providing case management services, sharing educational materials, buying medications in bulk, pooling isolated patients to form ongoing support groups, and providing support for isolated practitioners by facilitating their contact with other therapists.

Finally, rural mental health professionals can work over the long term to change their communities so that they are more supportive of people with HIV disease. By educating their own employees, other health care workers, politicians, and community “opinion leaders,” mental health professionals can evoke the sympathetic and altruistic traits of community members to support their HIV-infected neighbors and family members.

**Conclusion**

Differences between rural and metropolitan communities account for intensified feelings of isolation, abandonment, and discrimination often experienced by people with HIV disease living in rural settings. To respond to this situation, the most important task for rural therapists is to seek ways to create supportive networks—by acting as advocates and allies, by employing innovative methods to bring people with HIV disease together, and by working to create support for therapists in isolated and some-

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**References**


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HIV Migration to Rural America

An epidemiological study found that the migration of people with AIDS from cities back to the rural areas in which they were raised accounted for an increase in HIV disease in rural North Carolina. A large number of seropositive cases (60 percent) and AIDS cases (45 percent), however, are now "homegrown," that is, occurring among people who have lived in the area continuously since 1970.

Researchers analyzed data on 199 AIDS and 202 HIV-infected patients who were treated at the University Medical Center of Pitt County (UMCPC) on or before December 31, 1990. They compared overall results with data for North Carolina and New York State, and made distinctions between seropositive people with and without AIDS, and between "homegrown" versus immigrant HIV-infected patients.

In the area served by UMCPC, the number of AIDS cases doubled every 12 months, while in New York and North Carolina incidence leveled off. In addition, in the UMCPC area, the proportion of AIDS cases rose among non-Whites, heterosexuals, women, and people under age 30.

Seropositive people without AIDS in the UMCPC area were most often White, female, injection drug using, and covered by health insurance. When compared with seropositive people without AIDS, those with AIDS were more frequently migrants to the area and people who had contracted HIV through sexual contact.

Immigrants from places like New York transmitted HIV—through heterosexual contact and injection drug use—to rural residents. In comparisons between immigrants and natives, home-grown HIV-infected people were younger and had health insurance, while a larger percentage of immigrant patients died. Women constituted 84 percent of HIV-infected patients.

Seroprevalence among Migrant Workers

A study of rural migrant workers in South Carolina found that 13 percent were HIV infected. Of those who were sexually active within the preceding three months, 46 percent did not use condoms. Significant risk behaviors included heterosexual sex (20 percent), homosexual and bisexual sex (12 percent), injection drug use (12 percent), both drug use and homosexual or bisexual practices (8 percent), and blood transfusion (12 percent). In addition, 36 percent of the cases were attributed to unknown factors.

Researchers administered a questionnaire and offered on-site HIV antibody and syphilis testing and counseling to workers in 15 migrant camps during the summer of 1990. They collected demographic data, and information regarding risk behaviors and history of sexually transmitted diseases. Of the 198 participants, 91 percent were Black, 85 percent were male, and 75 percent were unmarried.

Seroprevalence was higher in this study than in the general population. The fact that testing was done in migrant camps, as well as in health clinics, suggests that increased accessibility may account for the fact that the rate is also higher than that reported in migrant worker studies.

AIDS Group Counseling by Telephone

Innovative “conference call” support groups for rural AIDS patients successfully increased social support and decreased isolation, according to a North Carolina report. These results suggest that telephone technology is effective in overcoming some of the special problems facing people with HIV disease in rural areas.

The group was facilitated by a social worker and consisted of six telephone conference calls among three people with AIDS. The ordered sessions took into account theories of group development and the social service needs of people.

Rapid changes caused by economic conditions—the disruption of the farm economy and the resulting boom-and-bust cycles—have increased mental health complications in rural areas.

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with AIDS. They proceeded through six stages: acquainting members with each other and developing rapport; understanding medical and social care systems; building relationships with family and friends; recognizing and dealing with feelings and beliefs about AIDS and safer sex practices; more discussion on emotions and feelings, as well as spiritual and existential concerns related to dying; wrap-up, review, and evaluation of the group experience. The concerns invariably raised in each session were whom to tell, what to tell them, and how to tell them about having AIDS.

Telephone conference call counseling can overcome several obstacles that may hamper successful HIV-related group support in rural areas. People with AIDS in low-incidence rural areas are often separated by great distances, and they may have difficulty traveling long distances when ill. Both of these problems are compounded by the inadequacy of rural transportation systems. In rural areas, where anonymity is difficult to ensure and HIV-related stigma may be severe, people with AIDS may fear meeting openly in group sessions. In response to these problems, telephone “conferencing” can offer a source of support and communication to people who may be both geographically and emotionally isolated.

**Mental Health in the Rural U.S.**


Despite an increasing need for mental health services in the rural U.S., these areas face a shortage of therapists and have inadequate delivery systems. An overview article on rural mental health describes the characteristics of the rural environment, issues of rural mental health service delivery, the U.S. government response to these issues, and policy considerations for future responses.

Demographics and economic state predispose rural residents to mental health problems. The poor, the elderly, and the disabled, who are at greater risk for mental illness, constitute a disproportionate share of rural populations. The last decade has seen major economic disruption in rural life: the nonfarm population outnumbers the farm population by seven to one, and 40 percent of the nonfarm population is dependent on manufacturing. This sector, with its boom-and-bust cycles, increases mental health complications as the stresses of rapid change take their toll. The general economic downturn has resulted in unemployment leading to the loss of health insurance benefits, and in a decrease in land values that has diminished property tax revenues and the ability of communities to pay for health services.

Rural mental health services are often unavailable or inaccessible. Mental health providers in rural areas are hospital-based and therefore greatly affected by the closure, since 1980, of more than 200 of 2,700 rural hospitals in the U.S. Since mental health training programs are not based in rural areas and do not emphasize rural issues, education reinforces an urban bias. Geographic distance and inadequate transportation and outreach diminish the accessibility of mental health services.

Rural values that emphasize self-reliance, distrust of outsiders, and a lack of knowledge of mental health services exacerbate these problems. This interaction results in a disinclination to use mental health services even when they are available.

**Next Month**

After more than a decade and hundreds of thousands of deaths worldwide, grief has become normalized among those hardest hit by the AIDS epidemic. The May and June issues of *FOCUS* explore the effects of grief on two communities: HIV care providers and gay men and lesbians. In the May issue, Kitsy Schoen, LCSW, a therapist who specializes in managing grief and loss in the workplace, and who has worked in HIV-related hospice and bereavement care since 1984, examines the effects of grief on people who work in HIV care organizations. She discusses the organizational symptoms of grief and loss, the strategies for addressing grief in both small and large workplaces, and the obstacles that present themselves during this process.

Also in the May issue, Michael Kuller, manager of Critical Care America, and Jerry Santek, a member of the Grief and Loss Committee at the San Francisco AIDS Foundation, offer insights from their first-hand experiences addressing grief-related problems in their organizations.
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