AMERICAN INDIANS WITH HIV/AIDS: HEALTH AND SOCIAL SERVICE NEEDS, BARRIERS TO CARE, AND SATISFACTION WITH SERVICES AMONG A WESTERN TRIBE

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Abstract: This study investigated the health care and social service needs, barriers to care and satisfaction with services among American Indians with HIV/AIDS in a western tribe. Individual interviews were conducted with 28 respondents, which constituted nearly the entire population obtaining HIV/AIDS medical services from the IHS in the target area. The survey found that expressed need for services in this frontier rural area were lower than urban counterparts, but that access to needed services was lower. Common unmet medical needs include mental health services, eye and dental care, traditional Native medicine, and substance abuse treatment. Common unmet social service needs include housing assistance, help obtaining food and clothing, and transportation. Limited access to essential services impedes the ability of American Indians with HIV/AIDS to maintain effective medical regimens.

As the AIDS epidemic moves beyond urban areas, rural and reservation based communities are challenged to address the health and social service needs of American Indian and Alaska Native (AI/AN) people with HIV/AIDS (PWHA). Empirical data is needed to inform a rational planning process that takes into account the complex medical, financial, social, and spiritual needs of vulnerable and often stigmatized individuals within a health care environment experiencing rapid changes due to shifts in Medicaid financing, and tribal contracting and compacting. The ability of people with HIV/AIDS to access services profoundly impacts their ability to adhere to the rigorous HIV/AIDS medical regimens that improve quality of life and reduce opportunistic infection and health care costs (Freedberg et al., 1998; Mehta, Moore, & Graham, 1997).

In an effort to improve the quality of life for tribal members with HIV/AIDS, a large tribe undertook a comprehensive needs and capacity assessment to determine HIV related needs across the patient, provider, and system domains. Funding for this project was awarded to the tribe from the Health Resources and Services Administration's (HRSA) HIV/AIDS Special Projects of National Significance (SPNS) initiative. This article reports the results of the respondent-level needs assessment that determined the medical and social service needs, barriers to care and satisfaction with services of tribal members with HIV/AIDS residing on or near a reservation in the western United States.

Background

Compared to other groups, mortality attributable to AIDS is relatively low among AI/ANs (Mahoney & Michalek, 1998; see Stevens & Estrada, 2000). A recent study, however, found that the 5-year AIDS incidence rate among men who have sex with men is rising faster among AI/ANs (53%) than any other ethnic group while incidence among White men in the same risk category is decreasing (Sullivan, Chu, Fleming, & Ward, 1997). The true extent of HIV infection among AI/AN populations is not known; however, the Indian Health Service Area Office that serves the tribe in this study experienced a 25% increase in new AIDS cases in 1997 (J. Iralu, personal communication about incidence of HIV/AIDS in this Indian Health Service [IHS] Area Office, from the infectious disease consultant for the IHS Area Office, 1998). This increase is probably due to better access to state-of-the-art HIV care at this IHS area and not to an increase in infected individuals.

There are currently no empirical studies identifying the health care and social service needs of any AI/AN with HIV/AIDS. Former HIV-related studies targeting AI/AN communities have focused on the need for culturally relevant prevention services and on the prevalence of HIV-related risk behavior and HIV (Fenaughty, Fisher, & Cagle, 1998; Fenaughty, Fisher, Cagle, Stevens, Baldwin, & Booth, 1998; Fisher, Cagle, Davis, Fenaughty, Kuhrt-Hunstiger, & Fison, 1997; Paschane, Fisher, Cagle, & Fenaughty, 1998; Rowell & Kusterer, 1991; Stevens, Estrada, Glider, & McGrath, 1998). For example, one study found that integrated theoretical approaches, good ethnographic data, and rigorous pilot evaluation are needed for the development of successful school-based prevention curricula (Baldwin, Rolf, Johnson, Bowers, Benally, & Trotter, 1996). Another report details an urban-based qualitative prevention needs assessment that incorporates discussions of traditional values and healing practices (Brassard, Smeja, & Valverde, 1996). In a study among Native people living on Reserves in Canada, regression analysis determined the predictors of consistent condom use (Calzavara, Burchell, Myers, Bullock, Escobar, & Cockerill, 1998). A study investigating the use of condoms and partner ethnicity among drug users in Canada found that White men pairing with Native women were least likely of all respondents to use condoms (Fenaughty & Fisher, 1998).

Studies of the health and social service needs of other HIV-affected groups are available and are an important starting point for service planning among AI/AN peoples. Most studies have been conducted among large urban populations and have found widely varying levels of need and unmet need. In San Francisco, Marx, Katz, Park, and Gurley (1997), found health care needs high for medical, dental, and mental health services; need for basic necessities was high for food and living expenses. Unmet health care needs were common for dental, home health care, and alternative therapies; basic necessities were common for childcare, household help, and transportation. Another study of unmet need among people with HIV/AIDS in 10 cities found only 20% of respondents with one or less unmet health care or social services need (Bonuck, Arno, & Green, 1996).

An extrapolation of access to care and level of need for urban residents with HIV/AIDS to rural areas is problematic. Rural residents with HIV/AIDS often have lower financial resources, are more socially isolated and stigmatized, and do not have convenient geographic access to HIV specialty care (Berry, McKinney, & Marconi, 1997).

Methods

The Institutional Review Boards of the Tribal Health Department, the National Indian Health Service (IHS), and a Research University in the western United States approved the survey. From December 1997 through March 1998, a total of 28 respondents were interviewed using a standardized instrument adapted from a large metropolitan area HIV needs assessment study (Marx, et al., 1997). Staff from the IHS and an American Indian AIDS organization, PWHA's and a researcher changed the instrument to include barriers specific to a frontier-rural health care delivery system and issues specific to American Indians. Participation in the survey was limited to those who were IHS health care eligible and who self-disclosed HIV infection. A $25 incentive (gift certificate) was provided to participants to compensate for the time commitment involved. Peer interviewers, trained by the University research team, were HIV-positive bilingual AI's from the reservation population. The small sample size and limited number of peer interviewers eliminated the possibility of duplicate respondents. Interviewees were referred through one of the following sources: (a) an AI-operated private nonprofit HIV prevention and treatment organization operating on the reservation, (b) IHS providers, (c) self referred from information received through posters placed at key locations throughout the reservation, and (d) the tribal health department AIDS Office. Respondents eligible for the study were told of its aims and instructed to call the interviewer team to schedule an appointment if they were willing to participate. All surveys were anonymous and administered in English in one session of approximately 40 minutes. Questions included sociodemographic information, medical care and use within the previous four months, HIV risk group, CD4 cell count, length of time HIV-infected, and perceived need for and receipt of specific HIV-related services in the previous four months. Questions about perceived barriers to services and satisfaction with services received were also asked. Frequency distributions were tabulated using SPSS.

The small number of respondents and convenience sampling strategy of this study limit its ability to be generalized to other AI/AN people with HIV/AIDS. Although the number of respondents is small, the Area IHS Office of Infectious Disease reports only 29 known HIV+ cases in the service area currently receiving treatment.

Results

Profile of American Indians with HIV

Table 1 details demographic information about the respondents. Most participants were male or transgender (86%) and all but two were members of the target reservation tribe. Approximately half of the respondents were under 35 and nearly 90% were under 45 years of age. Nearly 60% of respondents had monthly incomes of less than $500 and another 20% lived on between $500 and $1,000 a month. Educational levels were relatively high with half having some college education or a college degree. Half of the respondents identified as gay and the most common at-risk category was having unprotected sex with infected men. Thirty-six percent (10 respondents) stated they did not have any form of health insurance, although the assumption is that they are all eligible for services from IHS; another third of the sample was on federal insurance. Although many felt their health status was “excellent,” over half of the respondents’ stated they were retired or disabled. The most recent CD4 count was below 500 for 57% of the sample with over 20% unaware of their CD4 levels.

Table 2 outlines health care utilization and living situation for this group of AIs with HIV. The majority of respondents (86%) had received medical care in the previous four months. On average, respondents visited medical clinics four times with three respondents averaging more then ten office visits in the recall period. A third of respondents had sought care in an emergency room and six respondents (21%) had been hospitalized in the four months prior to the survey. Almost a third of the sample (32%) lacked

Table 1
Respondent Demographic and Health Information *N* = 28

Respondent Demographics	Percent	*n*
Gender		
Male	79	22
Female	14	4
Transgender	7	2
Tribal Affiliation		
From target reservation	93	26
From near-by reservation	4	1
Other Indigenous	4	1
Age		
25-35	50	14
36-45	40	11
≥ 46	11	3
Income ($) month		
0	4	1
1 - 500	56	14
501 - 1000	24	6
> 1000	16	4
Education		
High School	48	13
Some College	41	11
College Degree	11	3
Employment		
Full Time / Part Time	26	7
Unemployed	15	4
Retired / Disabled	56	15
Student / Other	4	1
Health Insurance		
Medicaid	35	9
Veterans' Administration	4	1
Private or HMO	11	3
Indian Health Service	18	5
None	36	10

Table Continues

Table 1 (Continued)
Respondent Demographic and Health Information *N* = 28

Respondent Demographics	Percent	*n*
Most Recent T cell Count		
<200	21	6
Between 200 and 500	36	10
> 500	21	6
Don't Know	21	6
Excellent Health		
Agree	71	20
Disagree	29	8
Risk Category		
Men or Transgender		
Unprotected Sex with Men	57	16
Sex with Men and Injected Drugs	11	3
Other Injection Drug Users	7	1
Heterosexual Transmission	14	1
None / Refused	11	3
Women		
Unprotected Sex with Infected Men	4	1
Blood Transfusion	4	1
Injection Drug User	4	1
None / Refused	4	1

Table 2
Respondent Health Care Utilization and Living Situation *N* = 28

Respondent Responses	Percent (%)	*n*
No. of times received care in last 4 months:		
In an office or clinic (mean 4.1)		
0	14	4
1 – 4	57	16
5 – 9	18	5
≥ 10	11	3

Table Continues

Table 2 (Continued)
Respondent Health Care Utilization and Living Situation *N* = 28

Respondent Responses	Percent (%)	*n*
In an emergency room (mean 1.0)		
0	68	19
1 – 4	25	7
5 – 9	7	2
≥ 10	0	0
No. of nights in hospital (mean 0.9):		
0	79	22
1 – 4	11	3
5 – 9	11	3
≥ 10	0	0
Current Living Situation		
Permanent Housing	68	19
Hotel or Shelter	11	3
Staying w/ Friends/Relatives	4	1
Trailer	18	5
Home Amenities		
Telephone		
Yes	56	15
No	44	12
Running Water		
Yes	85	23
No	15	4
Electricity		
Yes	96	26
No	4	1
Transportation		
Yes	30	8
No	70	19
Indoor Toilets		
Yes	56	24
No	14	4
Heating Source		
Electric	26	7
Gas	44	12
Wood/Wood Stove	26	7
Propane Gas		

permanent housing. The majority of respondents had no transportation (68%) and nearly half had no phones (43%). One-fourth of the participants relied on firewood to heat their homes. A small number of respondents (four and one, respectively) lived without indoor toilets and/or electricity.

Service Needs and Barriers to Care

The service needs were high for this population. All 28 respondents reported the need for at least one service and 85% (24) needed four or more services in the previous four months. The most common health or social services needed were medical care (93%), case management (82%), traditional Native medicine (68%), dental care (46%), eye care (40%), mental health treatment (32%), and alcohol and drug abuse treatment (29%) (Table 3). The need was high for transportation (54%), food and clothing assistance (50%), and assistance finding a place to live (32%). No respondents expressed a need for hospice, childcare, foster care, or legal services.

The need for services across categories varied, but the sample's overall acquisition of care was low except for medical care, case management, and transportation (Table 3). The very low economic status of the respondents suggests that service need might have been higher if more community-based services were visible. It may be difficult for people with HIV in remote areas to conceive of services or identify need if the availability of a service has never been historically present.

Of the services for which respondents did express need, some were clearly more difficult to access than others were. Housing assistance was unavailable to all the respondents who expressed need for it (Table 4). Half or more of the respondents needing traditional Native medicine, dental care, food and clothing assistance, and alcohol and drug treatments were unable to access the needed service. Access to eye care and mental health therapy was a problem for a smaller proportion of the sample. The most common barriers to care were lack of knowledge that the service was available or the service not being available, lack of money, no transportation, and long waits for appointments and inconvenient office hours. Although lack of money and transportation and a rigid service delivery system were significant barriers to care, discrimination against this population prevented access as well. Respondents felt that rude and insensitive staff, fears of lack of confidentiality, and inappropriate services prevented them from accessing mental health and drug and alcohol treatment.

Satisfaction with Services

Respondents rated satisfaction with services across multiple dimensions such as location, length of wait, perception of technical expertise,

Table 3
Respondent Needs, Services Received by Total Sample $N = 28$

Service Type	Needed		Not Received*	
	Percent	*n*(#)	Percent	*n*(#)
Medical Care	93	26	14	4
Case Management	82	23	29	8
Traditional Medicine/Herbs	68	19	68	19
Transportation	54	15	57	16
Assistance Paying for Food or Clothes	50	14	79	22
Dental Care	46	13	82	23
Eye Care	39	11	75	21
Assistance Finding a Place to Live	32	9	100	28
Mental Health Therapy	32	9	82	23
Help for Drug or Alcohol Habit	29	8	56	24
Food From Food Bank	29	8	82	23
Assistance Paying For Rent	21	6	89	25
Money Management	14	4	93	26
Legal Advice	11	3	93	26
Volunteer Buddy	11	3	96	27
Translation Services	7	2	100	28
Respite Care	4	1	96	27
Home Health Care	4	1	100	28
Hospice Care	0	0	100	28
Childcare	0	0	100	28
Foster Care	0	0	100	28

*Percent of total sample (28) who did not receive care

and quality of patient/provider interaction. Of services received, satisfaction was high for most aspects of care and with overall experience with the agencies. Location convenience and time with agency staff were scored lower than other aspects of care (Table 5). Overall experience with service was highest for traditional Native medicine, medical care, transportation, and case-management. The only service provided by a non-Indian agency, food and clothing assistance, scored lowest in the satisfaction scale.

Discussion

Rural, reservation-based AI/ANs with HIV live in unique physical and cultural environments that make their need for and access to services both similar to, yet fundamentally different than their urban counterparts. A

Table 4
Percent Did Not Receive Among Those Expressing Need, Top Seven Services Needed *N* = 28

Service	Percent Needed (*n*)	Percent DID NOT Receive* (*n*)	Top Three Reported Barriers to Receiving Care
1.Traditional Medicine/Herbs	68 (19)	53 (10)	1. It's not available. 2. Couldn't afford it. 3. No transportation.
2.Assistance finding a place to live	32 (9)	100 (9)	1. Didn't know service was available. 2. Couldn't afford it. 3. Appointment time not available right away.
3. Assistance paying for food/clothing	50 (14)	57 (8)	1. No transportation. 2. Didn't know service was available. 3. Couldn't afford it.
4. Dental Care	46 (13)	62 (8)	1. Appointment time not available right away. 2. Agency hours not convenient. 3. No transportation.
5. Eye Care	39 (11)	36 (4)	1. Agency hours not convenient. 2. Appointment time not available right away. 3. No transportation.
6. Mental Health Therapy	32 (9)	44 (4)	1. Services not appropriate. 2. Appointment time not available right away.
7. Help for a drug or alcohol habit	29 (8)	50 (4)	1. Services not appropriate. 2. Staff was rude / insensitive. 3. Worried about confidentiality.

* Among those expressing need for the particular service.

comparison of needs between this rural American Indian sample and an urban sample found similarities in needs for medical care, food and clothing, and housing assistance (Bonuck et al., 1996; Marx et al., 1997). Access to and utilization of medical care and food and clothing assistance were comparable, but while approximately half of urban residents were able to access housing assistance, none of the rural AI/ANs in need of housing services were able to obtain them. Housing stability has a potent effect on the capacity of people with HIV/AIDS to adhere to medical regimens and on overall quality of life (Bonuck & Drucker, 1998).

Table 5
Respondent Satisfaction with Top Five Needed Services

	Service Types					
Agency Aspects	Medical Care (25)	Case Mgt. (22)	Tradnl. Med. (7)	Food/Clothing Assistance (6)	Trans-portation (12)	Mean
Getting through by phone	2.5	2.2	2.5	3.0	2.0	2.4
Getting an appointment	2.8	2.0	3.0	3.0	2.2	2.6
Location Convenience	3.2	3.1	3.9	3.2	2.8	3.2
Length of Wait	3.4	2.9	1.7	2.8	2.3	2.6
Time w/ agency staff	2.9	2.4	3.0	3.0	2.5	2.8
Explanation of service	3.0	2.3	1.9	3.2	2.0	2.5
Technical Skills	2.4	2.5	1.9	2.8	1.9	2.3
Personal manner of staff	2.2	2.2	2.3	2.6	1.8	2.2
Overall experience w/ agency	2.1	2.2	1.7	2.6	2.1	2.1
Mean	2.4	2.4	2.9	2.2	2.5	2.5

1=excellent, 2=very good, 3=good, 4=fair, 5=poor

This sample's needs were lower than urban respondent needs for dental, mental health therapy, legal advice, buddy/companions, and surprisingly, assistance paying for rent. Although needs were lower in these service categories, rural AI/ANs experienced less access to dental care, mental health therapy, and food assistance than their urban counterparts (Marx et al., 1997). The rural AI/AN sample expressed higher needs for traditional Native medicine/alternative therapies, and transportation, and had less access to traditional, "alternative" therapies. It is likely that close extended family and clan networks work well for some AI/ANs with HIV/AIDS in rural areas. For those outside the protection of material and emotional support networks, however, access to needed services is lower than in many urban environments with denser AIDS specific medical and social service systems.

That 75% of the PWHA's in this survey were unemployed is problematic, given that 71% rated their health as "excellent." It could be that they have yet to adjust to HIV/AIDS as a chronic illness or that the overall unemployment rate on the reservation (46%) affects their ability to obtain meaningful work. In either case, employment training or assistance, not a traditional Ryan White Care category, may be needed.

Berry, McKinney, and Marconi (1997) propose three dimensions that impact the development of rural HIV service networks: degree of rurality, prevalence of HIV infection and the eipidemiological characteristics of the infected population. Their typology correctly predicts both the current lack of access to services and the planning currently underway among tribal members. The present lack of services is partly due to the “frontier” character of this rural environment and its distance to a Standard Metropolitan Area (SMA) where specialized HIV treatment is more readily available. In addition, the small numbers of cases has, to this point, lulled public health and medical care planners into a false sense of security about the impact of HIV in their area and has hindered effective long-term planning. The model also predicts the current planning efforts as a product of the time afforded providers who are not yet inundated with HIV respondents. Other important variables hinted at in the rural typology (Berry, et al., 1997) are evident here. Namely, the leadership demonstrated by an extraordinary IHS physician and tribal health department planners and the existing well-structured network of care of the Indian Health Service. To the authors’ knowledge, only a few IHS Areas have adopted the gold standard of HIV treatment reflected in this Area’s protocol. Another important factor in the current planning efforts is the availability of federal funds specifically addressing the lack of services for “hard to reach” populations, to wit, the HRSA Special Projects of National Significance (SPNS) initiative. These funds are important in an environment in which many states feel little obligation to extend their federal HIV care funds to tribal populations. This tribe, along with most tribes, receives no Ryan White Care dollars.

It is clear from this study that more culturally relevant and accessible services are needed for rural AI/ANs with HIV/AIDS. More research is needed to develop the methods of providing relevant, cost-effective services for rural, frontier communities. Although unmet need is generally higher, the overall need for services among rural AI/ANs PWHA is lower than urban PWHA. The assumption is that existing family and community networks are providing support for this population. Information about the impact of HIV/AIDS on already stressed family and community social networks is also needed.

Since this data was gathered, this area’s IHS has documented a small number of new cases of HIV among pregnant women. This alarming occurrence speaks to the need to increase prevention services and institute active surveillance in this population. Forthcoming recommendations from the tribe to IHS will ask for active surveillance among substance abuse treatment program respondents, pregnant women, and emergency room patients. Effective treatment and prevention service planning rests upon knowledge of the extent of HIV infection among tribal populations.

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