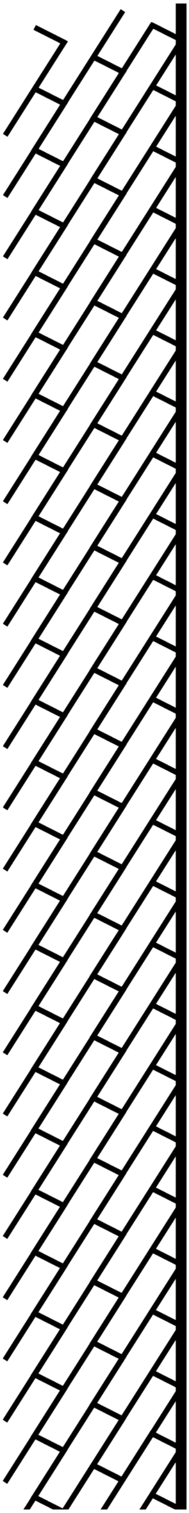

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PATTERNS AND PREDICTORS OF HIV RISK AMONG URBAN AMERICAN INDIANS

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Abstract: A preliminary survey of HIV risk and service preferences among American Indians residing in the New York metropolitan area included 68 women and 32 men (M age=35.8 years). Overall, the sample was knowledgeable about the mechanisms of HIV transmission, and 58% reported having taken an HIV test. However, of the 63% who reported sexual activity in the last six months, 73% reported engaging in vaginal or anal sex without a condom with at least 1 partner, and 52% used condoms none of the time during vaginal and anal sex. Almost half (43%) reported alcohol or other drug (AOD) use for nonceremonial purposes in the last six months. Alarmingly, 44% reported lifetime trauma, including domestic violence (20%) and physical (29%) or sexual (26%) assault by a family member or stranger. Bivariate and multivariate analyses indicated trauma and drug use were factors that may place respondents at risk for sexual transmission of HIV. Trauma variables were better predictors of HIV risk behaviors than social cognitive variables providing preliminary support for the use of a postcolonial framework in American Indian HIV studies.

The Relocation Act (Public Law 959) of the early 1950s instigated a mass migration of American Indians (AIs) from reservation and rural settings to large cities across the United States (U.S.). The Act constituted a modern day attempt by the federal government to deculturate and assimilate AIs. As a result, today more than 60% of AIs from federally recognized tribes live in cities (Bureau of the Census, 1991), with urban communities constituting microcosms of national tribal representation. Migration of AIs from rural to urban settings has led to increases in health problems among this population, including susceptibility to the HIV epidemic.

Only a handful of studies provide any relevant data on urban AI health-related concerns. One from Washington (Grossman, Krieger, Sugarman, & Forquera, 1994) indicated urban AIs were much less healthy than European Americans. For example, risk factors for poor birth outcomes were significantly higher for AIs than for European Americans and resembled the rates among African Americans. All communicable diseases studied were significantly more common among urban AIs than European Americans. Urban AIs also suffer a poverty rate three times that of any other ethnic group, and, as in reservation settings, low socio-economic status correlates with poor health outcomes. These data on the economic vulnerability and ill health of AIs suggest they may be disproportionately at risk of HIV infection (Metler, Conway, & Stehr-Green, 1991).

Despite the risk, only a few published studies in refereed journals offer empirical research regarding AI HIV/AIDS knowledge, attitudes, and behaviors (Brassard, Smeja, & Valverde, 1996; Hall, Wilder, Bodenroeder, & Hess, 1990). The available research indicates AIs are as knowledgeable regarding HIV as the general population (Hall et al., 1990; Meyers, Calzavara, Cockerill, Marshall, & Bullock, 1993), tending to know less about HIV transmission and more regarding specific clinical properties of the disease. One study indicated no overall knowledge difference between AI men and women; however, younger respondents were more informed than older respondents about HIV transmission through blood, casual contact, kissing, and indirect contact (Meyers et al., 1993). In one unpublished study of HIV sexual risk behaviors among AIs living off reserve in Canada, 83% of the 376 sexually active AIs reported at least one incident of condomless sex in the previous 12 months (Bullock et al., 1996). Unprotected sex was significantly more likely for AI men (vs. women) and individuals with a steady (vs. a casual) partner. Consistent condom use was more likely among those familiar with AI traditions and among those reporting a history of physical abuse, whereas inconsistent condom use was positively associated with age and a history of sexual abuse.

Alcohol use and abuse have been well documented as critical co-factors for HIV risk behaviors (O'Hara, Parris, Fichtner, & Oster, 1998; Paul, Stall, & Davis, 1993). Studies have indicated high rates of alcohol abuse among AIs, although there is tremendous variation over time, by tribe, and by reservation (May, 1996). Some studies of reservation-based samples indicate a pattern of lower problem drinking and higher rates of abstinence compared to the U.S. general population, although some urban samples have demonstrated higher rates of drinking (Beltrane & McQueen, 1979; May, 1996). The comorbid relationship between AOD use and precocious sexual activity and potential HIV sexual-risk behavior among AI youth has been well documented (Beauvais, 1992; Conner & Conner, 1992; Walker et al., 1996). However, the specific mechanisms by which alcohol may act as a cofactor for HIV infection are still unclear, and no studies exist that specifically identify the relationship between alcohol use and HIV sexual risk behaviors among adult urban AIs.

Anecdotal and empirical evidence suggests that sexual and drug-related risk behaviors are associated with the legacy of trauma and persistent destructiveness of colonization that AIs have endured (Tafoya & Delvecchio, 1996; Weaver, 1998; Yellow Horse Braveheart, 1998). Alcohol-related problems have been associated with delayed trauma related to child sexual abuse (Flanigan, 1990) as well as other forms of violent crime and trauma (Stewart, 1996). Exposure to traumatic and abusive childhoods (Bartholow, Doll, Joy, & Douglas, 1994; Singer, 1995); sexual abuse (Miller & Paone, 1998); lifetime physical or sexual abuse by a spouse or boyfriend (Fischbach & Herbert, 1997); and rape (Cunningham, Stiffman, Dore, & Earls, 1994) have been associated as well with HIV sexual risk behavior (Wingood & DiClemente, 1998). Research among other groups has indicated that HIV disproportionately affects families already confronted with multiple stressors, including AOD use, abusive childhoods, and other histories of victimization (Havens, Mellins, & Pilowski, 1996; Singer 1995). The cumulative effect of these traumas among AIs has been characterized as a “soul wound,” (Duran, Duran, Yellow Horse Braveheart, & Yellow Horse-Davis, 1998) which must, according to the AI postcolonial framework (Duran & Duran, 1995), be incorporated into any conceptualization of contemporary AI health problems.

Given the potential vulnerabilities and dearth of data on urban AI needs, the current authors undertook a survey of HIV risk behaviors and service preferences among AIs. The focus was on New York City (NYC), the epicenter of the AIDS epidemic and the third largest urban AI community in the U.S. (46,191 in the Metropolitan Statistical Area for NYC according to the 1990 U.S. Census). Although AIs account for fewer than 1% of all AIDS cases reported in NYC, the 1997 cumulative AIDS case rate of 238/100,000 reflects the sizable impact the epidemic has had on this group (NYC Department of Health, 1997). Of the reported AI AIDS cases documented in the AIDS surveillance data in New York City (*N* = 34), 91% are male. Injection drug use (IDU; 39%) and sex with other men (35%) were nearly equal transmission risks among men, while heterosexual transmission (66%) predominated among AI women. HIV seroprevalence studies conducted in NYC have not collected data on AI ethnicity (see Stevens & Estrada, 2000, for an overview of national HIV seroprevalence studies among AIs). The one exception is a linked serostudy from 1991 to 1994 of voluntary testing among drug treatment clients in NYC. Although there were much lower numbers of AIs tested each year than other groups, the percentages of AIs testing positive in each of the four years (20%, 13%, 4%, and 13%, respectively) were comparable to those of African Americans (19%, 17%, 13%, and 11%, respectively).

In this article, we report findings from a focus group and a pilot survey. In addition to descriptive as well as program planning information, preliminary data on predictors (including AOD use and trauma variables) of lifetime HIV risk behaviors and condom use are provided. We aimed to identify, in a preliminary manner, individual or contextual factors that relate to risk behaviors, which is a standard approach utilized for HIV needs assessment studies and community planning groups (Kelly, 1995; Valdiserri, Aultman, & Curran, 1995). Because the majority of HIV studies utilize conceptual frameworks based on social cognitive theory (Bandura, 1986) and the theory of reasoned action (Fishbein & Ajzen, 1975), we assessed HIV knowledge, self-efficacy for safer behavior, and perceived personal risk (Jemmott & Jemmott, 1991; Somlai, Kelly, Wagstaff, & Whitson, 1998) as potential predictors of HIV risk behaviors. We utilized AI postcolonial theory (Duran & Duran, 1995) as the fundamental framework for the mulitvariate exploration of the relationships among trauma, substance use, and HIV risk behaviors.

Method

Participants

The sample consisted of 100 AIs—68 women and 32 men. They ranged in age from 18 to 75 years (*M*=35.8; *SD*=12.6) and were fairly well educated, with 88% having earned a high school diploma/GED and 32% at least a bachelor’s degree. Monthly income surpassed $2,400 for 47% of the sample. Over the previous 12 months, 55% were employed full-time, 25% part-time, and 20% were unemployed. The sample was predominately heterosexual (91%). Although 55% reported a steady intimate partner, only 16% were legally married (note that “valid” percentages are reported throughout the paper—i.e., participants with missing data on the particular item were excluded).

Self-reported individual blood quantum across all tribes varied as follows: 1-25% (20%), 26-50% (43%), 51-75% (18%), 76-99% (9%), and full-blooded (10%); 53% of participants were enrolled in an AI tribe. Two percent had attended an AI boarding school. Only 9% had lived on an AI reservation or tribal lands within the last year. One-third of the sample had been adopted (4% by AI families and 28% by non-Indian families). Most (86%) had learned English as their first language.

Measures

Questionnaire items assessed HIV sexual and drug risk behaviors, attitudinal items, trauma, barriers to condom use, female condom attitudes, and program planning issues. Items validated in other studies of HIV risk (e.g., Kelly, 1995; Somlai et al., 1998) were used when possible.

Lifetime HIV Risk Behaviors

From a checklist of 15 HIV risk behaviors (see Table 1 for the actual items), respondents indicated those in which they had engaged at any time in their life. As indicated in Table 1, the risk factors were collapsed into three risk categories. Three items referring to IDU either by itself or in association with sexual behavior were used to calculate an IDU-sex risk variable. The two items referring to sexual behavior while drunk or high were used to calculate the high-sex variable. Seven sexual risk behavior items were combined to form an indicator of sex risk (omitting condomless vaginal, anal, and forced sex because of their conceptual overlap with trauma and steady partner). As the sum scores for these three variables were not normally distributed, dichotomous indices were created such that respondents having engaged in any of the relevant items were assigned a “1” and others a “0”.

Sexual Behaviors

Respondents indicated whether they had sex with any man or woman in the past 6 months (we defined “sex” for the respondents as physical contact that goes beyond hugging and kissing but does not necessarily include intercourse). Those who answered affirmatively indicated the number of their male and female sexual partners during that period as well as the number of partners with whom they had engaged in vaginal, anal, and oral sex with and without a condom (e.g., “your penis in her vagina—without a condom”). Consistency of condom use during oral sex and vaginal/anal sex was assessed with two additional items scored from *none of the time* (1) to *every time* (5).

Substance Use

Respondents reporting AOD use outside of ceremonial or religious settings in the last 6 months described how frequently they had used alcohol to the point of being drunk, cocaine powder, crack cocaine, marijuana, inhalants, amphetamines, heroin, ecstasy, hallucinogens, sedatives, and IDs as *not at all*, *a few times*, or *fairly often*. The IDUs indicated if they had used only clean needles. Additionally, respondents indicated with two yes/no items whether their condom use had been affected by their own (or their partner’s) AOD use in the past 6 months.

Attitudinal Factors

Three measures were used to assess cognitive and attitudinal constructs according to social cognitive theories. Participants' *knowledge* of HIV transmission was assessed with 23 true or false items (Kelly, St. Lawrence, Hood, & Brasfield, 1989). Internal consistency (Cronbach's alpha) in the present sample was .69. A scale of nine items was used to assess *self-efficacy* for safer drug and sexual behaviors (Smith, McGraw, Costa, & McKinlay, 1996). Respondents were asked how sure they were that they could, for example, talk about safe sex with a sexual partner or buy condoms. Each item was scored from *not at all sure* (1) to *extremely sure* (5). Internal consistency in the present sample was .86. Finally, one item asked respondents to estimate their *perceived risk* of contracting HIV/AIDS from *no risk* (0) to *high risk* (3).

Trauma

With a checklist of six items (e.g., physically assaulted by family member), respondents indicated whether they had ever been physically or sexually assaulted by a spouse/partner, family member, or stranger.

Barriers to Condom Use

From a checklist of 16 items (Meyers et al., 1993), the sexually unsafe participants were asked to indicate all the reasons they did not use a condom or barrier during vaginal and anal sex in the last 6 months.

Attitudes Toward the Female Condom

Participants were asked six yes/no items about the female condom. Internal consistency in the present study was .59.

Community and Program Planning

Finally, in a series of checklists and one open-ended item, respondents indicated targets for HIV communication they had used and preferred, service preferences, and barriers to accessing services.

Procedure

The present survey constituted the first step in a comprehensive assessment of HIV risk behaviors and service among AIs in NYC. A literature review, key informant interviews, a focus group of HIV educators (described later), and pilot testing of measures preceded work on the survey.

Two AI women active and known in the AI community were informed about the project and trained to distribute the present survey at an AI gathering (powwow) in an outer borough of NYC in the summer of 1997. The two workers recruited a convenience sample by encouraging AI men and women who approached the American Indian Community House (AICH) HIV outreach table to complete the survey and by circulating at the powwow and encouraging AI individuals to go to the table to complete the questionnaire. AI individuals who did not want to approach the table were given the survey to complete away from the table.

The study's title (American Indian Wellness Project) and eligibility criteria (at least age 18 and of AI descent) were clearly printed on the cover sheet of the questionnaire. The introduction thanked respondents for volunteering and stated that the information provided would be used to access funding and to provide services that will better assist AI people. Respondents were paid $5 for completing the survey, which required less than 30 minutes.

Results

The qualitative themes that emerged from the focus group and key informant interviews are highlighted below, followed by a discussion of the quantitative results. To identify any potential subgroups at risk, we ran bivariate analyses using chi-squares, *t* tests, and Pearson correlation coefficients with all the general and Indian-specific demographic indicators and the main variables of interest. The very few that were significant are controlled in the multivariate analyses.

Qualitative Data

To identify critical community-based needs and themes, we interviewed key informants, including service recipients and other community members, and conducted a focus group with eight AI service providers (four men and four women), including case managers, outreach workers, and staff. This preliminary qualitative work suggested AI gay men, youth, and women in violent relationships were at increased risk for exposure to HIV due to unsafe sexual practices. Sex traders, IDUs, and their partners were also identified as being at risk. Participants expressed concerns regarding circular migration; in particular, they cited AI men who come to the city for job-related concerns and have anonymous sex with other men and then return to their wives in AI communities upstate. In terms of AOD use, the outreach coordinators stated that AI youth are likely to engage in sex and alcohol use simultaneously, thereby increasing their risk for HIV exposure. They also mentioned culturally specific risk behaviors, including skin piercing, marking (i.e., tattooing), and the use of indigenous healing practices that involve blood (i.e., piercing, blood letting). One member noted that during ceremonies (e.g., at Sun Dance which involves piercing the chest for men and dancing until feet might become bloody for both men and women), some medicine people are beginning to take precautions to protect against HIV infection such as cleaning piercing equipment.

Attitudinal Factors: Risk Perception, Self-Efficacy, and HIV Knowledge

Two survey respondents indicated they were HIV seropositive; others reported they had no (32%), low (52%), moderate (13%), or high (2%) risk of getting HIV/AIDS. The mean level of self-efficacy for safer behavior was 4.55 (*SD* = .69) of a possible 5 and was highly negatively skewed. The mean level of HIV knowledge also was fairly high (19.91 of a possible 23; *SD* = 3.03). Items most frequently missed (and the correct answers) were: “People who have the AIDS virus quickly get sick” (F), “A negative result on the HIV test can happen even if somebody has the AIDS virus” (T), “No case of AIDS was ever caused by social (dry) kissing” (T), “By having just one sex partner at a time you can protect yourself from AIDS” (F). Four independent-samples *t* tests indicated HIV knowledge was generally higher among the 81% of the sample who personally knew someone with HIV/AIDS, $t(98)=-2.25$, $p\leq.05$; the 41% who had family or close friends with HIV/AIDS, $t(97)=-1.87$, $p\leq.10$; the 78% who had considered having a test, $t(98)=-2.24$, $p\leq.05$; and the 58% who had actually taken the test, $t(98)=-2.34$, $p\leq.05$. HIV knowledge was positively correlated with self-efficacy to engage in safer behaviors, $r(98)=.36$, $p\leq.001$, but, contrary to social cognitive models, neither predicted any drug, trauma, or HIV sexual risk behavior indicator.

Lifetime Exposure to Trauma

A relatively small number of respondents reported physical assault by a family member (16%), spouse/partner (16%), or stranger (19%), or sexual assault by a family member (13%), spouse/partner (7%), or stranger (15%). However, when responses were collapsed across perpetrator, another, more disturbing picture emerged: 29% reported physical assault by a nonpartner, 26% reported sexual assault by a nonpartner, and 20% reported physical or sexual assault by a partner (i.e., domestic violence). All three were intercorrelated.

Patterns of Risk Behavior

Lifetime drug and sexual risk behaviors. From a checklist of 15 lifetime drug and sexual risk behaviors, participants reported engaging in an average of 3.40 (*SD*=3.31); 76% had engaged in at least one. Percentages for each behavior are shown in Table 1.

Table 1
Lifetime Risk Behaviors

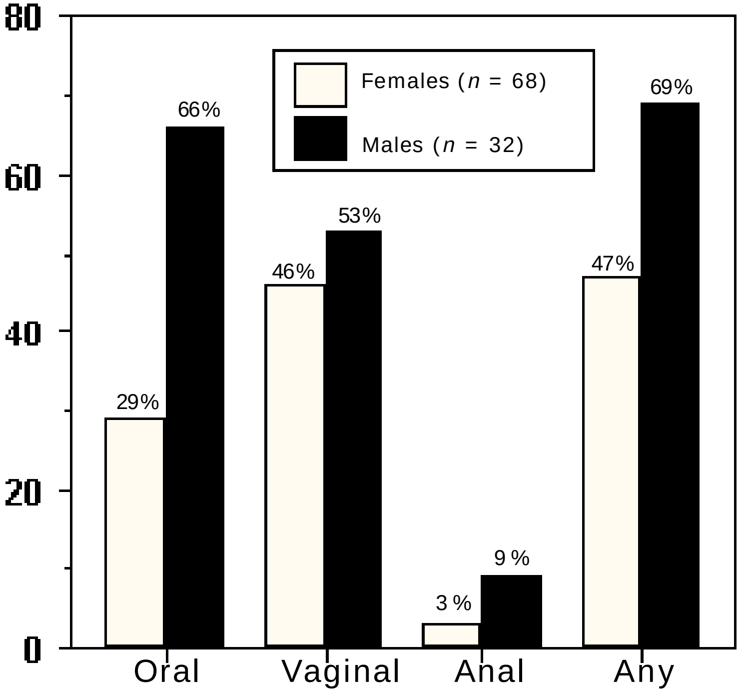
%	Behavior
67	Condomless vaginal intercourse
51	[3]Sex while drunk or high
42	[3]Condomless sex while drunk or high
31	[2]Sex with a non-monogamous partner
29	[2]Sex with a stranger
24	Condomless anal intercourse
22	[2]More than 2 sexual partners in a month
20	[2]Sex with someone with an STD
19	[2]Had an STD
13	Forced condomless sex
10	[1]Sex with an injection drug user
8	[2]Traded sex for money, drugs, or favors
4	[1]Injected nonprescription drugs
4	[2]Sex with HIV+ person
3	[1]Shared dirty needles

Note: *N*=96–98. STD=sexually transmitted disease. 1=used to calculate the IDU-sex risk indicator. 2=used to calculate the sex risk indicator. 3=used to calculate the high-sex indicator.

Sexual risk behaviors in last 6 months. Analyses indicated 63 participants (39 women and 24 men) reported sexual activity in the last 6 months. Among the sexually active participants, 73% had engaged in condomless anal or vaginal sex with at least one partner. Rates of unsafe sex (condomless vaginal, oral, or anal) within each relationship dyad were as follows: female participants with women (*n*=1) 100%, female participants with men (*n*=40) 78%, male participants with men (*n*=4) 100%, male participants with women (*n*=21) 82%. Figure 1 shows rates of unsafe sex by gender. The two items assessing consistency of condom use indicated only 17% of participants used condoms all of the time (52% none of the time) during vaginal/anal sex and 7% used condoms all of the time (85% none of the time) during oral sex.

Drug risk behaviors in the last 6 months. In the past 6 months, 43% of the participants reported AOD use for non-ceremonial purposes. Twenty-seven percent had used alcohol to the point of being drunk, 22% used marijuana, 4% used IDUs, and less than 6% used each of the remaining drugs. Only 3% of respondents said their condom use had been affected because they were drunk or high (2% said because their partner was drunk or high).

Figure 1
Percentage of Male and Female Participants Engaging in Oral, Vaginal, and Anal Sex Without a Condom in the Last 6 Months



Predictors of Risk Behaviors: Multivariate Analysis

A correlation matrix of bivariate analyses (depicted in Table 2) indicated trauma and drug use may be correlated with sexual risk behaviors. To further explore these associations, we created three multivariate sexual risk behavior models—one for lifetime sex risk behaviors and the other two for unsafe sex in the past 6 months. Variables were selected for inclusion in the models based on their significance in the bivariate analyses.

Lifetime Sex Risk Behaviors

Trauma exposure variables (domestic violence and nonpartner sexual assault) as well as lifetime IDU-sex and high-sex behaviors were explored as predictors of lifetime sex risk behaviors in a simultaneous least squares

Table 2
Intercorrelations Among Main Variables

Variable	%	1	2	3	4	5	6	7	8	9	10
Trauma Variables (Lifetime)											
1. Nonpartner physical assault	29										
2. Nonpartner sexual assault	26	.51***									
3. Domestic violence	20	.18†	.34***								
AOD and Sexual Risk Behaviors (Lifetime)											
4. IDU-sex risk	12	.24*	.14	.35***							
5. High-sex	51	.19†	.21*	.10	.25*						
6. Sex risk	51	.14	.25**	.35***	.30***	.57***					
Demographic Factors											
7. Steady partner status	55	-.02	.04	-.01	-.10	.21*	.01				
8. Income	na	-.11	-.11	-.20†	-.05	-.06	-.14	.20*			
Risk Behaviors (Last 6 Months)											
9. AOD use	43	.09	.05	.07	.05	.28***	.23*	.23*	-.10		
10. Condomless vaginal/anal sex	73	.06	-.01	.19	.02	.12	.12	.36***	.29*	-.06	
11. Condom consistency for vaginal/anal sex	na	-.05	-.24†	-.21	-.18	-.18	-.17	-.44***	-.25†	.03	-.49***

Note: *N*=97-100, except for #10 and #11 where *N*=58-63. Statistics are Pearson correlation coefficients.

†$p<.10$. *$p<.05$. **$p<.01$. ***$p<.005$.

logistic regression (refer to Walters & Simoni, 1999, for an analysis of women only). Steady partner status was not included because the model included risks across the lifetime and only current partner status was assessed. The simultaneous logistic regression model was significant (X^2 [4, *N*=95], *p*<.005, Hosmer-Lemeshow statistic=1.75, *df*=4, *p*=.78), indicating respondents who had engaged in sex while drunk or high were 14.35 times more likely than those who had not to engage in risky sexual behaviors (odds ratio [OR]=14.35, 95% Confidence Interval [CI]=4.65, 44.25). Additionally, those who had experienced domestic violence were 9.26 times more likely than those who had not to engage in risky sexual behaviors (OR=9.26, 95% CI=1.80, 47.53). Neither sexual assault nor IDU-sex risk had a significant net effect on lifetime sexual risk behaviors.

Unsafe Sex in the Last 6 Months

Income and steady partner status were explored as predictors of condomless vaginal or anal sex in the last 6 months in a simultaneous logistic regression (trauma and AOD were not significant in bivariate analyses and, therefore, not included). The logistic regression model was significant (X^2 [2, *N*=62], *p*<.01, Hosmer-Lemeshow statistic=7.50, *df*=4, *p*=.11), indicating that respondents in steady partnerships were 4.33 times more likely to engage in condomless vaginal or anal sex than those without steady partners (OR=4.33, 95% CI=1.11, 16.77). Monthly income status had no net effect on condomless vaginal or anal sex.

Consistency of Condom Use in the Last 6 Months

Nonpartner sexual assault, steady partner status, and monthly income were explored as predictors of consistency of condom use during vaginal and anal sex in the last 6 months in a simultaneous regression. The model accounted for 23% of the variance in consistency of condomless sex, *F* (2,52)=7.69, *p*.<005. Having a current steady partner (*B*=-.40, *T*=-.22, *p*≤.005) as well as a history of nonpartner sexual assault (*B*=-.27, *T*=-2.25, *p*≤.05) were predictors of decreased consistency of condom use. Monthly income had no net influence.

Reasons for Not Using Condoms

The 48 participants who had unsafe vaginal or anal sex in the past 6 months indicated from a checklist of 16 items all the reasons they had not used a condom. The majority indicated being with their steady partner (87%), assuming they were safe (68%), not having the AIDS virus (63%), and simply not wanting to (57%). They less frequently endorsed their partner not wanting to (41%), their partner saying he or she did not have the AIDS virus (37%), not having a condom at the time (29%), the sex being so exciting they didn't want to use one (26%), finding condoms painful or uncomfortable (14%), using AODs (10%), desiring pregnancy (6%), their partner getting angry for suggesting using one (6%), and being too embarrassed to get condoms (4%). Two percent each said not being able to talk about it, not being able to afford condoms, or being forced to have sex against their will were reasons for not using condoms.

Attitudes Toward the Female Condom

Respondents reported generally positive attitudes toward the female condom. Most reported having heard about (88%) or seen (55%) this new contraceptive and would consider using it (67%) or would like to learn how to use it (57%). However, far fewer had personally bought or obtained (11%) or actually used one (6%).

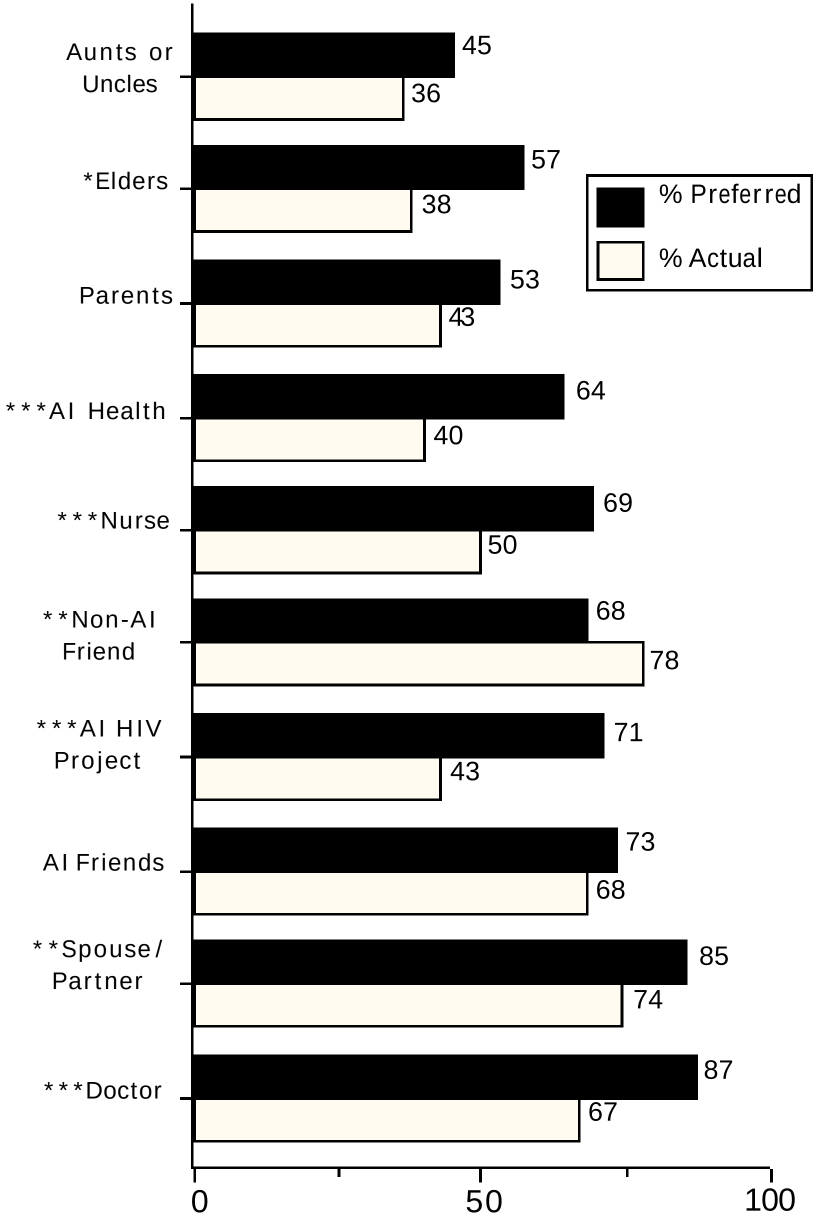
Community and Program Planning Issues

As shown in Figure 2, most respondents indicated they would prefer to speak about HIV/AIDS to doctors, followed by their spouse/partner and AI friends. Paired *t* tests of mean responses indicated a higher percentage of respondents preferred to speak to doctors, their spouse/partner, AI HIV project staff, nurse, AI health representative, or elders than those who actually did speak to these targets, whereas a lower percentage of respondents preferred to talk to non-AI friends than those who actually did.

In answer to an open-ended item on what services would decrease respondents' risk of getting HIV/AIDS or would assist them if they had HIV/AIDS, respondents indicated culturally relevant peer counseling and outreach, telephone hot line, outreach to youth (especially in the schools), condom negotiation skills, peer groups, TV programs, free condom distribution, and public workshops by healthcare providers. Additionally, in response to a checklist of which HIV services would be most helpful to them, respondents indicated sex education and condom use to AI youth (77%), HIV education services at the AICH (75%), cultural approaches to negotiating condom use (62%), instruction in how to use the female condom (61%), HIV education services available in your home (52%), and instruction in getting a partner to use a condom (45%).

Responses to the checklist of means of being informed about HIV/AIDS services indicated respondents preferred direct, face-to-face encounters such as educational talks or workshops (68%) and community outreach workers (36%), followed closely by more anonymous methods such as television (55%), AICH bulletin (34%), pamphlets (31%), radio (29%), word-

Figure 2
Preferred and Actual Sources of HIV Information



Note: *N*=94-100. Statistics were paired *t* tests of mean preferred versus mean actual percentages for each target.
**p*<.05. ***p*<.01. ****p*<.005.

of-mouth (26%), or other (15%). Only eight respondents needed or wanted information, education, or treatment related to HIV in the last 6 months. As only four attempted to access these services, we did not conduct analyses of reported barriers.

Discussion

A survey of 100 AIs at a powwow in NYC provided some of the first data available on the HIV risk behaviors of urban AIs. Findings indicated relatively high knowledge and self-efficacy for safer sex behavior, which may indicate that HIV education and outreach have been successful with this population. However, elevated knowledge and self-efficacy were not associated with safer sex behaviors (i.e., consistent condom use), which may suggest that community education and outreach does not adequately change community behaviors. Although this study did not adequately test social cognitive models, these findings suggest the effectiveness and applicability of such models need to be further considered with respect to urban AIs.

The majority of respondents knew someone living with HIV/AIDS. Over half had been tested for the virus, and 2% were HIV-positive. This seroprevalence is almost three times the estimated rate for NY state of .8% and corresponds with initial Indian Health Service seroprevalence estimates of 1-3% for AI populations. Of course, we employed a nonprobability sampling design, limiting the extent to which we can generalize these findings.

Among the 63 participants who were sexually active in the last 6 months, rates of condomless sex were high and related to having a steady partner. Inconsistent condom use was related to having a steady partner and nonpartner sexual assault. These findings support targeting couples for safer sex condom interventions. Future research will need to identify the specificity of the HIV risk associated with condomless sex among different types of steady partner relationships (i.e., monogamous or nonmonogamous). Because approximately one-third of all AI children are estimated to be at risk for becoming victims of child abuse, with AI girls incurring disproportionate sexual and physical abuse (National Indian Justice Center, 1990), it is imperative that future studies identify the cumulative effect of sexual trauma on condom use among AIs. The finding also highlights the importance of integrating sexual trauma survivor issues into HIV prevention strategies.

Over two-thirds of the sample engaged in at least one unsafe sexual or AOD risk behavior in their lifetime. Moreover, exposure to trauma, AOD use, and sexual risk behaviors were intercorrelated, suggesting these factors needed to be considered in concert to decrease HIV risk among urban AIs.

These initial findings on the relationship between AOD use and exposure to trauma are supported by previous research. Preliminary studies of both non-AI male and female samples suggest that there is a causal connection between childhood victimization and development of drinking problems (Flanigan, 1990). Kovach (1986) postulates that the link between childhood abuse and adult alcohol abuse might be mediated by a delayed onset of posttraumatic stress disorder (PTSD) symptoms in adulthood with which the individuals attempt to cope through alcohol abuse (i.e., self-medication hypothesis). Other studies also supported this linkage with respect to exposure to other forms of violent crime and trauma (Stewart, 1996). Kilpatrick, Acierno, Resnick, Saunders, and Best (1997) found that the severity of trauma symptoms is positively associated with comorbid alcoholism across a variety of traumatic events. Future research with AI populations will need to identify the role of PTSD or other traumatic symptomatology as a factor related to AOD use in sexual encounters. Previous trauma might have implications for current sexual behavior, negotiation skills in sexual encounters, and alcohol use as a form of self-medication (Stewart, 1996) among AI populations.

Future research will need to discern how the patterns of sexual risk behaviors are temporally associated with AOD use and exposure to trauma. For example, the self-medication hypothesis postulates that AOD use dampens cognitive symptoms (Stewart, 1996). Individuals exposed to trauma may be at increased risk for learning to drink to reduce tension. Consistent with a postcolonial framework (Duran & Duran, 1995), alcohol may be used as a coping mechanism for those who have experienced prolonged, cumulative trauma, although future research will need to empirically substantiate this possibility. Although there is evidence of the comorbidity of alcohol-related problems and trauma among AI populations, studies of comorbidity fail to resolve the temporal ordering of AOD alcohol use, trauma exposure and subsequent HIV sexual risk behaviors. Future research will need to identify the temporal patterns of exposure to trauma (including delayed traumatic reactions) and alcohol-drug use (including drinking styles) to ultimately discern the mechanisms by which alcohol and trauma may act as covariates in sexual risk-taking. Moreover, the mixing and phasing of AOD while simultaneously engaging in risky sexual behaviors reinforces the importance in future research of identifying the contextual use of alcohol in relation to sexual expectations (i.e., alcohol-sex expectancy).

The data on services have implications for community-based HIV preventive program planning among urban AIs. Findings that 57% of the respondents were willing to learn how to use the female condom indicate the eagerness of AIs to incorporate new HIV prevention strategies. AIs in the study also identified preferred targets for HIV communication (e.g., doctors), but we need further information as to the preferred gender, age, ethnicity, and tribe (if these preferences exist). Some AIs may not want to access a local tribal-affiliated organization for fear that via the "moccasin telegraph" their questions or concerns will not remain confidential. Participants also indicated a strong preference for direct, face-to-face encounters for public dissemination of HIV education, suggesting the possibility of home visits. In fact, in a study of domestic violence among urban AIs, Norton and Manson (1995) successfully used home visits. Perhaps a culturally appropriate home-visit intervention could address domestic violence and HIV risk simultaneously.

There are several important methodological limitations to these data. First, because we employed a non-probability convenience sample (of mainly heterosexual, educated women), generalizability of the findings is not possible. Future studies might incorporate modified probability sampling methods, such as multiplicity sampling (Rothbart, Fine, & Sudman, 1989). Second, because the data were self-reported, the findings may be subject to social desirability. Future research comparing self-administered versus interview survey methodologies among AIs are warranted to decrease cultural insensitivity and social desirability. The results from the focus group and key informant interviews support matching respondents by gender for survey interviewing techniques given the charged nature of the HIV sexual risk behavior questions. Third, our assessment of trauma, AOD use, and sex risk variables was primarily dichotomous and did not provide depth and breadth or the social context related to such behaviors. For example, drinking styles (abusive vs. moderate), chronicity, frequency, and quantity of AOD use were not addressed. Additionally, we did not identify the role of the steady partner and meaning of that relationship to the respondent (again it was a dichotomous variable) which would give us a better understanding of what steady partner status means in terms of inconsistent condom use. Further quantitative and qualitative methods for psychometric refinement regarding trauma, AOD use/ abuse, and HIV sexual risk behaviors clearly need to be cultivated, validated, and refined in collaboration with AI populations. Finally, our cross-sectional design precludes any causal interpretations.

Despite these methodological limitations, the study has provided some preliminary data on an understudied and potentially at-risk population. Future preventive efforts should consider the strengths and resources of those who are using condoms consistently. Incorporating the role of resilient AI community members into the development of research and community intervention would not only facilitate construction of culturally meaningful interventions, but would also reinforce the current resilience and strength of urban AI communities.

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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

Agency Aspects	Service Types 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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THE *AHALAYA* CASE-MANAGEMENT PROGRAM FOR HIV-INFECTED AMERICAN INDIANS, ALASKA NATIVES, AND NATIVE HAWAIIANS: QUANTITATIVE AND QUALITATIVE EVALUATION OF IMPACTS

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Abstract: The Ahalaya *case management model was designed to provide culturally sensitive services to HIV-positive American Indians (AI), Alaska Natives (AN), and Native Hawaiians (NH). This program started in 1991 and expanded across the country in 1994. The evaluation plan included a client satisfaction survey, along with focus groups and key informant interviews. Of the 389 active clients enrolled, 132 responded to the anonymous 35-item questionnaire. Responses were favorable regarding benefits of the programs. Self-reported quality of life changes after enrollment also were significantly improved (Wilcoxon Signed Rank Test: T=6.87, p=.000; n=131). Qualitative data highlighted other important issues. Social relationships—with staff, community, and family—were critical to client welfare, as a source of both strength and fear. While AI/AN/NH case management programs have been shown effective, services need to expand, and they have to facilitate resolutions to problems in clients' social relationships.*

The emergence of HIV/AIDS among American Indians, Alaska Natives, and Native Hawaiians (AI/AN/NHs) has had a profound effect on communities, seen not only in the greater numbers of HIV infections and AIDS cases (Centers for Disease Control and Prevention, 1998; Hawai'i Department of Health, 1998; Stevens & Estrada, 2000) but also in the allocation of resources. Case management is but one component of the entire suite of activities directed toward prevention, education, care, and research services, but it is vital in its role as the primary entryway and advocate for client services.

Case management is pervasive in the health and social service industries, but there is little consensus about definition (e.g., Baldwin & Woods, 1994; Centers for Disease Control and Prevention 1997; Graham & Birchmore-Timney, 1990; Piette, Fleishman, Mor, & Dill, 1990). Services are highly varied and appear to reflect the core of programs (i.e., medical, mental health, substance abuse, or social, etc.), the locus (e.g., the services linked to and managed by a program), and the source of funding, among others (e.g., Piette, Thompson, Fleishman, & Mor, 1993). Given this variability, it might be best to understand case management as "...the provision for some greater continuity of care through periodic contact between case manager(s) and the client that provides greater (or longer) coordination and brokerage of services than the client could be expected to obtain without case management" (Orwin, Sonnefeld, Garrison-Mogren, & Smith, 1994, p. 154).

HIV/AIDS case management specific to AI/AN/NH populations is confronted by a unique set of circumstances. This subpopulation is characterized by the over-representation of problems found to describe the population as a whole. Data from the 1990 U.S. Census (1993) depict an AI/AN population that has a lower life expectancy than the general population, higher rates of poverty and unemployment, and lower rates of educational attainment. Most AI/ANs live in urban areas (56.2%), while much smaller proportions reside in rural, non-reservation locations and on reservations (D'Angelo, 1996; Snipp, 1996; U.S. Census 1993). Access to health care through the Indian Health Service (IHS) is limited by the Service's role as a provider of "last resort" and its restriction to reservation-based populations within the thirty-three "reservation states." Even in some of these communities estimates suggest that less than half of eligible AI/ANs use these services (Burhansstipanov & Dresser, 1993). Urban populations experience even more extreme conditions, receiving less than 1.2% of the IHS annual budget to support a network of 34 urban clinics (Indian Health Service, 1997). Native Hawaiians exhibit similar patterns, with greater rates of poverty and low income, higher mortality rates, and lower rates of educational attainment in the lower and higher grade levels, among others (U.S. Census, 1992).

Case management clients exhibit these same traits and are subject to these same discrepancies, but all at notably higher levels. Compounding these conditions are cultural, historical, and ethnic differences that keep many AI/AN/NH clients from engaging mainstream service programs (Lockart, 1981). These barriers, in fact, constitute major problems for AI/AN/NH clients and impede their ability and desire to seek services. These circumstances, when superimposed on an HIV infection, have demanded Native-specific case management to overcome many of the barriers to care encountered by these individuals (Barney & Duran, 1997).

The Ahalaya HIV/AIDS Case Management Model

The *Ahalaya* case management program was designed on a model developed and evaluated by AIDS Arms of Dallas (Piette et al., 1993). This free-standing community-based agency functions as an independent entity, free from any direct affiliations with medical or other service providers. Hospital-based case managers typically have greater access to entitlements, and free-standing case managers have better access to the clients (Indyk, Belville, Lachapelle, Gordon, & Dewart, 1993). The latter type of case management service is better able to address the very broad diversity of needs found among AI/AN/NH HIV/AIDS clients.

The *Ahalaya* case management model incorporates the basic structure of the AIDS Arms project (Piette et al., 1993), and expands its utility through the incorporation of Native-specific elements (Barney & Duran, 1997; Bellymule, 1992; Bellymule & Geren, 1993). The model possesses two principal structures, the *linkage framework* and *case management procedures*. The framework consolidates access to medical, mental health, spiritual, social, emergency, and educational services. Case managers establish affiliations with other care-giver agencies and access those services as needed by clients. Unique to the *Ahalaya* model is a foundation built on cultural, spiritual, and traditional healing dimensions. These characteristics offer clients greater support and access to information than afforded by non-Native programs. In addition, this same cultural/spiritual paradigm is made available to the wider community, and particularly to non-Native care-givers, through training programs administered by case-management staff.

Case management procedures prescribe a plan by which case managers interact with clients. Case managers conduct client assessments, work with clients to develop care plans, make and follow-up on referrals to other service providers, monitor client compliance with referrals and related activities, and advocate for clients in their relationships with other agencies and providers. *Ahalaya* case managers also provide or facilitate access to traditional/cultural services. One of the more important elements of the *Ahalaya* model is the flexibility to work with clients in virtually any setting, allowing the case manager to maximize access to the clients.

The *Ahalaya* program was started in 1991 in Oklahoma City and Tucson by the National Native American AIDS Prevention Center (NNAAPC), and supported by funding from the Special Populations of National Significance (SPNS) office of the Health Resources and Services Administration (HRSA). The model was formalized and implemented, and in 1992, SPNS requested that NNAAPC replicate the model in sites across the country. Financial support was sufficient to expand the program to 12 additional sites in 1993 to implement the case management model. In 1997, a new cycle of SPNS monies required the reduction in the number of sites supported to a total of nine.

One important component of the *Ahalaya* program was the collection of data from all clients enrolled in services. The resulting database included a suite of intake information and a more limited collection of follow-up data. Client satisfaction surveys also were used, as well as focus groups and individual semi-structured interviews. These data constitute the foundation of the evaluation plan, the results of which have been used to inform ongoing model development.

Methods

Participants

The National Native American HIV/AIDS Client Database includes intake data for all clients enrolled in the case management program. Currently, over 600 individuals have been documented, but at the time when the satisfaction surveys were initiated (June, 1996), 402 persons were identified in the database.

The 402 individuals recorded in the database were diverse in terms of documented traits, but as a single cohort they exhibited the following profiles (Table 1; also see Rowell & Bouey, 1997). Males comprised 81.3% (*n*=327) of the total, and females 18.7% (*n*=75). Average age was 33.7 years. Seventy-two American Indian tribes were represented among 81.0% of the total client population, in addition to Alaska Natives (3.5%), Native Hawaiians (14.5%), and other indigenous groups (0.7%). General health status was documented as excellent among 9.2% of clients, good among 37.9%, fair among 35.4%, and poor among 17.5%.

Identified risk categories were dominated by men having sex with men, and followed at less than half that number by heterosexual contact and other risk factors (Table 1). The general male pattern is similar to that exhibited in the Centers for Disease Control and Prevention (CDC) AIDS Surveillance data (Centers for Disease Control and Prevention, 1998; Stevens & Estrada, 2000), although some of the values differ (e.g., heterosexual). Female data are inversely related to the CDC data, since the latter document injecting drug use (IDU) contacts as a larger proportion of the total than heterosexual contacts (Centers for Disease Control, 1998; also see Stevens & Estrada, 2000).

At enrollment into case management services, HIV/AIDS status was identified as asymptomatic HIV among 33.6% of clients, symptomatic HIV among 27.3%, and AIDS among 39.1% (Table 2). Clients having a history of mental health problems accounted for 23.0% of the total, whereas those undergoing treatment currently or within the previous year represented 28.5%. Alcohol abuse history was identified among 61.6% of the client base, and drug abuse among 49.6%. Homelessness history was noted by 26.8% of clients.

Satisfaction Survey forms were sent to all active clients (n=389), and 132 (33.9%) of those individuals returned their forms. Respondent profiles exhibited some variation with that of the entire database population. According to the variables that were common to both databases, gender distributions were similar (X^2=2.513, df=1; p=0.113), whereas ethnicity (X^2=15.094, df=3; p=0.002) and transmission (X^2=34.314, df=5; p=0.000) categories were different (Table 1). Possible bias introduced by these differences would appear to be minimal, however, since response patterns were so robust.

Seventy-four percent (n=97) of Satisfaction Survey respondents were male, and 26% (n=34) were female. The average age of all participants was 34.3 years (Table 1). American Indian ethnicity accounted for 67.7% of the respondents, Alaska Native for 3.1%, Native Hawaiian for 25.2%, and other indigenous for 3.9%. Respondents were distributed across HIV risk categories at slightly different levels than found in the entire client population (Table 1). The general pattern, dominated by men having sex with men, remained constant; only the proportions varied moderately between the two samples. Health status was documented as excellent among 9.3% of respondents, good among 50.4%, fair among 29.5%, and poor among 10.9% (Table 1). Residence in urban areas was identified by 64.0% of respondents, rural areas by 29.7%, and reservation by 6.3% (Table 3). Employment status was dominated by unemployed with 77.5% of clients, while part-time status accounted for 10.1% and full-time for 12.4% (Table 3).

Design and Procedures

Data collected for the National Native American HIV/AIDS Client Database was obtained when a client first enrolled into case management services. These data, as well as more extensive histories and current needs information, were recorded by a case manager. This material was used to design specific case management plans and to assist the clients with their various issues. Only a small fraction of the data collected are submitted to the main NNAAPC office, all others remaining in confidential client files.

Satisfaction Survey forms, with addressed return envelopes, were given to all active clients between June and August 1996 (Barney, 1996). Respondents were asked to complete the surveys at their own convenience and send the forms to the main NNAAPC office. Surveys were anonymous and unlinked. The instrument included 35 questions, ranging from simple demographic queries to questions regarding client perceptions of services received. In the perceptions section of the survey, clients were asked to rate their level of agreement with several statements. The response scale was broken into seven categories, ranging from “strongly agree” to “strongly disagree,” “neutral” occupying the central position.

Table 1
Frequency Distributions of Client Characteristics Common to the National Native American HIV/AIDS Client Database (NNAH/ACD) and to the Client Satisfaction Survey (CSS)

	NNAH/ACD		CSS	
Mean age (*SD*)	33.7 (8.8)		34.3 (8.9)	
Ethnicity				
American Indian	326 (81.0%)		86 (67.7%)	
Alaska Native	14 (3.5%)		4 (3.1%)	
Native Hawaiian	58 (14.5%)		32 (25.2%)	
Other Indigenous	3 (0.7%)		5 (3.9%)	
Health Status				
Excellent health	37 (9.2%)		12 (9.3%)	
Good health	152 (37.9%)		65 (50.4%)	
Fair health	142 (35.4%)		38 (29.5%)	
Poor health	70 (17.5%)		14 (10.9%)	
HIV Risk Category	Male	Female	Male	Female
MSM	206 (63.0%)		54 (55.7%)	
IDU	43 (13.1%)	22 (29.3%)	8 (8.2%)	4 (11.8%)
MSM/IDU	30 (9.2%)		6 (6.2%)	
Heterosexual	31 (9.5%)	41 (54.7%)	7 (7.2%)	23 (67.6%)
Hemophilia	1 (0.3%)	0 (0.0%)	0 (0.0%)	0 (0.0%)
Transfusion	4 (1.2%)	2 (2.7%)	4 (4.1%)	1 (2.9%)
Maternal	2 (0.6%)	6 (8.0%)	0 (0.0%)	0 (0.0%)
Unknown	10 (3.1%)	4 (5.3%)	18 (18.6%)	6 (17.6%)

Analyses were based on consolidated measures of “agreement” and “disagreement” (Table 4). Respondent proportions to each question are described according to a combined category of “agreement,” that is, “strongly agree,” “agree,” and “somewhat agree” are aggregated into a single proportion to characterize this pool of clients. “Disagreement” includes responses for “strongly disagree,” “disagree,” and “somewhat disagree.” “Neutral” responses constitute a separate category. A final pair of questions asked how well the client thought he/she was doing at two separate points of time: before they entered the case management program, and within the four weeks previous to their completing the survey (and logically, while they have been enrolled in case management services). Clients were given five

Table 2
Frequency Distribution of Client Characteristics Unique to the National Native American HIV/AIDS Client Database

	Yes	No
HIV/AIDS Status		
Asymptomatic HIV	134 (33.6%)	
Symptomatic HIV	109 (27.3%)	
AIDS	156 (39.1%)	
Current Mental Health Treatment (Currently or within last year)	113 (28.5%)	283 (71.5%)
History of		
Mental Illness	91 (23.0%)	304 (77.0%)
Alcohol Abuse	241 (61.6%)	150 (38.4%)
Drug Abuse	191 (49.6%)	194 (50.4%)
Homelessness	103 (26.8%)	281 (73.2%)

Table 3
Frequency Distributions of Client Characteristics Unique to the Client Satisfaction Survey

Residence	
Urban	82 (64.0%)
Rural	38 (29.7%)
Reservation	8 (6.3%)
Employment	
Full-time	16 (12.4%)
Part-time	13 (10.1%)
Unemployed	100 (77.5%)

Table 4
Frequency Distributions of Questions Regarding Care Management Services Received in the Client Satisfaction Survey

Question	Response			
	Agree	Neutral	Disagree	Not Appl
Helped by case management programs	119 (92.2%)	7 (5.4%)	3 (2.3%)	
Glad to have services from programs	122 (93.2%)	5 (3.8%)	4 (3.1%)	
Reduced stress	101 (78.9%)	17 (13.3%)	10 (7.8%)	
Not as sad	108 (83.1%)	19 (14.6%)	3 (2.3%)	
Benefited from traditional healers	81 (65.9%)	29 (23.6%)	13(10.6%)	
Liked affiliation of program	120 (92.3%)	7 (5.4%)	3 (2.3%)	
Program better because of affiliation	108 (83.1%)	18 (13.8%)	4 (3.1%)	
Learned about prevention strategies	112 (86.9%)	14 (10.9%)	3 (2.3%)	
Reduced alcohol consumption	55 (67.9%)	15 (18.5%)	11(13.6%)	[49]
Reduced drug use	52 (74.4%)	12 (17.1%)	6 (8.6%)	[59]
Assistance with family issues	76 (73.1%)	21 (20.2%)	7 (6.7%)	[26]
Assistance finding a home	43 (60.5%)	16 (22.5%)	12(16.9%)	[58]
Assistance making appointments	70 (82.3%)	11 (12.9%)	4 (4.7%)	[45]
Assistance getting medication	72 (79.1%)	10 (11.0%)	9 (9.9%)	[40]
Liked support groups	71 (76.4%)	19 (20.4%)	3 (3.2%)	[36]
	Yes	No	Not Sure	
Program made life better	114 (87.7%)	4 (3.1%)	12 (9.2%)	
Want to learn more about prevention	80 (61.5%)	50 (38.5%)		
Quality of Life (How are things going?)	Good	Neutral	Bad	
Before enrollment	24 (18.3%)	61 (46.6%)	46(35.1%)	
Last four weeks (after enrollment)	79 (60.3%)	39 (29.8%)	13 (9.9%)	

Note: Not Appl=Not Applicable.

possible responses. These categories were scored, a “5” used to designate the most positive response and a “1” the most negative. Scores were totaled for the entire sample and the before results evaluated against the after. The Wilcoxon Signed Rank test was used to ascertain the significance of the difference between the two scores. Clients also had the opportunity to submit any other comments they thought appropriate in this context.

In contrast to the quantitative instrument—used in this evaluation with a relatively limited goal—qualitative techniques were utilized to obtain a more complete illustration of this population and their perceptions. These methods offer an opportunity to supplement the survey data, and more significantly, to gain more insight into issues of particular relevance to the clients. Four focus groups—two with staff and two with clients—and 18 key informant interviews were conducted by NNAAPC personnel in January and February, 1996. Both methods employed semi-structured strategies, and facilitators and interviewers employed written guides to perform this work. All discussions were taped and transcribed, and the transcriptions were coded and evaluated subsequently.

Results

Satisfaction Survey – Quantitative Data

Survey forms continued to arrive until March 1997. By this date, 132 surveys (33.9% of the total) had been received. Frequencies and proportions received varied by site (Table 5), and appeared to be related to the initiative taken by the case manager when encouraging clients to respond.

Overall responses to the case management project were very positive (Table 4). Respondents agreed they had been helped by these programs (92.2%), and they were glad to have received these services (93.2%). Respondents also felt that they experienced reductions in stress (78.9%), alcohol consumption (67.9% of applicable responses), drug use (74.4% of applicable), and sadness (83.1%). These clients also felt that they received assistance when dealing with families (73.1% of applicable), finding a home (60.5% of applicable), making appointments (82.3% of applicable), and getting medications (79.1% of applicable).

Respondents also liked the AI/AN/NH affiliation of these projects (92.3%), and most thought the programs were better due to this connection (83.1%). A significant proportion also liked having access to traditional healers (65.9%) and support groups (76.4% of applicable). Respondents acknowledged that they learned about prevention strategies from these projects (86.9%), and many expressed an interest in learning more (61.5%). Overall, respondents felt that the program made their lives better (87.7%).

Table 5
Client Satisfaction Survey Response Rates by Case Management Site

Site	Responses (n=132)	Distributed (n=389)	Percent Responding
1&2[a]	25	101	24.8
3	6	32	9.4
4	2	7	28.6
5	5	43	11.6
6	3	9	33.3
7	16	31	51.6
8	7	32	21.9
9	11	21	52.4
10&11[a]	40	69	58.0
12	3	11	27.3
13	14	33	42.4

[a] Two sites, one project

Questions regarding quality of life pertained to periods of time before and after participation in the case management programs. These two questions were scaled according to five possible answers about how life has been going in the recent past; the scale ranged from “very well” to “very bad,” with “about equal” in the central position. Employing only positive responses, a favorable quality of life *before enrollment* was documented by 18.3% of respondents, while favorable quality of life *after enrollment* was noted by 60.3%. A Wilcoxon Signed Rank Test was run on these responses, after they had been scored. Results supported the proposition that clients believed that their quality of life was improved after they had enrolled in the case management programs (T=6.87, p=.000).

Focus Groups and Interviews – Qualitative Data

In contrast to the quantitative data, qualitative discussions elicited responses concerning what clients believed were program aspects that facilitated or encumbered their acquisition of care and support. Discussions supported the positive responses identified in the quantitative instrument, and conversely, they also allowed information that was not as flattering. Some of these issues pertained to the case management programs, but more significantly, clients pointed to linked service programs, communities, and families.

Clients offered statements regarding the improvements in their lives, particularly in the form of increased self-esteem and lessened stress and sadness. Through participation in these programs, clients also noted they had obtained more information regarding HIV and treatment options, they received greater emotional support, and they improved their access to food and housing services. Clients expressed appreciation for the range of services offered through these programs (especially social services), and identified program personnel for whom they had great respect and admiration. They also acknowledged the value of the AI/AN/NH affiliation of these case management programs and of community support. Community, in this instance, refers to those individuals who work at or use the services of these programs.

Simultaneously, a few clients thought they should have received more information, particularly HIV prevention related, and social support through these programs. They noted that some case management sites were too limited in the range of services offered. Personnel at some locations also were described as difficult to work with or not sufficiently supportive of the clients. Clients noted that some staff were obviously uncomfortable working with homosexual clients, resulting in poorer quality, and sometimes no services. Case managers validated many of these personnel issues, although they also noted that some clients were very difficult and problematic. The threat of staff burnout was an ongoing problem, as was the need for staff support systems.

Beyond the case management sites, clients identified a variety of issues pertaining to linked services. They noted for different settings a lack of quality medical services, inadequate social services, no HIV testing programs or prevention information, and most significantly, the insufficiency of transportation services. Transportation was cited several times by both clients and staff, emphasizing the prominence of this issue for nearly all program participants. Clients described problems in urban areas when clients lacked cars and money for public transit, and they also cited poor public transit systems. On a larger scale, some clients also spoke to the complete absence of transportation systems in rural areas. Receiving rides from other individuals was helpful, although problems in confidentiality sometimes arose when the driver discovered that the client was HIV-infected.

Personnel issues at other agencies were complicated when staff were perceived as incompetent or a threat to a client's confidentiality. The latter was most serious when service agencies were located in community settings where a client was a community member. This type of community is the home context of a client, different than the organizational community cited above. Clients and case management staff further noted the poor quality of medical care and the lack of support for pharmaceutical supplies at some clinics. Clients also felt that clinic staff sometimes obstructed the clients when staff did not assist them as they worked their way through the system.

In many cases, negative comments regarding medical care were directed against the local Indian Health Service facilities. Clients and case managers expressed tremendous frustration with some of these clinics, even citing specific instances of overt ill-treatment by providers and staff. Although these types of comments were prevalent, they were not unanimous. Some responses focused on the high quality of services received by clients at some IHS facilities, both rural and urban, and described efforts at those locations to improve the quality and expand the knowledge of agency providers.

Clients also spoke to behavioral patterns that they perceived as detrimental to their own management of their disease. Foremost among these problems were substance use and violence. Substance use, especially alcohol, was identified as a factor leading to primary infection, as well as facilitating secondary infections. Alcohol use was described as pervasive in many of these communities, and a cause for great concern in the realm of HIV/AIDS. Violence, both domestic and community, was viewed in a similar light. Although not as directly related to the risk of HIV infection as substance use, violence was seen to reflect various community ills, that in the composite worked to increase HIV risks. Issues underlying substance use and violence in the community are key to understanding many of these problems, but opportunities to explore these factors in greater depth were not afforded by the interview and focus group agendas.

Clients and case managers regularly referred to “community” in their discussions. Although there was no effort to define the concept specifically, most comments were directed toward their home settings. What was most prominent in these remarks were the cognizance of community as relevant to an individual’s well-being and of the general absence of community support in the case of the HIV-infected. Some home locations were described as supporting infected individuals and the work against the epidemic, but the trend was generally more negative. Community denial of the problem was identified in several settings, one extreme of which was the ostracism experienced by some individuals. Client fears around these types of responses underlie their concerns with confidentiality, an especially significant problem in the smaller community settings. The concept of family paralleled that of community. The diversity of responses about family were comparable to those of community, but even more critical in the sense that family support was seen as even more fundamental. Clients described a variety of family responses, and the most salient were those in which families rejected the client. Consequently, clients told about hiding their HIV status from their own families and their fear of losing their most important support network.

Discussion

Data from both quantitative and qualitative contexts support the conclusion that the *Ahalaya* model is successful in its objective to provide high quality case management services to AI/AN/NH peoples. Quantitative patterns offer a compelling argument regarding project success. Responses to program attributes were consistently favorable, and the quality of life measure supported the assertion that utilization of case management services contributed to the improvements in clients' lives. One might argue that factors other than the programs were responsible for these client perceptions. While such a comment is true in principle, the data—both quantitative and qualitative—suggest that the case management services played a significant role in the improvement of clients' lives.

Focus group and interview discussions buttressed the survey results, describing programs as fundamentally of good quality. Conversely, these same discussions allowed for the expression of various types of discontent and the identification of numerous options for improvement. Salient themes in the qualitative data reflected the complexities and difficulties of client and provider lives outside the direct purview of the case management programs. Most prominent among these was the encompassing domain of social relationships, with three primary components: staff, community, and family. Case management, as well as other agency staff were recognized as primary gatekeepers to and providers of care. Clients were dependent on these individuals for a wide variety of services and support, and consequently the quality of their relationships was very important. Any encounters with difficulties or incompetence in those persons threatened the integrity of those interactions, and consequently, the security of the client's support network.

Communities were viewed similarly, in that they were seen as a primary means of support and emotional care. The complete absence of support—or worse, the overt rejection of an HIV-infected individual—created great instability and disorientation among clients. In situations where individuals regularly received community validation, the loss and isolation resulting from formal or informal rejection can be devastating. Relationships with families are even more intensive. The positive attributes of family acceptance and support outweigh many other negative experiences, and logically, the loss of a supportive family would have more severe and negative consequences.

Clients and case managers acknowledge the critical importance of relationships, and in a similar vein, the fears and frustrations they express are based on the same issues. Behavioral decisions are considered in the context of relationships, and if an individual experiences some weakness in that network, they are more likely to compromise their abilities to make their best decisions. Compounding problems associated with the domain of social relationships are the issues of substance abuse and violence. These specific concerns also reflect, at least to some extent, the same relationships with community, family, and self. This particular data collection venue was not designed to explore these topics in greater depth, but it was evident that the patterns were repeated in many different settings. These circumstances demand a more intensive and comprehensive response than that used in this evaluation.

Results indicate that in general terms providers, services, communities, agencies, and the clients themselves erect barriers to completely successful care. Simultaneously, these are the same venues within which the resolutions must arise. The simple presence of a Native HIV program is a necessary response to this need, but it is not sufficient on its own. Case management programs must also increase their quality and professionalism, and they must work to manifest more completely the collaborative efforts of individual and community participants.

These evaluation results have been used to reflect on the progress made in model implementation, and they have been incorporated into ongoing model development. Currently, the *Ahalaya* model has been expanded to integrate substance abuse treatment, prison outreach, and provider training as formal program components, adjusted to the immediate needs of each program site. Underlying these activities, as well as those ongoing, is the effort to work more effectively to improve clients' support networks, to enhance the quality and strength of their social relationships. In addition, the evaluation itself has gone through a major revision, with the intent of monitoring client progress more accurately and closely, and of tracking service utilization and needs in greater detail. This strategy is to enhance the capacity of this model, such that improved care and more accurate monitoring will lead to wider and more enduring improvements in the quality of life for AI/AN/NH infected and affected by HIV.

Limitations on the generalizability of these data need to be highlighted as well. The relatively small sample size of respondents to the Client Satisfaction Survey and the inherent bias expected when using this type of survey technique compromise the strength of these interpretations. These two factors are related, particularly in the possibility that clients who did respond were those who felt most strongly about the surveyed issues. In addition, use of only two questions, one of which was retrospective, for the quality of life scale also represents a complicating factor. These potential problems are being addressed in the new evaluation program. At this time, however, these data are the *only* information available regarding services for HIV-infected AI/AN/NHs. As such, these data are the initial building blocks from which we can design improved service programs and improved analytical capacity.

On the basis of this work it is clear that various populations have special needs that must be integrated into programs if we are to achieve higher levels of quality client care in a more universal venue. Also salient is that evaluation procedures are critical. These measures permit monitoring of ongoing program development and implementation, and more relevantly, the collection of information vital to the future evolution of such services.

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UNMASKING DASHKAYAH: STORYTELLING AND HIV PREVENTION

Terry Tafoya, Ph.D.

Ana Kush Iwasha.....This is the way we begin a story in the Sahaptin language of the Warm Springs Indian Reservation of Oregon, telling our audience, "This is the way it was..." It is common to begin stories of many oral traditions with an equivalent ritual formula (Tafoya, 1983) that allows the distinction between what is happening now and what has happened before—long ago and far away. As a American Indian storyteller and as an HIV/AIDS educator and clinical psychologist, I have long been interested in the pragmatism of cross-cultural social discourse. As the linguist, Leap (1997), put it, grammar is about how a language functions, but discourse is what one actually *does* with the language. I find in doing HIV prevention, differences in communication often interfere with effecting behavioral change, especially when dealing with communities of diversity.

A few years ago, a Cree elder in discussing the concept of "Ceremony," pronounced it in a way linguists will sometimes describe as influenced by "language interference" –where one's Native language influences the pronunciation or structuring of an acquired language...in this case English. Thus, as he spoke, the word "ceremony" became "share-amony," which I felt greatly enhanced the meaning of the term, since we are taught in many American Indian and Alaska Native communities that anytime people come together it is a type of ceremony that we share. Storytelling—a significant element of ceremonies (or share-amonies) is structurally different from the act of writing. Writing, especially in an academic style, deals with an "imaginary" audience, and the author must contend with a stylized presentation of material and its logical stance and supportive evidence.

Storytelling in a traditional sense—in the Share-amony—deals with an audience that sits (or stands, or dances, or does beadwork, or fringes shawls, or nods off) right in front of the Storyteller. Storytelling is by its very nature, more interactive than any cutting-edge computer program. The audience influences the Storyteller by its reaction. Indeed, in one traditional form of Storytelling at Warm Springs, the Storyteller pauses in the story until the audience (in this case, normally children) says "Eiiiee," which means "yes," at which point the story is resumed. This continues until the children are silent, indicating they are asleep. Actually, they are considered to be in a half-conscious state, and at this point, positive affirmations can be whispered into their ears, the last thing they hear before they truly sleep. While the academic performance remains "stable," (permanently frozen in paper and ink) the performance nature of Storytelling can dramatically change.

After much thought, I have decided to focus on the idea of the share-amony, and write this article more in the manner of my speaking, rather than the artifice of academia, working with the idea of how one actually communicates with a living, breathing audience, rather than a standard chapter I might feel obliged to turn in. On one level, this is obviously impossible. The very structure of academic writing precludes being able to do this, and I must utilize stylized literary artifice rather than non-verbal cues of inflection, pauses, eye contact triggered reactions, and hand gestures. In attempting to be "comfortable being one with my duality," I will also rely on a shifting of typeface to convey the Storytelling as such, distinguishing it from the meta-cognitive commentary, where I try to "talk" to the clinical applications of this approach.

Readers specifically interested in more standard academic approaches to social discourse are directed to the excellent works of Leap (1997), Hall (1976, 1983), Tedlock and Tedlock (1975), as well as Scallon and Scallon (1995) in terms of American Indian issues. For "less" standard academic approaches, readers can enjoy the written words of American Indian authors/scholars, Silko (1996), Allan (1986), and Sarris (1993). In terms of specific "hands-on" HIV prevention within American Indian communities, readers might also look towards the community based models discussed in Tafoya and Wirth (1990). For a look at Native concerns of spirituality and psychotherapy see Tafoya and Kouris (in press). The use of therapeutic metaphor and the indirect use of storytelling in clinical practice has a long and distinguished history (pastoral counselors are referred to Matthew, chapter 13, where the disciples of Jesus ask, "How come you tell us so many stories?" [not an exact quote] to which the reply is: "He who has ears to hear, let him hear!" [which is an exact quote] preceded by the parable of the seeds that fall upon stony ground and the seeds that fall upon fertile ground..."I speak in parables, because seeing they do not see and hearing they do not hear, nor do they understand.") Interested readers can find much in the field of Ericksonian approaches (Erickson, 1982), this is a tasty introduction to Milton H. Erickson's talents—Erickson, by the way, was of American Indian ancestry; and the work of Gilligan (1987) which develops the theme of Erickson along with clinical analysis of the techniques, and is quite inspirational.

Ruthanna Boris, known as "Ballanchine's Ballerina," was offered a prestigious position at a major university. When she approached Ballanchine for his advice, he replied, "You should take it—but you won't like it. You will want to talk about doing and the people there will want to talk about talking about" (personal communication, 1984).

With that in mind, let me tell you a story. Ana Kush Iwasha…

There is a story that comes from the Pacific Northwest, about a boy who went camping on the wrong side of the tracks one night, and met Dashkayah. Now Dashkayah is a distant relative of the Swift-Moving One…or the being the White people call Bigfoot or Sasquatch. And she's not alone. She's got sisters. But we won't concern ourselves with her sisters right now. This little boy had not actually gotten lost. He had left home that morning to go hunting and was enjoying the day so much—it was bright and sunny, one of those rare days in the Pacific Northwest—that he wandered too far from his Longhouse to make it back before sundown. So he thought, "I'd better just camp out where I am for the night and start back first thing in the morning," just as his elders had taught him to do.

Well, it wasn't long before Dashkayah smelled the boy. She's got a supernatural sense of smell, and for a good reason. She eats children. She carries a big basket on her back that can hold as many children as she can eat in a sitting. And she's always hungry.

This little boy had just gotten settled in, when all of a sudden, he heard an eerie whistling in the dark. After a while, the clouds slowly moved across the face of the moon to reveal a giant, hairy figure standing quite still, looking directly at him. Now this boy had taken Monsters 101 and knew that what was standing over him was none other than Dashkayah, the celebrated devourer of children. Besides—nothing human could smell as bad as she did.

I should mention here that Dashkayah's no dummy. Catching kids with all her unwanted notoriety was a tricky business. She knew that if she were going to nab this morsel of a kid, she'd have to use cunning. She heard the boy's stomach grumbling from hunger. He hadn't caught much that day to eat. She put on the best face she could muster under the circumstances—and by this we mean she was so ugly, even a smile looked terrifying—and teetered over the boy who was shaking rather uncontrollably.

> "Know who I am," she grumbled to the boy, who was now covering his eyes and nose. "Well, never mind what you've heard about me, I'm sure it's all negative. But it's all untrue. In fact," she muttered, and leaned over to assess the boy's plump little arms," In fact," she continued saying, as she reached into the basket on her back, "I'm not really a bad person at all." She smiled—her teeth eating the slight light of the moon—"I know little children need lots of good food, and I bet you haven't eaten a thing all day."
>
> And she stretched out her hand to the boy, and piled high on her palm, were juicy berries. "Open your eyes!" she screeched despite herself. "I've got something good to eat here."
>
> And he did, slowly at first, until he saw the hairy outstretched hand of Dashkayah, which resembled the hard claw of a bird of prey, an owl perhaps, and piled high on her palm, were the biggest, juiciest berries he had ever laid eyes on. Just then, they both heard his stomach grumble.
>
> "Go on," Dashkayah purred with only a hint of impatience. After all, there were more children to catch and this one was taking forever to make up its mind. Well, there was no denying the boy was hungry. And children don't deny themselves things like some adults might. Dashkayah knew that.
>
> So as the boy tentatively reached out his own hand, carefully avoiding the menacing talons, Dashkayah was busy wiping a sticky resin across her other palm, which she had carefully hidden behind her hairy back. And just as the moon was once again obscured by the clouds, she struck out, smearing the boy across the eyes with that sap, blinding him, and gluing his eyes together so he couldn't see to run away. With a grunt, she grabbed hold of him within his blanket with her talons, and heaved the boy over her shoulder and into her basket. "Now, maybe a little girl," she thought to herself as she disappeared back into the woods, whistling her eerie song.

Dashkayah blinds the young boy in order to capture him. As the story goes, the boy is carried off to Dashkayah's campsite and dumped out of the basket on to the ground, next to other children she had captured. Soon Dashkayah begins to build a huge campfire to barbecue the boy and his companions.

> She is so delighted by her catch, she begins to sing and dance around the campfire. The boy hears her song and his heart sinks, the way the moon has gone beyond the horizon. He begins to think about how his day had started, wishing to himself that he had never walked so far from his home that morning. He wishes the day could start over again. He begins to think about how the day began, so warm and so wonderful. The warmth of the fire reminds him of the sun against his face, and he draws closer and closer to the campfire to feel the heat against his face. The heat of the fire begins to warm the sap across his eyes and ever so slowly, the sap begins to melt. Soon the boy can see out of one eye, and the world comes into focus.

> He sees the hulking figure of Dashkayah dancing around the fire, and around him he sees many children, blinded as he was, all around the campfire. Next to him, is a little girl. He turns to her very slowly and tells her how he managed to melt the sap from his eyes. He tells her not to be afraid—that he has thought of a way to save them all, and instructs the girl to turn to her neighbor and whisper the secret into her ear. Soon, all the children begin to see again. Now, Dashkayah had been dancing for some time, and her voice had grown hoarse and she was tired. After all, she was no young woman as far as supernatural monsters go. So she turns her back to the fire, and faces the children she had readied for roasting. And just as she does, the children jump up at once, and run directly towards her, pushing her with all their might, into the fire. And she begins to burn, her long hair singes, and she begins to crackle and hiss and her burning body explodes into sparks which light up the sky, and from these points of lights, emerge mosquitoes. That is why, even today, mosquitoes live off the blood of young children.

Stories, as so many people of the First Nations have said, are a form of medicine. For most American Indian peoples, whose first language is not English, the word “medicine” has an additional meaning beyond its connection with healing—it normally carries with it a connotation of sacredness. Having taught at the University of Washington’s School of Medicine for a number of years, I was fascinated to discover that the only difference between medicine and poison is the dosage.

American Indian elders tell us it is important for us to tell these types of traditional stories because there is something about them for the past, for the present, and for the future. And it may well be that there are no longer huge hairy monsters who come out of the woods and steal our children, but there are other things that steal the ones we love, only these days we call such things AIDS. We call such things gang violence. We call such things addiction.

Traditional legends of American Indians (and other cultures) provide a blueprint or model of how to deal effectively with the challenges life can provide. If we focus on the "structure" of these stories rather than the "content," the stories become more accessible to public health specialists, as well as care providers and educators. In other words, if one looks at the idea of the metaphoric value of the story, it can be used in many ways.

If you were about to be burned up in a fire, would you really lean closer into the fire? As a therapist, I find that what you fear the most will probably provide you the most insight, if you have the courage to face that fear. Just so, if the boy in the story had obtained insight, but kept it to himself, he would still have perished. This story teaches us from an HIV perspective, that by sharing his insight with his social network, he was able to bring about meaningful transformation and change.

On an alternative level, this is also a story I have used in initial treatment of suicidal patients, whose lives have become like Dashkayah—huge and overpowering and devouring. Traditional stories provide an audience an indirect way of understanding cultural values—those things a people are taught to seek out, or those things to avoid. As a result, even similar stories across cultures may teach different ideas. For example, there is a European fairy tale about an old witch who likes to eat children, but eventually ends up pushed into her own oven to be burned up. But the distinction between "Hansel and Gretel" and "Dashkayah" is a fundamental difference between European and American Indian philosophy.

In European culture there is an idea that evil can be identified and then destroyed. Indeed, there seems to be an obligation to do so. [This is quite pre-Christian—witness the Teutonic myths of the "Twilight of the Gods" (Davidson, 1977) upon which "Wagner's Ring Cycle" (Wagner, 1876; Magee, 1988) is based, or the Celtic myths of the battle between the forces of light and dark.] There is always a witch to burn or a dragon to slay. But Dashkayah does not die, she is transformed. As in many American Indian stories, there is a theme of transformation and restoration to harmony, rather than a European approach of attempting to dominate nature by deleting an undesirable (by human standards) aspect of it.

Thus, Dashkayah can provide a more functional model for individuals who may suffer from an "incurable" condition such as AIDS (or diabetes, alcoholism, or certain cancers) where we don't know how to "kill the enemy." Dashkayah teaches us that even overwhelming challenges, if dealt with in an appropriate manner, may be transformed into something manageable we can face on a day to day basis.

On yet another level, both AIDS and Dashkayah are at first perceived as something monstrous. Yet in the Pacific Northwest, where Native people still actively participate in Vision Quests, to receive the Vision of Dashkayah is considered to be a great blessing. The cannibal woman who devours children represents great wealth and power. Our old people tell us that a tragedy will always come with a gift in its hand, but we are often so frightened by the tragedy, we forget to look for the gift. While AIDS has come with a tremendous cost, it has certainly brought a gift of allowing an open discussion of sexuality that has never been permitted in contemporary experience, and has expedited an interdisciplinary approach to medicine and speeded up our understanding of the immune system.

Among the coastal people of the First Nations who use wooden masks, there is a type called a “transformation mask.” At a certain point in the ceremony, the dancer will pull a concealed string, and the outer mask splits open, revealing a hidden mask within. Just so, as we learn in dealing with the cultural diversity issues of HIV work, when we meet those different from ourselves, we first see them through a mask of “otherness.” As we learn to know them, that mask of “otherness” splits open to reveal the inherent humanity that connects us all.

There is something about these stories for the past, for the present, and for the future. Some of the traditional stories warn about what happens when one leaves the safety of the community circle, tempted by desire. The Cherokee tell of one of the *Yunwitsansdi*—the Deer Woman. She appears at powwows and the post-powwow celebrations called Forty-nines that go on long after the dance events have ended. Forty-nines are often associated with alcohol and sexual expressions, as participants will sometimes disappear together under the cover of darkness, moving away from the warmth of the fire towards a different warmth.

The Deer Woman is beautiful, with long ebony hair that glistens in the firelight like a blackbird wing. She dresses in the finest of traditional clothes and moves with supernatural grace in her shawl with long fringes that dance as she sways to the heartbeat of the drum. The only difference between her and the most beautiful of human females is the fact her slender ankles end in sharp hooves.

In an almost vampiric sense, the Deer Woman fascinates, locking eyes with her victim, seducing him hypnotically away from the fire, into the darkness, leaving hoof prints next to his footprints—a trail his relatives will follow the next day to discover his cold body, where they will see that she killed him by dancing on his genitals with her hard and unforgiving hooves.

What a powerful metaphor for someone who feels they “lost” control in the heat of passion—powerless before someone they wanted so badly, leaving behind the warning of elders that to abandon the campfire of the community may cause trouble. The story of Deer Woman can be used to introduce concepts of high-risk behavior.

> Just so, in the Pacific Northwest, it is said that long ago, the daughter of a chief was warned by her elders to be careful as she went to pick berries, because many bears were around. She went out anyway, and as she drew near the berry bushes, she stepped into bear dung.
>
> Upset, she cursed the bears, as she tried to clean herself. Bear people emerged from the woods and abducted her. Inside their cave, she sat sadly in a corner, until a tiny thin voice spoke to her and she looked into the bright wise eyes of Grandmother Mouse.
>
> "Tell them they must take you out to relieve yourself—and that as a proper person, you must do this in privacy." Then Grandmother Mouse touched the gleaming copper bracelets that the young woman wore, indicating her high-class status. "Take off your bracelets and break them into small pieces and leave them on the ground."
>
> When the young woman did as she was instructed, the Bear people inspected where she had gone to relieve herself and whispered to one another. "No wonder she complains of our dung. She is so high-class that she shits copper!"

Impressed, they inform the Bear Chief, who marries the young woman, and thus the Bear Clan was begun. Whether it is the message that unregulated desire can have dire consequences, or that not listening to the wisdom of your elders (and then reaping the benefits that respecting the words of elders can provide) can place you in great danger; the stories also offer another issue to consider when working with clients and patients to initiate behavioral change.

We have known since the time of Freud that people posses specific self-defense mechanisms. These include: (a) denial ("I don't have a problem."); (b) repression ("I don't know that I have a problem."); or (c) projection ("It's not my problem—it's your problem.") (Freud 1894, 1900, 1915; Freud, 1936). Milton H. Erickson, the noted psychiatrist, once said, "What we call a neurosis is really the complex way in which a patient deals indirectly with his problem" (personal communication with Stephen Gilligan, 1982, regarding M. Erickson during training seminar, 1982).

Erickson was suggesting that if a patient could deal directly with his or her problem, the patient would probably not need therapy. When we attempt to directly confront individuals in prevention and intervention work, we tend to engage their self-defense mechanisms. The stories, in the form of therapeutic metaphors tend to bypass self-defense mechanisms because we are not talking about sexually transmitted diseases (STDs) (for example)—we're talking about Deer Woman. This indirect approach of storytelling can allow clients and patients to be more open in exploring alternatives to high-risk behaviors or ways of coping with chronic illness.

Indirect approaches to discussing topics of sexuality are also critical in the sex-negative culture of general America, where many citizens are uncomfortable with any public discussion that touches on issues of a carnal nature (Irvine, 1990; Money, 1986; Parker, Russo, Sommer, & Yeager, 1992; Tanahill, 1980) . This is even more complex in working cross-culturally from a linguistic aspect. English is a melange (French) of languages, a conglomeration (Latin) of xenologic (Greek) words superimposed on a foundation of Anglo-Saxon. Due to the unusual circumstances of the historical and cultural realities of English, it is a language that can allow "code-shifting," from "basic" Anglo-Saxon to Latin or Greek based words. Latin and Greek words are associated with medical and scientific (and therefore "high class") meaning, while Anglo-Saxon terms have a "vulgar" (or "low class") association. In speaking publicly, it is possible to linguistically "code-shift" when discussing sexuality, where Latin/Greek based terms like "anal intercourse," or "masturbation" are acceptable in public discourse, while the one-syllable equivalents in Anglo-Saxon would not be contextually acceptable.

Not all languages have this code-shifting potential, so HIV specialists working cross-culturally may have few options in utilizing interpreters to share information about prevention and sexuality in ways that will not be considered offensive, other than resorting to the indirectness of metaphor and with sexuality (for example, American Indian Coyote legends or African Anazi ones) are ways to begin initiating the discussions dealing with STD and HIV prevention in a less threatening manner. To initiate prevention discussions, it might be useful to begin at the beginning:

> Long ago, in a time beyond time, so many years ago we don't have words for the number of years, the Cocoon Man floated without awareness—and as even more years passed, he slowly became aware—and with awareness comes knowledge of one's limitations, and so the Cocoon Man began to condense—to coalesce, and the surface of his skin began to slough off and formed the land—until finally he stepped forth.

> And he felt a compulsion to walk to the East, and he walked East until there was no more East left to walk, where he found a baby—an infant boy. This surprised the Cocoon Man, who thought he was the only one around. Concerned about the baby dying of exposure, he wove a great basket of cedar and placed the infant within it, and put the basket on his back.
>
> Now he felt a need to walk to the South, so he walked South until there was no more South left to walk, and there he found a young boy—about four years old. Again surprised, but not wanting to abandon the child, he picked him up and placed him within the basket.
>
> Now the Cocoon Man felt a need to walk to the West, so he walked West until there was no more West left to walk, where he found an adolescent boy. By this time, the Cocoon Man was getting used to this, and placed the adolescent within the basket.
>
> Now he felt a need to walk to the North, and he walked North until there was no more North left to walk, where he found a young man. "It was I who gave you the idea of creating this world," the young man said. "It was I who whispered into your inner ear and suggested you walk to the East, to the South, to the West, to the North—if you don't believe me, look inside your basket."
>
> Quickly the Cocoon Man pulled the basket off his back and looked inside.
>
> And the basket was empty.

So too do we carry the basket of our life upon our back and the voices of our childhood, our adolescence, our adulthood, whisper into our inner ear with the messages we have gathered in our journey of life. We bear a burden—both treasure and dysfunction that helps shape our response to what surrounds us. There are messages about sexuality and disease, of relationships and responsibilities, reflecting our various cultures, genders, and sexual orientations. This Creation Story of the Warm Springs people can be a way to model for clients the exploration of their own messages.

Importantly, the stories move in circles, spreading out in the way of ripples from a stone cast into a pond, as they provide patterns of recognition that allow us to acknowledge similar experiences in our own lives to the stories we are told.

And finally, there are some stories that are so powerful, we don't just tell them—they tell us. Stories are a form of medicine. The only difference between medicine and poison is the dosage.

One such story of power is that of Cinderella—not the Walt Disney version, but the older, darker version of the legend, where the two step-sisters can't fit their feet into the glass slipper, so their mother intervenes. One daughter—she cuts off her toes, and the other daughter, she cuts off her heel and then tells them to shove the bloody stumps of their feet into the glass slipper.

Just so, this story has set up a frightening pattern of recognition for American children who grow up with the message there is only one way to be a "good American"—to fit a model that was never made for the majority of citizen:

> To be a good American means to be male.
>
> To be a good American means to be Caucasian.
>
> To be a good American means to speak English as your first and only language.
>
> To be a good American means to be Christian.
>
> To be a good American means to be Heterosexual.
>
> To be a good American means to have a certain level of income.
>
> To be a good American means to have a certain level of education.

And the message is clear. If you don't meet these criteria, then you are to slice off whatever doesn't belong.

You slice off your language—your sexuality—your gender—whatever doesn't fit.

As a therapist, I see many people we deal with who have turned to alcohol and other drugs (and "high-risk" sexual behaviors can be a drug to some) as a form of anesthetic in an attempt to numb the terrible pain of this amputation.

Many of the "high-risk" clients and patients feel themselves to be "*dismembered*"—ripped apart into disconnected parts of oneself. The opposite of the word "*dismember*," as Susan Griffin (1978) points out, is the word "*remember*" (p.77). The stories we tell and encourage others to tell (which is ultimately what therapy and support groups are all about) help people "*remember*" whom they are, to allow them to become whole again. In the Indo-European roots of English, the word "heal" is related to the word "whole" which is itself related to the word "holy".

Stories, as so many people of the First Nations have said, are a form of medicine.

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