

UCLA

Recent Work

Title

Culturally Competent HIV/AIDS Prevention for American Indians and Alaska Natives

Permalink

<https://escholarship.org/uc/item/78h8m3jv>

Author

Satter, Delight E.

Publication Date

1999-06-01

Satter, Delight (1999) Culturally Competent HIV/AIDS Prevention for American Indians and Alaska Natives. In Cultural Competence for Providing Technical Assistance. Evaluation and Training for HIV Prevention Programs. CRP, Inc. Washington D. C. funded by the Centers for Disease Control and Prevention, Contract #200-97-0644.

Culturally Competent HIV/AIDS Prevention for American Indians and Alaska Natives

Delight E. Satter, MPH

UCLA, Center for Health Policy Research

Introduction

Approximately 1.9 million people self-identified as AIAN in the 1990 Census. There are 554 federally recognized Indian tribes in the U.S; the only group with a recognized political status with the United States government. These Tribes are recognized sovereign nations within the United States. AIAN are the only “minority” group which has direct government-to-government relations with the United States.

The purpose of this review is to summarize the published literature on culturally competent HIV/AIDS prevention for AIAN. Because there was so little found on this subject, publications regarding cultural competence and related public health issues were also included. This review will be useful in the development of culturally competent interventions as well as data collection, policy development, programming and resource allocation for the prevention of HIV/AIDS and related public health areas.

Epidemiology of HIV/AIDS in AIAN

Epidemiologic data on AIAN and HIV/AIDS is sparse. There are many indications that AIAN populations are at substantial risk for HIV (e.g., high rates of sexually transmitted diseases (STDs), teen pregnancy, and alcohol and other drug use). However, there are limited data on HIV prevalence rates. Current data on incidence, prevalence, and mortality data likely underestimate the impact of HIV in AIAN communities. This is due to underreporting and misreporting of AIAN racial/ethnic classification (Satter et al. 1998; Metler et al. 1991).

This section represents a brief review of the most current epidemiology studies on AIAN, HIV/AIDS and surrogate risk factors: (1) CDC 1998; (2) Sullivan et al. 1997; and (3) Metler et al. 1991.

The most comprehensive epidemiologic study to date was published in the March 6, 1998, Morbidity and Mortality Weekly Report (MMWR). The authors: (1) described the characteristics of AIAN with AIDS reported to CDC through 1997; (2) summarized trends in AIDS incidence among AIAN from 1986 to 1996; and (3) compared, for the 25 states in which HIV and AIDS surveillance was conducted during 1994–1997, the characteristics of AIAN who had reported HIV infections (without AIDS) with those of AIAN who had

AIDS. A total of 1783 AIAN reported with AIDS to CDC through December 1997, 1756 (98%) were at least 13 years old.

A higher percentage of AIAN were aged 20-29 years, and a lower percentage were aged 40-49 compared to U.S. All Races. More than half of AIAN with AIDS resided in California (25%), Oklahoma (11%), Washington (7%), Arizona (6%), and Alaska (4%), at the time of AIDS diagnosis. The five metropolitan statistical areas with the highest percentages of AIAN with AIDS were San Francisco (6%), Los Angeles-Long Beach (6%), Seattle-Bellevue-Everett (4%), Tulsa (4%), and San Diego (3%). A lower proportion of AIAN resided in metropolitan areas with populations greater than 1,000,000 a higher proportion resided in rural areas with populations less than 50,000, compared to U.S. All Races.

In 1996, the estimated AIDS-OI incidence rate was 10 cases per 100,000 population for AIAN, compared to 11 per 100,000 for non-Hispanic whites. The rate was four times higher for men than for women (22 per 100,000 versus 5 per 100,000). For states reporting HIV surveillance (California, the state with the largest population of AIAN, does not report HIV surveillance), 267 cases of HIV (without AIDS) and 327 cases of AIDS in AIAN aged greater than 13 years were reported. Selected characteristics of AIAN who had HIV (without AIDS) was compared with AIAN who had AIDS. A higher percentage of HIV (without AIDS) cases occurred in women (33% versus 21%); in adolescents (5% versus 1%), and in persons aged 20-29 years (40% versus 21%).

Sullivan et al. analyzed surveillance data on men who have sex with men in the U.S. They found that overall clinical AIDS rates increase by 12% from 25.5% to 28.5% from 1990 to 1995. Five-year increases in AIDS rates were highest for AIAN at 53%. Metler et al. found that of 20,036 AIAN applicants for military service, between 1985 – 1990, 17 were HIV-positive. The seroprevalence rates per 1000 were higher for AIAN (0.8) than for whites (0.5). Several studies have reported the disparities between sexually transmitted diseases in AIAN compared to other populations (Belongia et al. 1995; Lee et al. 1987; Romanowski et al. 1984; Orr, et al. 1994).

The rate for AIAN teen pregnancy has declined 12% from 1991-1996 (CDC 1998). However, the overall AIAN birth rate was 25.6 per 1,000, compared to the U.S. All Races birth rate for 1993 of 15.5. The number of births to AIAN women under 20 years was 20,470 (U.S. Department of Health and Human Services, Public Health Service, Indian Health Service, Office of Public Health, Division of Community and Environmental Health, Program Statistics Team, 1998).

Limitations of data

Three factors should be briefly highlighted which contribute to the limitations of data on AIAN: (1) underreporting and racial misclassification; (2) aggregating data; and (3) mislabeling of race/ethnicity in research.

Underreporting and racial misclassification is a contemporary and well-documented issue for AIAN (U.S. Department of Health and Human Services, Public Health Service, Indian Health Service 1996; Lieb et al. 1992; Hoskins and Burhansstipanov

1999; Burhansstipanov, in press; Hahn 1992). *In Adjusting for Miscoding of Indian Race on State Death Certificates*, a 1996 U.S. Department of Health and Human Services publication, the authors report that IHS Areas with the greatest percentage of inconsistent classification of AIAN race were California (30.4%), Oklahoma City (28.0%), Bemidji (16.1%), and Nashville (12.1%). Dr. Edward Sondik, Director of the National Center for Health Statistics, stated that American Indians in general are undercounted by 38% nationwide (Burhansstipanov, L., in press).

The major explanations for racial misclassification are the use of Spanish surnames to determine a person's race, and the subjective use of personal observation in completing the race item on the death certificates and other health records.

The second limitation is the practice of aggregating data on AIAN into one category. Most AIAN statistics are reported using the category AIAN, or worse in "other." Most data is reported at the national, Department of Health and Human Service Regional level, and state level. The reasons for this practice are that the sample sizes in national surveys are too small to report Tribal specific information, and that reporting information for some of the smaller Tribes could lead to breaches in confidentiality.

The 554 federally recognized tribes, the numerous state recognized, and the numerous self-identified AIAN *do not now nor have they ever belonged to one pan-Indian group*. While there are similarities in indigenous peoples, there are many cultural, behavioral and social differences that must be taken into account. The issue for public health interventions is that there is not enough data to describe the health status of a Tribe or urban Indian community, the locus of interventions. This data is necessary to make informed policy, planning, and resource allocation decisions for the health improvement of the population. By aggregating AIAN into one category we compromise the effectivity and impact of public health activities.

The third limitation is the terminology used on race/ethnicity in research. For example, in the literature review it was found that researchers frequently used the term AIAN or Native American in the title and body of their published research. However, upon further investigation of the methods, these studies only included subjects from one or two tribes. Four articles were found with these terminology problems (Baldwin 1999; Salloum et al. 1989; Harvey 1995; Sanchez et al. 1999). This over-generalizing is inappropriate and reinforces the pan-Indian myth, especially for the non-Indian reader. This mislabeling is not culturally competent.

Methods

A literature review was conducted to identify culturally competent HIV/AIDS prevention literature for AIAN. Dates used for the search were from 1985 to 1999. In the first literature search Medline, PschInfo, and the Centers for Disease Control and Prevention MMWR databases were searched using the terms American Indian, Alaska Native, Native American and HIV/AIDS. Each available publication was reviewed and categorized as highly relevant (the article described an intervention that included information on cultural competence), moderately relevant (the article was moderately relevant), and not relevant

(no relevant information). Additional articles were identified through reading the above publications.

Only five articles directly addressed HIV/AIDS prevention, AIAN and cultural competence. Therefore, a secondary literature search using Medline, and PsychInfo was conducted using the terms cultural competence and American Indian, Alaska Native, Native American, teen pregnancy, sexually transmitted diseases, and alcohol and other drugs. Four additional articles were identified.

Lastly, the National AIDS Clearinghouse database was searched for publications regarding HIV/AIDS prevention materials, using the dates 1992 to 1999. Several abstracts were identified. In addition to the publications found through the literature search, two publications obtained through other sources were included. A total of 69 publications were reviewed of which, 46 were included in this review.

Because the articles included were identified through a selected search strategy, some relevant studies may have been excluded. Due to funding constraints, the literature review was limited; additional publications could have been obtained given further resources.

Program/Intervention Reviews

The review will be divided into two sections. The first includes studies that are directly relevant to the topic. The second includes studies that are less relevant.

Primary Literature Review

Seven publications directly addressed HIV/AIDS prevention and cultural competence for AIAN populations: (1) Miller et al. 1990; (2) Sullivan 1991; (3) LeMaster and Connell 1994; (4) Lego 1995; (5) Baldwin et al. 1999; (6) Brassard et al. 1996; and (7) Magee and Montalvo 1999. These are summarized below.

In general, these authors found that it was important to (a) Partner with local AIAN people and organizations, (b) to utilize traditional and religious consultants, (c) to invite and support the community control of programs, (d) to pay attention to language, (e) to use ongoing evaluation and be ready to make changes in the program, (f) to incorporate traditional, visual and participatory activities into the intervention, and (g) to seek tribal organization support.

Miller et al. (1990) described the results of an AIDS knowledge and attitudes survey of adolescents in the rural southwest. The survey was administered to American Indian (61.8%, predominately Navajo), Hispanic (19.8%), white (13.2%), and black adolescents (1.2%). Miller et al. discussed the importance of culturally competent education outreach for population targeted programs.

Their first recommendation was to include members of the target population in the development of the intervention. Communities can help design how sensitive topics can be approached. Bringing the community in to develop the intervention has a secondary

benefit, creating a sense of ownership over the intervention. This is critical for the longevity of an intervention.

Furthermore, community participation will ensure local values and concepts are incorporated into the intervention. Miller et al. suggested four specific areas that need to be understood by program developers: (1) the local religious and cultural morals regarding sexual activity, homosexuality, drug use, and contraception; (2) the cultural and spiritual concepts of illness and health and their significance; (3) the language that is used in the home and will be used to discuss AIDS among the family; and (4) who in the community and family is turned to for advice.

Miller et al. recommended that a simple intervention is always better. Visual aids and skits keep an intervention fun and participatory, and curriculum should be taught by members of the target community, in the native language. Finally, they acknowledge the need for outreach programs to rural areas.

Like Miller, Sullivan (1991) described risk factors for HIV transmission, and gave recommendations for education and prevention program development for the Navajo Nation. She described the importance of tribal organization support for all research or program interventions. This support includes political and religious leaders. Sullivan makes several suggestions in her paper. She suggests being sensitive to Navajo culture as a first step to developing interventions. She suggests defining AIDS and high-risk behaviors from the Navajo perspective, using anthropologic techniques of watching, listening and asking questions to define these concepts. These definitions will be facilitated by the use of native consultants.

Sullivan's first suggestion is that AIDS prevention may not be appropriate in a STD prevention or alcohol program. Programs that use negative pressure, abstinence and fear-based strategies to effect change for STD and alcohol behaviors would be a poor match for HIV/AIDS prevention programming. Additionally, interventions housed in these programs will send a message that only people with STD and alcohol risk behaviors are at risk for HIV/AIDS. She recommends HIV/AIDS prevention should be incorporated in a "positive context within all tribal applications."

Sullivan's second suggestion involves AIAN peoples perception that HIV/AIDS is like a disease of the past; A European disease that severely impacted the Navajo Nation. Her recommendation is to "give as much control as possible over the AIDS program planning to those persons most likely to be affected." The intervention must be positive and practical. The intervention must be designed in a way that participants feel they have control over the spread and effects of the virus.

Her third suggestion is to incorporate "old" and "new" ways. This would include partnership with traditional healers and religious practitioners for support and expert advice. The fourth suggestion is to involve the community. This will help to ensure the cultural sensitivity of the intervention, as well as mobilize the community. In particular she suggests interviewing key persons regarding Navajo values and learning about sickness, death and burial. For the Navajo, Sullivan describes the importance of an intervention that focuses on life, not death.

Sullivan acknowledges the need for prevention programs in cities. This is critical in reducing the risk factors to the Navajo when they are away from the reservation. She recommends partnering with non-Indian businesses for their support. For example, condom distribution interventions in businesses that serve alcohol. Finally, Sullivan recommends interventions be designed specifically for Navajo subpopulations. This will improve their effectiveness. She recommends small group activities.

In their 1994 article, LeMaster and Connell reviewed health education interventions among AIAN. Their review included one intervention on HIV/AIDS.¹ Their recommendations for surrogate HIV/AIDS risk factors will be reported elsewhere in this document.

LeMaster and Connell reviewed a health promotion campaign entitled “Health is a Community Affair.” This was a door-to-door intervention among residents in the Northwest Territories of Canada. The campaign focused on healthy lifestyle choices and emphasized HIV/AIDS. Pamphlets were produced in six languages, including the four dialects of Inuktitut. Audiocassettes were used for the Dene, whose language is primarily oral. Community Health Representatives implemented the campaign, many of whom spoke the community language. The respective political bodies were informed of the campaign in person and in writing, and the support of the Elders was obtained. The campaign was considered a success due to the “high level of involvement of community members.”

Borkowsy and Dunning were interviewed by Grace Lego of “Seasons,” a publication of the National Native American Aids Prevention Center (1995). Borkowsy and Dunning described a culturally competent HIV/AIDS intervention for AIAN middle-adolescents through the Native American Magnet School in Buffalo, NY. The intervention incorporated the concepts of culture, self and HIV prevention in a nine-unit curriculum, implemented in a community youth program. Borkowsy and Dunning utilized a community advisory panel of professional Native Americans, community members, Elders, and representatives from community agencies.

Borkowsy and Dunning suggested that to assure participation, interventions must incorporate culturally related activities. They incorporated the following activities into their intervention program: traditional speakers, ribbon-shirt and dance outfit sewing projects, sports activities, Elders presenting traditional arts and crafts, and HIV-positive youth speakers. Borkowsy and Dunning stated, “We learned long ago that kids will not come for prevention-related workshops alone.” By incorporating these activities into the intervention they reinforced protective factors and positive social skills.

Borkowsy and Dunning also suggested designing curricula for people who are not trained teachers. The units must be simple and behaviorally defined. They discussed the

¹ The original published article was unavailable to the author, but is listed here for reference: Crown et al., “Making HIV Prevention Work in the North.” *Can J Public Health* 84:S55-S58, 1993.

importance of participatory activities, with the theory of what is being taught not needing to be overt.

Following the nine unit curricula the middle-adolescents become trainers of the community. Currently, the Native American Magnet School hosts wellness fairs where these adolescents teach community members about HIV/AIDS. Attendance at these wellness fairs has increased as a result. At these fairs the students are responsible for developing an HIV/AIDS prevention activity they can use to teach the community. Activities they created have included plays, murals, posters and videos.

In concert with the above, Baldwin et al. (1996) describe a multi-component school and community-outreach HIV/AIDS and alcohol and other drugs (AOD) prevention program for adolescents in the rural southwest, developed and implemented by the Native American Prevention Project Against AIDS and Substance Abuse (NAPPASA). The intervention is based on an adaptation of Social Action Theory. The intervention was developed in partnership with local AIAN education, health and community-based organizations to ensure cultural sensitivity.

The intervention is two-staged with twenty-four sessions in eighth grade and twenty-four sessions in ninth grade. Baldwin et al. described the critical components to the development of their culturally sensitive intervention. These steps are outlined below.

Baldwin et al. sought a theory that would allow them to integrate both Native American indigenous holistic health belief systems and the biomedical view of health and illness. While they found little published on the efficacy of behavior change theories and AIAN, they chose Social Learning Theory. Additionally they borrowed from an AOD abuse prevention curriculum called SODAS (Stop, Options, Decide, Act/communicate, and Self-praise), and from the Beauty Way Curriculum, a substance abuse prevention curricula developed by the Navajo Nation.

Baldwin et al. obtained community input to develop culturally sensitive and relevant curriculum. Throughout the curricula development they implemented formative research including pilot testing, focus groups and ethnographic interviews. They were able to learn: styles of communication, communication barriers, normative beliefs, perceptions of peer pressure, beliefs about HIV risk factors, etc. They were able to design a curriculum that responded to the community's interest in a holistic approach to HIV/AIDS and AOD prevention.

They found that for communications about sexuality there would need to be gender specific training and discussion. They also found that adolescents and adults generally did not discuss sexuality, but if they did it would be with someone of the same sex. This information helped Baldwin et al. design a curriculum that was implemented by a pair of instructors (one male and one female). Cross-gender role-playing was conducted to carefully "minimize embarrassment to students."

Baldwin et al. used interventionists recruited from the host schools and communities to implement the curriculum. The training included discussions of sensitive session topics and cultural issues.

The curriculum was revised following formative evaluation with students, instructors, and local advisory groups. The curriculum was designed to be more grade

level specific. It was expanded to be more comprehensive and more reflective of traditional Native American approaches to health, and more visual and action-oriented. The total developmental stage took one year, followed by field trials and the creation of the ninth grade curriculum.

Baldwin et al. found that Social Action Theory adapted to AIAN community well. They found the combination of HIV/AIDS and AOD prevention curriculum useful in motivating the community to take action toward the “invisible” threat of HIV/AIDS.

Brassard et al. (1996) described a needs assessment for HIV/AIDS prevention and education for urban Natives in Montreal, Canada. Their work illustrated the importance of community controlled program planning, which allows programs to incorporate traditional values and healing practices. Brassard et al. also used a steering committee to ensure the validity of their findings. They suggested three interventions for high-risk groups: (a) increasing personal coping skills; (b) reinforcing community action; and (c) reorienting services.

Increase personal coping skills by: using humor to promote the use of condoms; using role playing or puppet shows to reduce tension surrounding condom use; incorporating traditional activities, such as sweat lodges and healing circles, into self-esteem workshops.

Reinforce community action by: using symbols and social values in interventions (for example, pride of self and of the Nation, respect for yourself and all life, fear of destruction of the race); targeting prevention toward commuters and newcomers from rural communities; encouraging rural communities to implement HIV/AIDS education and prevention to prepare its members before travelling to urban areas.

Reorient services by: using creative locations for interventions, such as, information in airplanes, and skits in bars; providing overnight resources for women not accepted in shelters; and creating associations devoted to Native gay and lesbian’s needs.

Finally, the 1999 “Native American & HIV: Summary of Ongoing Special Projects of National Significance (SPNS),” of the Health Resources and Services Administration (HRSA), was reviewed. The majority of the chapters focus on HIV/AIDS case management, and will be discussed later in this document. One chapter in particular, “The Indian Health Council, California,” written by Magee and Montalvo describes an HIV/AIDS intervention in southern California.

In 1994 a three-day retreat called “The Native Traditional Family, Youth and Elder Healing Ceremonies,” was held in southern California. The retreat was coordinated by The Indian Health Council of Pauma Valley (IHCPV), and was guided by the San Diego County American Indian AIDS Task Force. The retreat was attended by 400 people. Participants included HIV-positive AIAN and their families, spiritual and traditional practitioners with and without experience in serving AIAN with HIV, and Indian community leaders.

The intervention had four goals: (1) provide AIAN HIV-positive and HIV-affected individuals with social support; (2) educate participants about the healing potential of the

body, mind, emotion, and spirit through participation in ceremonies and healing activities, (3) improve the quality of life of the HIV-infected and HIV-affected AIAN participants by obtaining balance in life in the traditional manner; and (4) increase self-esteem and empowerment by “remembering” the power and healing inherent in Indian cultures.

Three objectives were developed to reach the goals: (1) coordinate and implement one AIAN traditional retreat for AIAN infected and affected by HIV/AIDS in and around San Diego County; (2) increase access to AI traditional and spiritual healing leaders and services by HIV-infected and HIV-affected AIAN; (3) educate and “sensitize” traditional and spiritual leaders, family members, and communities about HIV/AIDS services, prevention and education.

Magee and Montalvo expressed the importance of designing programs and interventions that incorporate Indian values, spirituality, and healing practices. The retreat was designed with (*special attention to respect and cultural competence*). Strategies used are described below.

Local Indian spiritual practitioners and tribal Elders were consulted on the purpose of the retreat, approached to providing a variety of healing services, how to advertise the event, and protocols to be followed. A Traditional Committee was developed to assist with planning and to evaluate the retreat.

Program logistics, including location and format, were focal points of the design. The retreat was not advertised in order to reduce the number of uninvited visitors. A policy was established specifying rules for media, including the prohibition of filming ceremonies. Entrance to the retreat was protected and guarded to maintain a sense of security. Meals were provided, and a first-aid station was staffed by western medical doctors.

Traditional healers were recruited from California, Arizona, Colorado, South Dakota and Canada. The local Youth Empowerment Project provided the healers with a basic AIDS 101 training course before the retreat began. The youth were selected for this training as the organizers felt the traditional spiritual practitioners and Elders would feel most comfortable with youth than adults. The Northern California healers sang and blessed the grounds.

Culturally specific activities included: morning sweats (women’s, men’s, community, and medicine); HIV-positive Talking Circles for men, women, and gay and lesbians; youth activities; sessions on learning traditional songs; puberty ceremonies; dancing; healing ceremonies; hiking; healing and teaching through crafting; games; giveaways; and evening storytelling. Each participant chose the ceremonies or activities in which she/he would participate. The activities were individual, small group, family, and large group gatherings.

Although evaluations of the retreat were limited, the IHCPV believes the retreat was a success. They would like to find a way to evaluate future retreats in a way that does not impose on the health-centered nature of the retreat. Specific recommendations for future retreats follow.

When incorporating AI traditions and spirituality, learn the local protocols and follow them precisely; Indian healing and ceremony secrets must be maintained. The

location of the retreat must be guarded. This will make participants more comfortable and will prevent “New Agers” and tourists from invading the retreat.

The site must have a wilderness area and place of historical meaning; it should be easily accessible and disabled-friendly. It should have a large group meeting space; and have water and showers. Retreat planners must determine historical relationships between tribes of clients and tribes of traditional practitioners.

In sum, the IHCPV believed HIV-positive and HIV-affected AIAN had an unmet need of traditional healing and spirituality. They developed an intervention to address that need. Their hope was that, through both Western medicine and tradition medicine and healing, HIV-positive and HIV-affected Native people would be able to live life in harmony.

Summary of Primary Literature Review

This concludes the literature review of the seven publications that were directly related to cultural competence and HIV/AIDS prevention for AIAN. There are nine major themes that emerged from these studies. They are:

- 1) Partner with local AIAN people and organizations by creating community advisory boards or steering committees. Utilize traditional and religious consultants. These people will help you with support, expert advice, and the development of culturally competent programs.
- 2) Seek tribal organization support (political, religious and social) for all research or program activities.
- 3) Invite and support the community control of programs in order to improve the quality, to ensure longevity and to create a sense of ownership, and maintain cultural competency of the program.
- 4) Use formative evaluation including focus groups and ethnographic interviews.
- 5) Incorporate traditional values and healing practices into the intervention.
- 6) Recruit interventionists from the community.
- 7) Language is important whether it be a tribal language, or the localized use of English.
- 8) Incorporate traditional, visual and participatory activities into the intervention.
- 9) Develop simple interventions.

It is also important to highlight the fact that the only known tribe represented in any of the seven publications was Navajo. Other communities were identified as Canadian Indian, AIAN of the southwest, AIAN of Buffalo, NY, and AIAN in the San Diego County area. In addition, three were targeted toward adolescents. The extent to which these interventions are generalizable to other AIAN populations is unknown. However, the recommendations seem to be appropriate in most AIAN communities.

Secondary Literature Review

The remainder of the publications reviewed had some information on developing and implementing HIV/AIDS interventions for AIAN, or related health interventions for AIAN. For the most part, these were found in brief descriptions of the intervention processes. These have been grouped by theme below. Two reinforce what was found in the previous section: the importance of community partnering and participation; and the use of formative evaluation to ensure cultural competency. In addition to these two central themes, five additional themes/components emerge: information on posters and materials; ideas for promoting interventions; recommended culturally competent intervention components and activities, which expand on some of the publications described in the primary literature review; lessons from HIV/AIDS case management; staying contemporary; and avoiding stereotypes.

Community Participation

The following recommendations build on partnering with community in the previous section: (a) respecting customs and traditional medicines, (b) doing a good job, (c) achieving a reciprocal relationship with communities and abandoning paternalistic forms of health education (Kroeger 1982; LeMaster and Connell 1994); (d) hiring community members as interventionists (Salloum et al. 1989; Calzavara et al. 1998); and (e) consulting Tribal Elders (LeMaster and Connell 1994; Hoskins and Burhansstipanov 1999).

Baldwin (1999) recommends leaving behind tangible products for the community, once the project is completed. For example, manuals, curricula, posters, videotapes and summaries of study results. She cautions that without clear communication, communities may sometimes mistake long-term research as service delivery.

Formative evaluation

Several techniques for formative evaluation were described: listening to the feedback provided by community members and grass-root workers (Kroeger 1982); anthropologic techniques including “pile sorting” to understand how target groups relate risk behaviors cognitively (Trotter and Potter 1993); the use of ethnography (LeMaster and Connell 1994); and the use of focus groups (Schinke 1996; LeMaster and Connell 1994).

Posters/materials

The use of cartoons was described to be helpful in stimulating and developing discussion during intervention sessions (Kroeger 1982). Creating messages that promote a sense of pride in one’s self and one’s Tribe can lead into discussions of the strengths and positive attributes of AIAN (Schinke 1996).

Fact sheets, brochures, comic books, newsletters and posters are available by contacting the National HIV/AIDS Clearinghouse, the Northwest Portland Area Indian Health Board Project Red Talon, Haskell Indian Junior College, the National Council for International Health AIDS Program, National Native American Aids Prevention Center, the American Indian Community House HIV/AIDS Project, and the Minnesota American Indian AIDS Task Force. The Native American HIV/AIDS Coalition of Kansas/Missouri

developed a training manual with instructions on how to approach a potential interviewee, appropriate ways to ask survey questions, listening skills, and how to avoid biasing the interview (Hoskins and Burhansstipanov 1999).

Promoting interventions

Using a traditional feast including drummers and dancers, advertising at powwow booths (LeMaster and Connell 1994), and special attention to the name of an intervention (Harvey 1995; Burhansstipanov, in press) are recommendations for promoting interventions.

Other recommended culturally competent intervention components and activities are-

- 1) The promotion of traditional diets, and activities that encourage cultural awareness (LeMaster and Connell 1994).
- 2) For school-based interventions, incorporating topics appropriate to student's cultures, such as Native land claims, arts and crafts and history (Harvey 1995; Schinke 1996).
- 3) Enhancing interventions by adding storytelling, humor, folk tales and legends, and oral traditions (Schinke 1996; Rowell 1990).
- 4) Using Native languages where appropriate (Calzavara et al. 1998).
- 5) When conducting interviews on behaviors it may be appropriate to ask for forgiveness for asking questions that are personal. A tribally specific gift should be given to survey participants (Hoskins and Burhansstipanov 1999).

Additional lessons from HIV/AIDS case management: secondary prevention

Case managers have recognized the need and usefulness of linking clients to AIAN healers (Journal of Okla. 1995; Claus et al. 1999; Harris et al. 1999; Rowell and Kusterer 1991). It is important to avoid "New Age Shamans [who] are resented within Indian Country because of their disrespect and subsequent 'bastardization' of Indian ceremonies." To ensure AIAN client referral to tribally accepted traditional healers it is imperative that staff be AIAN, or programs have working relationships with AIAN community-based organizations or Tribes (Barney et al. 1999).

Sometimes a non-Indian case manager or counselor is more appropriate for a client. They are perceived to have less opportunity to breach confidentiality than AIAN (Claus et al. 1999). The need for confidentiality is paramount. Speier (1999) describes the negative impact breaking confidentiality had in a program in Alaska.

Harrison et al. (1999) describe aspects of a culturally competent intervention in the southwest. Individual counseling and social support includes: careful listening, laughing, and singing. Clients are also accompanied to visits with healers. They also describe a support retreat at which stress reduction/relaxation, traditional therapies, and writing wills take place.

Harrison et al. also described ways to avoid stigmatizing in small communities. The interventionists regularly make appearances at events providing information on a variety of healthful behaviors. They are also frequently asked to join parents in homes to share advice on how to talk about sexual issues with their children. These normal

appearances anywhere-anytime, prevents community members from assuming people speaking to the interventionists are HIV-positive, a stigmatized disease in the community.

Staying contemporary

Culture is dynamic. Don't assume an article over fifteen years old is appropriate now, even if it was culturally competent when originally published (U.S. Department of Health and Human Services, Public Health Service, Alcohol, Drug Abuse, and Mental Health Administration 1992). This may be especially important when working with reemerging and infectious diseases.

Avoid stereotypes

The majority of Americans have limited experience with AIAN. It is critical to avoid "stereotypes [that] get in the way of health professionals providing education, prevention, surveillance, and information, the results can be tragic" (Rowell, 1990). The following facts should help people avoid the most common stereotypes. AIAN are of mixed-racial descent; (appearance) phenotype expression is not a valid indicator of race/ethnicity.

Demographers estimate that between 55-70% of AIAN live off reservation, depending on the Tribe. While the majority of AIAN do NOT live on reservations, many return frequently. Others only leave the reservation for periodic economic migration (Paschane et al. 1998). Some AIAN will return to the reservation when they are ill to be with family and to participate in spiritual and healing ceremonies (Ganga and Schafer 1992).

Implications and Recommendations

Data Recommendations

Because of the dearth of data available on HIV/AIDS and related risk behavior, for AIAN additional studies are needed. Specifically surveillance and epidemiologic studies, "pockets-of-need" studies, culturally competent interventions, and evaluation studies are needed (Fenaughty et al. 1998; Nannis et al. 1998). Funding agencies might collaborate on publishing findings of research and programs, to narrow the gap in information being published from Indian country.

More appropriate and meaningful data collection, analysis and reporting must be a priority. A system for collecting AIAN health data at the local level that can also be useful at state, regional, and national levels can and should be developed and implemented. Another method could be to group Tribes by the ten anthropologic/cultural regions (Pacific Northwest Coastal, California, Plateau, Plains, Southwest, etc.), such a method would lead to more specific information, while protecting confidentiality. The issue would then be how to address non-reservation and urban Indians, the majority of the population.

The elimination of racial misclassification on AIAN death certificates and health records must be a priority for federal, state and local health reporting agencies (Indian

Health Service, 1996). The practice of aggregating distinct and separate Tribes into one pan-Indian group must be eliminated. Researchers must be more clear and precise in their publications.

Without better data we risk the health of AIAN, perhaps especially smaller Tribes, as evidenced in the infectious disease pan-demics of the past 500 years. With better data Tribal health planners and administrators, Community HIV-prevention planning groups and CARE Act planning councils would have better information to prioritize health programs, develop policy, and allocate resources.

Educational opportunities for AIAN in public health

The best community-based interventions are designed and implemented by community members themselves. A huge unmet need persists for AIAN in the public health profession. This educational disparity should be prioritized by tribes, federal agencies and academia.

Future literature reviews

Tribal Health Divisions, urban Indian programs, and state health departments have implemented many HIV/AIDS prevention programs in Indian country. These programs, however, have not been published in scientific journals (LeMaster and Connell 1994). Therefore, a more thorough and culturally competent literature review would require direct contact with Tribes and urban Indian organizations to learn about their HIV/AIDS prevention and control programs. This “standard” literature review barely scratches the surface of programs and interventions being implemented in Indian country.

Conclusion

A literature review was conducted on culturally competent HIV/AIDS prevention for American Indians and Alaska Natives. Published articles were sparse and focused on only a few tribes and tribal communities. The extent to which these interventions are generalizable is unknown.

Nevertheless major recommendations for developing culturally competent HIV/AIDS prevention are: (1) obtain community input; (2) seek Tribal organization support, particularly when on reservations; (3) invite and support community participation and control (4) access traditional healers, spiritual people, and Elders; (5) use formative evaluation to improve the intervention; (6) pay particular attention to confidentiality; (7) avoid stereotypes and ethnocentricity; and (8) publish findings.

There is a great need for additional and enhanced surveillance, epidemiologic, culturally competent interventions, and evaluation studies, using more appropriate and meaningful data collection and analysis. This would greatly benefit the development of culturally competent interventions and programming, policy, and resource allocation for the prevention of HIV/AIDS and related public health areas. There is a great need for

more AIAN in the field of public health. Creative methods and strategies should be taken for a comprehensive review of HIV/AIDS interventions in AIAN populations.

Definitions

Alaska Native: The term collectively refers to Eskimos, Aleuts, and American Indians who are indigenous to Alaska.

American Indian: This includes enrolled members of Federal and/or State recognized tribes as well as people who are self-identified as “American Indian” on the U.S. Census and other similar reports.

Cultural competence and sensitivity: There are three different ways this concept is used. The semantic conception underscores the importance of conveying the prevention message so that it is understandable to the desired population; this includes using linguistic and stylistic characteristics that are familiar to the target population. The instrumental conception underscores the importance of understanding the cultural context of the target population’s behavioral norms regarding health. The principled conception has a foundation that is respect for the cultural integrity of those to whom public health efforts are directed and the moral claims of pluralism. Principled cultural sensitivity prohibits those interventions that violate the cultural norms of those to whom they are directed (Bayer 1994).

Indian Tribe: Any Indian tribe, band, Nation, rancheria, Pueblo, or other organized group or community, including any Alaska Native village, group, regional, or village corporation as defined in or established by the Alaska Native Claims Settlement Act, and is recognized as eligible for the special programs and services provided by the United States to Indians through government to government relationships, specifically treaties. A tribe may be federally recognized, state recognized, or self-recognized.

Reservation: The geographic area reserved by treaty or other law for a federally recognized Indian tribe.

U.S. All Races: A phrase, used to describe the entire U.S. population (American Indians, Aleuts, Eskimos, Whites, African Americans, Asians, Hispanics, Latinos, Native Hawaiians, and so on).

References Cited

- Baldwin, J. 1999. Conducting Drug Abuse Prevention Research in Partnership with Native American Communities: Meeting Challenges Through Collaborative Approaches. In *Conducting Drug Abuse Research with Minority Populations: Advances and Issues*. The Haworth Press, Inc. 77-93.
- Baldwin, J., Rolf, J., Johnson, J., Bowers, J., Benally, C., and Trotter, R. 1996. “Developing Culturally Sensitive HIV/AIDS and Substance Abuse Prevention Curricula for Native American Youth.” *Journal of School Health*. 66(9): 322-327.
- Barney, D and Burhansstipanov, L. 1999. “The Ahalaya Project, Oklahoma.” In *Native Americans and HIV: Summary of Ongoing Special Projects of National Significance*. U.S. Department of Health and Human Services, Public Health Service, Health Resources and Services Administration, HIV/AIDS Bureau.
- Bayer, Ronald. 1994. “AIDS Prevention and Cultural Sensitivity: Are They Compatible?” *American Journal of Public Health*. 84(6): 895-898.
- Belongia, E., Besser-Wiek, J., DeBoer, J., MacDonald, K., Osterholm, M., et al. 1995. “Increasing Incidence of Gonorrhea – Minnesota, 1994.” *Morbidity and Mortality Weekly Report*. 44(14):282-286.
- Brassard, P., Smeja, C., and Valverde, C. 1996. “Needs Assessment for an Urban Native HIV and AIDS Prevention Program.” *AIDS Education and Prevention*. 8(4): 343-351.
- Burhansstipanov, L. in press. “Urban Native American Health Issues.” *Cancer*.
- Calzavara, L., Burchell, A., Myers, T., Bullock, S., Escobar, M., and Cockerill, R. 1998. “Condom use among Aboriginal people in Ontario, Canada.” *International Journal of STD & AIDS*. 9:272-279.
- CDC. 1998. “HIV/AIDS Among American Indians and Alaskan Natives – United States, 1981 – 1997.” *Morbidity and Mortality Weekly Report*. 47(8): 154-160.

CDC. 1998. "State-Specific Birth Rates for Teenagers – United States, 1990-1996." *Morbidity and Mortality Weekly Report*. 46(36):837-842.

Claus, C., Estrada, A., Polk, B., and James, C. 1999. "Native American pathways Program, Phoenix, Arizona." In *Native Americans and HIV: Summary of Ongoing Special Projects of National Significance*. U.S. Department of Health and Human Services, Public Health Service, Health Resources and Services Administration, HIV/AIDS Bureau.

Fenaughty, A., Fisher, D., Cagle, H., Stevens, S., Baldwin, J., and Booth, R. 1998. "Sex Partners of Native American Drug Use." *Journal of Acquired Immune Deficiency Syndromes and Human Retrovirology*. 17:275-282.

Gallion, S. 1999. "Seattle Indian Health Board HIV Case Management." In *Native Americans and HIV: Summary of Ongoing Special Projects of National Significance*. U.S. Department of Health and Human Services, Public Health Service, Health Resources and Services Administration, HIV/AIDS Bureau.

Ganga, U. and Schafer, L. 1992. "Tuberculous Paratonsitis: A Case Report and Literature Review." *University of South Dakota School of Medicine*. October: 27:287-289.

Hahn, R., Mulinare, J., and Teutsch, S. 1992. "Inconsistencies in Coding of Race and Ethnicity Between Birth and Death in U.S. Infants: A New Look at Infant Mortality, 1983 Through 1985." *Journal of the American Medical Association*. 267:259-263.

Harris, C., Gubiseh-Ayala, D., and Edwards, T. 1999. "American Indian Community House, New York." In *Native Americans and HIV: Summary of Ongoing Special Projects of National Significance*. U.S. Department of Health and Human Services, Public Health Service, Health Resources and Services Administration, HIV/AIDS Bureau.

Harrison, M., Wilson, J., and Burhansstipanov, L. 1999. "Southwestern AIDS Network (SAN)." In *Native Americans and HIV: Summary of Ongoing Special Projects of National Significance*. U.S. Department of Health and Human Services, Public Health Service, Health Resources and Services Administration, HIV/AIDS Bureau.

Harvey, E. 1995. "Mental health promotion among American Indian children." *Arctic Medical Research*. 54(Suppl.)1:101-106.

Hoskins, S. and Burhansstipanov, L. 1999. "Native American HIV/AIDS Coalition Kansas/Missouri." In *Native Americans and HIV: Summary of Ongoing Special Projects of National Significance*. U.S. Department of Health and Human Services, Public Health Service, Health Resources and Services Administration, HIV/AIDS Bureau.

Kroeger, A. 1982. "Participatory evaluation of primary health care programmes: an experience with four Indian populations in Ecuador." *Tropical Doctor*. 12:38-43.

LaFavor, C. and Burhansstipanov, L. 1999. "Positively Native...and Healing." In *Native Americans and HIV: Summary of Ongoing Special Projects of National Significance*. U.S. Department of Health and Human Services, Public Health Service, Health Resources and Services Administration, HIV/AIDS Bureau.

Lee, C., Brunham, R., Sherman, E., and Harding, G. 1987. "Epidemiology of an Outbreak of Infectious Syphilis in Manitoba." *American Journal of Epidemiology*. 125(2) 277-283.

Lego, G. 1995. "Developing HIV Prevention Curricula for Native American Youth." *Seasons*. Autumn: 18-22.

- LeMaster, P. and Connell, C. 1994. "Health Education Interventions among Native Americans: A Review and Analysis." *Health Education Quarterly*. 21(4):521-538.
- Lieb, L., Conway, G., Hedderman, Yao, J., and Kerndt, P. 1992. "Racial Misclassification of American Indians with AIDS in Los Angeles County." *Journal of Acquired Immune Deficiency Syndromes*. 5:1137-1141.
- Magee, D. and Montalvo, R. 1999. "The Indian Health Council, California." In *Native Americans and HIV: Summary of Ongoing Special Projects of National Significance*. U.S. Department of Health and Human Services, Public Health Service, Health Resources and Services Administration, HIV/AIDS Bureau.
- Metler, R., Conway, G., and Stehr-Green, J. 1991. "AIDS Surveillance among American Indians and Alaska Natives." *American Journal of Public Health*. 8(11): 1469-1471.
- Miller, W., Qualtere-Burcher, P., Lauber, C., Rockow, J., and Bauman, K. 1990. "AIDS Knowledge and Attitudes among Adolescents in the Rural Southwest." *The Journal of Rural Health*. 6(3): 246-255.
- Nannis, E., Schneider, S., Jenkins, P., Sharp-Breslau, E., Daniell, F., and McKee Jr., K. 1998. "Human Immunodeficiency Virus (HIV) Education and HIV Risk Behavior: A Survey of Rapid Deployment Troops." *Military Medicine*. 163(10):672-676.
- Orr, P., Sherman, E., Blanchard, J., Fast, M., Hammond, G., and Brunham, R. 1994. "Epidemiology of Infection Due to Chlamydia trachomatis in Manitoba, Canada." *Clinical Infectious Diseases*. 19: 876-883.
- Paschane, D., Fisher, D., Cagle, H., and Fenaughty, A. 1998. "Gonorrhea Among Drug Users: An Alaskan Versus a National Sample." *American Journal of Alcohol Abuse*. 24(2):285-297.
- Romanowski, B., Sutherland, R., Love, E., and Mooney, D. 1984. "Epidemiology of an outbreak of infectious syphilis in Alberta." *International Journal of STD & AIDS*. 2: 424-427.
- Rowell, R. 1990. "Native Americans, Stereotypes, and HIV/AIDS: Our Continuing Struggle for Survival." *SIECUS Report*. February/March.
- Rowell, R. and Kusterer, H. 1991. "Care of HIV Infected Native American Substance Abusers." In *Counseling Chemically Dependent People with HIV Illness*. The Hawthorn Press, Inc. 91-103.
- Salloum, S. and Crysdale, W. 1989. "Ear care for a Canadian native population." Presented at the Annual Meeting of the Canadian Society of Otolaryngology-Head and Neck Surgery. Toronto, Ontario.
- Sanchez, T., Plawecki, J., and Plawecki H. 1999. "The Delivery of Culturally Sensitive Health Care to Native Americans." *Journal of Holistic Nursing*. 14(4):295-307.
- Satter, D., Seals, B., Dooley, S., and Tullier, C. 1998. "The CDC, Division of HIV/AIDS' American Indian, Alaska Native and Native Hawaiian HIV Prevention Partnership Initiative." Presented at the Annual Conference of American Public Health Association. Washington, D.C.
- Schinke, S. 1996. "Behavioral approaches to illness prevention for Native Americans." In *Handbook of diversity issues in health psychology*. The Plenum Press, Inc.
- Speier, T. 1999. "Alaska Native Villages HIV/AIDS-Prevention Program." In *Native Americans and HIV: Summary of Ongoing Special Projects of National Significance*. U.S. Department of Health and Human Services, Public Health Service, Health Resources and Services Administration, HIV/AIDS Bureau.

Sullivan, C. 1991. "Pathways to Infection: AIDS Vulnerability among the Navajo." *AIDS Education and Prevention*. 3(3) 241-257.

Sullivan, P., Chu, S., Fleming, P., and Ward, J. 1997. "Changes in AIDS incidence for men who have sex with men, United States 1990-1995." *AIDS*. 11:1641-1646.

Trotter, R. and Potter, J. 1993. Pile Sorts, A Cognitive Anthropological Model of Drug and AIDS Risks for Navajo Teenagers: Assessment of a New Evaluation Tool. In *AIDS and Community-Based Drug Intervention Programs: Evaluation and Outreach*. The Haworth Press, Inc.

"Adjusting for Miscoding of Indian Race on State Death Certificates." 1996. U.S. Department of Health and Human Services, Public Health Service, Indian Health Service, Office of Planning, Evaluation, and Legislation, Division of Program Statistics.

"Ahalaya Project providing assistance to HIV-infected Native Americans in OKC, Tulsa." 1995. Journal of the Oklahoma State Medical Association.

"Cultural Competence for Evaluators: A Guide for Alcohol and Other Drug Abuse Prevention Practitioners Working With Ethnic/Racial Communities." 1992. U.S. Department of Health and Human Services, Public Health Service, Alcohol, Drug Abuse, and Mental Health Administration.

"*Regional Differences in Indian Health*." 1998. U.S. Department of Health and Human Services, Public Health Service, Indian Health Service, Office of Public Health, Division of Community and Environmental Health, Program Statistics Team.

"*Trends in Indian Health*." 1998. U.S. Department of Health and Human Services, Public Health Service, Indian Health Service, Office of Public Health, Division of Community and Environmental Health, Program Statistics Team.