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HIV ISSUES AND MAPUCHES IN CHILE

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Abstract

Chile is a country with an incipient HIV epidemic. Just as in other countries, disadvantaged groups in Chile are contributing to the increased incidence of the disease. The *Mapuche* indigenous population is one such group that has been affected by the spread of HIV. However, no prevention programs are tailored to the culturally specific needs of this community. In recognition of this discrepancy, an academic-community partnership was formed to develop an HIV educational module for a *Mapuche* community.

The module was developed for use as part of an already established health-related program. The aims of the module were to identify perceptions about HIV among *Mapuches* and present information specific to HIV and its prevention. Focus was placed on cultural sensitivity. The module was carried out in connection with a first-aid course in an attempt to increase effectiveness of the intervention by working jointly with an established community program. Sixteen (16) *Mapuches* participated voluntarily and demonstrated some knowledge regarding HIV, but they lacked an overall understanding as to how it is transmitted and why prevention strategies are affective. Participants correctly identified sexual contact as a means of transmission, but when asked why, one person stated, “I just know it, I read it.” There were significant barriers to communication within the group, secondary to cultural practices related to age and gender.

Major obstacles in controlling HIV are the lack of prevention strategies targeted to disadvantaged groups. The module developed for this intervention was the first effort of the Academic

Community Partnership established between the Pontificia Universidad Católica de Chile and the *Mapuche* group around HIV prevention. Continued collaboration between academia and affected communities as well as incorporating HIV information into established programs are effective strategies for delivering prevention information to disadvantaged populations and for further understanding their perceptions and healthcare needs.

Keywords

indigenous population; HIV; AIDS; Chile; *Mapuches*; *Araucanos*

INTRODUCTION

The first AIDS case in Chile was diagnosed in 1984. Up to the end of 2001, the cumulative AIDS incidence was 43.7 per 100,000 Chileans, with homosexual men being the most affected group. In addition, an increasing number of new HIV cases were reported in rural communities (CONASIDA, 2003). Rajevic (2000) estimated that approximately 20,000 Chileans had HIV or AIDS in the year 2000, and that many of them were not aware of their HIV status. UNAIDS (2004) estimated that in Chile 25,000 adults were living with HIV in 2003, categorizing the country as one with an incipient epidemic.

Globally, HIV is steadily increasing among minorities (UNAIDS, 2004). This is also the case in Chile, where there is a lack of culturally appropriate information and HIV prevention programs targeted to minority groups. The *Mapuches*, the largest indigenous group in Chile, is one example of a Chilean minority group affected by the epidemic.

With this in mind, and at the particular request of a *Mapuche*, an academic-community partnership was established to identify the meanings and effects of HIV in the *Mapuche* population. An educational module on HIV prevention was planned and implemented, using a participatory approach. This methodology allowed the research team to explore meanings while carrying out interventions with the group (Minkler, 2000; Nichter, 1984; Whyte, Green, Davydd, & Lazes, 1990). The intervention sought to increase HIV related knowledge, using adult learning techniques to reduce negative attitudes toward people living with the virus.

DESCRIPTION

Chile and the *Mapuches*

Chile is located on the western coast of South America and shares borders on the north with Peru, on the east with Argentina and Bolivia, in the south with the South Pole, on the west with the Pacific Ocean. According to estimates by the Chilean National Statistics Institute for the year 2002, the Chilean population is approximately 15,823,957. With literacy at 95.8 %, Chile enjoys one of the highest literacy levels in Latin-America (Chilean National Statistics Institute, 2003).

The ethnicity of the Chilean population is 95% European descendents and 7% indigenous. The Mapuches are the largest indigenous group in Chile, constituting 6% of the population.

Roughly half of this population group live in the southern part of Chile, around a city called Villarrica, and the other half have moved to the capital, Santiago, in search of better economic opportunities (Chilean National Statistics Institute, 2003).

Although they represent 6% of the Chilean population (Chilean National Statistics Institute, 2003), the *Mapuches*, commonly known as the *Araucanos*, function as a subculture within Chile and have limited connection with the rest of society. The culture is recognized as a human patrimony and has survived the attacks of both the Spanish conquistadors and contemporary society. They have their own language, traditions, and distinctive ethnic characteristics. Their rituals and beliefs stem from a different view of the cosmos, and much value is placed on the extended family unit as well as war strategies to protect what they value. For over three centuries, they have avoided total immersion in contemporary Chilean life, and, because of their unique culture, traditional health care providers frequently misunderstand them.

The social unit of the *Mapuches* is based on the extended family. All male descendents live with their families of origin. When they marry, the wife is taken in and accepted as a permanent member of the husband's family. Each extended family is called *lof*, and they all live in homes referred to as *rukas*. *Rukas* are circular houses made of straw, with a roof that is open at the center in order to provide ventilation for cooking fires (Parentini, 1996).

The majority of *Mapuche* people live in extreme poverty. They have a precarious survival-based economy, in which earnings are immediately used for trade or expenditure. *Mapuch*e men often work as farmers for property owners in the nearby countryside. They may also be dependent on financial support from relatives, living in Santiago or other urban cities, as a source of supplemental income (Peyser, 2003; Saavedra, 2002).

As cited by Aguilar (2005), the first indigenous law was passed in 1866 in an attempt to end centuries of fighting between *Mapuche* tribes and the Chilean population. This law continues to have repercussions today. The law was designed to break up the extensive *Mapuche* lands among *Mapuches* and Chileans, in exchange for peace. As a consequence of this, the best parts of the land were given to Chileans, leaving *Mapuches* with the smallest and poorest land for agriculture. Despite this, many Mapuches attempted to become farmers in adverse conditions. Several modifications have been made since this law went into effect, but Mapuche people continue to struggle economically (Parentini, 1996).

Outside of the extended family, a fundamental member of the *Mapuche* society is the *machi*. The *machi* is considered to be the most important person in terms of establishing moral values; she/he acts as a bridge between the natural and the supernatural world. Usually female, the *machi*, like a Shaman, acts as the healer of the tribe and interacts with spiritual forces, especially those of dead predecessors (Salas, 1994).

Health indicators among *Mapuches* in Chile

Current, accurate information about *Mapuche* health indicators is difficult to find. Most *Mapuches* live in the rural South of Chile, and do not necessarily attend traditional health care centers. Quite often, *Mapuches* only enter the national health care system when acutely

ill or dying. Because of these factors, determining health care indicators for this group has been difficult, and there is a large gap in background information.

The mortality rate of rural areas in the southern part of Chile is 5.8% higher than that of urban areas. Among *Mapuches*, this difference is even greater. According to the Chilean Ministry of Health (MINSAL) the cumulative mortality rate between 1999 and 2000 was 6.0 per 1,000 *Mapuche* inhabitants in the South of Chile. This was significantly higher than the general population of the region (MINSAL, 2000).

The five main causes of death in Chile are: cardiovascular diseases (25.5%), tumors (20.9%), accidents and poisonings (14.5 %), undefined symptoms (12.7%), and lung diseases (10.7%). Accidents and poisonings have a cumulative rate of 85.9 per 100,000 inhabitants, of whom 72.2% are men, and 64% occur in rural areas (MINSAL, 2000).

Upon analyzing the causes of death among *Mapuches*, several discrepancies with the Chilean population as a whole can be observed. The main cause of death in the male population is heart attack, with alcohol-related cirrhosis and prostate cancer for ages 50 and over also being significant. For women, the main cause of death is pneumonia, followed by cancerous tumors found in the gallbladder, stomach, esophagus, cervix, and breast (MINSAL, 2000). This shows that although the *Mapuches* form a significant portion of the Chilean population, as an ethnic minority group, there are many discrepancies with the general population.

Mapuches and HIV in Chile

No specific data are available regarding HIV and the *Mapuche* population. However, information from nongovernmental organizations and empirical data provided by *Machis* who work at health care centers in Santiago show that HIV is being seen more often among clients. Poverty, lack of formal education, and the high incidence of alcoholism are all indicators suggesting this group's possible involvement in high-risk behaviors. It is also important to note that *Mapuche* women have a high incidence of cervical cancer, which is associated with the human papilloma virus, another risk factor for HIV.

In recognition of the risks that *Mapuches* have in Chile, an Academic Community Partnership (ACP) was established between Pontificia Universidad Católica de Chile, School of Nursing Mano a Mano [Hand to Hand] HIV prevention projects and the Minority International Research Training Program (MIRT) from the College of Nursing, University of Illinois at Chicago, and a *Mapuche's* community. With this partnership, activities were planned in order to identify the needs of the community regarding HIV. In addition to requesting further information on prevention of spread of diseases and HIV, the group vocalized concerns regarding the growth of tourism and their inability to provide adequate first aid in case of accidents. In an effort to meet these needs, a First-Aid course with an HIV component was developed and implemented.

HIV prevention module

The HIV prevention module was constructed as a two-hour session based on adult learning strategies proposed by the Brazilian educator Paulo Freire (1970). Freire held that through

the sharing of knowledge, interests, concerns, and everyday experiences, participants are empowered to take control over their lives and take positive actions that will benefit them, their families, and the community.

The module content included: modes of transmission, epidemiology, prevention strategies, feelings, and experiences related to HIV. The materials were specifically designed for the educational level, learning styles, and culture of the targeted participants. A combination of visual materials, open discussion sessions, and demonstrations were used and found to be very valuable. The HIV module was taught at the end of the first-aid course. The facilitator guided the session according to the group's needs and interests.

In a non-judgmental environment, participants were asked to share personal opinions and experiences, concerning HIV. At the beginning of the session a chair-circle discussion was held, including both participants and the facilitator. The session began with everyone introducing himself or herself and sharing background information. The facilitator then asked questions to the group, such as “What is HIV/AIDS?” and “Is HIV/AIDS a problem in our community? If so, why?”

After listening to the participants’ opinions and knowledge, the facilitator distributed a handbook with brief explanations and pictures about modes of transmission, emphasizing HIV prevention strategies. The handout was read by one of the session members and afterwards discussed by the whole group. At the end of the 2-hour session, time was set aside for the group to ask questions, share opinions, and talk about personal experiences related to HIV. This process lasted an additional hour because the participants had many questions and concerns to discuss personally with the facilitator.

Sixteen *Mapuches* participated voluntarily in the First-Aid Course. It was conducted at a rural school, which was also a First-Aid Station in the community for both children and adults. The classroom where the training was held was similar to a wood cabin and without furnishings, except for about 20 desks, a chalkboard, and a few educational posters hanging on the wall. The community where the school is located is very poor. Most of the children live miles away from the school, and transportation to school is difficult, especially in bad weather conditions.

All the participants were dressed in modern-day clothing, as opposed to the traditional dress that some *Mapuches* are seen wearing in photos. The mean age of the participants was 22. Twelve participants were men, and four were women. The uneven distribution was not surprising, since men are expected to manage more information about health in the community. Men often hold prestigious positions that allow them to be the decision makers for the group.

Through their work with community members early in the preparation process, facilitators became aware that many of the people in the *Mapuche* community were illiterate and had not been educated beyond the sixth grade. This was surprising, initially, considering Chile's high literacy rate (Chilean National Statistics Institute, 2003). This phenomenon can be explained, in part, by the limited access the *Mapuche* people have to education, which is often due to factors such as discrimination, distance to rural schools, and lack of money to

buy textbooks and supplies. Another barrier may be the lack of value placed on formal education by *Mapuche* men, who tend to believe more in learning that has to do with nature, fighting strategies, and agriculture. Although this information is not well documented in the literature, it was recognized in the participatory process of designing the module.

The module began with a facilitator asking what attendees knew or believed about HIV. This was followed by a discussion regarding their feelings and views about the disease. The group talked about what they knew or what they had been told by other people regarding HIV. The main idea that emerged from participants was that HIV was different from other diseases, and that even the *Machi* could not cure it.

Regarding HIV transmission, a male participant said: “You can contract HIV/AIDS by touching blood and having sexual relations.” After his comment, many people looked uncomfortable and started to smile, trying to contain their laughter. They all seemed embarrassed that the topic of sex was brought up. One participant said: “Sex is not a topic to discuss with others, but we are willing to talk about HIV/AIDS.”

After discussing and clarifying the modes of HIV transmission, the facilitator asked the group how people could protect themselves from HIV in a sexual relationship. All the participants had ideas about protection and mentioned television as their main source of information. They also specifically mentioned that the “Machi does not address this, neither do other traditional providers.” Male participants reported abstinence, monogamy, and condom use as ways to protect themselves from HIV; nonetheless they did not understand how these strategies provide protection.

The facilitator then raised the following question: “Does anyone know how people get infected with HIV/AIDS through sex?” Participants looked at one another dumbfounded, and no one answered the question. A male participant stated: “*I just know it, I read it*.” Because the participant was the older male in the group, no further discussion was allowed. A young participant approached the facilitator after the session was over and explained that the situation was a demonstration of respect: “We Mapuches respect the experienced men in our groups, and we follow traditions and what they teach us.”

Because it was a First-Aid training program, participants were asked how they would protect themselves from HIV if a friend fell down and started bleeding. After the facilitator explained that HIV is present in some body fluids, such as blood, they all correctly identified the use of gloves as an effective HIV prevention strategy, but they still could not explain why.

Related to HIV experiences, the facilitator asked the question: “Does anyone know a person living with HIV?” This was met with a long silence, and no one was willing to answer. The group manifested the belief that “*This disease affects other people.*” Nonetheless, they briefly discussed how this disease might affect someone in the tribe, “But chances are the same as getting hit by lightening.” In general there was no sense among the group of cause and effect in terms of risky behaviors increasing susceptibility for acquiring the virus.

Discussion about homosexuality and bisexuality did not spontaneously emerge in the session, not even when epidemiological data were presented to the participants. The facilitator tried to initiate discussion about this topic, but because the group included varying ages and a mix of men and women, it was not possible. The group also manifested the belief that the choice of sexual orientation was not an option for them.

At the end of the module, participants mentioned that they felt empowered to take an active role in HIV prevention. Consistent with the literature about successful adult education programs, a participative methodology should always be used to empower adults in HIV prevention (Cianelli, 2003; Cianelli, Ferrer, & Peragallo, 2003; Ferrer, 2004; Ferrer, Issel, & Cianelli, 2005; Marin, 2003; Peragallo et al., 2005). Further, connecting academia with the community appeared to strengthen the impact of the educational effort (Arno, 1986; Ferrer et al., 2005; Minkler, 2000; Omoto & Snyder, 2002).

Conclusions and Discussion of What Can Be Done

The HIV pandemic is increasing among disadvantaged groups in Chile. *Mapuches* require specific, culturally-sensitive prevention programs to stop the spread of HIV among the population. It is also necessary that these programs be planned and developed in partnership with members of the community in order to respect unique beliefs and ways of social functioning (Aiken, Herbert, & Lake, 1997; Brofman & Gleizaer, 1994; Minkler, 1997; Minkler, 2000).

Available literature suggests that a major obstacle in controlling the spread of HIV is the lack of prevention strategies targeted to minority groups. This is caused by a variety of factors, including inadequate research about minorities, lack of understanding of the issues regarding HIV, scarce resources available for programs, and the stigma and discrimination against people living with HIV (Hamill & Dickey, 2005).

The HIV module developed for *Mapuches* in Chile is an example of the first effort of an Academic Community Partnership designed to identify level of knowledge and beliefs around HIV in this group. The experience has helped in recognizing and documenting characteristics responsible for the spread of HIV among *Mapuches*. This experience highlights the relevance of the format and methodology used when conducting an HIV prevention program for *Mapuches*.

Machupes, as a group, would appear to respond better to a participatory methodology with attention to the distribution of participants, related to age and gender. Women and men do not discuss sexuality in the same room, and young people do not generally give their opinion after an older adult has spoken.

In regard to the participatory methodology, this experience was consistent with the philosophy of the Brazilian educator, Paulo Freire (1970). As he suggested, through the sharing of knowledge, interests, concerns, and life experience, participants can be empowered to take control over their lives and make positive decisions regarding areas such as HIV prevention.

In addition, *Machupes* do not generally feel vulnerable or perceive themselves at risk for acquiring HIV, and therefore, they may not independently seek out information regarding this topic. Incorporating an HIV module into previously established programs helps to make education more effective in terms of reaching the population (Aiken et al. , 1997). The HIV module within the first-aid and caregivers' workshops are good examples of this, demonstrating a way to educate targeted groups about HIV prevention. The module also showed the importance of committing to working on educational and health promotion programs that are needed to contain the HIV epidemic. Finally, establishing an Academic Community Partnership appears to be a non-threatening way to achieve the goal of incorporating HIV education as a component of already established and valued programs.

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