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Assessing the needs and generating ideas for curriculum development for support groups for HIV positive Latinos

Ofelia F. Hawk
San Jose State University

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**Assessing the needs and generating ideas for curriculum
development for support groups for HIV positive Latinos**

Hawk, Ofelia Fransisca, M.S.

San Jose State University, 1993

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300 N. Zeeb Rd.
Ann Arbor, MI 48106

ASSESSING THE NEEDS AND GENERATING IDEAS FOR CURRICULUM
DEVELOPMENT FOR SUPPORT GROUPS FOR HIV POSITIVE LATINOS

A Thesis
Presented to
The Faculty of the Department of Nursing
San Jose State University

In Partial Fulfillment
Of the Requirements for the Degree
Master of Science

By
Ofelia F. Hawk
December 10, 1993

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APPROVED FOR THE SCHOOL NURSING

Mary Reeve
Mary Reeve Ed.D., RN

Marian Yoder
Marian Yoder Ed.D., RN

Virgil Parsons
Virgil Parsons D.N.Sc., RN

APPROVED FOR THE UNIVERSITY

M. Lou Lewandowski

Abstract

ASSESSING THE NEEDS AND GENERATING IDEAS FOR CURRICULUM DEVELOPMENT FOR SUPPORT GROUPS FOR HIV POSITIVE LATINOS

By Ofelia F. Hawk

This thesis addresses the need to assess and generate ideas for curriculum development for support groups for HIV positive Latinos. It examines the rate of increase of HIV infection among Latinos and the particular cultural and psychosocial factors that contribute to the increase. It also focuses on interviews with three groups of people which consisted of (a) health care professionals, (b) individuals considered leaders of the Latino community, and (c) HIV positive Latinos.

Overall the informants involved in this study believed specific cultural and psychosocial factors should be included when designing a curriculum for HIV positive Latinos and their families. They also believed that HIV positive Latinos could benefit from this culturally sensitive curriculum. Based on culturally sensitive information HIV positive Latinos can better understand, recognize, and believe that they have self control in observing safe practices to prevent the transmission of the HIV infection.

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Chapter 1

INTRODUCTION

Acquired immunodeficiency syndrome (AIDS) and the human immunodeficiency virus (HIV) infection are considered by many to represent a modern day "white homosexual" plague (Gallo & Montagnier, 1988). The reality is that AIDS is no longer a white, homosexual disease, but is increasing dramatically and is occurring disproportionately in the minority population (Flaskerud, 1988).

According to the 1991 U.S. census, the two largest ethnic minority groups with the HIV infection were Blacks and Latinos (Hispanic). Based on the 1991 Centers for Disease Control statistics (CDC), these minority groups have shown a dramatic increase for HIV infection ("Morbidity and Mortality," 1991). The Public Health Service has estimated that over a half a million minority individuals have already been exposed to the AIDS virus in the United States (Morbidity and Mortality, 1991).

In Santa Clara County, California, Latinos are the largest minority group comprising 20.6% of the population in 1991 (Office of Public Health, 1991). According to the Santa Clara County Public Health Department, the county has experienced a dramatic increase in the number of AIDS cases reported among Latinos, especially persons between 13 and 45 years old. Latino representation among AIDS cases in Santa Clara County rose from 19% in 1989 to 20%

in 1990 and to 21% in 1991 (Office of Public Health, 1991). With the number of HIV positive Latinos increasing, the potential risk for the transmission of the HIV infection also increases. HIV positive Latinos are potentially more at risk for the HIV infection transmission for several reasons: (a) particular cultural customs, beliefs and practices that Latinos may be unaware of as being risk factors, (b) isolation from their families due to the cultural and societal stigma associated with the HIV infection, (c) more male Latinos are bisexual than homosexual resulting in an increased potential for transmission of the HIV infection to females and possibly to their children in utero, and (d) limited culturally sensitive resources available to them (Flakersud, 1988). Latinos who are HIV positive are not attending existing AIDS support programs in Santa Clara County largely due to lack of cultural sensitivity and bilingual services (Office of Public Health, 1991).

According to the CDC, HIV infection is likely to spread at much higher rates among minorities than among whites (Morbidity and Mortality, 1991). The increase of the HIV infection in minorities has important implications for controlling the HIV infection and slowing transmission.

Problem Statement

One of this country's distinguishing features is its diverse and ever growing ethnic populations. While the

ethnic populations are growing, so is the incidence of HIV infection (Selik, 1988).

Training, Education, and Communication for Latinos on AIDS (TECLA) is a program of the Health Education and Training Center (Health ETC), an affiliate of the San Jose Medical Center. Health ETC is a nonprofit organization dedicated to providing health education to residents of the San Jose area. It has been in existence for over 6 years and has vast experience working with the Latino community and health care issues such as AIDS. TECLA has presented AIDS educational training programs for high risk groups, such as minority youth in the Santa Clara juvenile correctional facilities and pregnant women in the Latino community since 1986. In addition, this organization has recently begun to address the educational needs of other high risk groups, such as Latino men who have sex with other Latino men, but do not consider themselves gay, and heterosexual partners of bisexual Latinos.

The Health ETC Board of Directors, composed of health care providers and community leaders who serve the surrounding San Jose community, was concerned that even with the culturally sensitive programs developed by TECLA, HIV infected Latinos were (a) neglected and isolated by their own cultural group, (b) unaware of cultural customs, beliefs and practices that were potential risk factors for the transmission of the HIV infection, and (c) lacking

public, culturally sensitive educational resources and available emotional support systems.

Traditionally, Latinos have turned to large extended networks of family and friends for support (Guinan & Hardy, 1987). Many HIV positive Latinos, however, have been isolated from these networks. Fear of contagion, ignorance about the disease, and societal stigma have contributed to this isolation. Many Latinos are also in the United States without their families, and these Latinos need to find alternative and, in some cases, additional support systems. There are many studies in the field of clinical psychology which have demonstrated that Latinos do benefit by participating in support groups (Leukerfeld & Fimbres, 1987).

There are existing support groups which assist individuals who are HIV positive, but many are primarily focused on the single, white, homosexual male. These support groups for those affected by the AIDS disease have been very effective, if not essential, in helping individuals to maintain the best quality of life possible (Leukerfeld & Fimbres, 1987). Additionally, these individuals need much information and education about HIV infection, financial benefits, legal issues, insurance, and civil rights. Support groups, however, need to be created which consider the context of the Latino culture.

Successful models of support groups have been developed for and by the gay community, but these models have limited

success in assisting people from different ethnic groups. Many Latinos, especially those who are not homosexual, are frustrated because present day support groups are not sensitive to their cultural, psychosocial, and language needs. An emotional support group, if designed with a culturally sensitive curriculum, can provide an important opportunity for HIV positive Latinos and their loved ones to meet, share, and support each other.

The nature of HIV infection necessitates that the infected person become knowledgeable about HIV transmission, the immune system, current treatments, and services available (Gallo & Monagnier, 1988). For the average Latino who has had limited access to health care and health education, acquiring this knowledge can be a phenomenal task. Adding an educational component to an emotional support group can assist in meeting this need. Culturally, the educational component attracts Latinos who are uncomfortable about the idea of sharing their feelings with strangers.

Supported by a California state grant and with the assistance of TECLA, a number of HIV Latino's were referred by the Santa Clara county testing site. They met as a group and expressed the need for a culturally sensitive educational/emotional support group. However, before a support group could be established, an appropriate culturally sensitive curriculum needed to be developed.

Purpose and Need

The primary purpose of this study was to conduct a needs assessment and generate ideas for the development of culturally sensitive curriculum for an educational/emotional support group for HIV positive Latinos and their families. Presently, there is no cure for the HIV infection, but it is preventable. However, there are several factors which could prevent Latinos from becoming aware of the HIV infection (Flaskerud, 1988). These include (a) certain religious beliefs and practices, cultural customs and psychosocial factors within the community, (b) lack of health care services and resources, and (c) lack of effective, culturally sensitive educational support programs. These particular factors have been suggested as promoting high risk behaviors which can potentially increase the transmission of the HIV infection.

HIV positive Latinos pose even more of a threat for transmission of the HIV infection. Most are not informed about the HIV infection and do not recognize high risk behaviors. Many do not get tested, believing in the societal stigma that the infection only occurs in the homosexual population. In addition, there is no existing culturally sensitive educational/emotional support group to inform, guide, and support these individuals who have HIV infection.

It was important to conduct a needs assessment to

generate ideas for the development of culturally sensitive curriculum for an educational/emotional support group. This group can assist HIV positive Latinos and families to learn in a culturally sensitive environment, not only about the HIV infection but also to culturally motivate them to practice safe behaviors. Also, through the culturally sensitive curriculum, Latinos who are HIV positive and their families can learn and understand that there are certain cultural values and environmental factors that promote high risk behaviors and potential transmission of the HIV infection to others.

Research Question

Because there are certain cultural values and environmental factors that promote high risk behaviors and potential transmission of HIV infection to others, the primary question asked was: What cultural or psychosocial factors should be addressed when developing a culturally sensitive curriculum for an educational/emotional support group for HIV positive Latinos?

Operational Definition of Terms

For the purpose of this study, the following terms were used:

1. Latino - A native or inhabitant of Latin America or a person of Latin American origin living in the United States.
2. Educational/Emotional support group - A group

that provides both education and emotional support to individuals about a particular subject.

3. HIV positive - A person who is positive with the antibodies of the human immunodeficiency virus.

Research Procedures

This research study was non-experimental using semi-structured interviews. A needs assessment was conducted to generate ideas for the development of culturally sensitive curriculum for an educational/emotional support group for HIV positive Latinos. The questions for the needs assessment were developed by this researcher with the assistance of Training, Education and Communication for Latinos on AIDS (TECLA) personnel. The needs assessment questions were developed through extensive research of the Latino population by a literature review of Latinos and the HIV infection, and support groups.

Three individual discussion groups were organized by this researcher with the assistance of TECLA. The discussion groups were developed to assess what psychosocial factors and values should be addressed when developing the curriculum for an educational/emotional support group for HIV positive Latinos and their families. The three groups were (a) five Latino health providers who primarily served, worked with, or came from the Latino population, (b) three members who were considered leaders in the Latino community, and (c) three HIV positive Latinos.

Scope and Limitations

The study was based on certain assumptions. Most of the participants interviewed were personally experiencing, working with, and/or serving Latinos who were experiencing concerns about culturally sensitive issues about the HIV infection and the Latino. Therefore, it was assumed that these participants would be particularly interested in participating in the discussion.

A limitation was that there is very little information on educational/emotional support groups for Latinos who are HIV positive. Another limitation was the small sample size of the discussion groups. Because the HIV infection is considered culturally unacceptable by Latinos, participants willing to discuss issues about the disease were difficult to locate. Also, the semi-structured interview is fraught with possible methodology problems, because it involves personal interaction variables which are virtually impossible to control. The researcher's past relationship with the subject, questioning bias, the time of the day for the subject all may have affected the subjects' responses to the questions asked and the possible resulting discussion.

CHAPTER 2

CONCEPTUAL FRAMEWORK AND LITERATURE REVIEW

Conceptual Framework

Bandura's (1969) model was selected as an appropriate framework for use in this study. Bandura (1969) initially developed the Perceived Self-Efficacy model and has continued to expand and refine it, especially in perceived self-efficacy in the exercise of control over the AIDS infection (Bandura, 1987). Perceived self-efficacy, derived from the social learning theory, is defined by Bandura (1987) as "people's judgement of their capabilities to organize and execute courses of action required to attain designated types of performances" (p.72). A core concept in the framework is that perceived self-efficacy is concerned with people's beliefs that they can exert great control over their motivation and behavior and over their social environment (Bandura, 1987). This concept provides the foundation upon which the needs assessment for the development of culturally sensitive curriculum for an educational/emotional support group for HIV positive Latino's was based. That is, information and support that are designed to the individual's needs (beliefs) increases understanding and control which assists the individual to make decisions and choices particularly about their behavior.

Prevention of further transmission of the HIV infection

requires people to exercise influence over their own motivation and behavior. Present social efforts designed to control the spread of AIDS have centered mainly on informing the public on how the human immunodeficiency virus (HIV) is transmitted and how to safeguard against such infection (Bandura, 1987).

It is widely assumed that if people are adequately informed about the AIDS threat, they will take appropriate self-protective action (Bandura, 1987). Heightened awareness and knowledge of health risks are important preconditions for self-directed change (Bandura, 1987). Unfortunately, information alone does not necessarily exert much influence on refractory health impairing habits (Bandura, 1987).

Practitioners have recognized that educational and preventive programs may not be providing the most appropriate content, because they have been based not on the data but on the public health issues (Bandura, 1987). Learning more about the sociocultural context of AIDS, the clinical course, and the interrelationship of the environment are more effective means of obtaining data on which information, treatment, and public policy could be developed (Lorig, 1988). The present social environment in today's world assumes that if a method was successful in one group, it should work for all groups. Such is the case with reducing the spread of HIV infection. Just because

education was successful in reducing the spread of the HIV infection in the single white homosexual male, there is no assurance that education would be effective in the Latino community.

The capacity to exercise control over one's own thought processes, motivation, and action is a distinctively human characteristic (Bandura, 1977). Because judgements and actions are partly self-determined, people can affect awareness and change in themselves and their situations through their own efforts and self-efficacy (Bandura, 1987).

Self-efficacy does not have to do with skills but rather with one's judgement or belief of how a person can apply these skills (Bandura 1987). For example, one might have all the skills necessary to carry out insulin injections but not have the belief that he or she can actually self-inject (Lorig, 1988). In the case with the Latino, he/she may have access to current AIDS education, but because it is not sensitive to their cultural needs and language, the likelihood that Latinos will believe that they have control in the prevention and transmission of the HIV infection is very slim.

Self-efficacy is also behavior specific (Bandura, 1987). That is, someone might have high efficacy for one activity and low efficacy for another. For example, most people have high efficacy for feeding and dressing themselves. However, these same people may have low efficacy for monitoring their

blood pressure or blood glucose (Lorig, 1988). The Latino may have a high efficacy in being healthy, but because of cultural beliefs, customs, and values, may have low self-efficacy to practice safe sex by using condoms. Thus, self-efficacy, unlike self esteem, is not a generalized condition. There is no such thing as an efficacious person; rather, one has the efficacy for specific performance or behaviors.

Prevention of HIV infection requires people to exercise influence over their own motivation and behavior. Presently, prevention of the HIV infection within our society mainly focuses on informing the public on how the HIV virus is transmitted and how to safeguard against the infection. Heightened awareness and knowledge of health risks are important preconditions for self-directed change (Strecher, Devellis, Becker, & Rosenstock, 1986). However, in order for heightened awareness and/or knowledge to be most effective, it must be taken one step further. It must be specifically tailored to meet the individual's needs. In order for the individual's needs to be met, cultural, emotional, and language needs must be included.

Not all individuals recognize their own beliefs or self-efficacy. Culturally sensitive educational and emotional support can motivate and empower the individual in becoming aware of his/her potential in believing that one has the control and motivation to change or influence a

specific behavior or action. For example, to effect self-directed change, people need to be provided not only with reasons to alter risky habits, but also with specialized means and resources to emotionally support the individual's decisions that will influence long term behavior or actions.

Literature Review

HIV infection was not recognized or described as a disease until 1981 (Heyward & Curran, 1986). Tracing HIV infection only began when doctors had seen enough cases to recognize the they were faced with a serious, previously unknown disease. In 1981, 316 people in the United States were known to have the HIV infection. By August, 1986, over 23,000 cases had been reported. As of October, 1991, it was estimated by the CDC that over a million people had been exposed to the HIV infection (Morbidity and Mortality, 1991).

A tremendous increase in the disease has continued. This is alarming, and scientists, health professionals, and the general public have all become very concerned about it. The Public Health Service has estimated that over a half a million minority individuals have been infected with the virus in the U.S. (Morbidity and Mortality, 1991). Of this number, an estimated 22% is Latino (Flaskerud, 1988).

There are several reasons for the wide ranging potential for increase of HIV infection in Latinos. Recent evidence suggests that Latinos may be more vulnerable than

whites, due to certain cultural values, customs, and practices (Flaskerud, 1988). Latinos are the fastest growing ethnic minority in the U.S., and may well be the largest minority group by the year 2000 (Amaro, 1987). Presently, there are over 28 million Latinos in the U.S., and they comprise 25% of the U.S. population.

Locally, Latinos are the largest minority group represented in the Santa Clara County, comprising 20.6% of the population in 1990. According to the Santa Clara Public Health Department (Office of Public Health, 1991), Santa Clara County has experienced a dramatic increase in the number of AIDS cases reported among Latinos, especially between the ages of 13 to 45 years old. In 1989, Latinos made up 19% of the AIDS cases in the county. As of November 20, 1990, there had already been an additional 30 cases of AIDS reported among Latinos, surpassing 1989 and raising Latino representation among AIDS cases from 19% in 1989 to 21% in 1990 (Office of Public Health, 1991).

The Santa Clara County Public Health Department estimates that by 1992, there will be 521 individuals living with AIDS, and 7,200 will be HIV positive but will not have developed AIDS. More current statistics are not available to verify this prediction. If Latinos continue to comprise the same proportion of cases as reported so far in 1990 (21%), then 1992 statistics will show approximately 98 Latinos to be living with AIDS, and 1,512 Latinos will be

HIV positive. This projects a dramatic increase in the number of cases among the Latino community in Santa Clara County.

Presently, there is no cure for HIV infection, but it is preventable (Gallo & Montagnier, 1988). However, there are several factors in the environment which could prevent the Latino from becoming aware of the HIV infection (Flaskerud, 1988). These include (a) religious beliefs, cultural customs, and psychosocial factors within the community, (b) lack of health care services and resources, and (c) lack of effective educational programs.

Within the Latino community, traditional cultural values and norms exist which influence existing behavior between the sexes and increase the risk for the HIV infection. For example, in the Latino culture, life centers around the family, and emphasis is placed on reproduction. Reproduction is a sign of a good strong man (Macho) or women (Marianismo) and indicates a blessing from God (Somara, 1981).

The traditional social role of the Hispanic woman is defined as passive, subservient, and she is defined primarily through motherhood. Marriage and pregnancy are her desired goal. Attractiveness is synonymous with sexual inexperience or "purity." A woman "prepared for sex (i.e., carrying condoms)," is perceived to be experienced, and therefore unattractive (Guinan, 1987, p. 2040). If the

woman suggests protective sex to the man, it can carry the connotation that she is not serious about pregnancy and marriage. While the present social milieu is to practice safe sex by using preventive measures such as condoms, this practice by a Latino woman would prevent pregnancy and thus goes against everything in which the Latino believes (Guinan, 1987).

It is important to note that there are stereotypical gender associations remaining at the core of a cultural belief system which affect how Latino women and men view and value themselves and each other. Many Latino men and women have non-traditional life styles, yet traditional gender roles continue to be an issue in their lives (Worth & Rodriguez, 1987). The implications of such values in the promotion of safe sex among Latino couples has made the prevention of the HIV infection more difficult to control (Rogers & Williams, 1987).

Over 80% of Latinos are Catholic. In the Catholic faith, religious teachings of the Bible emphasize the immorality of homosexuality (homophobia). This belief hinders the Latino's full awareness of the impact of HIV infection (Martinez, 1986). Since 90% of all HIV cases are found in the homosexual group, HIV infection is presently believed by many, including Latinos, to be a "gay disease." To many Latinos, AIDS is a disease that was God sent to punish homosexuals. A false sense of security has resulted,

making Latinos believe they are not at risk if they do not belong to this group.

According to Flaskerud (1988), homosexual contact or men who have sex with other men is the primary route for the transmission of HIV infection among all ethnic groups. However, many Latino men who have sex with other men may not identify themselves as gay. More often, these men will consider themselves as bisexual and may, therefore, not perceive themselves as being at risk.

Studies indicate that the rate of male Latinos having sex with other men is higher when compared to whites (Carrier, 1987). This may be due to a variety of cultural and social factors. Carrier reports that the selection of sexual partners made by the Latino may be limited by socioculture restraints which make many Latino women unavailable as sexual partners prior to marriage. A Latino's masculinity (machismo) is not affected by his having sex with other men. What is important is the role which he plays in the sex act. Carrier also suggest that among Latino men, anal intercourse is the preferred homosexual practice. Peterson and Marin (1987), report that minority gay men, including Latinos, may believe that high risk sexual activities are safe if they engage in these activities with minority men rather than white men. They also state that some data indicate that minority men dislike using condoms. Perceived problems associated with condoms

are their association with prostitution and uncleanness, diminished sensation, discomfort, or inconvenience.

CDC statistics indicate that the fastest growing risk group for the transmission of the HIV infection is the heterosexual community. Heterosexual contact and IV drug use are the primary routes for the transmission of the HIV infection among heterosexual Latinos. Local data for Santa Clara County indicate that the percentage of AIDS cases linked to heterosexual contact among Latinos increased from 2% to 6%, compared to 1% to 2% among whites. Most Latino men who have sex with other men do not consider themselves gay but more often bisexual. There are more bisexual Latino men compared to Caucasian men. There is, therefore, a greater likelihood for the spread of the HIV infection among Latino women and children compared to Caucasian women and children (Flaskerud, 1988).

Another high risk behavior and practice of HIV infection among Latinos is high use of intravenous drugs. HIV positive patients who are intravenous drug abusers are made up of 31% Latinos (Rogers & Williams, 1987). One of the major reasons for this devastating problem is that many Latinos are socioeconomically deprived. They are usually uneducated, have a language barrier, are under or unemployed, and have limited access to resources, such as health care (Flaskerud, 1988). As a source of income, many Latinos will turn to selling drugs, especially

IV drugs which are expensive and bring in a good fast income. To escape the worries of poverty and hopelessness, the Latino will often use the drugs which he/she is selling.

More Latino IV drug abusers might be infected than white IV drug abusers. A study of HIV infection among IV drug abusers in New York City revealed that HIV infection was higher for Latino (42%) IV drug abusers than white (14%) IV drug abusers (Rogers & Williams, 1987). In this same study, more whites (18%) than Latinos (8%) reported using new needles at least half the time. Whites were less likely to receive public assistance and were more educated than Latinos. It is possible that Latinos were less able to afford sterile needles and/or were less aware of the connection between sharing or re-using needles and HIV infection.

Intravenous drug abuse as a transmission route carries with it the risk of spread of HIV infection in Latino women. In Latino women, intravenous drug abuse and heterosexual contact account for 74% of cases of HIV infection (Flaskerud, 1988). Of the women with HIV infection, 21% became infected through sexual contact with infected men; 65% of these men were intravenous drug abusers (Flaskerud, 1988).

In addition, 52% of women with the HIV infection are themselves intravenous drug abusers. Women who are in their childbearing years (13 to 39 years old) with

HIV infection are of special concern, because 80% of the pediatric cases that are HIV positive can be attributed to perinatal or mother-to-infant transmission (Roger & Williams, 1987). Of children who are HIV positive, 22% are Latinos.

For most Latino women, motherhood is their predominant social role and cultural expectation. To prevent pregnancy or to use abortion to terminate pregnancy when the mother is HIV infected would violate cultural and religious norms. For Latino mothers who are drug abusers, addiction and poverty may outweigh concerns about pregnancy or neonatal transmission. Furthermore, mothers who are HIV infected but feeling well may have a hard time understanding the risk to an unborn infant. Due to bisexuality and IV drug abuse, the risk of the spread of HIV infection to the heterosexual community appears to be great in Latino populations (Flaskerud, 1988).

A number of other factors--fear of someone finding out that they are using drugs, poverty, language barrier, etc.--further aggravate the Latino's risk for HIV infection and prevent him/her from obtaining good health care. At least through good health care providers, Latinos can become aware of the HIV infection. Latinos also hesitate to seek health care since most health care professionals and physicians are not aware and sensitive to cultural diversity and psychosocial factors when

providing care. The Latino will initially see a curandero (local folk healer) before seeing a physician, or will use a combination of both (Somara, 1981). AIDS information and education material is primarily in English. A 1987 study of Latinos in San Francisco and the 1988 National Health Interview Survey have shown that Latinos between the ages of 13 to 45 are less knowledgeable than non-Latinos in this age range about AIDS and have more misconceptions about casual transmission of AIDS. Data from this same study indicated that Latinos are four to six times more likely than others to read English below the fourth grade level (Peterson & Marin, 1987). Although most Latinos speak English, English literacy is not well established. According to Dr. Rene Pasich, a recognized leader in the Latino community, "education remains to be the key instrument in the prevention of the HIV infection, but education and literacy levels of Latinos continue to be a community problem" (personal communication).

High infant mortality rates, sexually transmitted disease, teen pregnancy rates, and substance abuse rates reflect inadequate public education and prevention. This inadequacy is exacerbated by the lack of appropriate funding and other incentives (Flaskerud, 1988). It is alarming that teen pregnancy, sexually transmitted disease rates, and substance abuse in young adults are rising in Latino communities. These rising rates suggest that these groups

may be at risk for HIV infection, and they are not being reached by current public health education programs.

Most AIDS educational information is appropriate for the target audience (white, homosexual male), a group that currently represents a majority of the people with HIV infection in the U.S. However, this information often does not reach the Latino population, because it not does not address such issues as the language, psychosocial factors, cultural values, and stigma associated with certain behaviors and practices. In addition, for many HIV positive Latinos who are not citizens of the United States, immigration and possible deportation can become their overriding concerns. These undocumented persons have the least access to any type of assistance, yet remaining here without assistance is preferable to returning to their native country. In their home land, the stigma against the seropositive can be far greater, as people are less informed. There are often less or no medical services available, and there are more chances for infection with opportunistic diseases. For those Latinos who are not citizens of the U.S., it is unlikely that they will have insurance. Losing one's job then can easily make an individual incapable of affording treatment and may make it impossible to afford housing, food, and clothing (Leukerfeld & Fimbres, 1987).

The Latino who is HIV positive is at greater risk for the

transmission of HIV infection not only because of the issues mentioned above, but also because these individuals usually become isolated. Because of ignorance and strong cultural stigma related to homosexuality and AIDS, they cannot receive emotional support from the only support they have previously known, their extended family. What further complicates this issue is that society has isolated these individuals by assuming that present educational and emotional support will assist Latinos to combat the HIV infection just as it did in the gay community.

To summarize, there is no evidence that increasing a Latino's fear of AIDS will cause him/her to stop practicing unsafe behavioral activity. To try to change the environment would be an overwhelming task. The emphasis should be on developing culturally sensitive public resources, such as an educational/emotional support to teach and motivate Latinos who are HIV positive and their families about safe practices. Education and emotional support must not only be provided on an informational basis, but should be directed towards changing behavior and attitudes. Present organizational funding for AIDS education and prevention are often established to reach a specific target audience: English-speaking, gay, white, male. The information may be appropriate for the group intended, but culturally and linguistically sensitive educational information must be made available to the Latino

at risk and his/her community. If culturally sensitive methods and curriculum are not established to stop the transmission of HIV infection of Latinos, so that they have the capability of personal control or self-efficacy over behavior, there may be no end in sight for HIV infection in this population (Flaskerud, 1988).

CHAPTER 3

METHODOLOGY

Research Procedure

This study was non-experimental in design and employed semi-structured interviews. The goal was to conduct a needs assessment and to generate ideas for culturally sensitive curriculum development for an educational/emotional support group for HIV positive Latinos and their families.

Data Collection

The data were collected using extensive research of the Latino population by a review of the literature regarding minorities focusing on Latinos, AIDS, and support groups. Also, personal discussions were conducted with three groups of individuals who primarily served, worked with, or came from the Latino population. Approval from the Institutional Review Board for Human Subjects at San Jose State University was granted for this study.

Because information and groups providing educational/emotional support for HIV positive Latinos were limited, this researcher, with the help of TECLA, organized three groups of individuals who primarily served, worked with, or came from the Latino community. The goal was to assess the needs and generate ideas for culturally sensitive curriculum development for an educational/emotional support group for HIV positive Latinos and their loved ones.

Sampling Method

The three groups consisted of (a) health care professionals, (b) individuals considered leaders of the Latino community, and (c) HIV positive Latinos. These three groups met separately at three different times.

The first group that was developed consisted of five Latino health care professionals who primarily served and worked with the Latino community. The group consisted of one physician, one physician's assistant, one registered nurse, one psychologist, and one social worker. Three of these individuals were selected based on previous experience working with TECLA, either as a volunteer or as a consultant on health care issues in the Latino community. The other two individuals were recruited from local health care centers that were located in and primarily served the Latino community. All the individuals voluntarily agreed to participate in the discussion group.

The second group consisted of three individuals recognized as leaders in the Latino community. Two individuals were currently active members in politics in Santa Clara County. These two individuals had previously voluntarily consulted with TECLA on social issues concerning the Latino community. The third individual was from a local Latino political organization who contributed a great amount of volunteer time helping individuals in the Latino community. All three individuals agreed to participate in

the discussion group.

The third group consisted of three HIV positive Latinos. These individuals were referred to TECLA from the Santa Clara County testing site. All three individuals came to TECLA and agreed to participate in the discussion group.

Setting

The setting was informal. All three groups met at San Jose Medical Center in a conference room. Each group met individually and at different times. San Jose Medical Center was chosen because it was familiar to all the individuals and there was easy access to major forms of transportation. Also, San Jose Medical Center had conference/meeting room facilities separate from the hospital. These meeting rooms were designed to create a comfortable, non-threatening atmosphere appropriate for all three discussion groups.

Consent from the San Jose Medical Center institutional review board was not necessary because the individuals were not from San Jose Medical Center. All were seated at a round table where all individuals were visible to each other. Each individual was introduced in the group, and the purpose of this group was explained. The purpose was to bring individuals together from the Latino community to assess the needs and generate ideas for culturally sensitive curriculum development for an educational/emotional support group for HIV positive Latinos and their loved ones. The

definition of an educational/emotional support group was presented.

Data Collection

The format of the group was explained to the participants. Consent was obtained from each participant. Using an informal, semi-structured interview methodology, each group was presented one question at a time, and each participant was given the opportunity to answer each question. After all the participants were done answering each question, open discussion was encouraged to add to what was already said. A total of five questions were asked (see Appendix A). Participants were advised that a tape recorder would be used to record the discussion, but the only people that would have access to this tape would be the researcher and the Health ETC director.

The five questions that were asked in the interview were developed by this researcher with the assistance of TECLA. The first question asked if any of the individuals had been involved in any type of support group. If they were involved in a support group, did the group involve or deal with the Latino community? The second question asked if they believed there was a need for culturally sensitive curriculum for the educational/emotional support group for HIV positive Latinos and why? The third question asked what components or factors should be included in the culturally sensitive curriculum for the support group. The fourth

question asked, if one were to facilitate an educational/emotional support group for HIV positive Latinos who were HIV positive and their loved ones, what skills would be needed. The fifth question asked what pertinent cultural or psychosocial factors of Latinos should be considered when developing such a group. Even though the discussions were recorded, confidentiality was assured to the participants. The discussions lasted 1 1/2 to 2 hours.

The program was supported by a California State grant for culturally sensitive AIDS programs targeting the minority population. This researcher and Health ETC-TECLA chose to conduct a needs assessment as a preliminary project so as to generate ideas for culturally sensitive curriculum development of an educational/emotional support group for HIV positive Latinos and their families.

The data that were collected from the interview will be used as part of the culturally sensitive curriculum in the educational/emotional support group for HIV positive Latinos and their families. The data will be used to help empower HIV Latinos with culturally sensitive education/emotional support to motivate them to make decisions about HIV infection and its transmission.

CHAPTER 4

ANALYSIS AND INTERPRETATION OF DATA

Data Analysis

Three discussion groups of individuals who primarily worked with, served, or came from the Latinos community were developed by this researcher with the assistance of TECLA to help assess the needs and generate ideas for culturally sensitive curriculum development for an educational/emotional group for Latinos who were HIV positive and their loved ones. Responses to the questions from the three discussion groups (11 participants) were summarized and presented to the Health ETC Board of Directors. This board is a governing body composed of community leaders who provide guidance, direction, and support to issues that affect the surrounding community. The responses were evaluated by the Board of Directors.

Interpretation of Data

A total of five questions were discussed. The first question asked if any of the individuals were involved in a support group? If so, did this support group deal with the Latino community? Eight individuals stated that in one way or another, they had been involved in a support group. Three individuals stated that they were participants; five stated they had been volunteers and/or facilitators. According to all eight individuals, none of the support groups that they were involved in dealt directly

with the Latino community (See Table 1).

Table 1

Subjects involved in a support group.

	Yes	%	No	%
Were you ever involved in a support group? (N=11)	8	73	3	27
If you were, did the support group deal with the Latino community? (N=8)	0	0	8	100

The second question asked was, do you believe a culturally sensitive curriculum (program) is needed for an educational/emotional support group for HIV positive Latinos? It was unanimously agreed by all 11 participants that some type of program was absolutely necessary for Latinos who were HIV positive because of the following reasons:

1. There was a dramatic increase in the rate of HIV positive Latinos.
2. Most Latinos were unaware that certain cultural practices, customs, and factors contribute to the transmission of HIV infection.
3. Most HIV positive Latinos are isolated not only

from society but also from the only support they know, their families.

4. Limited public culturally sensitive resources exist to assist the HIV Latino and family to cope with HIV infection.

5. HIV positive Latinos are not attending organized educational and emotional support groups because these groups are not sensitive to their cultural and language needs.

Nine individuals stated that AIDS education and emotional support were initially designed for a group that made up the majority of individuals with HIV infection. This type of education and emotional support has been very effective in changing behavior and decreasing the transmission of HIV infection within this group. According to the 11 individuals, if high risk behavior is to be affected and changed in the Latino community, the same programs must be developed to meet the specialized needs of the individuals at risk, particularly the HIV positive Latino.

The third question asked what components or factors would be necessary to develop an educational/emotional support group for HIV positive Latinos. Ten of the individuals involved in the discussion group stated that one of the components necessary was to define the purpose and objectives of the group. Also, according to 10 participants in all three groups, the support group should

be formed keeping several structural guidelines in mind: (a) the group should be small, approximately 8 to 12 people, (b) a weekly drop-in model should be used, as attendance can fluctuate, especially where there are not large enough numbers of individuals at the same stage of dealing with their infection, and (c) the format of the group should be a planned and organized discussion type program, which enables individuals to participate. It was recommended by 10 participants in the group that, because of cultural values and norms, men and women should meet separately for emotional sharing. However, they may be together for educational programs or discussion.

It was also indicated by all 11 participants that several facilitators who have a strong understanding and experience in education and/or emotional support regarding HIV infection and the Latino culture should be chosen. It was suggested by the 11 participants that members of the support group should have the option to speak in the language with which they are most comfortable. Also, it was recommended by the 11 participants that most of the facilitators should be fluent in Spanish. It was strongly emphasized by the group that bilingual groupings which require extensive translating are not as successful. Some of the logistical factors identified by eight individuals were a permanent meeting location that provides a non-threatening, supportive, and comfortable environment,

available transportation, child care, and an appropriate time of day (See Table 2).

The fourth question asked if one were to facilitate an educational/emotional support group for Latinos who are HIV positive, what skills or techniques would be needed to conduct the support group most conducive to the members. It was indicated by all 11 participants, that in order to promote, support, and assist group members to reach personal goals, the skill of effective communication in Spanish was necessary. Another important skill mentioned by at least seven participants were that the facilitator should initiate the group, solicit participation, and introduce new directions when appropriate in order to effectively facilitate the group.

Active listening, giving feedback, providing appropriate silence, and disclosing personal reactions or experiences when appropriate was emphasized as important by eight participants. It was also mentioned by 11 individuals that in working with Latinos, many of these skills need to be understood in the context of the Latino culture. According to the psychologist in the group, for many HIV positive Latinos, the support group will be the first organized group in which they have participated. In this case, facilitators need to be particularly clear in pointing out and explaining what is expected and what is happening in the group (See Table 3).

Table 2

Factors necessary to develop culturally sensitive curriculum for an educational/emotional support group for HIV positive Latinos.

(N = 11)

	Numbers	Percentage
Define purpose and goal in context of Latino culture	10	91
Support group should be small, 8 to 12 members	10	91
Weekly drop-in model should be used	10	91
Format of group should be a planned and organized discussion type program	10	91
Men and women meet separately for emotional sharing, although they may be together for educational programs and discussion	10	91
Several facilitators should be chosen with a strong understanding and experience in education and/or emotional support regarding HIV infection and the Latino culture	11	100
Most of the facilitators should be fluent in Spanish	11	100
Members to have the option to speak the language that is most comfortable to them	11	100
A permanent location that provides a non-threatening, supportive comfortable environment	8	73
Available transportation	8	73
Child care be provided	8	73
Flexible time of day	8	73

The fifth question asked what pertinent cultural and psychosocial factors should be considered when developing such a group. According to 11 participants, many HIV positive Latinos (particularly Latinas) have low self-esteem and feel powerless to control their lives. These issues are further complicated by ongoing problems such as language barriers, discrimination, low socioeconomic status, or practicing sexual or drug behavior not acceptable to the norm. All of these factors contribute to these feelings. It was indicated by all the participants that all these issues should be incorporated, addressed, and discussed in the educational/emotional support group in the context of the Latino culture.

Nine participants recommended that the *conocimiento* (getting to know one another) process be used. According to the nine participants, this process is an important part of any educational program that includes Latinos. This process recognizes the importance of one's (Latino) heritage and past experiences in what is happening in the present, and it sets a tone of mutual "*respeto*" (proper respect) between the facilitator and the group members. Without a feeling of "*respeto*" from the facilitator, members will withdraw from the group. The *conocimiento* process also serves as the first step in nurturing "*confianza*" (trust) between members and the facilitator. According to nine participants, it is necessary for Latinos to establish "*confianza*" when

Table 3

Components to facilitate a culturally sensitive
educational/emotional support group for HIV positive
Latinos.

(N = 11)

	Number	Percentage
Effective communication (in Spanish and/or English)	11	100
Facilitator should initiate group	7	64
Facilitator should solicit participation	7	64
Facilitator should introduce new direction, when appropriate	7	64
Active listening	8	73
Give feedback (in Spanish and/or English)	8	73
Provide appropriate silence	8	73
Disclose personal reaction or experiences when appropriate	8	73
Many of skills need to be understood in the context of the Latino culture	11	100

interacting with a facilitator as well as with the other members of the group. The stronger the "confianza," the greater the participation of all members of the group.

Eleven participants suggested that another important cultural factor that should be included in the group is the concept of "personalismo" (personalism). "Personalismo" refers to the concept that Latinos stress personal relationships over institutional ones. Facilitators and members who are perceived as being warm, friendly, and interested in participants' lives will enjoy greater confianza with group members than will those who are perceived as clinical and distant (See Table 4).

Table 4

Pertinent cultural and psychosocial factors influencing the development of culturally sensitive curriculum for an educational/emotional support group for HIV positive Latinos.

(N = 11)

	Number	Percentage
Low self-esteem	11	100
Feeling of powerlessness	11	100
Language barriers	11	100
Discrimination	11	100
Low socioeconomic status	11	100
Practicing sexual or drug behavior not acceptable to the cultural norm	11	100
Conocimiento process, (Getting to know one another)	9	82
Confianza (Trust)	9	82
Personalismo (Personalism)	9	82

Chapter 5

SUMMARY, CONCLUSIONS, AND RECOMMENDATIONS

Summary

The purpose of this study was to conduct a needs assessment and generate ideas for the development of culturally sensitive curriculum for an educational/emotional support group for HIV positive Latinos and their families. A literature review regarding educational/emotional support groups for Latinos who are HIV positive and their families revealed no information located on this topic. The closest information that could be found related to this topic was literature discussing Latinos and AIDS. A literature review was also conducted on Latino support groups and Latino practices, beliefs, values, and customs. Information was available on these topics. Because information was limited on culturally sensitive educational/emotional support groups for HIV positive Latinos, this researcher, with the assistance of TECLA, conducted semi-structured interviews consisting of three discussion groups to assess the need for and to generate ideas for culturally sensitive curriculum development for an educational/emotional support group for HIV positive and their families.

These three discussion groups consisted of 11 individuals who either primarily worked with, served, or came from the Latino community. The first discussion group was made up of

five health care providers who primarily served the Latino community. The second discussion group was made up of three individuals who were recognized as leaders or influential members in the Latino community. The third group was made of three Latino individuals who were HIV positive. This last group of individuals were people referred to TECLA by the Santa Clara County Department Testing Site.

The semi-structured interviews consisted of five questions developed by this researcher, with the assistance of TECLA (See Appendix A). During the semi-structured interviews, each group was interviewed separately. Each subject was individually asked all five questions, one question at a time. Participation in the semi-structured interviews was voluntary. The program was supported by a California State Grant.

Conclusions

After all the groups were interviewed, it was unanimously recommended by all the participants in the group that there was a definite need for culturally sensitive educational/emotional curriculum for HIV Latinos and their families. Through this curriculum, the intent is to help empower and motivate HIV Latinos in a culturally sensitive method to believe they have the control to prevent the transmission of the AIDS infection.

AIDS education has been very successful in reducing the transmission of the HIV infection in the single, white

male homosexual community. It is assumed by many that if something was successful in one group, it should work for all groups. Just as AIDS education was developed to meet the need of the single, white homosexual community, the same process must be established for all groups, including the Latino community. Based on the analysis of the data from this study, this researcher was able to obtain solid information from which to develop a culturally sensitive curriculum for educational and emotional support for HIV positive Latinos and their families. This curriculum will be used in the group to help empower and motivate HIV Latinos, in a culturally sensitive manner, to believe that they have self-control in observing safe practices to prevent the transmission of the HIV infection.

Recommendations

This researcher recommends that the findings be presented to the Health ETC Board of Directors. The findings should be reviewed, evaluated, accepted and implemented by the board. The findings should then be shared with other health support services who primarily serve Latinos who may practice high risk behaviors, for example, the Santa Clara County jail for men and women, Planned Parenthood, local shelters, and school based clinics. It is also recommended that this information be presented to the Latino community, through groups such as the Parent - Teachers Association, local clinics, churches,

schools, and neighborhood meetings. As mentioned previously, this researcher was able to obtain solid data to develop a culturally sensitive curriculum for educational/emotional support for HIV positive Latinos and their families. This curriculum is recommended for future training of HIV positive Latinos and their families.

A limitation in the study is that there was a small sample size of HIV positive participants. This researcher recommends that in 6 months to 1 year after the support group is implemented, a needs assessment be repeated to reassess and re-evaluate any other culturally sensitive needs that may be essential to motivate Latinos and their families to believe that they have control to continue to practice safe behaviors.

Competition for resources for AIDS research is great and the emphasis necessarily will be on the major risk groups, such as gay males. However, Latinos who are HIV positive may be a major link in the spread of AIDS, primarily among the heterosexual population and to children. This group deserves more thorough research and investigation.

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APPENDIX A
Interview Tool

- TECLA -

TRAINING, EDUCATION, AND COMMUNICATION FOR LATINOS WITH
AIDS

Assessing the need for the culturally sensitive curriculum development of an educational/emotional support group for HIV positive Latinos and their families.

1. Were you ever involved in support group? If you were, did the group deal directly with the Latino community?
2. Do you believe there is a need for culturally sensitive curriculum for an educational/emotional support group for HIV positive Latinos and their families?
3. What components or factors would be necessary to develop a culturally sensitive curriculum for an educational/emotional support group for HIV positive Latinos.
4. If one were to facilitate a culturally sensitive educational/emotional support group for HIV positive Latinos, what skills or techniques would be needed to conduct the support group?
5. What pertinent cultural and psychosocial factors should be considered when developing a culturally sensitive curriculum for an educational/emotional support group for HIV positive Latinos and their families?

APPENDIX B
Agreement to Participate in Research

AGREEMENT TO PARTICIPATE IN RESEARCH

Responsible Investigator
Ofelia F. Hawk

Title: Assessing the need for the development of a culturally sensitive curriculum for an educational/emotional support group for HIV positive Latinos and their families.

I have been asked to participate in a research study to determine the need for the development of a culturally sensitive curriculum for an educational/emotional support group for HIV positive Latinos and their families.

I understand that there are no known risks associated with my participation in the study. The possible benefit of this study to me is that I will be contributing to the awareness about the need for the development of culturally sensitive curriculum for educational/emotional support groups for HIV Latinos and their families.

The results from this study may be published, but any information from this study that can be identified with me will remain confidential and will be disclosed only with my permission.

Any questions about my participation in this study will be answered by Ofelia F. Hawk (268-2755). Complaints about the procedures may be presented to Mary Reeve (924-3165, faculty graduate advisor). For questions or complaints about research subject's rights, or in the event of research related injury, contact Serena Stanford, Ph.D (Associate Academic Vice President for Graduate Studies & Research) at 924-2480.

My consent is voluntary without being coerced. I may refuse to participate in this study or in any part of this study, and I may withdraw at any time, without prejudice to my relations with SJSU or Health ETC-TECLA.

I HAVE MADE A DECISION WHETHER OR NOT TO PARTICIPATE.
MY SIGNATURE INDICATES THAT I HAVE READ THE INFORMATION
PROVIDED ABOVE AND THAT I HAVE DECIDED TO PARTICIPATE.

DATE

SUBJECTS SIGNATURE

INVESTIGATOR'S SIGNATURE

ACUERDO A PARTICIPAR EN UNA INVESTIGACION

Investigadora responsable:

Ofelia F. Hawk

Titulo: Evaluacion del necesidad para el desarrollo de un grupo sensibilidad cultural para el apoyo educacional y emocional para Latinos que son positivos para el virus del SIDA (HIV) y su familia.

Me han pedido que participe en una investigacion de estudio que investiga a deteminar la necesidad para el desarrollo de un grupo sensibilidad cultural para apoyo educacional y emocional para Latinos que son positivos para el virus del SIDA y su familia.

Entiendo que no se sepa riesgos que son asociado con mi participacion de este estudio. El beneficio posible de este estudio para me sera el aumento del conocimiento del necesidad para el dearrollo de un grupo sensibilidad cultural para apoyo educacional y emocional para Latinos que son positivos para el virus del SIDA (HIV) y su familia.

Los resultados de este estudio pueden ser publicados, pero culquier informacion del mismo la cual se identifique conmigo quedara confidencial y sera revelado solamente con mi permiso.

Cualquiera pregunta acerca de me participacion en este estudio puede ser dirigida a Ofelia F. Hawk. Algunas quejas sobre el procedimiento de la investigacion pueden presentarse a Mary Reeves (924-3165), consejera del programa graduado. Culquiere pregunta o queja de los derechos de los participantes, o en caso de cualquier dano personal, puede llamar a Serena Stanford, Ph.D, (Associate Academic Vice Presidentof San Jose State University) al numero, 924-2480.

Mi consentimiento es voluntario sin ser forzado. Puedo megarme a participar en este estudio cuando quiera, sin perjuicio a mis relaciones con la univ-
sidad de San Jose o con el centro de salud, educacion, y entrenamiento (Health ETC).

HA SIDO MI DECISION DE PARTICIPAR O NO. MI FIRMA INDICAQUE HE LEIDO LA INFORMACION YA CITADA Y QUE HE DECIDIDO A PARTICIPAR.

FECHA

FIRMA DEL PARTICIPANTE

FIRMA DEL INVESTIGADORA