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**HOW LATINAS COME TO KNOW ABOUT
AIDS AND AIDS PREVENTION**

by

Patricia Walker Caudle, MNSc, RNC, FNP

A dissertation presented to the
FACULTY OF THE PHILIP Y. HAHN SCHOOL OF NURSING
UNIVERSITY OF SAN DIEGO

In partial fulfillment of the
requirement for the degree
DOCTOR OF NURSING SCIENCE

February 1992

HOW LATINAS COME TO KNOW ABOUT AIDS AND AIDS PREVENTION

Abstract

By the year 2000, Latinos will become the largest minority group in the United States. Acquired Immunodeficiency Syndrome (AIDS) is occurring at a disproportionately high rate among Latinos. As care-giver and health decision-maker in the family, the Latina needs to know about AIDS and AIDS prevention. This research identified and offers an explanation of how the Latina comes to know about AIDS and AIDS prevention within the context of the family and the Latino culture.

Grounded theory methodology was used to explore the complex socialization patterns within the Latino community that affect how the Latina perceives HIV/AIDS. Data were collected by means of sixteen individual interviews and a focus group discussion with five Latinas.

Results indicated that knowing about AIDS for the Latina is more than defining a disease. It involves an interweaving of socialization patterns, relationships with men, and interpretations of television reports and gossip. Knowing about AIDS for the Latinas interviewed resulted in either preventing, pretending they were not susceptible, relying on their mate for protection, or in teaching family members.

The findings of this study have implications for nursing research, nursing education, and nursing practice. The major implication is the need for a for AIDS prevention education for Latinas that is both gender and culturally sensitive.

DEDICATION

To my family Morris, Marc, and Micah
and Aunt Grace, who would be so pleased.

ACKNOWLEDGMENTS

The completion of this dissertation could not have happened without the encouragement and assistance of my friends, dissertation committee, and the Latinas who participated.

I am grateful to Dorothy Kleffel who encouraged and challenged me to continue until completion.

I wish to thank Dr. Mary Jo Clark, my committee chairperson, for her patience, skill, and eternal optimism. She has set a standard that I will forever try to emulate.

I am grateful to Dr. Diane Hatton whose knowledge of and enthusiasm for grounded theory were inspiring.

I wish to thank Dr. Kathleen Heinrich for sharing her knowledge of and passion for feminism and women's studies. Never have I enjoyed learning so much.

My thanks to all my fellow doctoral students for emotional support, bolstering my self-esteem, and sharing the doctoral education experience.

I am very grateful to Sandra Rodriguez. Her translations, interpretations, and insights were the core of this work. It could not have been done without her.

My very special thanks to all the Latinas who shared their thoughts and lives with me.

Finally, I wish to acknowledge and express my gratitude to the Department of Health and Human Services, Public Health Services, Health Resources and Services Administration for the Training Grant that provided tuition for the doctoral program.

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HOW LATINAS COME TO KNOW ABOUT AIDS AND AIDS PREVENTION

Chapter 1

Introduction

By the year 2000, Hispanics will surpass Blacks in population growth and become the largest minority in the United States (Munoz, 1988; Portillo, 1987; Rosa, 1989; Salholz, Gonzalez, & Pena, 1990). In California, Latinos already comprise 25% of the total population (Romanowicz & Lloyd, 1989).

Acquired Immunodeficiency Syndrome (AIDS or HIV disease) is spreading faster and occurring at a disproportionately high rate among Hispanics (Centers for Disease Control, 1990; Gayle, Selik, & Chu, 1990; Rogers & Williams, 1987). Nursing research, however, has produced very few studies concerning the cultural health beliefs and perceptions of Latinos related to HIV disease. Since Latinos comprise a large segment of the population served by nurses, it seems important that research in this area be conducted. An understanding of aspects of the Latino culture could guide nursing practice in formulating preventive programs that are culturally sensitive and meaningful to the Latino community. The purpose of this study is to identify how Latinas come to know about AIDS and AIDS prevention.

Clarification of Terms

Latino, Chicano, Mexican American, Spanish American, La Roza, Cuban, Puerto Rican, Hispanic, and Spanish Origin are all terms that have been used to describe people of Latin American heritage or those who use the Spanish language in their homes. Often, for government surveys or other forms of research, the term Hispanic has been used for all of these groups. This causes confusion when researchers operationally define the term differently and generate non-comparable

samples (Hayes-Bautista, 1980). The heterogeneity of Spanish-language-using populations defies the use of a single term for nation-wide or even California-wide surveys of these groups (Aday, Chiu, & Anderson, 1980).

Portillo (1987) pointed out that the term "Hispanic" does not define a race nor is it the term of choice in Latino communities. She criticized the term as "a bureaucratic catch-all to describe immigrants and their descendants from more than 30 countries" (p. 229). According to Portillo, Mexican Americans, Puerto Ricans, and Cuban Americans prefer to be called Latinos (masculine or aggregate form) or Latinas (feminine form). Barabak (1991), however, noted surveys that have demonstrated that most Mexican Americans, Puerto Ricans, and Cuban Americans do not want to be lumped together as "Latinos" either. They prefer instead to be called Mexican American when the group is Mexican American, Puerto Rican, and so on.

To simplify reporting within this research, Latina will be used to identify the Mexican American, Mexican, and Central American women who participated in this study. The term Hispanic will be used when discussing national, state, and local statistics as these have been reported in the literature using this label. Occasionally, Mexican and Mexican American individuals are referred to separately in order to clarify issues related specifically to them.

Background and Significance

Acquired Immunodeficiency Syndrome (AIDS)

AIDS is caused by the Human Immunodeficiency Virus (HIV) and, given the current level of medical technology, once contracted will eventually cause death. It is transmitted via sexual fluids; blood exchange, including needle sharing; and from infected mother to infant either in-utero or during the birth process (Cantrell, 1990; "Update:...1981-1990", 1991). HIV infection has a long incubation period. The person who is HIV infected may not have symptoms of AIDS for as long as 10 years after

exposure (Peterman & Petersen, 1990). At present, there is no cure for this disease, nor has there been any vaccine produced that will prevent infection.

People who are most often infected with this virus include homosexual/bisexual males, intravenous drug users (IVDUs), heterosexual partners of bisexuals or IVDUs, and the children of infected men and women. Reported cases of AIDS and the prevalence of serum positive HIV infection are greater among Hispanics and Blacks than any other racial/ethnic minority group (Gayle, Selik, & Chu, 1990). The risk of AIDS for Blacks and Hispanics is three times that for Anglos (Selik, Castro, & Pappaioanou, 1988).

The percentage distribution of AIDS cases among women and children of color compared with the overall population is even more troubling. Black and Hispanic women make up about 21% of the overall female population in the United States but comprise about 74% of adult female AIDS cases. Similarly, Black and Hispanic children constitute about 26% of children in the United States, yet account for 75% of pediatric AIDS cases (Gayle, Selik, & Chu, 1990).

AIDS has only recently (as of 1981) been recognized as a disease category. The human immunodeficiency virus was identified as the causative agent even more recently (1985) (Perdew, 1990; Volberding, 1988). The rate of spread of this "new" disease is alarming. Between June, 1981 and May, 1991, 179,136 AIDS cases and 113,426 deaths from AIDS had been reported in the United States ("AIDS News Summary", 1991). In California, 34,701 cases and 23,005 deaths from AIDS had been reported as of May, 1991. Cumulative AIDS cases are highest in Washington, D.C., New York, Florida, New Jersey, and California (Quarterly AIDS map, 1991).

The onset of the epidemic in this country began among homosexual/bisexual males, and cases continue to be primarily from this group. There has been a leveling off in the number of new cases, however, as preventive strategies among white homosexual groups are making a difference. The increases among minority groups

continue, and AIDS cases (men, women, and children of all races) are presently being reported at a rate of about 100 per day (Osborne, 1989).

Cases among women have been relatively few but the numbers are beginning to rise as the incidence of heterosexual transmission of the virus increases. In 1988, 10.3% of reported AIDS cases occurred among women. By 1990, that figure had risen to 11.5% ("Update...", 1991). In New York, AIDS is the number one killer of childbearing women (Mays & Cochran, 1988; Nyamathi & Vasquez, 1989). For Blacks and Hispanics, the cumulative incidence of AIDS traceable to heterosexual contact is more than 11 times greater than the incidence for whites (Holmes, Karon, & Kreiss, 1990). Of all reported female cases of AIDS through September, 1990, 20% occurred among Hispanics (Centers for Disease Control, 1990).

Females with HIV disease are of particular concern because the primary mode of transmission to children is via the birth process. Reflecting the increased incidence of HIV infection among women, pediatric AIDS cases have also increased in the last two years. AIDS is now among the 10 leading causes of death for children ages 1-4 years (Gayle, Selik, & Chu, 1990). Cases among Hispanic children account for 26% of all pediatric AIDS cases reported in the United States as of September 30, 1990 (Centers for Disease Control, 1990).

In California, the rate of AIDS incidence is also increasing more rapidly among Hispanics than Anglos. Of the risk categories identified thus far, heterosexual exposure to HIV infection is increasing more rapidly among Hispanics than other groups studied (Romanowicz & Lloyd, 1989). Between 1990 and 1991, the number of AIDS cases among Hispanics in California increased from 13.5% of all cases to 16.6% (Creeger, 1991).

Of 54 counties in California, San Diego County ranks third in incidence of AIDS cases. Los Angeles and San Francisco counties rank first and second respectively (Staff, 1991, June 30). In San Diego County, a total of 2,765 AIDS cases

had been reported and 1,735 persons with AIDS (62.7%) had died as of July 31, 1991 (Ginsberg, 1991). Of those cases, 12.5% were Hispanic. Considering the long asymptomatic incubation period of HIV, there is a strong possibility that more people are infected and do not yet know it.

The Latina and AIDS

The Latina was chosen as the respondent for this study for three reasons. First, she is most often the care-giver and health decision-maker within the family. It is through her that cultural mores and health beliefs are transmitted to the children and other family members (Manzanedo, Walters, & Lorig, 1980; Mirande & Enriquez, 1979; Riding, 1989).

Second, statistics indicate that AIDS cases among Hispanic women are increasing. In San Diego County, from 1989 to 1991, the number of AIDS cases among Latinas has increased from 14 to 29 (Zamichow, 1991). Of the female persons with AIDS in San Diego County, 23% are Hispanic. This percentage is up from 16% reported in 1989 (Ginsberg, 1991). Given current medical technology, infection with HIV will eventually cause death. Therefore, Latinas could benefit from knowledge about the prevention of AIDS. With a better understanding of the Latino culture and mores, nurses could help the Latina gain more knowledge about AIDS and to disseminate that knowledge to her family.

Third, the route of transmission for HIV that accounts for almost all the pediatrics cases is from an infected mother either transplacentally, during the delivery process, or during breast feeding (Cantrell, 1990; Perdew, 1990). By assisting the Latina, nurses could also help to decrease the incidence of AIDS among Latino children.

Latinas in San Diego County are at risk for Acquired Immunodeficiency Syndrome (AIDS). They are at risk because many are poor, uneducated, and more likely to be exposed to the Human Immunodeficiency Virus (HIV) via needle

sharing and heterosexual contact than are Anglo women (Gayle, Selik, & Chu, 1990; Nyamathi & Vasquez, 1989).

The behaviors that facilitate the spread of HIV to Latinas occur within the social context of interpersonal relationships with men (Cochran, 1989). In addition, each Latina develops her own health beliefs about disease and disease transmission within the context of her socialization within the Latino culture. Cultural health beliefs have consequences for how the Latina comes to understand AIDS and how she will make decisions about using AIDS preventive behaviors. Nurses and other health care providers can provide information for Latinas that will assist them to choose preventive behaviors. But to do that, research is needed that will assist nurses to understand how Latinas come to know about sexual issues and disease and how their ways of knowing affect their perceptions about AIDS and AIDS prevention. Such understandings facilitate the development of culturally sensitive programs that will best meet the needs of Latinas and Latinos seeking to prevent the spread of HIV disease within their families and community. With few notable acceptances, nursing literature currently does not address this problem (Flaskerud & Nyamathi, 1989; Larson & Ropka, 1991).

Research priorities for nursing in regard to HIV disease have been set by the National Center for Nursing Research via the Priority Expert Panel to include five priority areas of investigation: (a) prevention of HIV transmission, (b) physiological aspects of nursing care, (c) psychosocial aspects of care, (d) delivery of nursing care, and (e) applied ethics. Research in the area of prevention as of June, 1990, was limited to five studies. Only one of these, by Flaskerud & Nyamathi, concerned Latinas and AIDS knowledge, attitudes, and practices (Larson & Ropka, 1991). Transcultural research to determine appropriate approaches to prevention education is needed.

Problem Statement

This study identified and offered an explanation of how the Latina comes to know about AIDS and AIDS prevention. It sought to answer the question, "How do Latinas come to know about sexual issues, acquired immunodeficiency syndrome, and AIDS prevention within the context of their family and culture?"

Assumptions

Grounded theory methodology informed the data gathering and analytic procedures used to explore the diverse, complex, and dynamic social world of the Latina in San Diego County. Underlying this methodology were four epistemological assumptions that guided the study.

First, it was assumed that knowledge gained from all cultures is valuable (Spradley, 1979). Knowledge about the real world and lifeways of Latinas will enable nurses to plan and implement nursing care that has meaning for the Latina (Leininger, 1985). Nurses need knowledge of cultural health beliefs in order to give assistance that will be acceptable to Latinos. According to Spradley (1979), informants or participants are selected by the researcher to act as teachers. They teach the researcher about the culture in their own words and they provide a model that is social in origin for the researcher to understand and imitate.

Second, "human beings act toward things on the basis of the meaning the things have for them" (Blumer, 1969, p.2). For the Latina, AIDS may have a different meaning than it does for Anglo, medically-oriented health care providers. The way in which the Latina has incorporated AIDS into her belief system will guide how she responds to preventive education, and, ultimately, may guide her decisions to take action to prevent AIDS.

Third, "meanings are derived from, or arise out of, the social interaction one has with one's fellows" (Blumer, 1969, p. 2). It is that interactional framework that shapes Latinas' health beliefs and their relationships with men. It is only through

direct involvement with Latinas that nurse researchers can tap that interactional system and derive an understanding of the cultural framework within which Latinas come to know about HIV/AIDS.

Lastly, "meanings are handled in, or modified through, an interpretive process used by the person in dealing with the things he encounters" (Blumer, 1969, p. 2). It is through social interaction within a specific culture that each person develops a frame of reference for defining and understanding the 'meanings' of concepts and ideas. Direct interaction with a person whose framework for interpreting AIDS is different will assist the researcher in understanding how the Latina comes to think of AIDS in the way she does.

Lofland (1976) stated that a degree of "intimate familiarity" can be obtained through lengthy interviews with selected members of the culture under study (p. 8). Such conversations were conducted either directly or by using the Latina informant who was fluent in both Spanish and English. Through these direct conversations, the Latinas' cultural modes of teaching children about sex and disease; how they have come to view AIDS; and how they relate to men were identified. This information will assist nurses to understand the Latina's point of view and to provide culturally sensitive AIDS education.

Methodology

Grounded theory methodology informed the data gathering and analytic procedures used to derive a framework that describes how Latinas come to know about sexual issues, AIDS, and AIDS prevention. This method allowed for identifying and explaining cultural modes for socializing and establishing gender roles and the impact of socialization on coming to know about AIDS and AIDS prevention.

Data were collected using sixteen individual interviews. The interview data were used to generate further avenues of inquiry as new knowledge was revealed

and new questions needed to be answered. Beginning interviews were semi-structured in that general questions guided the informant into a discussion of AIDS and participants' knowledge and beliefs about this disease. The interviewer used gentle probes to both encourage and allow the Latina respondent to express her perceptions and beliefs.

It was expected that most of the interviews would be conducted in Spanish because even if the Latina participant knows English, sensitive subjects such as sexuality and health beliefs about AIDS may be easier to discuss in Spanish. Four of the informants, however, agreed to be interviewed in English.

The Spanish interviews were conducted by a Latina registered nurse who was also an informant for this study. She had had several years of experience as both a registered nurse and as an interpreter within the health care setting. She was very knowledgeable of Latino culture in the area where the study was conducted, having lived there since infancy. The informant also had experience as a translator and research assistant for a major research project that was in progress at the University of San Diego.

All individual interviews were audio recorded. The twelve interviews conducted in Spanish were translated to English by the Latina interviewer. All were transcribed verbatim for analysis. To verify the translation, one other bilingual Latina experienced in translation and interpretation translated six of the tapes from Spanish to English. Two other Latinas collaborated to translate the seventh tape. A comparison of the transcriptions was made. Since the translations from the Latina interviewer and the second translations were so close, it was decided that continued double translation of the remainder of the tapes was not necessary.

The individual interviews took place within a community medical clinic in San Diego County where many Latino families come for care. Latinas age 18-34 who

were not pregnant and who self-identified as Latinas were approached for participation in the interview, either by the Latina interviewer or this investigator.

A focus group interview was convened to further verify data obtained from the original sixteen interviews. It was conducted in Spanish. This method had been used with success by others who had conducted research among Latinas (Nyamathi & Shuler, 1990; Nyamathi, Shuler, & Porche, 1990; Nyamathi & Vasquez, 1989). This focus group was composed of five Latinas who participated in programs at a Community Center in San Diego County. None of the focus group participants had been interviewed prior to the group discussion. Entree to the focus group was facilitated by a Latina interviewed early in the data collection phase of the study. Within the focus group, Latinas were given an opportunity to respond to data gleaned during the individual interviews. The focus group helped verify and clarify data and added new insights that were not apparent in the original interviews. This procedure provided a form of "member checking" described by Lincoln and Guba (1985) as a method used to increase the credibility of the findings.

Implications of the Study

Very little information is available to nurses regarding the cultural health beliefs and the acquisition of knowledge among Latinas concerning AIDS. In view of the Latinas' vulnerability to human immunodeficiency virus infection, this lack of information can be an impediment to nurses who are attempting to care for Latina clients.

Strategies used among Anglos to prevent the spread of AIDS cannot simply be translated into Spanish and expected to cross cultural boundaries. Explicit sexual and homosexual materials may not be culturally appropriate for Latinas to read or the translation may have ignored cultural communication patterns or educational levels of the group for which they were intended (Peterson & Marin, 1988; Singer, et

al., 1990). Direct information based upon the Latinas' everyday reality seems extremely relevant to nursing care that is specific for the Latino community.

Nurses in all areas of direct care are in positions where they can make a difference if they are cognizant of the cultural factors that affect how the Latino responds to and accepts information concerning the prevention of AIDS. This research essentially asks the consumer (Latinas) how they have learned about sex, AIDS, and AIDS prevention so that the most effective methods can be used to encourage AIDS preventive behaviors and intrafamilial teaching about sex and AIDS.

Structure of the Dissertation

The body of this dissertation is divided into 5 chapters. The introduction to the study has been presented in Chapter 1. In Chapter 2, a review of the literature that explores available material about socialization, cultural health beliefs, and gender roles within the Latino culture is presented. Literature and research concerning Latinos, Latinas, and AIDS is also discussed.

The method that was used to conduct the research is detailed in Chapter 3. The use of grounded theory is justified and the study setting and participants are characterized here. specific information about data gathering techniques and the methods used to ensure confidentiality for each participant are also presented.

Chapter 4 includes the discoveries made during the interviews with the Latinas, both individually and within the focus group. Here the Latinas' own words provide meaning and an understanding of Latinas' ways of knowing about sexual issues and AIDS. Also presented in Chapter 4 is the integrative diagram that explains how the Latinas interviewed came to know about AIDS and AIDS prevention and how the knowledge may affect subsequent behaviors.

Within Chapter 5, a brief summary of the findings and a synthesis of the findings with other theories of how women come to know is presented. The

implications of the findings for nurses and other health-care providers who are committed to preventing the spread of AIDS among Latinos in San Diego County are also presented in Chapter 5.

Summary

The incidence of AIDS is increasing among Latinos in San Diego County. Latinas seem particularly vulnerable because of their socioeconomic status, lack of education, gender roles, and sexual mores. This grounded theory research was planned in an effort to identify ways Latinas come to know about sex and AIDS that are relevant to nurses committed to culturally sensitive AIDS prevention programs. AIDS prevention programs that are grounded within an understanding of the Latino culture are more likely to be accepted and used by the Latino community.

CHAPTER 2

Review of the Literature

The purpose of this chapter is to present and critique selected literature related to Latinas and how they may come to know about sexual issues and AIDS. AIDS or El Síndrome de Inmunodeficiencia Adquirida (SIDA) is defined in the first section. This section also describes the impact of HIV/AIDS among Latinos in the United States, California, and Mexico. The second section presents literature regarding the possible effects of social, familial, and cultural influences of Latinas' perceptions of HIV/AIDS and its prevention. Lastly, research concerning the Latino community's knowledge, attitudes, and practices related to HIV/AIDS is presented. Within this section, research findings are presented in two parts. The first part reviews surveys by other disciplines concerning AIDS that included Hispanic subjects. The second part presents nursing research, surveys and focus group discussions, that included Latinas.

HIV/AIDS and Its Impact on Latinos

Acquired Immunodeficiency Syndrome (AIDS) or HIV disease is a viral syndrome that is transmitted through the exchange of body fluids - particularly semen, vaginal secretions, and blood. The human immunodeficiency virus (HIV) is a DNA virus that requires a host cell for survival. The host cell it selects is the T-Helper cell (or CD4 cell), a white blood cell (specifically a lymphocyte) that is usually active in fighting bacteria and other pathogens that may enter the body. When HIV attaches to and enters the T-Helper cell, it uses the cell's reproductive mechanism to reproduce itself. The fact that the virus is inside the cell makes it particularly

difficult to treat; treatment tends to destroy the cell where the virus resides. The destruction of the T-Helper cells diminishes the body's ability to fight infection (Lewis, 1988; Perdew, 1990).

Once the virus enters the body, it may lay dormant within the T-cells for years (in some cases, 10 or more) before it begins to multiply and destroy the host cells. The mechanism that triggers the onset of this stage of the disease is unknown. The disease state is diagnosed when an individual has a positive HIV blood test and develops an opportunistic infection such as Pneumocystis carinii pneumonia or Kaposi's sarcoma, a rare form of cancer. The person with AIDS will die either of infections that over-whelm the body or of cancers (Hatcher, et al., 1990; Perdew, 1990).

There has been much controversy concerning the definition of AIDS. Women, in particular, seem to have different forms of opportunistic infection and cancers than do men; particularly vaginal candidiasis, pelvic inflammatory disease, and cervical cancer (Frelberg, 1991b). Consequently, the Centers for Disease Control have proposed that the definition be changed to read "a positive HIV test and a CD4 (T-helper cell) lymphocyte count under 200", effective as of April, 1992 ("CDC Announces...", 1991, p.84).

During the time that the virus is present but the disease is not evident, the individual who has the virus can infect others. The primary modes of HIV transmission are sexual intercourse (anal or vaginal), blood to blood contact (including shared needles), and transplacentally or during passage of the fetus through the birth canal (Cantrell, 1990; Mantell, Schinke, & Akabas, 1988; Perdew, 1990).

In Southern California, as in other regions of the United States, the groups most often affected include homosexual and bisexual males, intravenous drug users (IVDUs), and the sexual partners and children of bisexual males and IVDUs.

Statistically, it is apparent that minority groups, especially Blacks and Latinos, are disproportionately affected by the disease (Cancela, 1989; Cochran, 1989; Flaskerud, 1988b; Romanowicz & Lloyd, 1989; Selik, Castro, & Pappaioanou, 1988). Latino persons with AIDS comprise 16.6% of all AIDS cases in California (Creeger 1991).

Heterosexual transmission, while still ranked third among exposure categories, seems of particular concern for Latinas. AIDS cases attributable to heterosexual exposure are increasing more rapidly among Latinos than among any other racial group (Romanowicz & Lloyd, 1989). In fact, AIDS cases attributable to heterosexual contact in the United States are 11 times greater for Hispanics and Blacks than for Anglos (Holmes, Karon, & Kreiss, 1990).

In addition, AIDS cases that have been attributed to heterosexual transmission occur among women 20 times more often than among men. Among Latinos, the ratio of female cases to male cases attributed to heterosexual contact was 4.3:1 (Holmes, Karon, & Kreiss, 1990).

The number of women with AIDS has increased steadily over the course of the epidemic. About 11.5% of all reported adult/adolescent cases of AIDS in the United States are among women. Among these, 21.9% are Hispanic ("Update...", 1991).

In California, 1180 or 3.4% of the reported cases of AIDS are among adult/adolescent women ("AIDS News Summary", 1991). New cases of AIDS among women in California increased from 119 to 173, an increase of 46.1% between June, 1990 and June, 1991 (Creeger, 1991).

Increased incidence of HIV infection among women means that the number of cases among children will increase. Since the donor blood supply is no longer a major source of HIV infection, virtually all pediatric AIDS cases occur from an HIV infected mother. An infected mother will deliver an infected child in about 50 to

65% of cases. This percentage is controversial, however, and has been reported as low as 20 to 40% (Cantrell, 1990).

The lack of agreement on the degree of risk to the newborn makes counseling for women at risk for delivering a child infected with HIV very difficult. Latinas, who value children very highly, may be more likely than other women to continue a pregnancy in hopes of delivering a child who will not have the infection. This preference was dramatically underscored by data from a survey of intravenous drug using women. Selwyn and associates (1989) studied 191 women in a methadone program whose HIV status was known prior to pregnancy. Seventy of those women were seropositive and 40 (57%) of the seropositive women were Hispanic. Twenty-four percent of the 70 seropositive women became pregnant one or more times during the study time frame. They chose to conceive and carry their infants to term even though they knew they were HIV positive. Such choices have the potential for increasing the number of pediatric AIDS cases in the United States.

California, a border state, has many immigrants from Mexico who come to the United States to work or visit. Some of these transients decide to stay in the United States, while many return to Mexico to immigrate again when jobs are scarce in Mexico. Because of this continuous movement of people, there is an increased potential for spreading HIV infection on both sides of the border.

AIDS cases were first acknowledged in Mexico in 1981. As of mid-1988, 1,502 AIDS cases had been reported. AIDS cases in Mexico are believed to be doubling every 7.7 months, with 87.6% being attributed to sexual contact. HIV infection in Mexico is spreading faster among heterosexuals than among homosexual and bisexual males. Persons with AIDS in Mexico are expected to number about 260,000 by the end of 1994 (Valdespino, Izazola, & Rico, 1989).

Reporting cases of AIDS did not become a legal requirement in Mexico until 1986 (Carrier, 1989). Mexico does not have "Centers for Disease Control" like the

United States. This, combined with the denial of the severity of the epidemic in Mexico and the lack of care facilities that will take persons with AIDS, has caused a great deal of underreporting ("AIDS clinic...", 1990).

Selik, Castro, Pappaioanou & Buehler (1989) computed cumulative incidence of AIDS by race and country of origin that seemed to agree with Valdespino, et al. (1989) and Carrier (1989). They found that Hispanics with AIDS who were born in Mexico numbered 25.3 per 100,000 population. This study did not include undocumented aliens, but the authors did not believe that the inclusion of this group would increase the cumulative incidence. While lower than the incidence of AIDS among white homosexual males and Puerto Ricans, the Mexican and Mexican American population does represent a major portion of the persons with AIDS in the United States. Singer and associates (1990) stated that AIDS cases among Mexican-born Latinos are about the same number as among Anglos, male and female.

This section has been used to describe HIV/AIDS and its impact on Latinos in the United States, California, and Mexico. The statistics presented demonstrate that the incidence of HIV/AIDS is increasing among Latino males and Latinas rapidly. The next section will be used to describe social, familial, and cultural factors that may influence Latinas' perceptions of HIV/AIDS.

Socioeconomic, Familial, and Cultural

Influences on Perceptions of HIV/AIDS

This discussion is limited to those aspects of the Mexican American and Mexican social, familial, and cultural influences that may affect Latinas' perceptions of sexual issues, HIV disease, and their decisions to use behaviors that prevent HIV infection. Mexican and Mexican American social, familial, and cultural influences were of primary interest because all but two of the respondents of this study were of Mexican heritage. Socioeconomically, Latinos of Mexican and Mexican American

heritage are among the poorest minority groups in American society. Within this context, HIV/AIDS becomes just one more of many problems.

The Latina's role as female, wife, and mother within the family affects how she perceives sex, HIV/AIDS, and the prevention of HIV/AIDS. Social expectations influencing the male role may also inhibit the Latina's perceptions of HIV/AIDS and her ability to prevent contracting HIV disease. This section will be used to present a few of the familial and gender related issues that would seem to have an impact on those perceptions.

Cultural perceptions of disease and disease acquisition may also affect how Latinas come to know about HIV/AIDS. Traditionally, Latinos have been described as believing that disease may arise from supernatural or magical causes. This section is used to present some of those beliefs and to speculate about how these beliefs may affect how the Latina comes to know about HIV/AIDS.

It is important to point out here that any discussion of this sort is limited in that the Latino culture is very diverse and heterogeneous. There are very few studies that can be applied across all members of this minority group with any absolute surety.

Socioeconomic and Class Issues: Latinos Within the Dominant American Society

About 70% of Mexican and Mexican Americans are people of Spanish and Indian descent who have been in the United States since the time of the Conquistadors (Munoz, 1988; Mirande & Enriquez, 1979). The remaining 30% are immigrants from Mexico, Central and South America, Puerto Rico, or Cuba. Mexican Americans, who comprise about 60% of the Hispanic population in the United States, are a conquered people. Their status is the result of the Texas War of Independence (1836) and the War with Mexico (1848) that resulted in the annexation

of land that became Texas, California, Arizona, New Mexico, Utah, Nevada, and parts of Colorado (Mirande & Enriquez, 1979).

Economic Resources

As a conquered people within the dominant American society, Latinos have a low socioeconomic status (Cancela, 1989). Statistically, Latinos have the lowest median family income of any ethnic group in America (Giachello, 1985; Munoz, 1988). In the United States, 2.6 million or 36.2% of the nation's 7.2 million Latino children live in poverty (Staff, 1991, August 27).

The lack of financial resources is an important deterrent to the utilization of health-care services. Lack of money, however, is not the only barrier. Others include language differences, class and cultural disparities, few Latino doctors and nurses, long waiting time for care, lack of health-care providers where poor Latinos live, lack of coordination between social services and health care facilities, and discrimination (Brecht, 1990; Funkhouser & Moser, 1990; Giachello, 1985; Ginsberg, 1991; Price, Desmond, & Eoff, 1989). Estrada, Trevino, & Ray (1990), in their evaluation of data from the Hispanic Health and Nutrition Examination Survey (HHANES) of 1982-84, noted that younger age group (average age is 23-25), lack of health insurance coverage, less acculturation, and poorer perceived health status are also barriers to health care utilization by Mexican Americans. Lack of access and under-utilization of available health care resources limits the amount of information about HIV/AIDS and its prevention, available to Latinos. Lack of information increases vulnerability to the disease. Limited or misinterpreted information may increase fear and contribute to beliefs that HIV can be transmitted by casual contact.

Like other lower socioeconomic groups, many Latinos live in urban areas in overcrowded, poor housing; if they have housing at all. They have the lowest levels of education of any ethnic group in the United States and a high unemployment

rate. Of those who are employed, most have low paying, seasonal jobs with no benefits. Because they are poor, Latinos are more likely to suffer from illnesses and other problems of the needy, such as hunger, decreased immunity, substance abuse, and higher infant mortality rates (Latinos-17.3 per 1000 live births; whites - 10.1 per 1000) (Cancela, 1989; Maldonado, 1990; Munding, 1985; Munoz, 1988; Rosa, 1989; Sumaya & Porto, 1989). Such deprivation may tend to cause poor Latinos' to perceive HIV/AIDS as a minor problem.

The high incidence of substance abuse among poor Latinos has increased their risks for contracting HIV/AIDS (Munoz, 1988; Rosa, 1989). There is also evidence that Latinos, especially Latinas, delay seeking health care until they are very ill and are less likely to obtain screening examinations such as HIV testing (Brecht, 1990; Munoz, 1988). Such tendencies have the potential for causing the spread of HIV/AIDS to accelerate as HIV positive persons not identified continue to expose others to the virus.

Educational Status

Of Mexican American males and females, the Latina not only earns the lowest wages but also has the least education (Baca Zinn, 1982b; Giachello, 1985; Portillo, 1987; Salholz, Gonzales, & Pena, 1990; Zambrana, 1987; 1988). The Latina is the least likely American to finish high school or obtain a college degree. Of Latinas who enter school, only 36% will finish high school (Hurtado, 1989; Zambrana, 1987). Enrollment of Latinas in graduate studies has actually decreased in the last decade (Zambrana, 1987). Several reasons have been suggested for this lack of education, including racial segregation, improper teacher behavior toward Latinas, inappropriate instructional practices, lack of same sex/ethnic group role models, inadequate counseling, non-involvement of parents in school functions, and, in some areas, lack of bilingual classes (Castillo, Frederickson, McKenna, & Ortiz, 1988).

Other sources describe Latinas as being disinterested in education because of their belief that the family is the most important aspect of their lives. Being a wife and mother does not require an education. In addition, the boy of the family is considered "el rey", the king. He is given an education before his sisters because he is perceived as a future breadwinner who will have to support a family. Education for his sisters is not considered important because, as wives and mothers, they will be cared for by their husbands.

Mirande and Enriquez (1979) noted that education does not come easily to Latinas. Within their culture, Latinas are expected to be non-confrontational. Their identity is defined by the men in their lives, whether they are husbands, fathers, or brothers. The American educational system expects the Latina to speak out in class, to question, and to investigate. The vocal Chicana who succeeds in school and joins the few of her gender and race who graduate from college, risks being labeled unattractive. She may have difficulty attracting a mate, especially if none of her potential mates have attained the same level of education.

Lack of education has been correlated with lack of knowledge of HIV/AIDS and increased misconceptions about HIV transmission (Dawson & Hardy, 1989). The Latina, then, would be expected to have little knowledge of this disease. More about the role of education in the understanding of HIV/AIDS is presented in the Research section of this chapter.

Familism

Familism or familismo is a key cultural value for the Latino. Familism means that there is nothing as important as the family and that each family member, male or female, has an obligation to the family. This obligation includes keeping the family intact and providing emotional and material support to all family members, nuclear and extended (Marin, 1989).

Familism also includes a strong love for children. Fertility and procreation are highly valued. When viewed from the perspective of the HIV epidemic, familism and the love of children become both a potentially negative and a potentially positive influence on prevention efforts. It is potentially negative when the male will not use condoms because he wants more children. Familism is a positive influence when it can be used as a reason to decrease risk behaviors, especially for males (Marin, In press; Singer, et al., 1990).

The family, both nuclear and extended, takes precedence over individual identity (Riding, 1989; Smith, 1988). The illness of one family member is a family illness. Decisions concerning that illness are made by the family; mother decides who is sick and father decides when to spend money for medical care (Gonzalez-Swafford & Gutierrez, 1983; Manzanedo, Walters, & Lorig, 1980; McKenna, 1989; Ross, 1981). Diseases such as AIDS have a stigma attached that may cause the family to close ranks and attempt to conceal a family member who is affected.

There is evidence that movement between Mexico and the United States by seasonal workers or persons seeking permanent residence, occurs most often if there are family members available who will temporarily house the migrant (Melville, 1981). Such movement may contribute to the spread of HIV/AIDS on both sides of the border.

The family is a source of support (emotional and financial) available to the Latino in times of trouble or change. The family is also a focus of obligation, not only when another family member is in need but also when family members need information. Marin (In press) asserts that familism may compel Latinos to talk to other family members about the prevention of HIV/AIDS.

Singer and associates (1990) and Melville (1980) argued that Latino families, especially in inner cities, have been disintegrated by poverty, alcoholism, drug use, and violence. When families break apart, the mother usually takes the children.

This is also true among Latinos. Many Latinas are heading households. In California, more Latino families with female heads of households live below poverty level than any other minority, including Blacks (Kirk, 1988). Disintegrated families under these conditions contribute to increased incidence of HIV/AIDS among Latinos. Children who grow-up without the security of an intact family are more likely to choose risk behaviors such as drug use that may expose them to HIV disease.

Gender Roles and Issues

Gender roles and issues seem to have a tremendous bearing on how the Latina comes to know about AIDS. HIV disease, for the Latina who is drug-free, is primarily a sexually transmitted disease. The way she perceives HIV/AIDS is affected by how she is socialized into the female role and how she learns to relate to men.

While characterizing gender socialization and gender relations among Latinos, it is important to be aware that the context within which these occur is not static and each is affected by historical, political-economic, and individual circumstances (Singer, et al., 1990). The variability of gender socialization and gender relations, then, cannot be totally characterized within this section. In view of this limitation, specific issues that may inhibit HIV/AIDS awareness, limit prevention strategies, or cause unwarranted fear among Latinas are discussed.

Latinas

Latinas, according to Pavich (1986), can best be discussed if they are thought of as being in one of three groups. The first group represents those with more traditional beliefs and perceptions. Traditional women are usually new immigrants who have not been exposed to Americanization for very long. These Latinas are usually unable to speak or understand English.

The second and largest group consists of women who are bicultural; that is, they have perceptions, beliefs, and behaviors representative of the traditional group and of American society, as well as a blend that is uniquely their own. Within this group are individuals who can speak both Spanish and English, but have varying abilities with English (Pavich, 1986).

The last group are Latinas who are totally "Americanized". Their values and beliefs are consistent with the dominant culture and the language spoken in their homes is English (Pavich, 1986). Unfortunately, "Americanization" may also mean a higher incidence of drug use. Amaro and associates (1990) found evidence within data from HHANES in 1982-84 that acculturation as reflected in English language use was associated with higher incidences of drug use among Hispanic males and females.

Most of what has been written about and studied within the Latino culture has dealt with the traditional group. Females within this group (and to some extent, the bicultural group) have been depicted as submissive, demure, naive, masochistic, dependent on the men of the family, highly fertile, unworldly, chaste, valuing others above self, giving without question, and interested only in motherhood and the care of their husbands (Clark, 1970; Kay, 1980; Medina, 1987; Melville, 1980; Pavich, 1986; Poma, 1987; Portillo, 1987; Riding, 1989; Rubel, 1960; Worth & Rodriguez, 1987).

Traditional Latinas have limited knowledge of sexuality and female physiology (Poma, 1987). Their parents avoided discussions of sex and sexual issues and they do not discuss these issues either (Maldonado, 1990; Medina, 1987). For instance, to speak with a pre-adolescent girl about menstruation, sexual intercourse, or pregnancy is considered taboo; even for her mother (Johnson, 1980). Such beliefs also reflect a present orientation and the consideration of menses and sex as natural events to be dealt with when they occur (DeSantis & Thomas, 1981).

Within the Mexican belief system, women are dichotomized as either 'good' or 'bad'. The good woman is sought after by a man as wife and mother of his children. She is the female ideal who is virginal, saintly, and most like his mother (Riding, 1989). A "good" Latina must be ignorant of sexual intercourse until she marries and her husband teaches her (Carrier, 1985; 1989; Maldonado, 1990; Nyamathi & Vasquez, 1989; Riding, 1989). After marriage, she should continue to be faithful and not demonstrate any sexual interest, and should submit to her husband for procreation only (Carrier, 1985; Pavich, 1986).

A "good" woman with all these traits is said to have marianismo. Under this cultural edict, a "good" Latina is expected to live with one man all her life and to accept quietly his infidelity (Singer, et al., 1990). Mays and Cochran (1988) suggest that a woman who is submissive and obedient must rely on her mate for HIV/AIDS protection, either through monogamy or the use of the condom. At the same time, these traits also prohibit the Latina from asking her mate to use a condom (Cancela, 1989). Some Latinas may even experience physical or verbal abuse and threats for merely suggesting that their mate use a condom (Cochran & Mays, 1989; Peterson & Marin, 1988; Peterson & Marin, 1988; Mays & Cochran, 1988).

The 'bad' woman is one who has sex before marriage and becomes a mistress to married men. She exists to service the erotic sexual desires of men (Pavich, 1986). To have relations with a "bad" woman may be considered immoral and as causing problems in determining the paternity of children. However, men who want to prove their virility may choose the "bad" woman. Sexual liaison of this sort are said to add variety, excitement, and learning opportunity for men (Marin, 1989). Such encounters also add a potential for exposure to HIV disease.

Marin (In press) conducted open-ended interviews with over 200 Hispanics and non-Hispanics in San Francisco regarding their perceptions of AIDS prevention. An interesting component of her findings from among the Hispanic population was

that sexual issues are not often discussed between men and women. A "good" woman is not supposed to know about sex, condoms, or sexually transmitted disease. These findings support Mays and Cochran (1988) who asserted that the Latina who suggests that a condom be used will be considered "loose" or promiscuous; a "bad" woman.

The maternal role among Latinos is very highly valued and a girl is not considered a woman until she has had a baby (Melville, 1980; Pavich, 1986). Children supply their mothers with warmth and love that they do not always receive from their husbands or mates. In addition, to have no children calls into question a woman's gender role and sexuality. In addition, if she uses birth control methods to prevent a pregnancy, she goes against the teachings of the Catholic Church (Poma, 1987; Urdaneta, 1980). For poor women, children may also represent an economic resource and/or a potential for cultural survival within the dominant American society (Mays & Cochran, 1988).

Latinas, brought up to value others above themselves, familism, and maternity, perceive a relationship with a man and having children as imperative. Within this context, HIV preventive messages directed toward poor minority women who are unmarried are unrealistic when they direct her to question her prospective mate about his sexual and drug history. Poor Latinas are not negotiating from a position of equality in these situations. They are vulnerable because of their life expectations, gender, and social position. They risk abandonment by questioning their male partner about such issues (Mays & Cochran, 1988; Nyamathi & Vasquez, 1989).

Poor Latinas may also refrain from questioning potential mates about their sexual past and HIV status because they know that many men either lie or make the risks seem minimal (Mays & Cochran, 1988). In addition, such behavior changes do

not offer any reward for poor Latinas. They are asked to risk losing a mate without any guarantees that there will be another man available.

Despite perceived male superiority within the Latino culture, the Latina is considered vitally important within the family (Riding, 1989). She offers strength and stability. She is the "life force" which keeps the family together ("Cross-cultural...", 1990). Women are crucial to the family because they are responsible for transmitting religious beliefs, customs, and mores to their children (Riding, 1989). They are also the designated care-givers for anyone within the nuclear or extended family who becomes ill (Manzanedo, Walters, & Lorig, 1980; Worth & Rodriguez, 1987).

Latino Males

According to Riding (1989), there are different social expectations for Latino males when it comes to sex and gender relations. Mexican males are encouraged to experience sex from an early age. By age 15, most boys have had sexual encounters with either males or females or both (Carrier, 1985).

Such encounters are thought important for the male who wants to prove his machismo. Machismo is the male equivalent of marianismo as it describes those traits most desired in a man. According to Medina (1987), machismo refers to the belief that men, because they are male, are superior to and must exercise authority over women. Over time, many have come to think of machismo as synonymous with swaggering, chauvinistic male dominance (Mirande & Enriquez, 1979).

Substance abuse, especially alcohol and drug addiction, is more prevalent among poor Latino males than among other ethnic groups in the United States because of machismo (Rosa, 1989). Within this context, drinking and drug use are equated with being strong, virile, and manly. This form of machismo is more often seen within the lower socioeconomic groups of Latinos (and other ethnic groups) who live in inner cities where the drug and AIDS problems are so prevalent.

According to Carrier (1985), Latino males do not marry until the mid to late 20s, after they have had numerous sexual encounters with both males and females. After marriage, the male is not expected to stop having sexual affairs outside of marriage (Riding, 1989; Maldonado, 1990; Marin, in Press; Nyamathi & Vasquez, 1989). Maintaining a mistress (casa chica) and a wife and family (casa grande) is an accepted practice. Under this system it is understood that the male will provide for his wife and her family first, that he will treat his wife with respect, and that he will be responsible for any children born to his mistress (Pavich, 1986). Through this tradition he maintains his machismo, but at the same time has the potential of exposing himself and his family to HIV/AIDS.

Mirande and Enriquez (1979) depict machismo as having a different meaning for some Latinos. While it is true that men have more freedom and privileges, they take their responsibilities for the family very seriously. Their authority as senior male in the family is used in a just and fair manner. If they misuse that power, they will lose respect or respeto within the community.

Respect toward men and elders is pervasive among Latinos (Marin, 1989; Mirande & Enriquez, 1979; Pavich, 1986). Marin (1989) depicted respeto (respect) as a need to maintain personal integrity. For instance, if a person receiving drug treatment does not feel that he or she is treated with respect, the treatment will be rejected. In addition, respeto demands that a Latino does not question an authority (like a doctor), even if they do not understand or do not intend to follow advice (Marin, In press). This cultural value has implications for how Latinas come to know about HIV/AIDS. Even if she does not understand, the Latina will not question the doctor or her husband, both of whom she sees as authority figures.

Rodriguez and Casaus (1983) described respect as reciprocal within the Latino family. A father and husband expects respect from his family and in return he gives respect. Machismo, in this context, becomes pride, dignity, strength, virility,

authoritarianism, courage, honor, and provision for the needs of the family (Pavich, 1986; Rodriguez & Casaus, 1983). Combined, *machismo* and *familismo* could be existing characteristics that could be tapped to increase AIDS preventive behaviors among Latinos (Marin, 1989).

Male dominance within the Latino culture is a complex issue that has been addressed widely in the literature. Some believe that male dominance should not be considered the norm within Latino families. Baca Zinn (1982a; 1982b), Ybarra (1982), Andrade (1982a; 1982b), and Rodriguez and Casaus (1983) all contend that there is no research supporting absolute male dominance within Latino families. Ybarra (1982) and Baca Zinn (1982a) have demonstrated that egalitarianism is more prevalent than male dominance among Latino families; especially if the wife works outside the home.

Andrade (1982a) and Baca Zinn (1982a) assert that most of the studies that have identified elements of male dominance within families did so using lower socioeconomic class participants. Most lower socioeconomic class families with a male head of the household, regardless of race or ethnicity, are subservient to that male. Therefore, generalizations about male dominance should not be made based on ethnicity.

Riding (1989) supported Andrade (1982a) and Baca Zinn (1982a) when he stated that paternalistic and authoritarian structure within the family seems to the advantage of poor Latinos. The subservient role, learned in the family, prepares the Mexican to work in menial jobs under strict hierarchical conditions. Conversely, this same structure would reinforce strict, authoritarian male dominance within the poor family. After all, the only persons who accept the poor man as powerful are his wife and children who are dependent on him for sustenance.

Paternalism and male authoritarianism are also reflective of religion within the Mexican American culture. About 85% of Latinos are Roman Catholic (Klor de

Alva, 1988; Smith, 1988; Moore & Pachon, 1985). The Catholic Church also instructs its parishioners that sex is only for procreation and that artificial means of birth control such as condoms are not to be used (Mays & Cochran, 1988). The male, being in a position of dominance over the female, determines whether birth control devices will be used and may use physical coercion if the female insists on condom use (Peterson & Marin, 1988; Mays & Cochran, 1988; Cochran, Mays, & Roberts, 1988).

Homosexuality and Bisexuality

Homosexuality and bisexuality are the risk factors most often associated with HIV/AIDS. Among Latinos, homosexuality and bisexuality are taboo and rarely acknowledged. Osborn (1990) has called bisexuality the "quietest" of risk factors that facilitate the spread of HIV/AIDS (p. 1).

Carrier (1985) studied male bisexuality in Northwestern Mexico for 15 years using both participant-observation and interviews. He found that 53 of 73 of the males studied in one area of Northern Mexico had both heterosexual and homosexual experiences. Carrier (1985; 1989) also noted that there is extreme homophobia in Northern Mexico, leading many men who prefer sex with other men to marry and have children, but to continue homosexual relations. In addition, sex with other men is not considered homosexual conduct by the Mexican if the male plays the inserter role. It is only the male who is penetrated who is considered effeminate and homosexual.

In the United States, Selik, Castro, and Pappaioanou (1988) found that AIDS cases transmitted by homosexual/bisexual contact were more prevalent among Latinos than Blacks. Homosexual contact is probably more prevalent among Latinos than had been recognized before the AIDS epidemic (Friedman, et al., 1987; Peterson & Marin, 1988; Rogers & Williams, 1987).

Homophobia and pretending that one's mate has not and does not have relations with other men may expose the Latina to increased risks for contracting

HIV/AIDS. Homophobia also has implications for how the Latina comes to know about HIV/AIDS.

Other Latino Cultural Values

In addition to familism and respect, Marin (In press) and Marin (1989) described two cultural values that may affect how Latinas come to know about HIV/AIDS and the prevention of HIV disease: simpatia and personalismo. Simpatia mandates politeness and respect in all relationships and rejects assertiveness, negative responses, criticism, and any form of confrontation. Therefore, the behavior of a woman who confronts a man about condom use is inappropriate. In addition, simpatia makes it important that the Latino appear to agree with messages, especially from an authority figure. Simple yes and no questions will be answered in the affirmative regardless of the Latinos' true level of understanding (Marin, In press). It is more effective to encourage the Latino learner to repeat that which is to be learned.

Personalismo refers to the Latinos' preference to be with other Latinos of their background and social standing. They prefer health-care providers whom they have come to know through "pleasant conversation". Therefore, they are more likely to trust other Latinos or health-care providers who have taken the time to have pleasant conversations with them (Marin, In press).

Perceptions of Illness and Disease

The Latino's perceptions of illness and disease are different than those of other cultures. Most information about Latinos and their perceptions of illness and disease is available from anthropology and other social sciences. Nursing literature has little information concerning this ethnic group. Within this section are some of the illness beliefs of Latinos that have been discussed in the literature. It is speculated that these beliefs may have relevance for understanding Latinos' perceptions of AIDS.

The more traditional groups and many of the bicultural Latinos are fatalistic and present-oriented. Health is a day-to-day thing and is not thought of in terms of how it will be in the future. Health and death are a matter of chance (Markides, 1981; McKenna, 1989; Rubel, 1960). HIV infection may lie dormant within the host for up to 10 years without causing obvious disease symptoms. For many Latinos, being without symptoms means that there is no sickness. It may be difficult for them to accept preventive behaviors when there are no symptoms and they are told of things that may happen in the future.

Latinos, traditionally, accept their fate and believe in destiny; "Si Dios quiere" (If God wills it). If they become ill with a disease that is fatal, they accept it. This does not stop them from seeking healing advice and medical assistance, however (Cross-cultural..., 1990).

When a family member becomes ill, the first one consulted is the mother. If she cannot help with her home remedies, then neighbors and friends are consulted to validate that the symptoms are of concern. The neighbor or cousin may offer medications that they have obtained elsewhere for similar ailments. These medications or vitamins may be injectable and the same needles may be used for everyone (Cancela, 1989; Marin, 1989). Needle sharing is also done for tattooing, ear piercing, and within "shooting galleries" where illegal drugs are injected for anyone who comes in (Cancela, 1989).

When it is decided that an illness is not responding to home care, then a curandera or curandero may be consulted. A curandera or curandero is a person who has a gift for healing. This person will diagnose the illness and offer remedies based on folklore and cultural beliefs about the cause of the illness. For example, an infant who has been vomiting and having diarrhea and fever may be taken to a curandera who by examining the fontanelle, will diagnose caida de la mollera (sunken fontanelle). This malady is thought to be a shift in the body part caused by a

blow to the baby's head, or from pulling the child away from the breast too soon. The remedy is for the curandera to replace the misplaced mollera by pressing the baby's palate upward. This is done while prayers are spoken. It is believed that replacing the part will cure the baby (Clark, 1970; Marsh & Hentges, 1988; Rubel, 1960).

The shift of a body part is only one of many theories of illness causation. Another cause of physical disease is thought to be an imbalance in the body between "hot" and "cold" (Clark, 1970; Gonzalez-Swafford & Gutierrez, 1983; Rubel, 1960). This is an ancient theory first seen in the writings of the Greek Hippocrates, and probably came to Mexico via Spanish explorers. The theory is that any disease that is "cold" should be treated with a "hot" remedy and if the disease is "hot", it should be treated with a "cold" remedy. There are lists of foods and medicines in each category, but selection of these foods or medicines depends on local custom and does not always follow the ancient guidelines. No literature was found that discussed whether Latinos consider AIDS a "hot" or "cold" disease.

Another theory of disease causation is that illness is caused by magical events or witchcraft. An example of this is mal de ojo or "evil eye". This is sickness believed to occur when a small child is admired by someone (usually a woman) who does not touch the child. The perpetrator of the malady may not even be aware that they have caused the child to become ill. Such problems must be diagnosed and treated by a curandera who is familiar with the problem (Clark, 1970; Rubel, 1960).

An anecdote that appeared in Newsweek told of a Latina who was infected with HIV through heterosexual relations with her husband who was an IVDU. She sought help from the family curandera. There she was treated with herbs, incantations, and prayer. When the disease persisted, the curandera told the sufferer that the persistent disease was a sign that she had "strayed too far from Latino culture and is being punished by God" (Cowley & Marshall, 1990, p. 27).

Similarly, in a study of knowledge of sexually transmitted diseases in Black and Mexican-American migrant farmworkers, Smith (1988) found that more than half of Latinos (males and females) attributed the cause of these diseases to supernatural events. Usually these supernatural events were explained as "unhappy family spirits" (p. 56).

Diseases of emotional origin are susto (fright) and bilis (anger). Bilis comes to adults when they become very angry. Symptoms include nervous tension, fatigue, and malaise. It is treated with herbs "to quiet the nerves" (Clark, 1970, p. 176).

Susto is very common among children. It occurs because something scares the mother while she is pregnant, thereby, affecting the infant. Or, something scares the child, and he or she continues to be frightened. Symptoms include becoming thin and pale and not wanting to eat. The child may have headaches, shakes, and tremors. Rituals, herbs, and prayers are used to remedy this malady (Clark, 1970). AIDS among children may be attributed to an experience the mother may have had during her pregnancy. None of the literature reviewed discussed Latinas beliefs about how infants may contract AIDS.

Mexican Americans also recognize moral illness, that is, illness that has been caused by the excesses of the person affected. Examples include alcoholism and drug addiction. Since AIDS has been associated with drug addiction, it may be perceived as a moral illness by Latinas. Such illnesses are believed to be the responsibility of the family and must be approached via the head of the household. Without the cooperation of the patriarch, treatment will not be accepted (Gonzalez-Swafford & Gutierrez, 1983).

Understanding the etiology of disease from the perspective of the Latina is important to treatment of that ailment (Foster, 1976; Gonzalez-Swafford & Gutierrez, 1983). Marsh and Hentges (1988) pointed out that being aware of the client's beliefs

about how an illness has occurred and discussing these beliefs openly with the client will help to avoid conflicts and potential injury to the client. It is always advisable to ask the Latino, "What do you think caused your illness?" and "What have you or your family done about this problem?" (p. 261-262).

In summary, the literature suggests that Latinas may perceive disease causation as a shift of a body part, an imbalance between hot and cold in the body, witchcraft or mystic causes, or moral illness caused by excesses. How much these beliefs will affect how Latinas come to know about AIDS and AIDS prevention remains to be discovered.

Research: Surveys and Focus Groups

The last section of this review is comprised of two parts. The first presents available research on Latinos who have participated in surveys related to their knowledge, sources of information, attitudes, behaviors, and beliefs about HIV/AIDS. A wide review of nursing, psychological, and medical literature revealed few studies in this area that included Latinos. Nursing research that concerns Latinas and HIV/AIDS is presented in the second part. Again, there were few studies available in this area.

While the medical model has established the nature of HIV disease and how it is transmitted, it has had little concern for how to begin to bring about behavior changes, build support services, or mobilize funding resources. According to Friedman and associates (1987), the medical model focuses on individual risk reduction through increased knowledge of HIV disease and how it is transmitted. From this perspective, high risk groups such as IVDUs are the primary focus of educational efforts. The communities where those high risk individuals may be involved with persons who are not otherwise at risk are not included.

In addition, history has proven that education alone does not necessarily lead to preventive behaviors (Brandt, 1988). For instance, many smokers know the risks

of smoking but will not or cannot stop smoking. Without knowledge, however, people are more vulnerable to diseases such as lung cancer and HIV/AIDS.

Knowledge that people have about HIV infection, as well as their beliefs, attitudes, and behaviors are all relevant for study when the goal is to prevent HIV/AIDS. Each of these constructs affects decision-making related to preventive behaviors. And yet, not much is known about cultural variations in HIV infection knowledge, beliefs, attitudes, or protective behaviors (Friedman, et al., 1987; Hu, Keller, & Fleming, 1989).

Lack of research about cultural variations stems, in part, from a legacy of omitting ethnic qualifiers on questionnaires and in surveys. It was not until 1970 that the United States Census asked a sample of households if they were of Spanish origin. It was not until 1980 that the Census questioned all households in the United States about ethnicity that included listings for Mexican American, Cuban, Chicano, Puerto Rican, or other Spanish/Hispanic (Davis, Haub, & Willette, 1988) (see also Hayes-Bautista, 1980; Melville, 1980, 1988; Munoz, 1988; Portillo, 1987; Zambrana, 1987).

Similarly, research among Latinos concerning AIDS has been slow to develop. Peterson and Marin (1988) pointed out that the supplemental questions on AIDS in the National Health Interview Survey did not include an Hispanic identifier until May, 1988. In addition, the first surveys were written only in English. Considering that a large portion of the persons with AIDS are Hispanic, it would seem that these additions and changes would have been more helpful if they had been made earlier.

Surveys

In this part of the literature review, five surveys that included Hispanic participants will be described. These surveys addressed level of knowledge, attitudes, sources of information acquisition, and reported behaviors among Latino subjects.

DiClemente, Boyer, and Morales (1988) surveyed adolescents in San Francisco high schools and found that Latinos were less knowledgeable about AIDS and had more misconceptions about the disease than Anglos or Blacks in the same sample. Data were collected using the AIDS Information Survey which has three sub-scales; Knowledge Scale of AIDS, Misconception Scale of Casual Contagion, and Scale of Perceived Susceptibility. Alphas for internal consistency for each of these scales were 0.72, 0.75, and 0.55 respectively.

Knowledge deficits of particular interest to the authors included lack of awareness of the primary routes of HIV infection and measures (such as condom use) to lessen risks of HIV infection. Less knowledge of disease among the subjects of this study was correlated significantly with greater likelihood of perceived susceptibility and related feelings of anxiety. DiClemente, Boyer, and Morales (1988) recommended that preventive AIDS education become more available to adolescents.

Hu, Keller, and Fleming (1989) conducted a survey regarding AIDS information acquisition and knowledge among 216 Hispanics in three Oregon clinics. They found that the respondents in this sample were more likely to have received information from television (42.6%) than from radio (19.9%), newspapers (18.5%), or pamphlets (17.6%).

Only 50% of the Hispanics surveyed in this study thought condoms could prevent transmission of HIV even though 90% thought that HIV disease was sexually transmitted. Like the adolescents in the study by DiClemente and associates (1988), the Oregon Hispanics were more likely to believe that AIDS could be transmitted casually. Hu, Keller, and Fleming (1989) concluded that language barriers and illiteracy were major deterrents to the dissemination of AIDS prevention information among the Hispanics in their study. They suggested that

more Spanish educational information be broadcast via television and radio in order to reach the Hispanics in their region.

Perhaps the most extensive survey of Hispanic Americans concerning AIDS knowledge, attitudes, and behaviors was the National Health Interview Survey (NHIS) of 1988. Dawson and Hardy (1989) reported on data obtained from May through October of 1988. The National Center for Health Statistics developed the questionnaires for this continuous, cross-sectional household interview survey that included representation from all ethnic and racial groups. The questionnaire contained items on sources of AIDS information, self-assessed levels of AIDS knowledge, knowledge of basic facts about HIV and how it is transmitted, perceived effectiveness of preventive measures (such as condoms), and perceived susceptibility. The survey also asked each subject if they had any blood donation experience, whether or not the subject had been tested for HIV, whether the subjects were acquainted with anyone who had AIDS, and whether the subjects would submit to a seroprevalence survey.

Dawson and Hardy's (1989) report was based on the results of that survey among 1,022 Hispanics (of differing national origin or ancestry) and 19,963 non-Hispanics. Respondents were given seven alternatives for identifying their national origin. Categories included Puerto Rican, Cuban, Mexican, Mexican American, Chicano, other Latin American, and other Spanish. During analysis data for those subjects who had indicated they were Mexican, Mexican American, or Chicano were combined into one category, "Mexican".

Compared to the non-Hispanic group, those of Hispanic origin (all groups) were less knowledgeable about HIV disease. Like Hu, Keller, and Fleming (1989), Dawson and Hardy (1989) found that the Hispanic adults surveyed credited television as their primary source of information about AIDS (84%). Only 36% of the Hispanic adults surveyed had read pamphlets or brochures about HIV disease in the

month before the survey. "Understanding AIDS", a brochure mass mailed by the Surgeon General's office during the six months of this survey, may or may not have been the brochure read.

About half of the Hispanic adults surveyed had discussed AIDS with their children aged 10-17. About 60% thought their children had learned about AIDS at school. Hispanic men were less likely than Hispanic women to have talked to their children (Dawson & Hardy, 1989).

The higher the educational level of the Hispanic subjects, the greater their knowledge of HIV/AIDS. This relationship was also true of non-Hispanic subjects. Higher education also seemed to decreased misconceptions about HIV transmission among the Hispanics surveyed (Dawson & Hardy, 1989).

Perceived efficacy of two forms of prevention of HIV disease were investigated in the NHIS survey - condoms and monogamy. Of the Hispanics surveyed, 28% thought condoms were very effective; 45% thought condoms were somewhat effective. Hispanics with more years of education were more likely to think the condom effective. Hispanics surveyed were twice as likely to consider the condom ineffective as non-Hispanics (10% versus 5% of subjects respectively) (Dawson & Hardy, 1989).

Seventy-seven percent of the Hispanic adults surveyed thought that monogamy with an uninfected partner was very effective prevention of HIV disease. Non-Hispanics (83%) also thought monogamy was a very effective prevention method. Of the Hispanics surveyed, 76% felt that there were no chance that they would become infected with HIV disease. This was understandable since only 2% of the Hispanic adults interviewed reported belonging to a high risk group (homosexual men, IVDU, and so forth) (Dawson & Hardy, 1989). Only 9% of the Hispanics surveyed knew someone with AIDS.

When asked if they would submit to blood testing for HIV infection, 67% of Hispanic adults said that they would (Dawson & Hardy, 1989). This was surprising considering the stigma that has become attached to this disease and the assertions by Munoz (1988) and Rosa (1989) that Latinos are less likely to obtain screening examinations.

Interestingly, Hispanics belonging to the "Mexican" category were less knowledgeable about HIV disease than all the other Hispanic groups combined. They were also the group least likely to read brochures, least likely to have talked to their children about HIV, more likely to respond that they did not know anything about HIV/AIDS, more likely to have misconceptions about the transmission of HIV, least likely to have heard of the HIV blood test, and least likely to acknowledge knowing someone with AIDS (about 6%) (Dawson & Hardy, 1989).

In 1987, Hingson and associates (1989) interviewed by telephone 1,323 Massachusetts residents to assess exposure to AIDS education, AIDS knowledge, and whether knowledge of AIDS had changed any risk behaviors. Of the participants, 55 were Hispanic. Specific findings of interest from this random digit dial anonymous telephone survey were: (a) 9% of the Hispanic subjects did not know about male homosexual transmission, (b) 7% did not know about needle sharing risks or heterosexual transmission, (c) Hispanics, especially those who responded in Spanish, were less likely to have heard AIDS messages on television or radio than Anglos or Blacks in the same survey, and (d) of all the groups surveyed Hispanics were the most concerned about AIDS. These findings were similar to those of DiClemente and associates (1988).

In addition, Hingson and associates (1989) noted that those in the survey who continued unsafe sexual practices knew that the practices were modes of transmission for HIV/AIDS. Perceived susceptibility to HIV/AIDS was a much more consistent predictor of behavior change to prevent HIV infection in this study.

The last survey to be presented in this section concerns AIDS-related knowledge and behavior among women 15-44 years of age; of whom 641 were Hispanic, 2,771 were Black, and 5,354 were Anglo (McNally & Mosher, 1991). These findings were from Cycle IV of the National Survey of Family Growth conducted in 1988 by the National Center for Health Statistics. The data were obtained through personal interviews conducted in the subjects' households by trained interviewers.

McNally and Mosher (1991) reported on three topics from within this survey that were related to HIV/AIDS. The topics were misinformation, changes made in sexual behavior since hearing of HIV/AIDS, and perceptions of risk of infection with HIV/AIDS. The Hispanic women surveyed included Puerto Rican, Cuban, Mexican American, Central and South American, and other Spanish origin. The small number of Hispanic women surveyed (641) compelled the authors to give only summary data concerning this group. Of the Hispanic women, 32% thought HIV could be contracted by donating blood, 17% thought not be spread by sharing hypodermic needles, 8% thought that HIV could not be spread by male-male sexual relations, 7% said that heterosexual relations could not spread HIV disease, and 44% thought they could not get HIV disease from someone who had the AIDS virus but no symptoms of the disease.

Survey results are limited by method and language barriers when used with the Hispanic population (Berkanovic, 1980; Flaskerud, 1988a; Hayes-Bautista, 1980; Jones, 1987). Such methods cannot properly identify biologically-based, socially complex behaviors such as sexual practices and drug use that are central to the transmission of HIV disease (Cochran, 1989; Fineberg, 1988; Mays & Cochran, 1988). Person-to-person or focus group discussions of these issues, conducted in the language of the participants, have a greater potential for revealing these sensitive aspects of their lives.

Person-to-person interviews and focus group discussions, however, are limited in the numbers of persons that can be reached. It would seem that a combination of the two methods, with particular attention to improving survey tools for use with Latinos, would provide a broader based approach to the problem.

Nursing Research

Flaskerud and Nyamathi (1989) reported a pilot study conducted among 51 Black women and 56 Latinas from WIC programs in Los Angeles in an attempt to formulate such a survey tool. The study was conducted in order to determine AIDS-related knowledge, attitudes, and practices; and to test an instrument that would measure these variables.

Knowledge items included knowledge about symptoms, transmission, prevention, and community resources. Attitude items included attitude toward sexuality, drug use, and fear of HIV disease. Practice items included current sexual and drug practices. Responses were limited to "yes" and "no". The instrument was administered in English for Blacks and Spanish for Latinas.

In this study, Black women had higher incomes and educational levels than Latinas, were more often born in the United States, and were usually protestant. Latinas were more likely to be born in Mexico or Central America and were usually Catholic. Black women were less often married than Latinas. Black women were more knowledgeable about AIDS and their attitudes were more positive and less fatalistic than Latinas'. Sexual and drug use practices did not differ between the two groups.

The dimensions of the questionnaire were measured using exploratory factor analysis of a knowledge factor, an attitude factor, and a practices factor. Interestingly, when negative attitudes about sexuality, drug use, and fear of the disease were related to practice factors, Latinas were more likely to practice safe sex than were Blacks. Negative attitudes about AIDS included items such as "uncomfortable

talking about AIDS" and "take my child from school with child with AIDS". Practice items included "self or partner uses condoms" and "self or partner has sex with others". No explanation or speculation was given as to why Latinas may practice safe sex more than their Black counterparts (Flaskerud & Nyamathi, 1989).

Flaskerud and Nyamathi's study (1989) also revealed that more knowledge of AIDS was significantly related to being married. This supports previously cited literature that describes the Latina as learning about sexual issues from her husband.

They also found that negative attitudes about AIDS were associated with fewer years of education. This supports Dawson and Hardy's (1989) findings that respondents with more education had more knowledge about AIDS and fewer misconceptions about HIV transmission.

Flaskerud and Nyamathi's study (1989) also revealed that many subjects chose not to respond to many of the items. It was decided to use "don't know" as a third category in order to determine if non-responsiveness was due to lack of knowledge. It was also speculated that illiteracy may be another explanation of the non-response and plans were made to offer assistance in reading with future surveys.

The main point of Flaskerud and Nyamathi's research (1989), however, is that separate, culturally relevant education and prevention programs are needed for each of these groups. They recommended that such programs be based on an understanding of cultural AIDS-related beliefs and practices of each group.

Following this study, Nyamathi and Vasquez (1989) used focus group discussion to assess the concerns and stresses experienced by Latinas relative to AIDS. They also assessed coping responses, perceived feelings of self-esteem, locus of control, and emotional distress experienced by these women. The sample for this study included 43 Latinas. Of these participants, some were homeless; some were IVDUs or sexual partners of IVDUs; some were homeless; some had had a sexually

transmitted disease other than AIDS; and a few were prostitutes. These participants were not typical of the average Latina client.

Focus group interviews are a qualitative approach that creates an environment conducive to the expression of different points of view within a group setting. Content analysis of the discussions gave the women's own views of their world (Nyamathi & Vasquez, 1989).

The interviews revealed that regardless of their life experiences, caring for family, especially children, was the primary concern for these Latinas. They focused on overcoming threats to their role as provider for their children. Their fear of AIDS was not because they feared dying themselves, but because it would mean that their children would have to be cared for by someone else. These findings support the concept of Latino familism and demonstrate that the family is an important source of support, security, and strength for the Latina (Nyamathi & Vasquez, 1989).

Nyamathi and Vasquez (1989) stated the obvious when they noted that "providing AIDS education to a population struggling for survival on a daily basis is anything but ludicrous" (p. 312). They recognized that nurses are in an ideal position to help these women; not only with AIDS education, but in providing referrals that will help them obtain food, shelter, job training, and financial assistance. Help with the every day struggles will open the door for implementing AIDS education programs.

In 1990, Flaskerud and Nyamathi reported studying the effects of an AIDS education program on knowledge, attitudes, and practices of low income Black and Latina women. The study used a pretest-posttest nonequivalent control group design. Their sample was naturally assembled by participation in a WIC program (a food supplement program). Experimental group subjects (506) and control group subjects (206) were included. Within the experimental group, 250 were Latina and 256 were Black. The control group included 101 Latinas and 205 Black women. Of

the experimental group, 201 Latinas and 205 Black women or 80.2% participated in the retest given 2-3 months later.

Subjects who consented were given a five minute pretest then attended a 12 minute slide-tape educational program on HIV/AIDS. The program was presented in either English or Spanish, depending on the language of the group attending. After the program, subjects were given a five minute posttest. The instrument used for testing was developed via the pilot conducted by Flaskerud and Nyamathi (1989) reported earlier in this Chapter. It included sociodemographic data and it assessed AIDS related attitudes, knowledge, and practices. The posttest included the same items as the pretest, but the order had been changed and the demographic items had been deleted. In addition, the posttest included new items that had been added to elicit the subjects' planned changes in practice. The retest again asked the original items of the pretest but changed the order and asked the subjects to report any actual changes in behaviors (Flaskerud & Nyamathi, 1990).

To analyze the data, a single score was calculated for each of the five sets of items on the questionnaire. Differences between experimental and control groups and between ethnic/racial groups on the pretest-posttest scores on each of the five sets of items were examined using a two-way repeated measures ANOVA. Results of the analysis indicated that Black women in both the experimental and control groups had more knowledge about HIV/AIDS than did Latinas. Both racial groups improved in knowledge on the posttest in the experimental group with Latinas showing greater improvement than Blacks. There were also differences in pretest-posttest scores on the attitude items for the experimental group versus the control group but not for racial groups (Flaskerud & Nyamathi, 1990).

Analysis related to practice items indicated that Latinas reported more planned change in behavior at the time of the posttest than did Black women. Interestingly, only 5% of Black and 5% of Latinas indicated drug use or sexual

practices that were considered risk behaviors for HIV/AIDS (Flaskerud & Nyamathi, 1990).

Retest occurred 2-3 months later and the results were not significantly different from the posttests. Improvements in knowledge for both Black women and Latinas, however, were retained. Attitudes remained the same for the experimental group but differences between racial groups were significant. Black women had more positive attitudes than Latinas with Latinas actually exhibiting a decrease in the positive attitudes they had on posttest. For practice items on the retest, mean scores demonstrated that Latinas changed risk behaviors more often than did Black women. However, over-all changes in behavior were not statistically significant (Flaskerud & Nyamathi, 1990).

The fact that this experiment and the AIDS education program were conducted in an established community agency (WIC) and fit into the agency's agenda for education increased outreach to many low income Black and Latina women who are considered at risk for HIV/AIDS. There are few such programs in existence (Flaskerud & Nyamathi, 1990).

Flaskerud and Nyamathi (1990) list four limitations to their study: (a) lack of random assignment of subjects, (b) single geographic setting, (c) subjects may have experienced other programs or events during the 2-3 month interval before retest that affected their responses, and (d) effects of testing may have influenced posttest results. The authors also noted that their program lacked any personal contact with the subjects or follow-up. Recommendations, like those of the pilot study (Flaskerud & Nyamathi, 1989), included separate programs for Black women and Latinas because of the differing levels of education, attitudes, knowledge, and language (Flaskerud & Nyamathi, 1990).

In conclusion, research among Latinos concerning their perceptions of HIV disease and its prevention are few in number. In general, surveys have revealed

that Latinos as a group have little knowledge of the disease and its transmission but they are willing to submit to seroprevalence testing. Latinas have more negative attitudes about HIV disease than Black females but are more motivated to practice safe sex. Latinas, even those who are poor, IVDUs, or prostitutes, value their children and see AIDS as a threat to their ability to provide for their children. Lastly, prevention programs would be most beneficial for Latinos at risk if they are conducted in Spanish and in a culturally sensitive manner.

Summary

This chapter has presented a review of literature concerning Latinas and AIDS. Latinas are at risk for contracting HIV disease because they are poor, uneducated, and more concerned with family than themselves. Consideration of their cultural health beliefs and perceptions of AIDS should be the basis of AIDS education and prevention programs established to meet their needs. Chapter III will describe the methodology used and the participants included in this study conducted to answer the question, "How do Latinas come to know about HIV/AIDS and HIV/AIDS prevention within the context of their family and the Latino culture?"

CHAPTER 3

Methodology

The purpose of this chapter is to describe the method used and participants involved in this study. The question guiding the study was "How do Latinas come to know about HIV/AIDS and HIV/AIDS prevention within the context of their family and culture?" To gain the answer to this questions, Latinas were asked to describe how they came to know about menarche, sex, relations with men, sexually transmitted disease, AIDS, and AIDS prevention. Grounded theory was selected as the method to answer the research question because it offers explanations rather than just descriptions. Nursing practice needs explanations in order to grasp the reality experienced by Latinas within their culture (Stern & Pyles, 1985).

Choice and Justification

Grounded theory is a qualitative methodological approach that is used to develop theory to explain social interactions (Chenitz & Swanson, 1986; Glaser & Strauss, 1967). It is an appropriate approach when the aim of the researcher is to explain social interactions of another culture because the theory or explanation is "grounded" or arises from the data obtained directly from persons of that other culture (Stern, Allen, & Moxley, 1982; Stern, 1985).

Grounded theory relies on information from within the culture under study. This is called an emic perspective for research. This "insider's view" helps to explain social phenomena when little is known, when present knowledge may be biased, or in situations in which the culture under study is different from that of the researcher (Field & Morse, 1985; Leininger, 1985). All of these conditions existed for this study.

Another advantage of grounded theory is that the study can be conducted in the Latinas' own language and within the context of their lives. This approach gave meaning that could have been lost if other, more objective methods had been used. For example, surveys conducted among Latinos have usually been direct translations of survey tools used among Anglos. This direct translation loses meaning for Latinos whose language and cultural communication patterns differ (Berkanovic, 1980). This was more graphically demonstrated by Peterson and Marin (1988) who interviewed recipients of printed pamphlets about AIDS and found that Hispanic males did not know the meaning of Spanish equivalents of the English terms for anal or oral sexual relations used in these pamphlets.

Similarly, much of the research that has been done using survey tools or instruments to measure psychological phenomena with the Likert format have not yielded appropriate results when given to Latinos. Flaskerud (1988a) reported that Central American refugees who were asked to respond to a questionnaire using the Likert format for responses repeatedly chose to answer si or no. They were unable to make a choice among the four levels offered by the scale even after repeated instructions and explanations. This was true even when the Latino respondents were well educated.

Research among Latinas using questionnaires that are based on theories constructed within the Anglo culture may lead to a "superficial fit between theory and reality" (Hutchinson, 1986, p. 113). Grounded theory uses social patterns and everyday behavior to generate theory. Therefore, it is more relevant to the population studied. It is through understanding more about the Latina's reality that nurses may become more culturally sensitive and better equipped to give care that is acceptable to the Latino community.

Setting and Entree

The setting for the individual interviews conducted during the initial part of this study was a community clinic in San Diego County where many Latinos seek medical care. The clinic is supported by county, state and federal funds and offers clients less expensive medical care than can be found in the private sector.

Specific services offered by the clinic include family planning, prenatal care, well baby clinic, and sickness care for all age groups. Counseling and testing are available for those who are concerned that they may have HIV infection. Treatment for persons with AIDS is available at a satellite clinic that is a few blocks away from the main clinic.

Entree into this clinic was facilitated by the years that the researcher had worked there as a nurse practitioner. The staff and many of the patients know the researcher and have come to trust her. In addition, the Latina interviewer selected to conduct interviews in Spanish had lived in this area all her life and had worked in this clinic. She is generally well known and trusted, as well.

The Executive Director of the community clinic was approached and gave written permission (see Appendix A) for the research to be conducted at the clinic. She encouraged this investigator to request assistance should it be needed and to use clinic resources such as AIDS classes and counseling.

Entree was facilitated into the focus group discussion through the efforts of the first Latina participant in the study. She introduced this investigator to a Latina director in charge of language and crafts classes for Latinas and other women at a San Diego community center. The director convened the five member focus group and attended the one-hour session. In addition, she offered valuable comments and insights for this research.

Procedure

Data for this study were gathered from December, 1990 through May, 1991. Sixteen individual interviews and a five member focus group discussion were conducted, translated into English if obtained in Spanish, transcribed verbatim, and analyzed using the constant comparative method. The specific research strategies described below were designed to protect the rights of the Latina participants and to enhance the credibility of the study.

The Latina Interviewer

The Latina interviewer was the chief informant as well as the main interpreter and translator. The focus group discussion and all but four of the individual interviews were conducted in Spanish by the Latina interviewer. As a registered nurse, the Latina interviewer has extensive background in interviewing and translation, therefore, little training was required. At the time of the interviews she was also a research assistant and translator for a major government-funded project with care givers and clients who have Alzheimer's disease.

The Latina interviewer added richness and depth to the data. She was raised in the San Diego County community where the study was conducted and had worked as a registered nurse within the primary setting. Latinas were able to relate to the interviewer readily and shared relevant and, sometimes, very private information. DeSantis (1990) pointed out that the use of such a trained interviewer provides a broader perspective and understanding of the community than could be accomplished by an Anglo researcher with limited Spanish language abilities.

Participants

Women who were identified as Latinas by their use of Spanish, Spanish surnames, or by designation on their charts as Hispanics were approached to participate in the study. Those who self-identified as Latinas, who were not pregnant, who were between the ages of 18 and 34, and who agreed to participate were

interviewed. The 18 to 34 age group was selected because most AIDS cases among women occur during this age span (Centers for Disease Control, 1990).

Women selected for individual interviews presented at the clinic for health maintenance or illness care for themselves, their children, or another family member. They were told of the research and asked to be interviewed while waiting for pharmacy services or a ride home. Those that appeared too ill or who had very sick children were not approached.

Many of the women interviewed individually were shy and reluctant to discuss HIV/AIDS and sexual issues. After they were given a chance to talk freely, however, they became less reticent but still seemed reserved about some of the information. Some were living in isolation, away from family and friends because of their mates' work. Others were living with either their family of origin or their mates' family.

Individual interviews and data analysis proceeded in tandem until core variables were identified from within the data (Glaser, 1978; Hutchinson, 1986). To further clarify and verify the data, a focus group was convened. Focus groups are planned discussion groups brought together to obtain perceptions on a subject of mutual interest. Within the group, participants influence each other by responding to each member's ideas and comments. It is recommended that the groups not exceed 8-10 participants and that each session be guided by a skilled interviewer (Krueger, 1988; Nyamathi, Shuler, & Porche, 1990; Nyamathi & Vasquez, 1989). The Latina interviewer already identified conducted the focus group discussion.

The focus group proved to be very successful. The women participated more in the discussion and offered more information and advice to each other and to the interviewer than those Latinas interviewed individually. Only one of the five women in the focus group had to be encouraged to voice her opinions. Her

reluctance to speak may have been related to her age (18), as she was the youngest member of the group.

The women who participated in this study were diverse in background but, at the same time, had many of the characteristics of the Mexican and Mexican-American women described in Chapter II. For instance, they were poor, most were unemployed, they came from large families, and most were married and had children.

Of the 21 women who participated, 17 were from Mexico, two were born in California, one was from Guatemala, and one from El Salvador. All but two had come from large families. Twelve had 5 or more siblings. Seventeen Latinas were married, three were living with a mate, and one was single. The average age was 26 with a range of 18-34. All but one had children. The average number of children per participant was 2.2 with a range of 0-6. Most were unemployed; however, one was a custodian, one a cashier, and two were medical assistants. The time each had lived in the United States varied from 5 months to 26 years. Seven Latinas had been in the United States for less than three years. Eight had been tested for HIV; one in Mexico. Only one participant knew someone with AIDS. One other had had a patient who had AIDS. Some of the respondents had seen people with AIDS on television. Table 1 illustrates the demographic data obtained from the Latinas who participated in this study.

Data Collection

The Interview

Individual interviews were initially guided by a number of preliminary questions that had been generated from the review of the literature regarding cultural health beliefs, perceptions about AIDS among Latinas, and the research discussed in Chapter II. These preliminary questions are listed both in Spanish and English in Appendix B.

TABLE 1
Demographic Data

Latina & Age	Marital Status	Birth Place	Number Children	Years Education	Years in U.S.	AIDS Tested	Knows PWA	Siblings
1-30	M	Me	1	11	15	no	no	3
2-30	M	Me	6	3	2	no	no	9
3-20	M	CA	1	12+	20	no	no	3
4-30	LW	Me	2	6	9	no	no	6
5-26	M	Me	3	-	3	yes	no	0
6-22	M	Me	3	8	2	no	no	3
7-29	M	Me	2	-	2	yes	no	11
8-30	M	Me	3	8	5mo.	no	no	10
9-23	M	Me	1	5	7	no	no	5
10-20	S	Me	0	12+	14	no	no	6
11-26	M	CA	2	12	26	yes	no	4
12-28	M	ES	2	13+	7	yes	patient	6
13-19	M	Me	2	9	2	no	no	5
14-32	LW	Me	3	6	5	no	no	7
15-19	M	Me	1	9	1	no	no	12
16-24	M	Me	2	13	-	yes	yes	9
17-18	LW	Me	1	3	5	no	no	4
18-34	M	Me	3	6	6	yes	no	2
19-28	M	Me	2	6	7	yes	no	3
20-23	M	Me	2	12	6	yes	no	3
21-34	M	Gu	5	0	9	no	no	13

M = married
Me = Mexico

S= single
CA = California

LW = living with
ES = El Salvador

PWA = person with AIDS
Gu = Guatemala

After the initial interviews, changes were made for subsequent interviews based on emerging patterns in the data (Chenitz & Swanson, 1986; Glaser, 1978; Glaser & Strauss; 1967). Stern and Pyles (1985) noted that as hypotheses are formed from the initial interviews, changes can be made to both clarify information and to zero in on central themes.

Analysis of the data obtained from the 16 individual interviews resulted in specific questions for the focus group discussion. Those questions are listed in English and Spanish in Appendix C. In addition, demographic data were obtained from the focus group participants with a written questionnaire in order to streamline the discussion. This questionnaire appears in Appendix D in both English and Spanish.

The participants were encouraged to answer freely and ask questions if necessary. Every effort was made to ensure that each Latina had an opportunity to express her opinions related to the questions asked (Chenitz & Swanson, 1986; Schatzman & Strauss, 1973). Because both this investigator and the informant/interviewer were registered nurses, participants did ask questions requiring nursing intervention in the form of teaching about AIDS and other sexually transmitted diseases. Each participant was given requested information after the interview was completed. The community clinic also provided on-going AIDS education both in English and Spanish.

Audiotape Translation and Transcription

All interviews and focus group sessions were audiotaped. Audiotaping eliminated need for note taking and allowed for a continuous flow of ideas between the interviewer and the Latina. It also enabled the researcher to have access to all the interview data (Stern & Pyles, 1985).

After the interviews, the Latina interviewer translated Spanish interviews into English on a second tape. Verbatim transcriptions of the English translation

were completed by this investigator. Frequent conferences with the Latina interviewer about her perceptions of the information obtained from the participants were used to verify the researcher's impressions of the data.

Another Latina interpreter was asked to listen to six of the taped Spanish individual interviews and to translate them into English. This procedure seemed necessary to verify translation and lend credibility to the study. Since all the second translations of the first seven interviews closely duplicated the Latina interviewer's original translations, the investigator consulted a nurse researcher experienced in grounded theory method about whether the second translations were necessary. It was decided that further double translation of the interviews from Spanish to English was not needed.

Protection of Latina Participants

This study was conducted according to the University of San Diego and federal guidelines for the protection of human subjects (see Appendix E for Approval and Revision of Approved Protocol from the Committee on the Protection of Human Subjects). Each participant was told by the researcher or the Latina interviewer about the study, the possibility of some embarrassing questions concerning sex and AIDS, and that it was expected that the interview would last about one hour.

Those agreeing to participate at the time of the request were asked to read and sign the "Consent to Act as a Research Participant" that appears in English and Spanish in Appendix F. Several of the participants could not read so the consent was read to them by the interpreter. In addition, obtaining demographic data using the written questionnaire required that the Latina interviewer read the questionnaire to three of the five women who participated in the focus group.

Potential Risks

There were no physical risks for participants. However, there was the potential for psychological risks related to discussions of sex, sexual activity, and issues involving the transmission of HIV. Each participant was assured that she could withdraw from the interview at any time without fear of penalty. Most participated without apparent distress. One participant, however, began crying during the interview. This interview was cut short by this investigator because the participant was unduly uncomfortable with the discussion. Provisions had been made to provide a referral for counseling at the expense of the researcher, to Lifeline, a community counseling agency. The participant refused this service, however. Subsequent contact with this Latina has demonstrated that she has resolved the problem that precipitated the crying episode and has no evident lingering effects.

Participation in this study did allow the Latinas a non-judgemental arena for the discussion of sensitive sexual issues. In being able to discuss sexuality and AIDS, they were able to learn more about these issues. In addition, when it was discovered during interviews that the Latinas lacked an understanding of recommended practices for the prevention of HIV infection, they were given some education or information and referred to the trained AIDS health educator available in the clinic. The AIDS health educator is bilingual and experienced in discussing the prevention of AIDS with Latinas. Discussion may also have given the participants more confidence in communicating with their male partners concerning sexual issues.

Confidentiality

Each interview was coded using a number and the date of the interview. Each translation of an interview was coded using the same number and date and the word "English". No names or initials identifying the participant appear anywhere. The participants identity was protected using this method.

All audiotapes, transcripts, and computer disks used for data analysis and storage were kept in a locked box. No one has access to the box but the researcher.

Data Analysis

The data were analyzed using the constant comparative method to generate theory (Glaser & Strauss, 1967; Hutchinson, 1986). Patterns and incidents were identified, coded, and compared with other patterns and incidents as they emerged from the interview data. Categories of patterns were delineated and constructs identified. By constant comparative method, the categories and constructs were further scrutinized according to structure, temporality, cause, context, dimensions, consequences, and their relationships to other categories. To do this, memos (notes and ideas written by the researcher during the process), sorting, and sampling were done until saturation or a level of completeness of data was reached. This point was reached when all the data fit into established categories and the researcher achieved a "sense of closure" (Glaser & Strauss, 1967; Hutchinson, 1986, p. 125). A substantive theory emerged that explained "How Latinas come to know about sexual issues, AIDS, and AIDS prevention within the context of their family and culture".

Enhancing Credibility

The use of the focus group to corroborate the findings of the individual interviews enhanced the credibility of this study. Their comments were further substantiated by their support of each other during the discussion. When one of the Latinas in the focus group would respond, the others would elaborate or agree. In some cases, the communication between the group members seemed to help educate those less familiar with the issues related to HIV/AIDS.

In order to further enhance credibility of the data obtained, the discoveries and the substantive theory generated were scrutinized by a Latina nurse practitioner and educator who is currently enrolled in a doctoral program in San Francisco. She

and two of her comadres read and supplied positive comments concerning the authenticity of the data.

Summary

This grounded theory approach has been designed to answer the question, "How do Latinas come to know about AIDS and AIDS prevention within the context of their family and culture?" This chapter has detailed the method used to obtain the culturally rich data needed to answer this question. Central to this research was the protection of the Latinas who consented to participate. Strategies were included that minimized their risks, provided for informed consent, and ensured confidentiality.

CHAPTER 4

Findings

The findings derived from the interview of sixteen individual Latinas and a focus group of five Latinas are presented in this chapter. The interviews were conducted to answer the question "How do Latinas come to know about AIDS and AIDS prevention within the context of their family and culture?" The chapter consists of two sections. The first section is used to describe the salient dimensions of knowing about AIDS and to demonstrate how the process derived is grounded in the data obtained. An integrative diagram depicting the findings and a discussion of its components appears in the second section. The integrative diagram provides an understanding of the impact of certain familial and cultural influences on how Latinas learn about sexual issues, AIDS, and AIDS prevention.

Salient Dimensions of Knowing About AIDS

The basic process discovered in this study was knowing about AIDS. Such knowledge is more than merely learning facts about the disease. Knowing about AIDS encompasses learning about what it means to be female and how to behave as a woman within the Latino world. The emergent framework that explains the basic social process of knowing about AIDS consists of three antecedent conditions: (a) growing up in silence, (b) relating to men, and (c) gossiping and television. Consequences of knowing about AIDS include pretending, teaching, preventing, and relying. The remainder of this section will be used to describe how the basic social process, conditions, and consequences were "grounded" in the data.

Growing Up in Silence

Growing up in silence depicts how many of the respondents in this study described the atmosphere in which they learned about menarche, sexual relations, having babies, and sexually transmitted disease. The Latinas' responses revealed much about how they were socialized to be silent or to refrain from discussing all of these topics.

What My Mother Taught Me

What the respondents remembered about what their mothers had taught them gave the investigator the impression that subjects such as menarche, sexual relations, childbirth, and sexually transmitted disease were not subjects to be discussed with or around children. Some of the Latinas interviewed described their mothers as "antiquated" and not having the education to teach them what they felt they needed to know about these topics.

Most of the mothers of the respondents interviewed still lived in rural Mexico or Central America. According to the literature, Latinas in these countries have had little opportunity for schooling beyond the elementary levels and most are raised as Catholics (see also Rider, 1989 & Mirande, 1985). They are usually present-oriented and do not discuss even natural events until they occur. Mothers of the respondents, then, probably followed the traditions to which they had been socialized to raise their daughters.

When asked, "Who told you about menstruation?", eleven of the 21 Latinas said that they did not learn from their mothers. One Latina said,

"My mom told me, but I asked her first. I was real scared because I didn't know."

Another Latina explained more fully when she said,

"She (my mother) didn't tell me nothing. Because they (parents or mom) were born down in Mexico on

one of the ranches where no one tells nobody about nothing because when you get it you tell your parents and then they will tell you."

She went on to describe her own experience.

"I got scared when I had my menstrual period. I was real scared because...I didn't know what it was...the third day of my menstrual, I went 'well, this isn't stopping, I had better go and ask her.' And she told me, 'yeh, I didn't think you were going to get it for...a couple of more years.'"

One of the women in the focus group told about her first period.

"I was twelve years old and I was in a party and I was wearing a white skirt when I started to have my period. I got real scared...I started to cry."

Another, perhaps more poignant, recollection was,

"My mom started laughing when I started telling her (about my period) because I was so scared. Then she would tell me that's when a girl becomes a woman."

This first experience with an issue that involves the reproductive system sets the stage for how the respondents in this study learned about sexual issues and diseases such as AIDS. Silence and embarrassment about bodily functions are learned behaviors and girls who are raised in this manner may be forever reluctant to discuss such issues.

Many of the women interviewed had learned of menarche at school or from an older sister. One respondent said,

"...cause my parents, they never told me anything about this. I had to learn it all by myself in school. They never taught me anything about sex or anything."

Another Latina was the oldest of 7 children and she described how she had been teaching her younger sisters, even though her mother did not want her to do so. She risked angering her mother in order to prevent her sisters from experiencing the problems that she had had.

When asked about where they learned about having babies, several Latinas said, "I guess naturally"; that is, by living through the experience. All but one of the women interviewed had children. A few had had prenatal classes here in the United States. Only one said that her mother had helped her during childbirth, including staying with her through labor. Considering the traditions of mothers being with and helping their daughters during childbirth, this was an unexpected finding.

It was anticipated, however, that the respondents would not acknowledge learning of sexual relations from their mothers. This was based, in part, on interview segments that had revealed that mothers were not talking to their daughters about menarche. Respondents indicated that nothing having to do with sexual relations was communicated to them as little girls.

"You couldn't touch those kind of topics. We were all kept isolated from those kind of topics."

Two Latinas related what had happened when they had overheard adults talking about having babies or sex.

"My mother never, never told us about those things. When my mom was having a conversation with someone about babies, she would tell me to leave; that the conversation was only for grown-ups and we were not

allowed to hear...we shouldn't be listening to what adult persons were talking about."

"My father told me that things that have to do with adults shouldn't be overheard or questions asked."

One Latina in the focus group related:

"In my house, we had a dog that was going into heat and was after another dog. And, we as kids would stop to watch them. And my father came over and shot the dog. He said that we shouldn't watch that."

The same silence and secrecy shrouded the topic of disease, especially sexually transmitted disease.

"I have never heard these things in my family."

"She (my mother) is not accustomed to talking to me about relations or illness. She tries to keep us from getting those worries."

Most of the respondents related that they did not learn about sexual relations from their mothers. Two said it this way.

"...in those days, they (mom or parents) didn't want us to know anything. In Mexico, that is how it is. Mothers don't want us to know anything about that."

"No, my mother never spoke to me about that. They (parents or mom) probably thought that daughters did not have to know those kinds of things..."

This statement supported literature that indicated that Latinas are not told about sex because their husbands are expected to know and to teach their wives (see

Carrier, 1985 & Riding, 1989). These data also corroborated characterizations of Latinas indicated by Pavich (1986) who noted that Latinas acknowledge that their mothers rarely discussed such sexual issues as menarche, sanitary napkins, information about dating, birth control, sexually transmitted disease, or information about boys' sexual development. Dawson and Hardy (1989) and Singer and associates (1990) also noted that Latino children, especially Mexican Americans, receive less sexual and HIV/AIDS information from their parents than do Anglo children.

Further analysis of this point seems to also indicate a present-orientation among the respondents. According to DeSantis and Thomas (1981), people who live in rural, agrarian cultures do not plan for the future. Therefore, children are not taught about menarche, sexual relations, or childbirth that has not as yet occurred. Whatever the reason for not teaching little girls about these factors, the silence surrounding reproduction and sex reinforced the Latina respondents' reluctance to discuss such issues.

Many times what these Latinas remembered their mothers telling them about men was erroneous or depicted men as "sly" or "after only one thing". One participant said that when she had started her periods and her mother knew about it, her mother told her that if she sat beside a man she could become pregnant. For a long time she was afraid to sit next to any man. Another example was:

"...she (my mother) was always advising...because men can be dangerous if you don't know how to defend yourself...I was raised with this fear. (My aunt)... she was always saying, 'be careful because some man... can just do something bad to you and you can get pregnant and then you really messed up your life. So I was scared and I didn't have a boyfriend until I was 16 or 17."

Another respondent said,

"...She (mother) would tell me that men are very sly,
that there is only one thing they are going to ask
for..."

In spite of these warnings, mothers were very interested in their daughters getting married.

"She always said to do whatever I could to get
married. But, she did tell me that the men only
want to use the woman."

Such fear of men and ambiguity about sexual relations would seem to enforce silence and lack of communication from women. A silence that would make communication about sex with a man very difficult. One Latina summed up the parental attitudes of the previous generation:

"Our parents were really closed to reality and
they let us discover things on our own. They did
not talk to us very well, as they should of."

In spite of the fact that the Latinas perceived their mothers as being very secretive about sexual matters, five of them felt that of all the people in the world, their mom (parents) was the one most likely to care for them if they ever contracted HIV disease. One Latina said,

"My mom is just the main person in my life...I
would probably move in with her."

Another related that

"I would go to my family, with my mom..."

Another was tearful when she told this investigator that if she contracted HIV her relationship with her mother would not change. She said,

"I don't think it would change. It would be

making us close."

A couple of participants felt that their mother would not understand them during the first days of a disease like AIDS, "...and for that I would have to go through bitter moments.." By this the respondents may have meant that their mothers, who had tried to tell them what was right and what was wrong, would not understand how their child could have done such things as would have caused them to become infected with HIV disease.

The same Latinas, however, said that later their parents would come around to helping them. This corresponded to the findings conveyed via the video tape titled, The Forgotten People: Latinas with AIDS. This film documented how mothers (families) of Latinas with AIDS at first rejected them but after a while (sometimes as long as a year) the mother would again open her home to her daughter.

Many of the respondents felt that their mother (parents) were supportive regardless of their children's troubles.

"They are really the only ones that always understand us. Other people don't understand us like they do."

Another respondent said it this way,

"I know that no matter what we (me, my brothers or sisters) do, she (mom) still loves us."

The literature concerning how children are socialized and disciplined within the Latino culture indicated that the mother was the parent most involved in teaching children right from wrong and how to behave (see Melville, 1980 & Mirande, 1985). The mother is also described as very close to her children, nurturing, and always there for them. For many of these respondents, their mothers were perceived as the one person that they could turn to if they contracted a serious

illness like HIV disease. Their mothers, however, were also perceived as very secretive about any topics related to sex or disease. These types of responses raised the investigator's curiosity about how the Latinas who had learned from their mothers to be silent planned to teach their own children, daughters and sons, about sex and AIDS. Teaching, or helping others to prevent problems, is often a strong motivation for learning more about a disease like AIDS. Teaching children can also be perceived as a consequence of knowing about AIDS.

Teaching My Children

Growing up in silence had had a profound effect on how the participants of this study planned to teach their own children about sexual issues. Nine women said they wanted to tell their children everything so that they would learn at an early age. They said,

"...I am going to talk to my children...I am not keeping them with their eyes blindfolded like I was..."

"I would tell her not to have sexual relations before she gets married. If we did it, it was because we were ignorant. Because our parents were really closed to reality and they let us discover things on our own."

But what are they going to teach their children? Most often the response was that they were going to tell the children about sex and sexually transmitted diseases. They seemed to think that since their's was the voice of authority, that the children would learn from their lectures and advice. For example,

"I will tell her to always use condoms."

"...I would talk to her about the care that she needs to take with men. The violations that they do and all that."

"...that it (AIDS) is an infection that is very dangerous and it causes many bad things and that she has to take care of herself."

These one-way conversations also conveyed the same messages that the respondents had heard from their own mothers; that men will violate them in some way and they should be careful. Their responses indicated that they are going to teach their children in the same way they were taught.

In addition, two respondents seemed to convey that sex and extra-marital affairs were expected of males. One told the interviewer,

"...with regard to their wives (her sons)...they should respect their wives. And they should be very careful and not go with just anybody. They should be with people they are sure won't contaminate them if the relationship is outside the marriage..."

The other said she would tell her son,

"...if you are going to have sex...and you are not really serious...just use a condom..."

Two ideas are projected here. One, that extra-marital affairs and condom use when the man is not serious about a woman are expected of men. Two, that condom use with women they do not plan to marry will prevent sexually transmitted disease, including HIV/AIDS. More about the issue of extra-marital sex and condom use is discussed in the next section.

Two women wanted to teach their children, but their own experiences in growing up in silence were very evident when they talked about what they wanted to teach. They could not articulate the words for sex or disease.

"...I am going to tell them...that there is this and that they have to watch out for and this other.

When you are doing this and that, this is what is going to happen to you and this other is going to happen to you." The other example was, "I am going to tell her, 'you are going to have a boyfriend...(and) he is going to do this and that, so you had better be careful."

Among these respondents, "doing this and that" and going "here and there" seemed to be accepted terms for having sex and having sex outside of marriage. But will the children know what their mother is trying to tell them?

One Latina couldn't even use these terms with the interviewer. The following is an excerpt from her interview:

Question: What are one or two things you want her (your daughter) to know about AIDS?

"Well, you know, how it is transmitted...what she can do to protect herself in case she wants to... (gestures but does not speak)

Question: When she finds a boyfriend she wants?

"uh, huh"

Question: And what about a son? What do you want to tell your son?

"Uh, probably the same thing...you know, don't... (pause). You know, men are a little bit different, but don't just try to go with the girls just because they...(laughs)."

Of the twenty-one women interviewed, only three thought that their children should be encouraged to talk to them about sexual issues. These Latinas

knew intuitively that children need to talk and to have someone to talk to in order for them to begin to understand ideas, ethics, and growing up. One Latina stated:

"...I want her (my daughter) to always tell me what she is doing and give her a lot of understanding. And to try to have a lot of trust in her parents so that she can talk to us. Because if we don't give her that trust then how are the children supposed to talk to us about their problems or anything?"

Similarly, another respondent said:

"...I would tell her to protect herself (and) that she talk to me...I would tell her to have confidence in (me)."

Another Latina was very astute when she pointed out that,

"(in order to teach)...we have to set an example first. Because if we can't give them an example, I don't think we can give them advice."

Like their mothers before them, the Latinas interviewed also wanted their daughters to marry and to abstain from sex until marriage. For instance, one respondent said that she would tell her daughter,

"...she should have only one boyfriend and if she wants to get together with him, she should get married, even if she is young. So that she would not be going around having a lot of relations."

In fact, marriage seemed to be a method for preventing the spread of HIV and sexual relations outside of marriage was perceived as the greatest threat to all the Latinas interviewed. This point will be further discussed later.

Several of the Latinas expressed thankfulness that the schools were helping their children to know about menarche and other sexual issues. One said,

"Luckily, now they are doing a lot of classes at school over sex education."

Reliance on the school, which may or may not be giving the sex education needed, relieves the mother of embarrassing talks with her children. "Pretending" that the children are learning what they need to know about sex and HIV/AIDS is a consequence of growing up in silence and knowing about AIDS.

Regardless of what or how each Latina would teach her children, it is important to recognize that the women interviewed, like their mothers before them, were very attached to their children. The respondents conveyed that they had experienced being highly valued and loved by their mothers and now they as mothers valued and loved their children. To demonstrate how important their children were to the participants, excerpts from the interviews that asked how they thought their lives would change if they contracted HIV are presented.

Six of the participants said that they would leave the home so that the children would not be exposed to this deadly disease. Nine Latinas felt that they would continue to care for their children. One of the women of the focus group said:

"Our lives would be changed a lot. Principally, because we would have to think of the children."

Another respondent stated:

"I think I would keep on taking care of my children because they need me and before everything is them."

Another added,

"I would take care of them as long as Godpermitted me to ...because I cannot leave my children...they are my children."

Two Latinas interviewed would reach out to professionals for advice on how to care for their children if they contracted HIV disease,

"...I would be very careful but this I would need some sort of orientation from somebody who knows about it so that I can find out how..."

"I would have to consult people who knew about AIDS because I cannot leave my children...I would talk to professionals...people who...that know."

Another reflected what she had learned from her mother best when she said,

"Yes, (I would stay). I think that is the principal thing that a mother should do...or a father."

The participants in this study, then, were socialized into the adult world within the context of their family and culture. Growing up in silence and its consequences for the respondents' ability to communicate about sexual issues becomes more evident when the discussion turns to relating to men.

Relating To Men

Another condition for knowing about AIDS that emerged from the data obtained was relating to men. This terminology was used to denote relationships between Latinas and Latino males as they were perceived by the participants.

Socialization of Latinas and Latinos

Patterns for relating to men are a part of each Latinas socialization. These early lessons of conduct affect how the Latina comes to know about HIV/AIDS. which is a disease that can be transmitted via sexual relations. Data indicated that the respondents in this study perceived that the rules were different for boys. Boys in their families had more freedom and autonomy. The Latinas interviewed saw themselves as sheltered and protected. One Latina said,

"...so I was raised in that manner...all around me was that world...cause all the parents were really attached to their girls, you know, when we were invited to a party there had to be a mom or a dad with us..."

This same Latina related that her brothers did not have the same restrictions. Respondents indicated they were raised to be "good". To go out without escort was forbidden. To do so would make you "una mala mujer", a bad woman.

"And my mother always accustomed us (girls). She would say that the streets are for men and the homes are for women. That the street wasn't made for women. We stayed with those customs, that the women shouldn't be out in the street."

"Our parents thought that sex before marriage was a sin and a woman shouldn't have sex before marriage."

That the rules were different for boys was alluded to when one Latina interviewed stated that her brothers were under a lot of pressure from their male cousins and friends. She said,

"...guys always have more pressure than girls cause I think all the boys talk about is having sex (and they have not proven themselves until)...they go sleep with a girl and then they are happy."

These data seemed to support literature that described Latino males as being encouraged to seek sexual outlets early in life and to prove themselves as men. It also depicts the double standard that tradition has established for males and females. That is; the male has sexual freedom and is expected to have sex before marriage.

The female is forbidden by family and church to do so (see Carrier, 1985 & Riding, 1989). One Latina asked her husband,

"I asked him why they (men) insist that a woman
be a virgin and why not them?"

He would not answer.

Standards that encourage men to have many sexual encounters increases the risks for exposure to HIV/AIDS. At the same time, women are expected to be chaste and to refrain from questioning their mate's sexual past. By remaining silent, she increases her risks for contracting HIV/AIDS via sexual relations with a man who has had increased opportunity for exposure to the disease.

Marriage

According to the Latina interviewer who was born in Mexico, Mexican women (17 of the participants were born in Mexico) often marry because it is time and there is a man available, not for love. They speak of their mate as the father of their children but there may not be any love or affection in their relationship. This was reflected by responses to the question "What would you do if your husband had AIDS?" One Latina said,

"Well, I would not tell him that I was leaving him
because of that. He is the father of my children."

Another responded in a similar way:

Question: If your husband came down with AIDS, would
you support him?

"I would have to."

Three of the Latinas interviewed told of how they learned about sexual intercourse on their wedding night. They considered this to be "natural". One said,

"Well, I learned it, well, you know, natural."

Another reluctantly related how she had learned about sexual intercourse.

Question: Before your wedding you didn't get the talk about relations and those sorts of things?

"a little, but not, you know..."

Question: so you learned that "natural", huh?

"uh, huh"

Question: and he was your teacher?

"uh,huh"

The other respondent indicated that she had learned of sexual intercourse from her friends, her sisters, and her husband.

These findings indicated that the legacy of silence was extended into the marriage. It also verified literature (see Carrier, 1985; Riding, 1989) that depicts the new bride as chaste and naive and the groom as experienced enough in sexual matters to become her teacher.

Many of the respondents indicated that the sexual experience of their partners was not limited to pre-marital sex. They indicated that extra-marital sexual affairs were not unusual for the Latino male. One Latina in the focus group put it this way:

"...the men like to have their cathedrals and also many little parishes. It is very natural for a husband to have his wife and many other women on the side."

Others corroborated,

"...it is not acceptable, but it is expected."

"...men like to go here and there."

"...the Mexican male is very macho and believes that what he does is right and doesn't really see the danger in having a lot of women on the side...a lot of them are doing it."

These findings support literature that describe extra-marital affairs as a frequent occurrence among Latinos. He may have una casa grande (wife and family) and several casas chicas (mistresses) (Riding, 1989).

One participant took the opportunity to speak to the interviewer regarding her suspicions about her husband. She had been asked how she thought AIDS could be prevented. She said,

"...my husband does have the custom of going away at night and he would not come back until the next day... sometime...as long as two nights. And I told him he had better not bring any sicknesses home to me. Because I told him, I don't go anywhere and if I get something...he is the one that is out all the time. I told him he had better take precautions..."

When asked, "what precautions?", she replied,

"...I don't know but one day I found some condoms in his truck and I think that he probably uses these condoms when he has been out. But there is always the possibility that sometimes he uses them and sometimes he doesn't and I am afraid."

The interviewer tried to reassure her, "well, a condom is one of the best things that you can use...", but she said,

"...yes, but he says he doesn't like to use condoms."

What is so striking about this outburst is the lack of expression of concern that her husband might leave her for one of the other women and the lack of expression of sorrow or sense of loss that some would feel if they knew their husband was having sex with other women. Her chief concern, perhaps legitimately so, is that he may bring a disease such as AIDS home to her.

Conversely, another respondent knew of her husband's liaison but felt safe from disease. She seemed to accept that her husband was having affairs when she said,

"Yes, you can get AIDS from women who are around a lot of men but my husband told me that he always used condoms with the other women. Don't they say that if somebody has the AIDS virus the condom will keep them from getting it?"

One Latina thought that the other women were part of the reason married men had extramarital affairs. She said,

"I do know that men sometimes lie to the women, but the women don't really care. It makes it real hard on us because there are so many women that are willing to go after our men."

Blaming the other woman was also evident when the participants talked about infection with HIV or other sexually transmitted diseases that their husbands may expose them to:

"...if he has been...having sexual contacts with a lot of ladies or those ladies from the streets then I think he should take the test (HIV)."

"...if he has relations with other women and he comes to me then he is going to give it to me."

One Latina was very adamant that only the "other woman" could cause the spread of HIV.

Question: Can a husband give it to his wife?

"yes"

Question: How?

"Well, when he gets together with that woman that has it then he can get it, yes."

Question: Can the wife pass it to her husband?

"No"

Blaming the other woman is less dangerous than confronting one's husband. For most of the women interviewed, the husband was the "breadwinner" for her and her children. She had no other means of support.

When the respondents were asked if they had talked to their mates about the relationships the men had had before they married, seven Latinas said that their mates did tell them. A common (or similar) response to this inquiry was:

"Well, I have asked him but as you know they get very quiet and they don't want to tell you. They say they are clean about everything."

"...you know they keep everything in reserve. Well, for sure it is a divorce if you start asking those kind of questions."

Two of the women interviewed told the interviewer that they had never asked their mates about any previous relationships. This would seem to indicate that they were "pretending" that their husband had not "played around" before or after marriage or they were avoiding any confrontations with their mate.

When asked if their mates would use condoms, six said, "no". These respondents stated that the reason their mate would not use the condom was that "he didn't like it."

"...he said he would rather not even do it (have sex)"

One respondent revealed that using a condom would mean that the woman or man is "not real serious" or is not planning to marry and have children. When

the participant was asked how a woman should protect herself from AIDS she said,

"If she is going to have sex, by using the condom.

If she is not real serious with the guy, by using
the condom...and just be real careful with all the
guys."

Literature reviewed had depicted condom use among Latinos as being an indication that a man is not ready to marry and settle down (Worth & Rodriguez, 1987). None of the literature reviewed, however, had indicated that the use of the condom might indicate that the woman was not serious about a man. Rather, the literature conveyed that women who insist on condom use were considered unclean or prostitutes (Cochran, 1989; Mantell, Schinke, & Akabas, 1988; Marin, 1989).

One Latina indicated that she did not trust the condom for protection from HIV/AIDS. She said,

"I have always heard that condoms are not 100%
effective in the control of fertility...since
I know that condoms are not 100%, then there
would be the same kind of risk."

This respondent was dependent on her mate to tell her if he had become infected so that they could stop having relations. She believed that he would tell her if he were infected. Others thought that "men are not always honest" about their past. One said that couples who were planning to marry should "get the HIV test" to be sure that neither were infected rather than relying on the condom.

One woman perceived the condom as offering "one-way" protection. When asked how a woman might contract HIV disease she said,

"Well, I imagine that she can get it the same way
(having sex). Because a woman can't protect herself.
Only the man can protect himself."

Currently, there are no barrier methods readily available that protect women from AIDS. A woman is vulnerable and dependent on a man for protection via the condom. If she cannot, because of growing up in silence, negotiate "safe sex" she is powerless. If she negotiates for its use, she must do so without seeming "unclean". If he refuses to use the condom and she insists, she risks losing him to another woman who will not require that he use a condom (Frelberg, 1991a).

One Latina indicated that use of a condom was rejected by Latinos because of machismo,

"...Americans use condoms, and the Latino, no, that is an offense for them. They have a lot of machismo, they would never use a condom."

Two women who were asked about condom use responded that they had never asked their husband to use a condom. Conversely, ten Latinas said that they had or could ask their mates to use a condom and that their mates would. One Latina thought,

"We women tend to be afraid to ask them to do things to protect us...since no one tells the man anything then they think (they can go on as before)."

This participant indicates that the legacy of silence has caused many women to be reluctant to ask their mate to do things that protect them. She assumes that if there was better communication with the male, he would try to do all he could to protect his mate.

Seven of the women interviewed believed that their husband was their strongest ally. They told the interviewer that they would go to their husbands first if they were ever told that they had AIDS. It was the husband whom they felt would help them problem-solve and plan.

"...first and foremost, I would tell my husband.

And then he could take me to a clinic...I have a lot of confidence in him."

"...first I would talk to my husband and the two of us would try to find a solution to the problem."

Relating to men adds diverse perspectives to knowing about AIDS for each Latina in this study. Many ambiguities became evident from this data. Latinas don't trust men because they have been taught that men are "sly"; they want "only want one thing"; and that sometimes "men lie to the woman". They expect men to have mistresses but rely on men to "be clean" and not bring home any diseases. They are reluctant to ask men to use condoms because men "don't like them." They do not want to confront men about liaisons outside of marriage because their men might leave ("for sure its a divorce"). And through it all, "my husband" is perceived by many as their ally and confidant. He will help her problem-solve. Such ambiguities have a profound effect on what the respondents say about AIDS and AIDS prevention.

Another condition for knowing about AIDS that emerged from the data was how the respondents learned via gossiping and television. The discussion in the next section describes how gossiping and television contributed.

Gossiping and Television

Another intricate part of the basic social process of knowing about AIDS is gossiping and television. These modes of obtaining information were evident within the data from several Latinas. For these respondents, gossiping or the stories they were hearing from friends and relatives were real.

"They (my sisters) say things like 'look such and such person has it'...they say that so-in-so gave it to his wife. But I don't know what they are talking about..."

And,

"...girls that would get together and talk.

They would say to others, 'oh, you are going to catch AIDS!'"

And,

"Well, they tell me that it (AIDS) wasn't an illness that was very big. Others said that men who like to go with women and women who like to go with men would probably get it."

One focus group participant told this story,

"I heard that in Cancun, there was a man who had AIDS and he picked-up a girl and he didn't tell her that he had it and the morning after he had slept with her he left a little message on the mirror that said,... 'welcome to Club AIDS'. I heard this through an uncle of mine...So this man was doing it on purpose."

Another participant had heard her husband's family saying that,

"I heard that is an illness that men who go around with a lot of women get and bring it home and infect the wives...and the wives die in a short time."

These bits of gossip may tend to increase the fears of each wife who wonders where her husband was last night when he didn't come home. What if he did something that caused him to become infected with HIV? What if I catch HIV from my husband?

These data also indicate that informal teaching occurs among family members and friends. Inadvertently, they are teaching each other that monogamy

with an uninfected partner is the best prevention. There were two respondents who said they would teach adult family members about HIV/AIDS. One told the interviewer that if she were to become infected with HIV disease, she would "...talk to everyone because she wouldn't want the same thing to happen to them."

Another respondent told the interviewer of her efforts to teach her younger sister about HIV/AIDS. She said she was always talking to her sister and telling her to use protection during sexual relations because, "it is so very dangerous." This respondent also noted that her younger sister was "very shy and naive and [did] not want to listen." These findings correspond with literature that indicated that familism may compel Latinas to teach family members about HIV/AIDS prevention (Marin, in press).

Another form of gossiping was found that suggests an alternative to living and dying with AIDS.

"One of my sisters who was here a short while ago was telling me that a man who was from Mexico...the same place that I was from...that he was sick and that he now lives in (a border town)...he has AIDS and his wife came from Mexico to be with him because he wants to commit suicide...that is what I heard."

Suicide as an alternative to living with HIV/AIDS is further discussed in another section.

Gossiping, while indicated as a source of information by the data, was not the primary source identified by the Latinas interviewed. The source of information most often identified was television.

Television

Seventeen of the 21 respondents said their primary source of information about AIDS was television. These data corresponded with the surveys conducted by

Hu, Keller, and Fleming (1989) and Dawson and Hardy (1989). However, these data differed from the findings of Hingson and associates (1989) who found that Spanish speaking respondents were less likely to have heard AIDS messages on television.

Other sources of information were rarely acknowledged by the respondents. For instance, none of the respondents acknowledged receiving Understanding AIDS, a pamphlet that was mailed to all United States households from the Surgeon General's office in 1988.

One Latina put it this way,
 "(I learned of that disease) on the television cause
 people don't talk to you about AIDS."

A respondent who was asked what she would tell her little girls about protecting themselves from AIDS said,

"To be careful and to watch t.v."

The interviewer asked for clarification and learned that the participant felt that the best way for her daughter to learn about AIDS was to watch the television. This mother did not trust her own abilities as teacher as best for her child.

One respondent described how television may have given her family in Mexico information about AIDS:

"Now there is more television and they hear a lot
 more, but before there was nothing."

Television was also one of the ways for the respondents to have seen someone who had AIDS. However, most did not know someone with AIDS and could not list symptoms. This point is further discussed later.

Knowing about AIDS and all the issues surrounding this disease was complex and shrouded in silence and half-truths for many of the Latinas that were interviewed. Asking more specific questions about their knowledge of the disease

itself revealed more about how complex coming to know about HIV/AIDS was for the Latinas interviewed.

Knowing About AIDS

In this study, the process of knowing about AIDS explains how the Latinas interviewed had come to know about AIDS. Most had learned very little about the disease. What they did know they had learned within the context of growing up in silence and relating to men.

Growing up in silence had taught them that women should not speak of sex or sexually transmitted disease or using a condom. To do so would make the Latina una mala mujer, a bad woman. In relating to men, the Latinas had been socialized to accept that men have more sexual freedom and may seek extra-marital affairs. To question the male about his sexual past or condom use is confrontational and, therefore, uncomfortable and unacceptable.

Many of the Latinas who participated demonstrated their reluctance to discuss sexually transmitted disease when they initially responded to questions about AIDS with "I don't know". Typical responses were:

"I don't know the symptoms at all. I wouldn't know if I had it or if somebody else had it. I don't know."

"I have heard but I don't remember right now. I am not sure how it starts."

"I just remember how you can get it...that's all I want to know. I don't think that I'm going to get it so I don't need to know the symptoms."

Not knowing or not remembering may have reflected lack of knowledge or a reluctance to talk about the disease with the interviewer. Not knowing the symptoms because one does not feel susceptible is a form of denial or "pretending".

What is AIDS?

When asked, "what is AIDS?" typical responses included:

"I only know that it is a very bad disease that brings with it many problems."

"I have heard that it is a very painful death and a very hard one."

"Well, I really don't know that much but I have heard that (about that disease). It happens to people who have relations."

"I understand its what I can get from a man...I imagine it is a virus that gets into your body ...you cannot fight against it."

All those interviewed eventually said that AIDS is a deadly disease and they all described AIDS as sexually transmitted. Two respondents thought that AIDS could be cured, especially if "caught in time."

When the interviewer asked one of the respondents if people in Mexico knew about AIDS and how it's transmitted she said,

"I don't think so. Especially since a lot of people live on ranches and they don't hear a lot about this. Now there is more television and they hear a lot more, but before there was nothing."

Three other participants were asked if they had heard about AIDS while they were still living in Mexico. They said,

"No, it was not known in Mexico. I only heard about it here."

"No, I had never heard about it."

"No, I have only heard about AIDS since I have been here."

These responses may explain why none of the respondents described AIDS as a supernatural disease. Unlike mal de ojo and other like diseases they may have learned from within their Mexican culture, HIV disease has been learned from the Anglo culture where viruses and germs are explained as the cause of disease. Singer and associates (1990) also noted that the Hispanic focus group they interviewed discussed HIV/AIDS in biomedical terms they had heard on television and radio rather than using Latino folk constructions to describe the disease.

One respondent talked of her mother in Mexico not knowing about AIDS. She said,

"My mom is very antiquated. These kinds of things they (mom or parents) never saw before. They don't see them as normal...those things she just doesn't know. She doesn't even see a divorce as normal."

These comments demonstrate how divergent the respondent's new culture is from the culture she experienced in Mexico. It also illustrates that acculturation changes one's outlook. In addition, it verifies that HIV/AIDS is thought of in Anglo biomedical terms rather than in traditional folk ways or diseases that have been "seen before" (Singer, et al., 1990).

One respondent voiced an opinion about AIDS as a "natural" disease. She said,

"I think that even though it is a very dangerous disease, it is a natural one that can affect anybody. And, that if they do get sick it is just like a sickness you get."

Two of the women within the focus group agreed with her. They said,

"I think it is an illness like any other."

"Like you can get a cold or any other disease."

Another respondent said,

"It really depends on the circumstances. It depends on whether it was from a transfusion or a needle or something other than the husband."

She believed the disease to be "natural" unless it came from a husband who had been having sex with contaminated women. Then it becomes a consequence of his actions.

Another Latina interviewed told the interviewer that AIDS was a consequence of behavior. She said,

"...I think you get AIDS for some reason...cause you are doing some IV use or you're having sexual contact with the wrong person...it is not some kind of disease you get just because of nothing."

Another respondent felt that not only is HIV disease a consequence of illicit behavior but that it is that behavior that will determine whether the sick person will be supported by the family. She said,

"...if I did (get) it because I was...being a bad girl (my husband would treat me differently than) if I wasn't a bad girl and I just got it because of any other reason...(like) a transfusion ...that would be a different view...my husband he would support me...if that would happen."

Identifying an "innocent victim", as this Latina has done for herself, is a form of prejudice against persons with AIDS. It implies that the deaths of persons who have acquired the disease from contaminated blood or from an infected mother are more tragic than the deaths of those who took risks such as IV drug use or illicit sexual relations (Meisenhelder & La Charite, 1989).

Those who had seen people with AIDS on television or who had patients with the disease were more adept at describing the symptoms. For most of the Latinas interviewed, however, the symptoms of AIDS were not "real" because they had not experienced knowing someone with the disease. Latinas expressed not knowing the symptoms of AIDS in this manner:

"I have heard that you feel very bad and that you die. But I have never seen anybody who has it."

"That is all I heard, but I have never seen anybody."

"I think I would (know symptoms) if I had seen one (person with AIDS)."

Perhaps because of their lack of first hand knowledge of the disease, two of the women compared AIDS to cancer. By comparing a known disease, cancer, to the unknown disease, AIDS, the participant began to know about AIDS for herself. But the comparison stems from not knowing in the experiential sense.

"I think that once it is very advanced its like cancer and you can't cure it."

"Well, I think its like cancer, right? Cancer (sometimes) is curable but AIDS is incurable."

The association of AIDS and cancer was also reflected in the symptoms of AIDS that most often were given; especially, weight loss, fever, loss of appetite, and hair loss. These symptoms are readily apparent when someone is ill and seemed to signify severe illness for the Latina respondents.

One Latina had known a woman in her neighborhood (in Mexico) who had contracted AIDS because of "having sex with many men." This participant was able to relate more about the stigma attached to the disease because of what she had witnessed.

"...that girl that used to live in my neighborhood,

her life really changed radically. Everyone really despised her. People don't live with her because they are afraid they are going to catch it."

Another participant related another facet of the stigma attached to AIDS when she told the interviewer how she thought her marriage would change if she contracted HIV. She said,

"...possibly, little by little we would lose our friends and then our relationship in our marriage would change...friends have some influence in marriage...my husband, even if he loved me very much, he might start rejecting me...he would have to wonder how and from where I got AIDS, so bad ideas would start."

Stigma attached to HIV disease was again conveyed when a respondent was asked how becoming ill with AIDS would change her life. She said,

"...then you really find out who your real friends are...because then they may not want to come around and touch you...they may not want to bring their children near you."

These women know that people fear disease, especially disease that is associated with death and illicit behaviors such as sex or drug use. Knowing about AIDS and the consequent stigma and isolation that would occur if one were to contract HIV disease probably were the major reasons three of the respondents told us that they would choose suicide if they were told that they had AIDS.

Suicide is, perhaps, the ultimate expression of fatalism. Other Latinas interviewed expressed lesser degrees of fatalism. One said,

"...if you have it there is nothing you can do..."

Another related that:

"...I would just keep on living my life like I am right now...I don't think I will take it that bad cause if you have it it is for some reason you got it (I would be guilty of an offense such as illicit sex or drugs). I would just keep on living my life until its end...If I am going to die, I am going to die, there is nothing I can do about it."

This data supports the literature that depicts the Latino people as fatalistic (see Riding, 1989; Cancela, 1989; Markides, 1981). In addition, it demonstrates this respondent's strong Catholic affiliation, both in her acceptance of death and in the acceptance of AIDS as a consequence of her wrong behavior.

Transmission of HIV

When asked about transmission of the virus, several of the participants would initially respond, "I don't know." As the interviews progressed, however, all commented on at least one mode of transmission. That universal response was "through sexual relations." All of the respondents related this mode because it was the one risk activity in their lives. They know that the greatest threat to them is sexual relations with a husband that is having extra-marital affairs.

"...if I had AIDS that means he's got to have it..."

"I think that (if we had HIV) we should go to our husbands because it would be their fault that we had it."

"...I just tell him that it depends on him. If he is going to mess around he had better think about it.

RIGHT NOW I MIGHT HAVE AIDS (because of his

womanizing)...and I just keep telling him it is up to you."

This participant has given up her safety and personal power to her husband. She has placed her fate in his hands. She is relying on him for her safety from HIV/AIDS, just as she has relied on him to provide a home for her and for their children.

Many of the Latinas expressed not knowing about their husband's past or present sexual encounters.

"...he says that since he has been with me he has not been with other women, but who knows? That is just what he says."

"...there is no way for me to know that...he says that he has never been with anybody else, but how am I to know?"

"He says he is not (with other women) but I don't know. One is never sure."

"...I don't know what is happening whenever he is late. I really don't know what is going on."

When asked about taking the HIV test, one participant stated,

"...you should get a test (HIV) because husbands do not always tell you the truth...but, you know, they are men and they aren't going to tell you everything."

The one unmarried Latina who participated in the study felt that HIV testing should be a part of preparing to get married because,

"You don't know what to expect from anybody. You don't know their past life. I mean, if they don't want to tell you, how are you going to know? So take

the AIDS test...and have him take it, too...so that we can prevent from passing it...to more children. Because there are a lot of children dying from AIDS, and, you know, THERE IS NO REASON WHY THAT SHOULD HAPPEN."

Data depicting the Latina as not knowing about their mate's extra-marital affairs or past sexual history is in direct opposition to data indicating that such behavior is an accepted occurrence. One conclusion that can be drawn is that the Latinas who responded that they did not know if their husbands were having affairs were "pretending" that their husbands were monogamous. One participant referred to her sisters and cousins when she said,

"...the women act like they don't know what is going on."

Pretending that they don't know about their men's sexual liaisons is one way to "save face". If they pretend it is not going on they do not have to confront him and risk divorce.

Other risk behaviors less commonly listed included injections with contaminated needles (drug users, friends or relatives who give vitamins and medications by injections), transfusions, and to babies from an infected mother during pregnancy or breastfeeding. Since the Latinas did not always perceive themselves at risk for these modes of transmission, they usually did not enlarge on them unless asked specifically about certain practices. This investigator pressed, however, on the issue of shared hypodermic needles. Interestingly, many of the respondents said they knew of people who injected themselves with medicines and contraceptives purchased in Mexico. They also stated that the disposable needle was used and not reused by the people they knew.

Four of the women interviewed thought that breastfeeding could transmit the virus to babies. These women knew intuitively what has been confirmed by medical research. Two of the respondents said

"Yes, I think so, because it (breastmilk) is composed of the mother's body."

"...I think that from the moment that the mom is giving her milk to her baby she can pass it (HIV). I think it can be transmitted because the virus is within the organism of the woman. So it can be in her milk and since the baby is doing that...yes, I think he can get it."

As each interview progressed and the Latinas interviewed became more verbal, several modes of transmission were mentioned that are not usually accepted as risks by American medical research. For example: drinking from the same glass; touching a baby -"through the sweat"; saliva; using the same toilet, bathtub, toothbrush, or ear rings; using dirty forks or glasses in restaurants; physical contact; contact with skin lesions and clothes; hugging or talking to children; and tears.

Not knowing exactly how AIDS is spread, knowing that AIDS is a deadly disease with no cure, and knowing AIDS as a disease acquired through illicit sexual relations or drug use contributes to fear of contagion (Meisenhelder & La Charite, 1989). Such fear can lead to the promulgation of erroneous modes of transmission such as those given by the Latinas interviewed such as hugging, talking, dirty toilets, and tears.

What the Latinas who participated in this study were not saying also has important implications for knowing about AIDS. Without exception, the Latinas interviewed did not mention bisexuality or homosexuality or that their men could

have had sex with other men. This seemed a significant omission. Two explanations for this finding are offered.

Carrier (1985) determined during his study of males in Northern Mexico that homophobia in Mexico precludes males who have sex with other men from acknowledging their homosexuality. To hide their true preference they may marry and have children but continue to have sex with other men. Latinas may know that their mate has had sexual encounters with other men, but will not acknowledge this activity as homosexual because of the homophobia within their culture. Consequently, they may not refer to homosexuality when talking about their men's sexual relations outside of marriage.

Another explanation is that the Latinas interviewed were simply denying the existence of bisexuality or homosexuality among their men. Denying that it exists saves them from humiliation. When a Latina who is also a nurse practitioner and an educator was asked why she thought none of the participants in this study had mentioned homosexuality or bisexuality, she said,

"These women are such pretenders. They know that this is going on but they pretend that it is not."

Prevention

When the participants were asked how HIV disease could be prevented, there were varied responses representing both those that are scientifically accepted and those that are not. Nine said that each person should, "stay in their own houses," "just be one on one," and "you shouldn't be with anyone who isn't your husband or wife." Eleven thought the condom should be used as protection, especially since "there are people who are not honest." Six respondents thought that to prevent HIV spread, people should not "share dirty needles" (5) and "combat drug use"(1). One respondent thought that if one "lives a normal life" (free of drugs and with one partner) then they are protected. Lastly, one participant stated that to prevent AIDS

one should be "clean...your hygiene is good...you shouldn't sit down...in the bathrooms."

Summary

Much of what the respondents know about AIDS and AIDS prevention they were initially reluctant to say because of their legacy of silence. However, in the atmosphere of the interviews and the focus group discussion many of the women interviewed were able to discuss their perceptions of these topics.

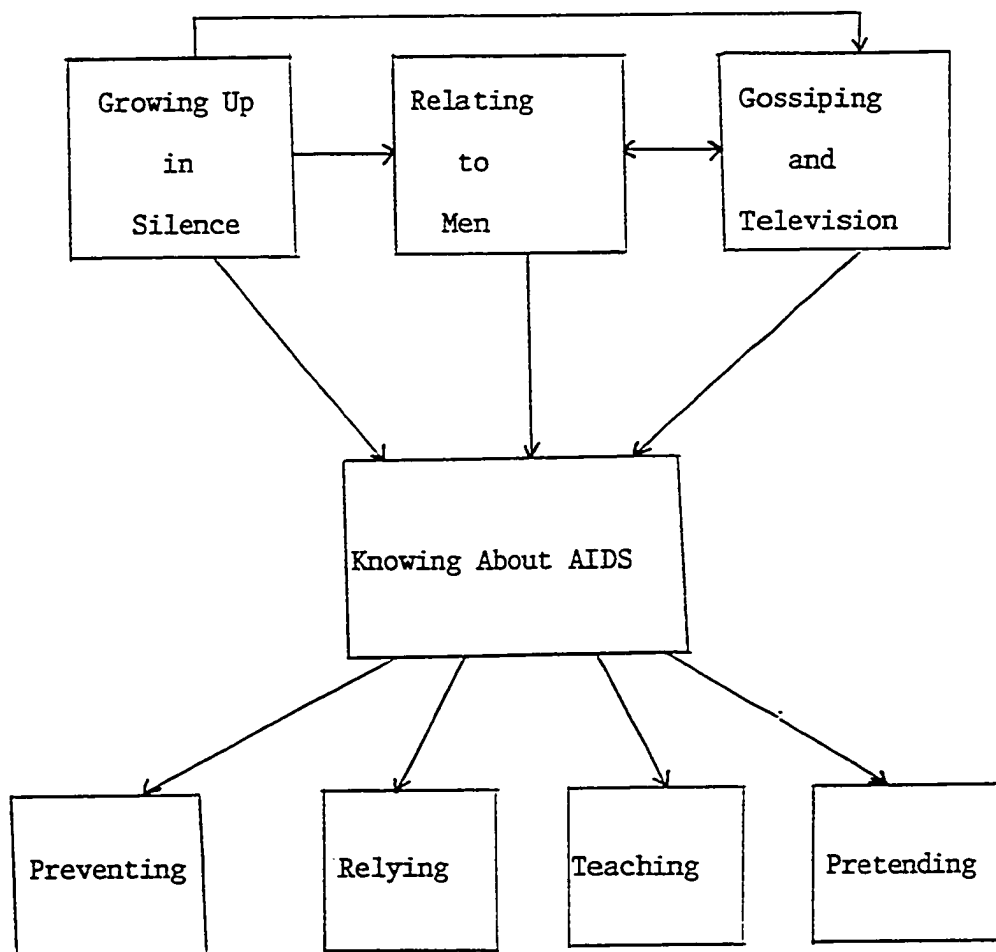
Among these participants there were several who had misconceptions about the disease and how it is transmitted. However, all of the respondents had an idea of what AIDS is and how it is transmitted based on the information they had obtained from gossip and television. Their conceptions of the disease were tempered by the way they had been socialized to avoid discussing sexual issues and disease and how they had been taught to relate to men. What the respondents know about AIDS has enabled them to articulate modes of prevention, both efficacious and erroneous. How they may actually behave is to be discovered by further research.

Integrative Diagram

The women interviewed for this study told about their world of being, a world that had been shaped by relationships with their parents, families, and men. Knowing about AIDS, for them, came about as the result of how they have interwoven information about AIDS with what they have learned throughout their lives within the context of their families and culture.

The integrative diagram in Figure 1 shows how social relationships and information about AIDS have been interwoven to form a web or matrix of knowledge for the Latinas interviewed. The diagram depicts the process of knowing about AIDS as the core category. Three antecedent conditions that contribute to knowing about AIDS are growing up in silence, relating to men, and gossiping and television. The arrows indicate that growing up in silence and relating to men are

Figure 1. Integrative Diagram: Knowing About AIDS



interrelated and both affect how the Latina interprets the information she receives from gossiping and television.

Growing up in silence reflects how the Latinas interviewed perceived what they learned as children about sexual issues such as menarche, sexual relations, child birth, and sexually transmitted disease. The respondents of this study told how they had been kept "blindfolded" about menarche and sexual relations until these events occurred. They were not allowed to eavesdrop on adult conversations about these topics. They learned, primarily from their mothers' actions, that one must be silent about sexual issues. Several felt safe from HIV infection as long as they could "be good" and follow the "rules" of their mothers. Growing up in silence also indirectly contributes to knowing about AIDS via gossiping and television in that all that is heard or seen is "filtered" through all that the Latina learned while growing up. Growing up in silence, then, is a condition for knowing about AIDS.

Relating to men is another condition that has consequences for knowing about AIDS. Here what the respondents conveyed was that they perceived the 'rules' as different for boys. Boys were perceived as having more freedom, especially in sexual matters. In "marriage" the rules continue to be different for men. The data indicated that Latino males are "expected" to have affairs outside of marriage but Latinas are not. For the women of this study, having sex with the man to whom they were married to or living with seemed to be the only risk factor for HIV disease. Many of the respondents, however, did not want to jeopardize their relationship with their husbands or mates by confronting them about extra-marital affairs. Instead they chose to blame "the other woman" for infection with HIV or to rely on their mate to protect them.

Gossiping and television are shown as the third condition that has consequences for knowing about AIDS. This part of the diagram shows how gossip influences what the Latinas interviewed knew about AIDS. It is through gossip that

the Latina learns about HIV/AIDS as it is perceived by her comadres and family members. Gossiping offers an important informal teaching mode that may or may not be effective in assisting the Latina in knowing about AIDS. In addition, gossiping with women friends offers the Latina an opportunity to speak about HIV/AIDS that they do not have anywhere else.

Television is placed within this dimension because it was given repeatedly as the major source of information about AIDS by the respondents. Because it is the major source of information, Latinas speak of HIV/AIDS in biomedical terms, not in Latino folk terms.

Four consequences emerged as a result of knowing about AIDS. They were preventing, teaching, pretending, and relying.

Preventing HIV/AIDS as a result of knowing about AIDS entailed "staying in the home" and not seeking sex outside of marriage, using the condom, not sharing dirty needles, and "living a normal life" (free of drugs and with one partner). For one Latina "preventing" meant not sitting on public toilets. Each respondent had formulated their ideas about "preventing" based on their socialization and the information they had received about this infection.

Teaching emerged as a consequence of knowing about AIDS. The Latina respondents wanted to teach their children more about sex and sexually transmitted disease than they had been able to learn as little girls. Even though their approaches closely resembled those of their mothers, they wanted their children to know more about sex and AIDS so that the children could protect themselves.

There was also evidence that some of the Latinas wanted to teach adult family members about HIV/AIDS. Familism is a strong motivator for teaching everyone in the family about HIV disease.

Pretending as a consequence of knowing about AIDS was noted when a few of the women interviewed seemed worried that their mates were having an affair with

another woman but said, "How am I to know", "one is never sure." They were denying or "pretending" that such liaisons do not occur.

Pretending that their mate is monogamous even though there is evidence that he is not keeps them from confronting their mate. Avoiding confrontation is a cultural edict. In addition, if the Latina is dependent on her mate for food and shelter, a confrontation would be dangerous for her. It is also less troubling to pretend that the "other woman" is at fault for extra-marital affairs rather than blaming one's mate.

The Latina respondents also seemed to be pretending that homosexuality and bisexuality are not risks for them. None of the respondents acknowledged homosexuality or bisexuality as a mode of transmission for HIV or that they knew any men who were having sex with other men.

Pretending was also evident when some of the respondents told the interviewer that they were glad that their children were learning about sex and HIV at school. Pretending or believing their children are learning about these issues at school relieved mothers of embarrassing talks with their children.

Relying is also a consequence of knowing about AIDS and relating to men. Many of the women interviewed were relying on their mate to protect them, either through use of the condom, monogamy, or both. One said,

"I just keep telling him 'it is up to you'". Relying means that the Latina has placed her fate in her mate's hands. She is made vulnerable to HIV/AIDS. At the same time, relying extends her traditional dependent status. All her life she has been dependent on a male; either her father, brother, or mate.

This chapter has presented the findings of the study. Chapter 5 contains a reiteration of the substantive theory derived. It also contains a discussion of how the substantive theory derived in this study combined with theories of women's development and ways of knowing may offer new strategies for preventing

HIV/AIDS among Latinas and their families. Lastly, it contains the implications of this study for nurse researchers, educators, and nurses in practice.

CHAPTER 5

Implications

This study has examined "How Latinas come to know about sexual issues, acquired immunodeficiency syndrome (AIDS), and AIDS prevention within the context of their family and culture." In doing so it has revealed that each of the Latinas interviewed formulated knowledge about AIDS that was strongly influenced by how she was socialized into the adult female role and the modes of information that were accessible to her. This chapter will address the limitations of the study; reiterate knowing about AIDS; discuss the substantive theory in relation to women's development and ways of knowing; and address implications for nursing research, nursing education, and nursing practice.

Limitations

The limitations of this study are those of any qualitative research. The sample was selected as each Latina became available and consented to be interviewed. Each of the women selected may or may not share the same ideas that other Latinas may have about how they learned about sexual issues, AIDS, and AIDS prevention. The generalizability of this research is limited to the Latinas involved in the study. This research sought to specify dimensions that contribute to the process of knowing about AIDS among the respondents interviewed. It is unlikely that the sample could be replicated elsewhere.

As discussed in Chapter 3, the credibility of the study was enhanced by the evaluation of the data and discoveries by the Latina educator and her friends. The Latina who assisted with interviews and offered information based on her personal experiences as a Latina, also contributed to the credibility of the study.

Knowing about AIDS

Knowing about AIDS is complex and multifaceted. It is much more than knowing the definition and signs and symptoms of a disease. To know about AIDS is to have formulated a "web" or matrix of understanding based on how one as a Latina and a woman is socialized within a patriarchal society. The matrix includes cognitive, emotional, and relational facets that are intertwined, each touching and affecting the other. It entails a matrix of different aspects of the disease that are most pertinent to the Latina who perceives HIV/AIDS as a threat to herself and to her family.

Cognitively, knowing about AIDS is to have learned via television and gossip that there is a deadly new disease that is contracted via illicit drug use and/or sex. For the women in this study, the most frequently acknowledged mode of transmission was sexual contact. Sexual contact is recognized because it is the only mode of transmission that may put the Latinas in this study at risk. It is the only risk they have experience with.

Knowing about AIDS for the Latina respondent means knowing about the disease in Anglo biomedical terms. There are no Latino folk constructs for this new disease. It is beyond traditional forms of definition or cure. Since they do not have a traditional construct for this disease, knowing about AIDS entails comparing HIV/AIDS to what they have experienced with other diseases; most notably cancer or other contagious venereal diseases. Experiential knowledge helps the Latina construct knowledge of HIV/AIDS. Transferring knowledge of other diseases combined with fear of contagion, however, contributes to the generation of erroneous modes of transmission such as hugging, talking, toilet seats, and tears. A few of the Latinas in this study related how they looked at eating utensils in restaurants for evidence that they were unclean in an effort to avoid contracting HIV

disease. These were some of the same respondents who had listed correctly the modes of transmission of HIV disease.

Emotionally, knowing about AIDS is knowing and feeling the stigma that is attached to this disease and to persons who have it. Collectively, the Latinas in this study knew through gossip, television, and personal experience that people who have HIV/AIDS are shunned; ostracized from families and communities. This stigma generates a fear of loss of relationships. Three of the Latinas interviewed would choose suicide over living in isolation with HIV/AIDS.

Knowing about AIDS also involves fear for the well-being of children. The Latinas interviewed knew that they wanted their sons and daughters to know more about sex and sexually transmitted disease than they had learned as children. Talking about sex and disease, however, is embarrassing. Latinas have not usually been socialized to discuss these issues freely. The "code of silence" surrounding sex and disease affects them, especially with children who are supposed to be shielded from such worries. Many of the Latina respondents preferred to pretend or believe that their children were learning about sex and disease in school. The "code of silence" and fear for the children contributed to the use of patterns of communication similar to those used by the respondents' mothers;

"If you sit next to a man you will get pregnant."

"Don't do 'this and that' or 'this and that' might happen".

Two of the Latina respondents wanted to teach other family members as well. They felt obligated to teach adult family members what they knew about the disease.

Knowing about AIDS and that it is transmitted via sexual relations caused the Latina respondents to come to the realization that the only risk factor in their world was husbands or mates who were not always home at night. Knowing that their culture and belief system allows men to have extra-marital affairs, they turn their

backs and pretend that the "other woman" is to blame or pretend that they don't know if their mate is monogamous. They also pretend that they are not susceptible; that they are not at risk.

Many of the Latina respondents lacked education and resources (Chapter 3, Table 1). Many depended on their mates for support and direction. Some had been taught that they needed a man to take care of them and that they must marry.

"She (mother) always told me to do whatever I could
to get married."

Knowing about AIDS means knowing that the condom may be protective. But the Latinas in this study do not always fully trust the condom. Women have become pregnant when the condom was used. In addition, Latinas know that their mates do not like to use the condom during relations with them. The wife is supposed to be "clean". If he uses a condom it may mean that he has contracted a disease or that he considers his wife "unclean". Use of the condom before marriage may indicate that he is not "serious" about the relationship.

Knowing about AIDS entails knowing that the use of the condom goes against the teachings of the Catholic Church. Using the condom also precludes fulfilling the cultural mandate that the Latina become a mother, early and often.

Knowing about AIDS means that to insist on the use of the condom or to question a male's past sexual history is to risk severing a relationship with him.

"...for sure its a divorce."

The Latina respondents valued their relationships with their mates. They do not want to lose them. In addition, they are negotiating from a subordinate position. Knowing about AIDS brings into focus the gender issues where "power-over" is the model operating as Latino males and Latinas negotiate sex. He is expected to determine where, when, and how sexual relations will occur and whether or not condoms will be used. He is also expected to have extra-marital affairs and to pursue

activities that prove his *machismo*. The Latina is expected to be submissive and demure; to acquiesce to him; to rely on him to protect her.

Emotionally, the relationship with her mate is binding. To lose him would be like losing a part of herself. She will not risk losing him because of a condom. After all, HIV/AIDS may or may not occur.

When knowing about AIDS is considered within this context, HIV/AIDS prevention strategies among Latinas must take into account gender and relational facets that are so much a part of the lives of Latinas. To promote "safe sex" among women who are dependent on men for relationships and economic support is not going to be successful as the sole teaching strategy. The next section is used to discuss theories of women's development and ways of knowing that, combined with the substantive theory of this study, can be used to construct alternative strategies for prevention of HIV/AIDS among Latinas.

Women's Development and Ways of Knowing

From evidence gleaned during this research, Latinas, like other women, learn through their affiliations with others. First, through their attachment to their mothers, then with sisters, cousins, their mates, *comadres*, and female-in-laws. They speak out about their ideas when they are in groups where they are strengthened by their connections with other women of similar backgrounds and culture whom they know. This was evident during the focus group discussion.

Baker-Miller (1986) and Surrey (1991) have postulated that women evolve and grow within a context of connections with others. Women's learning is based on connections or affiliations. Their sense of self is based upon their ability to make and maintain relationships. For many women, the relationship they have with others, such as mates, family, and children, are more important than their own advancement.

Contrasted to men, who are encouraged and rewarded early in life to individuate and become independent, women continue their deep attachments to others throughout their lives. As they grow from child to adult, they transfer their attachment from their parents to a mate (Baker-Miller, 1986).

Girls are socialized to be aware of feelings and needs of others; to be receptive, intuitive, caring, empathetic; together with, not separate from. They learn early in life that satisfying the needs of others is their own personal need. Separateness frightens them (Eichenbaum & Orbach, 1988). Because of this fear, they will maintain attachments to their mates, even if it may mean that they risk contracting HIV/AIDS.

The desire for continued connection and affiliation has led to subservience. Subservience causes many women to experience an inability to value their own thoughts, feelings, and actions as important. Because of this, women may actually perpetuate their own subservience and oppression (Baker-Miller, 1986). As the Latinas in this study demonstrated, women do not want to speak out or confront men to whom they are attached because they do not want their mate to be uncomfortable. In addition, they do not want to do anything that may sever their relationship with their mate. A loss of that relationship would be tantamount to a loss of part of the self (Baker-Miller, 1986; Eichenbaum & Orbach, 1988).

Surrey (1991) proposes "power with" or "power-together" where two people in a relationship interact in ways that build their connection and enhance each partner's personal power. This type of relationship for a Latino couple would mean that each would have to give up part of the cultural ideas of how men and women should act toward each other. The man would have to choose only those aspects of *machismo* that enhance his support of his wife and family. These aspects include obligation and responsibility to keep his family safe and intact. And, the woman would have to give up parts of *marianismo* that dictate that she be silent, demure,

and submissive. Rather, the Latina would enter into negotiations for sex assured of equal status with her mate. She would speak out and expect to be heard.

Baker-Miller (1986) stated that the need for connection to others should not be considered a weakness but, instead, as a strength. Surrey (1991) advocates enhancing this strength through relationships with other women that facilitate development of all involved. Her model of growth-in-connection capitalizes on women's need for connection and promotes a two-way interactional model where each woman understands and is understood, each empowers the other and is empowered.

Belenky and associates (1986) determined that one way of knowing for women is learned through connecting personal experiences with the views and knowledge of others like themselves. That is; if one has heard about or experienced sexually transmitted disease and she compares her own experiences with those of her friends, she will learn in a much more powerful way about HIV disease. Women who learn this way were identified as "connected knowers" by Belenky and associates (p. 112). Knowledge for the connected knower does not come strictly from authorities. It can come both from experience and through gossip with women friends. Gossip not only gives women verbal accounts about HIV/AIDS, but it also exposes the learner to the responses of the person with whom they are sharing the gossip (Spacks, 1982). It is through this connection with others that some of the Latinas who participated in this study had learned much of what they knew about HIV/AIDS.

Baker-Miller (1986), Belenky and associates (1986), Eichenbaum & Orbach (1988), and Surrey (1991) all have advocated that women join together and use connections to add to their existing deep inner strengths. Each person within these groups should be given the opportunity to grow within the relationships there. Each group member should be encouraged and challenged to maintain connections and to

foster the growth of each other. Surrey (1991) stated that such relational connections lead to mutual empowerment.

Mutual empowerment through support groups is similar to group empowerment to gain political and social power advocated by Freire (1970). Freire (1970) also stressed that changes in politics and society must arise from within the oppressed group. Latinas are twice an oppressed group; they are female and they are Hispanic. Consequently, it can be surmised that the prevention of HIV/AIDS from within the context of the Latinas' world could best be approached through Latina formed consciousness raising support groups. Women from within these groups could offer out-reach to other women who are isolated because of poverty and language barriers. Each member of the group would be a teacher and would offer advice and support.

Such groups should capitalize on familism, a strong cultural value among the Latinas studied. Familism, another form of connectedness, and the importance of children are probably the strongest motivations for the prevention of HIV/AIDS for Latinas and Latino males. Connectedness, familism, and consciousness raising groups form the basis for the implications for nursing that follow.

Nursing Implications

There are several nursing implications apparent within the findings of this study. Within this section, nursing implications are divided into those for nursing research, nursing education, and nursing practice.

Nursing Research

Much more needs to be known about the Latino culture in order to provide holistic nursing care. For instance, studies could be conducted to determine if Latino males perceive learning about sexual issues, AIDS, and AIDS prevention in the same way as the Latinas in this study. Studies of couples and their perceptions of sexual relations and the transmission of sexually transmitted disease could also be

enlightening. Such studies could further explore the importance of family cohesion and children in an individual's choice to avoid behaviors that may expose the family to HIV/AIDS.

Studies of Latinas at differing levels of acculturation within the United States, perhaps including a group from Mexico, could increase knowledge of how acculturation affects knowing about AIDS and AIDS prevention. Latinas at differing socioeconomic levels may also have different perceptions that could be valuable.

Studies of the perceptions of parents of what their children are learning in school, what children should learn in school, and what children should learn at home, could help to produce changes in school curricula that would better meet the needs of the Latinos there. Also helpful would be research that describes the sex education within the schools as it exists compared to how Latino parents perceive what is being taught.

Nursing research could also include comparative studies for other cultures. For instance, are there similarities in the way Black women come to know about sexual issues, AIDS and AIDS prevention? How does coming to know about sexual issues, AIDS and AIDS prevention within the Asian culture differ from the Latino culture? How do men in various cultures view sexual issues, AIDS and AIDS prevention?

As the AIDS epidemic widens to include more women and children, prevention education will become more and more important. Nursing research could help to provide the basis for prevention education that begins early in the life of Latinos, Asians, Blacks, and Anglos. Education that will give each participant a voice that allows them to discuss sexual issues with parents, partners, and children.

Nursing Education

Nursing faculty can contribute immeasurably to nursing education by enhancing cultural awareness and sensitivity among nursing students. Cultural

awareness should not be limited to the stereotypical depictions in current nursing literature, however. Rather, cultural awareness should be enhanced by direct contact with members of the cultures that students will be involved with in their practice. Seminars that include members of diverse cultures and give students and guests opportunities to share ideas enhance the students' experiential knowledge of other cultures. Experiential knowledge will enhance nurses' abilities to formulate prevention programs best suited for people of diverse cultures.

Nursing education can also reach out for and encourage potential nursing candidates of differing racial and cultural backgrounds to enter nursing. According to statistics, there are few Latino nurses available even though Latinos will become the largest minority group in the United States by the year 2000. Latino nurses are needed as role models and community leaders in programs formulated to prevent the spread of HIV disease.

Nursing educators can also be very helpful to nurses in practice arenas who are searching for funding for their prevention programs. Nursing educators can lend their expertise as grant proposal consultants and writers. They can also contribute as information experts by making available to nurses in practice current information about grants available for AIDS prevention programs.

Nursing Practice

This study has demonstrated that the prevention of AIDS begins with the socialization of children into the adult world. To change long existing patterns of socialization is a long term, formidable goal. However, nurses who are involved with the primary care of Latino children are in a unique position to teach mothers and their children about sexual issues such as menarche, sexual relations, and sexually transmitted disease. Nurses can demonstrate to mothers how to begin to have two-way conversations with their daughters and sons. Two way conversations that allow the children to voice their opinions and thoughts will enhance

intellectual ability and a strong ethical sense that will help them avoid behaviors that put them at risk for HIV/AIDS. The nurse can also coordinate efforts with existing school and community programs. Without coordination, separate programs may confuse the children.

Adolescents need male-female socialization guidance and can benefit from connectedness that can happen within group sessions about sexual issues (relationships and negotiations), AIDS, and AIDS prevention. Such groups can be initiated and conducted by nurses. Co-ed groups of this type could offer mutual support, empathy, and development that helps the participant to form and maintain relationships with the opposite sex. These types of groups would also enhance self-efficacy and self-esteem so that girls would not hesitate to discuss sexual issues such as condom use and boys could learn more about how to communicate with girls without taking a "power-over" stance.

Mutual empowerment within communities could produce prevention programs most culturally appropriate for Latinos. Leaders of such programs should be representatives from within the Latino culture. Nurses who practice in these communities and want to establish a formal program would be most successful if they approach the leaders in the community and enlist their assistance from the beginning.

Programs that include neighborhood women who are often sought out for advice are strengthened by the familiarity of these women to others. Women leaders (consejeras or counselors) such as these can be assisted to establish and continue teaching others in the neighborhood about sexual issues, AIDS, and AIDS prevention. No one is more familiar with the problems of the women of the community. Such outreach programs would be very beneficial in reaching those Latinas who are currently in isolation. The programs should be sufficiently flexible

to deal with other problems in the community so that when education about HIV/AIDS is done it will be received as a part of a valuable program.

Nurses can also encourage programs for adult married couples concerning the prevention of AIDS. Much of the Latino culture seems to separate males and females. Couples education could do much to enhance cohesion, connectedness, and familism. Again, leadership of such classes or seminars should come from known, respected members of the neighborhood.

The current social system does not offer the Latino the same opportunities for education and advancement that it offers more affluent Anglo Americans. Nurses can be instrumental in changing the system through political awareness and action. AIDS has become a disease of the poor and disadvantaged. If the political system can be changed so that all people have the same opportunities and education, then AIDS can be prevented more readily. As one respondent argued, "...there are children dying of AIDS, and, you know, there is no reason why that should happen."

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September 10, 1991

Philip Y. Hahn School of Nursing
University of San Diego
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To Whom It May Concern:

Patricia Caudle, F.N.P., D.N.Sc.(c) has permission to conduct her research at Vista Community Clinic from December, 1990 through May 1991.

She and her Latina Interpreter may use space available to conduct interviews and, if necessary, may access charts via the computer banks.

It is understood that all of the interviews will be strictly confidential and the identity of each participant will not be revealed. Mrs. Caudle has agreed not to interfere with clinic flow and she will not approach any one who appears to ill to participate.

We are looking forward to working with Mrs. Caudle during this endeavor.

Sincerely,

Barbara Mannino
Executive Director

Appendix B

Interview Guide - English

Demographic Data

How old are you?

Where were you born?

Tell me about your home. Do you have a job?

Are you married?

How long have you been married?

How many children do you have?

Do you know anyone who has tested positive for AIDS?

Have you ever been tested for AIDS?

Basic Questions

Tell me what you know about AIDS. (Probe questions to clarify and elicit more data. Example "Tell me more...")

I would like to hear about what you think are behaviors that can cause a person to get AIDS. Why would HIV infection start?

Do you believe that sharing needles for medications or vitamins will spread HIV infection?

How do you think HIV infection should be treated?

What does HIV infection do to you?

How does it work?

How would AIDS affect your ability to function as a family member?

How severe is AIDS?

Tell me about how you believe infants can get AIDS.

How would becoming ill with AIDS affect your life?

How would becoming ill with AIDS affect your family?

How would becoming ill with AIDS change your relationship with your mother?

How would becoming ill with AIDS change your relationship with your husband or boyfriend?

How would you feel if someone in your family had HIV infection?

What would you tell your daughter about HIV infection and AIDS?

What would you want your daughter to know about dealing with AIDS issues in her relationship with her boyfriend?

Appendix B

What would your husband or boyfriend do if you asked him about his sexual relationships before and after meeting you?

Would you ask your husband or boyfriend to use a condom during intercourse?

How do you think he would react?

What else would you like to tell me about what you know about AIDS?

I've asked you many questions, are there any questions you would like to ask me?

Appendix B

Interview Guide - Spanish

Informacion

Cuantos años tienes?

Donde nacistes?

Dime sobre tu hogar.

Tienes trabajo?

Estás casada?

Cuanto tiempo has estado casada?

Cuantos niños tienes?

Conoces a alguien que ha tenido una prueba positiva para la SIDA?

Tu has tenido una prueba para la SIDA?

Cuantos años de escuela tienes?

Preguntas

Dime lo que sabes de la SIDA. Dime mas.

Que son los comportamientos para contagiarse con la SIDA?

Como puede contagiarse una persona con la SIDA?

Unas personas dicen que compartiendo agujas o jeringas
para medicaciones o vitaminas puede propagar la infección
de la SIDA, que piensas tu?

Como crees que la infección de la SIDA se debe curar?

Que te hace a ti la infección de la SIDA?

Como trabaja la infección?

Como un miembro de tu familia, como te afectará la SIDA?
(tu habilidad de hacer ciertas cosas?)

Que grave es la SIDA?

Como crees que bebitos pueden contagiarse con la SIDA?

Como te afectara la vida si tu te enfermarás con la SIDA?

Si tu te enfermaras con la SIDA como afectara tu familia?

Si tu te enfermaras con la SIDA como cambiara tu relación
con tu madre?

Si tu te enfermaras con la SIDA como cambiara tu relación
con tu esposo/novio?

Como te sentirás si alguien en tu familia tenía la
infección de la SIDA?

Como le dirias a tu hija sobre la infección de la SIDA?

Appendix B

Que quisieras que tu hija supiera sobre la SIDA cuando
hablando sobre esto con su novio?

Que hiciera tu esposo o novio si le preguntabas sobre sus
relaciones sexuales antes y después de conocerte?

Usara un condon tu esposo/novio durante el acto sexual?

Como crees que el reaccionará?

Que cosas puedes hacer para evitar la SIDA?

Que pasará si tu te enfermarás con la SIDA?

Conoces a alguien que tiene la SIDA, como piensas que se
contagiaron?

Que más me quieres decir sobre la SIDA?

Yo te he preguntado muchas preguntas sobre la SIDA, hay
preguntas que me quieres hacer a mi?

Appendix C

Focus Group Interview Guide (English)

In the past few months we have talked with 16 Latinas about AIDS and how they thought AIDS might affect their lives if they were to become sick with it. Today we would like to ask you your opinions about what they have said.

- (1) First, we will talk about AIDS. What is it? How is it transmitted? Is there any cure? What are some of the symptoms? What do people with AIDS look like? Can you tell if someone has the virus just by looking at them?
- (2) When we asked women how AIDS would change their lives if they were to become ill with the disease, some said they would leave their family - isolate themselves in a hospital or clinic. Others were very determined to stay with their family -especially with their children. They wanted to carry on with their lives as before. What do you think?
- (3) We also asked the women who they would go to first if they found that they had the disease. Many said to their husbands. Others said to their mothers. Who would you turn to?
- (4) Once when we asked a Latina about AIDS she said that she thought AIDS was a natural disease just like any other disease. Others have said that one gets AIDS because they have done something bad, like take drugs or have sex outside of marriage. Do you think AIDS is a natural disease or a punishment for being bad?
- (5) Now there are a few questions that we asked that concerned prevention. One was "where have you heard about AIDS and how to prevent it?" Many answered newspapers and television. Some answered family members, especially sisters and cousins. Where or from whom have you heard about AIDS and how to prevent it?
- (6) We also asked them about their relationships with men. When we asked if their husbands or boyfriends had told them about any relations that the men had had before they met the Latina we were interviewing, most said that they had. Some said that they had asked but their men did not want to tell them those things. What do you think? Would you ask your mate about his past relations? Would he tell you?
- (7) The condom is considered protective when it comes to AIDS, yet many men do not like to use them. The women we talked to said that their men didn't like them but many women felt that if they asked the man to use the condom, they would. What do you think? Would your husband use the condom if you asked him?

- (8) The last section of questions concerns how women learn about menstruation, sex, sexual relations, and diseases like AIDS. The women we interviewed said that their mothers did not talk to them about sex or disease. Many learned at school or through their own experiences. What about you? How did each of you learn about these things?

-

Appendix C

Focus Group Interview Guide (Spanish)

En los últimos meses hemos hablando con 16 Latinas sobre la SIDA y como ellas pensaban que la SIDA podría afectar sus vidas si se enfermanan con ella. Hoy queremos preguntaries sus opiniones sobre lo que ellas han dicho.

- (1) Primero, vamos a hablar sobre la SIDA: Que es la SIDA? Como es transmitida? Hay cura? Que son las síntomas de la SIDA? Como se ve la gente que tiene la SIDA? Como parecen? Puede notar uno si alguien tiene el virus solamente con mirarlo?
- (2) Cuando les preguntamos a las mujeres como la SIDA iba a cambiar sus vidas si se enfermaran con la SIDA, unas dijeron que iban a dejar su familia, unas internarse en un hospital o clínica. Otras estaban muy determinadas a quedarse con su familia - especialmente sus niños. Otras querian seguir sus vidas como antes. Que piensan ustedes? Que harían ustedes?
- (3) Tambien les preguntamos a las mujeres que con quien iban a confiar primero al saber que tenían la enfermedad. Muchos dijeron que sus esposos. Otras dejieron que a sus mamás. Con quien iban a ir ustedes?
- (4) Una vez cuando le preguntamos a una Latina sobre la SIDA, ella dijo que pensaba que la SIDA era una enfermedad "natural", como cualquier otra enfermedad. Otras han dicho que una agara la SIDA porque han hecho algo malo, como tomar drogas o teniendo relaciones afuera del matrimonio. Creen ustedes que la SIDA es una enfermedad "natural" o un castigo por haber sido mala?
- (5) Ahora, hemos preguntado unas preguntas sobre la prevención de la SIDA. Una pregunta era: Donde ha oido sobre la SIDA y como prevenirla? Muchas contestaron periodicos y la television. Otras dijeron que familiares les habian dicho sobre la SIDA, especialmente hermanas y primos. Donde y de quien han oido ustedes sobre la SIDA y como prevenirla?
- (6) Tambien les hemos preguntado sobre sus relaciones con hombres. Cuando les preguntamos a las 16 Latinas si les habian preguntado a sus esposos o novios sobre sus relaciones antes de casarse o juntarse con ellas, muchas dijeron que si les habian hecho preguntas. Otras dijeron que les preguntaron a los hombres pero que ellos no les querían decir esas cosas. Que piensan ustedes? Les preguntaran a sus esposos sobre sus relaciones pasadas? Ellos les dejieron?

Appendix C

- (7) El condon es considerado como proteccion para la SIDA, pero a muchos hombres no les gusta usarlos. La mujeres que intrevistamos dijeron que sus hombres no les gustaba usarlo, pero si ellas les pedian que los usaran, que si los usaban. Que piensan ustedes? Sus esposos usaran un condon si le pedian?
- (8) La última seccion de preguntas se trata de como mujeres latinas aprenden sobre la regla, sexo, relaciones sexuales, y enfermedades como la SIDA. Las latinas que intrevistamos dijeron que sus mamás no les hablaron sobre el sexo o enfermedades. Muchas aprendieron en la escuela o con sus propias experiencias. Ustedes como aprendieron? Como aprendio cada una de ustedes sobre estas cosas?

Appendix D
Focus Group Demographic Data Sheet
Favor de Contestar

1. How old are you?
Cuantos años tiene?
2. Where were you born?
Donde nacio?
3. Are your parents still living?
Todavia viven sus padres?
4. How many brothers and sisters have you?
Cuantos hermanos y hermanas tiene?
5. Among your brothers and sisters are you the oldest? the youngest?
which one are you?
Es usted la mayor de sus hemanos y hermanas? La menor? Cual es usted?
6. How long have you lived in the United States?
Cuantos anos ha vivido en los Estados Unidos?
7. Did you go to school in Mexico?
Fue a la escuela en Mexico?
8. How many years have you gone to school?
Cuantos anos ha ido a la escuela?
9. Are you married? How long have you been married?
Está casada? Cuanto tiempo ha estado casada?
10. Do you have any children?
Tiene ninos?
11. How many boy children and how many girl children?
Cuantos ninos y cuantas ninas tiene?
12. Have you ever had a blood test for AIDS?
Ha tenido una prueba da sangre para la SIDA?
13. Have you ever thought about getting a blood test for AIDS?
Ha pensado tener una prueba de sangre para la SIDA?
14. Do you know anyone who has the AIDS illness?
Conoce a aúaen aue tiene la enfermedad de SIDA?

Appendix F

University of San Diego

Consent To Act as a Research Participant

Patricia Caudle is conducting a research study of the cultural health beliefs and perceptions of Latinas concerning Acquired Immunodeficiency Syndrome (AIDS). Since I have been selected to participate in this study, I understand that I will be interviewed about my beliefs about sex and AIDS. I further understand that I will be asked about practices that I may use to prevent AIDS.

This data collection will take about one hour for an interview and, if I agree, a group session with other women scheduled on a different day. Participation in the study should not involve any risks or discomforts to me except for possible minor fatigue or discomfort in answering personal questions about sex.

I understand that my research records will be kept completely confidential. My identity will not be disclosed without consent required by law. I further understand that to preserve my anonymity only group data will be used in any publication of the results of this study.

Patricia Caudle has explained this study to me and answered my questions. If I have other questions or problems related to the research, I can reach Patricia Caudle at 723-9892.

There are no other agreements, written or verbal, related to this study beyond that expressed on this consent form.

I, the undersigned, understand the above explanations and, on that basis, I give consent to my voluntary participation in this research.

_____ Date: _____

Signature of Participant

_____ Date: _____

Location

_____ Date: _____

Signature of Principal Researcher

_____ Date: _____

Signature of Witness

Appendix F
Universidad de San Diego
Consentimiento Para Actuar Como Un
Participante de Investigacion

Patricia Caudle está dirigiendo un estudio de las creencias de salud culturales y las percepciones de Latinas sobre el Síndrome de Inmunodeficiencia Adquirida (SIDA). Como he sido escogida para participar en esta investigación, entiendo que yo será entrevistada sobre mis creencias sobre el sexo y las SIDA. Mas entiendo que me preguntaran sobre las practicas que yo podre usar para evitar la SIDA.

Esta colección de datos tomará aproximadamente una hora para la entrevista y, si estoy de acuerdo, una sesión en grupo, con otras mujeres será planeado para otro día. Participación en esta investigación no envuelve ningún riesgo personal o incomodidad excepto una posibilidad de fatiga menor o incomodidad en contestando preguntas personales sobre el sexo.

Entiendo que mis registros sobre esta investigación serán completamente confidenciales. Mi identidad no será revelada sin mi consentimiento como es exigido por la ley. Y más entiendo que para conservar mi anonimato solo datos de grupos serán usados en la publicación de los resultados en esta investigación.

Patricia Caudle me ha explicado esta investigación y me ha contestado mis preguntas. Si tengo otras preguntas o problemas relacionadas sobre esta investigación, puedo comunicarme con Patricia Caudle al 723-9892.

No hay otros acuerdos, escritos o oral, relacionados a esta investigación afuera de los explicados en este consentimiento.

Yo, el infrascrito, entiendo las explicaciones escritas arriba y, en esa base, doy mi consentimiento para mi participación voluntaria en esta investigación

_____ Fecha: _____

Firma de la Participante

_____ Fecha: _____

Localidad

_____ Fecha: _____

Firma de Investigador Principal

_____ Fecha: _____

Firma del Testigo