

LA PROTECTORA (THE PROTECTRESS): A METAPHOR
FOR HIV⁺ HISPANIC WOMEN

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BY

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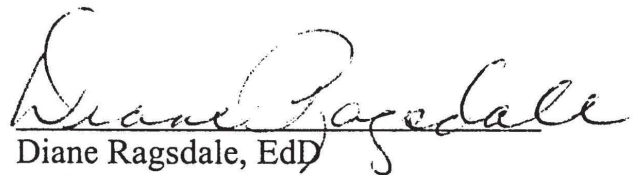
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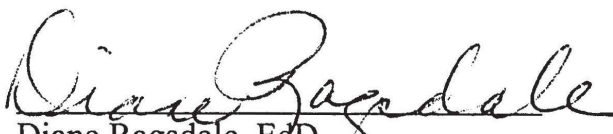
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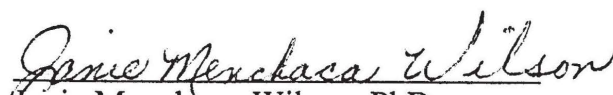
I am submitting herewith a dissertation written by Maria del Rosario Valdez entitled, "La Protectora (The Protectress): A metaphor for HIV⁺ Hispanic women." I have examined this dissertation for form and content and recommend that it be accepted in partial fulfillment of the requirements for the degree of Doctor of Philosophy with a major in Nursing.


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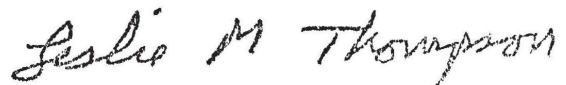
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DEDICATION

In memory of my mother and mentor,

Beatrice M. Valdez

whose undying love and encouragement
guide me to be all that I can.

&

To my father,

Guadalupe G. Valdez

whose struggles, sacrifices, and example provided me
a foundation strong in family values
and the inspiration to succeed.

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Protectora may not have emerged.

Finally, I would like to acknowledge the women who were willing to tell their stories as they live with HIV. Their willingness to be open, tell their stories, and share their lives, despite their fears, made this study possible.

LA PROTECTORA (THE PROTECTRESS): A METAPHOR
FOR HIV⁺ HISPANIC WOMEN

ABSTRACT

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HIV/AIDS can represent an overwhelming disruption for Hispanic women. Beliefs provide a source of comfort when attempting to cope with failure, threats, challenges, and with living in a society with different attitudes, values, and lifestyles. Few researchers have studied the health needs, health status, health beliefs, health-seeking behaviors, or family roles of Hispanic women. No research was found related to cultural influences and folk health practices of women affected by HIV.

The purpose of this exploratory qualitative study was to identify folk health practices of HIV⁺ Hispanic women. Theoretical sampling was used to identify respondents at an outreach center in a large southwestern city in the United States. Nine respondents were interviewed and audiotaped using a semi-structured interview guide and open-ended questions. Observations were conducted at the outreach center, during support group and alternative therapy sessions, and at the respondents' homes. Data analysis included the constant comparative method consistent with the grounded theory approach.

The core variable of La Protectora (The Protectress) emerged from the findings. Response to the affirmation of HIV⁺ serostatus becomes a process by which the Hispanic woman chooses to live her life and unfolds into a positive attribute of marianismo, La Protectora. Five main categories emerged that describe how the Hispanic woman deals with life after the revelation of her HIV⁺ status. They were Revelation of Death, Ofrecer (an offer to change), Living, Revealing, and Duality. Two subcategories emerged from each of the three categories, Living, Revealing, and Duality. Dealing and Surviving emerged from Living. Protecting and Advocating emerged from Revealing. And Intensifying and Actualizing emerged from Duality.

As most of the Hispanic women were pregnant when their serostatus was revealed, their lives had purpose amidst a life sentence of death. The Hispanic woman's purpose was to live for her child and her family. With the infant as the driving force, the Hispanic woman was motivated, sought out, and participated in activities to promote her own well-being. La Protectora emerged as she intensified in her mother role and actualized in her role as a woman with HIV.

The findings have implications for nurses and other healthcare professionals that provide service to Hispanic women, pregnant women, and those affected by HIV/AIDS. HIV⁺ Hispanic women see themselves as women first. The inequalities they face are recognized as "women issues" rather than cultural issues. How they live their lives, care for their families, and face the prejudice of being HIV⁺ are based on being women. They assume a pro-active role as they live and take responsibility for their disease.

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CHAPTER 1

INTRODUCTION

The problem of Human Immunodeficiency Virus (HIV) infection has reached pandemic proportions. Heterosexual transmission is escalating globally and may account for 80% of HIV infection by the end of the decade (Neal, Fleming, Green, & Ward, 1997). The World Health Organization (WHO) projected that the total number of HIV-infected adults would reach 30 million and there would be 10 million pediatric cases by the year 2000 (DiScenza, Nies, & Jordan, 1996; World Health Organization [WHO], 1997). The most rapidly growing segments of the Acquired Immune Deficiency Syndrome (AIDS) population were blacks and Hispanics (American Public Health Association, 1996; Centers for Disease Control [CDC], 1997a).

At the beginning of the AIDS epidemic, approximately 80%-90% of HIV transmission in the United States (U.S.) resulted from homosexual contact or intravenous drug use (IDU) [DesJarlais & Friedman, 1988; Holmes, 1991] and was most prevalent among homosexual and bisexual men (Chu, Peterman, Doll, Bueler, & Curran, 1992; Holmes, 1991). Men who have sex with men (MSM) accounted for more than half of all AIDS cases reported to the CDC through December 1995 (Sullivan, Chu, Fleming, & Ward, 1997). Because of AIDS in MSM, HIV infection was the leading cause of death in men aged 25-44 since 1991 (Kochanek & Hudson, 1995) and responsible for 23% of all deaths of men in this age group in 1994 (Singh, Kochanek, & MacDorman, 1996).

The United States is now seeing a change in the trend of new HIV infections and AIDS diagnoses. No longer is the incidence of HIV/AIDS in homosexual and bisexual men rising, but rather it is leveling.

Women, the minority population in the HIV pandemic, are fast becoming one of the highest subgroups to be infected (National Center for Health Statistics, 1995; Phillips, 1997; Wortley & Fleming, 1997). HIV infection in women is a problem of growing magnitude and concern in the United States. From 1985 to 1996, the proportion of reported U.S. AIDS cases occurring among women increased from 7% to 20% (CDC, 1997b). Minority women were dramatically over-represented among the AIDS cases reported to the CDC in 1996. HIV infection disproportionately affected African-American and Hispanic women (Rogers, 1997). The rate of HIV among black women was 17 times, and Hispanic women 7 times higher than for white women.

Ellerbrock, Bush, Chamberland, and Oxtoby (1991) used data gathered from 1981 to 1990 by the CDC for an epidemiological analysis of women with AIDS. Overall, 51% of the women acquired the disease through the use of contaminated equipment for IDU, such as needles and syringes. Twenty-nine percent were infected by heterosexual contact. Between 1986 and 1990, the number of women who acquired the disease by use of contaminated equipment for IDU decreased. Those who acquired the infection through heterosexual intercourse increased. The majority of women with AIDS were black or Hispanic (72%), and of reproductive age, 15 to 44 years old (85%).

According to the CDC (1997b), in the first two quarters of 1996, the estimated

number of AIDS deaths was lower than the estimated number of AIDS deaths in 1995. Deaths declined in men by 15% but increased among women by 3%. Ward & Duchin (1997) reported that HIV infected persons were living better and longer lives. However, if improvements in clinical management and patient survival are not matched by reductions in HIV incidence, the population of HIV infected persons will increase.

AIDS is a leading cause of death for women 25 to 44. An overwhelming proportion of these women are black or Hispanic, with a disproportionate number being Hispanic women, (Peragallo, 1996; Wortley & Fleming, 1997). AIDS-related deaths reported in the United States accounted for twelve times as many black women than whites in 1992 and ranked third as the cause of death for Hispanic women age 25 to 44 (Levy, 1995). By 1994, Hispanic women represented 20% of all accumulated AIDS cases among women in the United States.

Hispanic women are believed to be at greatest risk for HIV infection and AIDS (Barken et al., 1998). Behavioral, cultural, and environmental factors have been suggested as sources for the higher risk of heterosexual transmission of the disease (Diaz, Buehler, Castro, & Ward, 1993). Hispanic women compared to white women also differed in having lower condom use (Marin, Tschann, Gomez, & Kegeles, 1993), greater reluctance to suggest condom use to male partner (Marin & Marin, 1992), and less confidence about avoiding HIV (Marin et al., 1993).

Among women with AIDS, 66% reported heterosexual contact as the source of infection (CDC, 1995). From 1985 to 1996, the proportion of U.S. AIDS cases attributed

to heterosexual transmission increased from 2.5% to 15.1% (CDC, 1997b; Neal et al., 1997). Drs. Thomas Lehner and Mary Ann Chiasson (1998) conducted a cross-sectional survey at a New York-based sexually transmitted disease clinic serving predominantly African-American and Hispanic patients between 1988 and 1993. They found that of the 3,069 male subjects, 415 reported having sex with men. They also found that of those 415 men, only 13% ($n=55$) were classified as "homosexual," which was defined as having sex with men exclusively. In addition, 35% ($n=145$) were classified as "bisexual" and 52% ($n=215$) were classified as "heterosexual." Lehner and Chiasson concluded that HIV transmission from bisexual men in African-American and Hispanic communities to their female sex partners played a larger role in heterosexual transmission than was previously thought. These findings also emphasized the need to take into account the cultural, ethnic, and behavioral diversity of these men and their sexual partners---both male and female.

Hispanic women were at greater risk for HIV transmission from bisexual men, given the higher level of bisexuality found among Hispanic men (CDC, 1993). It has been documented that some Hispanic men who engage in male-to-male sex do not regard themselves as homosexual, or even bisexual, as long as they assume the dominant role (insertive as opposed to receptive) and/or continue to engage in heterosexual sex (Salgado de Snyder, Diaz-Perez, & Maldonado, 1996). There is no stigma attached to this behavior, as long as the male fulfills his "masculine," i.e., heterosexual role. In addition, extramarital sexual activity among males in Hispanic society is sanctioned

culturally.

Despite the disproportionate number of minority women who are HIV infected, the majority of the research and educational programs have been directed at gay white males. Most of the research on women (e.g., Kline, Kline, & Oken, 1992; Nyamathi, Bennett, Leake, Lewis, & Flaskerud, 1993; Nyamathi, Leake, Flaskerud, Lewis, & Bennett, 1993) relates to women's attitudes towards health, sexual practices, knowledge, and perceived risks of HIV for the prevention of AIDS. No studies were found to explain the health-seeking behaviors of HIV⁺ women.

A need exists for continued research in the area of women with AIDS. Much of the research has been related to the prevention of HIV/AIDS and very little has been devoted to the lifestyles, the health-seeking behaviors, and the concerns of those affected (Nyamathi & Flaskerud, 1992). HIV/AIDS-related research and HIV-infected persons' access to adequate health services must be increased (de Bruyn, 1992).

Several researchers (e.g., Michaels & Levine, 1992; Modlin & Saah, 1991; Shapiro, Schiltz, Lee, & Dondero, 1989) found that HIV⁺ women were difficult to access because they were among the economically disadvantaged. They had no financial support and therefore, lacked access to care. As Hispanics and women are among the rising groups affected by HIV/AIDS, concern for their access or lack of access into the healthcare system is important.

Hispanics are one of the fastest growing population groups in the United States. With an estimated 31 million Hispanics, the United States has the fifth largest Hispanic

population in the world following Mexico, Spain, Argentina, and Columbia. This statistic does not include the 3.5 million persons in Puerto Rico, nor the number of undocumented workers (estimated at 3-6 million). In 1996, persons of Mexican origin were the largest Hispanic group in the United States, comprising 63% of the total Hispanic population. Hispanic women comprised 49.4% of the total Hispanic population in the United States (U. S. Bureau of the Census, 1997, 1998).

Although Hispanics represented an estimated 11% of the total United States population, they accounted for 18% of the 641,086 AIDS cases reported in the United States through December, 1997. In 1997, 60, 634 new AIDS cases were reported to the CDC. Of these, 12,466 (21%) occurred among Hispanics. The AIDS incidence rate (the number of new cases of a disease that occurs during a specific time period) among Hispanics was 37.7/100,000 population in 1997, almost four times the rate for whites (10.4/100,000) and almost half the rate for African Americans (83.7/100,000) [CDC, 1998a].

Despite the rapid population growth, little is known about the health needs, health status, and health services use of Hispanic women (Bracho de Carpio, Carpio-Cedraro, & Anderson, 1993; De la Rosa, 1989). The limited information available revealed a large disparity in their socioeconomic and health characteristics compared to Hispanic men or non-Hispanic women in the United States. Giachello (1995) and others (e. g., Lieberman, Stoller, & Burg, 1997; Michaels & Levine, 1992; Rogers, 1997) have argued that urban poverty and the limited culturally appropriate health services available to

Hispanic women are the strongest factors associated with their poor health status.

Hispanic women experience a series of racial and social inequalities. Many poor

Hispanic women are undereducated, experience employment and housing discrimination, and are geographically concentrated in inner city areas.

Hispanic women experienced a series of financial, cultural, and institutional barriers to obtaining health services and unequal treatment once they entered the medical care system (Giachello, 1994). Once Hispanic women entered the medical care system, they found that health services were often middle-class oriented and might be designed around policies and practices that reflected underlying biases and attitudes toward women in general and women of color in particular. The healthcare system in the United States had limited flexibility to meet the needs of populations who may have different illnesses, cultural practices, or languages. Even though acculturation among Hispanic women did occur, in the form of adopting the predominant behavior patterns and language, structural assimilation (gaining access to American institution, including the medical care system for prevention screening, and treatment) continued to be difficult (Giachello, 1988, 1994, 1995).

In a situation of social change, traditional customs and values often become obsolete and individuals are required to adjust to new values and folkways. For some, this change represents a challenge---for others, an overwhelming, disruptive, emotional experience. When efforts to cope with threats and challenges lead to failure, individuals naturally turn to those sources of comfort that were successful in combating unpleasant

circumstances in the pre-change period (Kiev, 1968).

A complex system of beliefs, customs, and traditions exist among Hispanics. These customs have persisted in large part because of the difficulties encountered in becoming a part of American society. These beliefs "make sense" in terms of Hispanic values, attitudes, personality, and conflicts. Furthermore, these beliefs provide a source of comfort when attempting to cope with failure, threats and challenges, and with unpleasant circumstances related to living in a society with different attitudes, values, and lifestyles (Clark, 1959, 1970; Gonzalez-Swofford, & Gutierrez, 1983; Leininger, 1977; Maduro, 1983; Martinez, 1978; Nall & Speilberg, 1967).

Hispanics have been called the "silent or invisible minority" because few researchers have studied their health needs, health status, health beliefs, health-seeking behaviors, and/or family roles (Giachello, 1985; Zambrana, 1987). However, Hispanics have serious health problems that healthcare providers can be instrumental in alleviating. The health problems of this group include diabetes, injuries and violence, substance abuse, HIV/AIDS, limited access to health care, and many other problems shared by the poor and disenfranchised.

By the year 2000, Hispanics will become the "majority of the minority population." Hispanics are expected to outnumber blacks by 2005, making them the largest ethnic minority group. It is projected that by the year 2050, the Hispanic population will account for 25% of the total United States population, up from 11% in 1996 (CDC, 1998b; Department of Health & Human Services, 1995). Learning

culturally sensitive ways may assist healthcare providers intervene effectively with Hispanic clients.

For many Hispanic women, HIV/AIDS can represent an overwhelming disruptive emotional experience. When efforts to cope with new threats and challenges lead to failure, individuals naturally turn to those sources that provide comfort and "make sense." No research was found related to cultural influences and folk health practices of Hispanic women affected by the disease. Research needs to tap into these sources to help nurses and other healthcare providers to "make sense" of this disease. This knowledge may enable them to assist Hispanic women obtain healthcare, decrease the risk of HIV transmission, and create new healthcare systems targeted to these women so that they may have an improved quality of life and be able to care for their children and families.

In reference to this issue, Antonia C. Novello, MD, former U. S. Surgeon General stated:

When we talk about improving data collection strategies, it means responsiveness to all ethnic groups and subgroups and accountability to the truth. It means that our population of 22 million people needs to be accounted for and counted in. It means getting comprehensive data, identifying what is and is not appropriate, and making accurate assessments and reasonable predictions about the real status of Hispanic/Latino health. Developing a comprehensive research agenda goes hand in hand with collecting better data. We cannot expect to understand where we are headed and where we ought to be in terms of health until we understand first, where we are today. It means finding a way by which we benefit from what science has to offer by tailoring its benefits to our needs. It means focusing on the diseases that kill us and putting priorities on research aimed at Hispanics/Latinos and other minorities.... (U. S. Office of the Surgeon General, 1993, p. 11).

Health seeking behaviors of HIV⁺ Hispanic women need further study to understand how access to care is influenced by culture and folklore. When there is little to no information about a complex social phenomenon, qualitative research methods are appropriate (Leininger, 1985). Qualitative methods are used when there is little to no knowledge about a phenomenon "to identify recurrent or patterned life ways of people" (Leininger, 1985, p. 40) and to provide rich detailed accounts of complex data. The qualitative approach, with analysis by the logic of grounded theory, may help discover folklore (e.g., health/illness beliefs, body humors, dislocation of body parts, diseases of emotional state, magico-religious practices) and health practices of HIV⁺ Hispanic women. Knowing how beliefs and orientations guide practices will help formulate a substantive theory (Glaser & Strauss, 1967) of folklore and health practices of HIV⁺ Hispanic women.

Research Questions

This review brought to the forefront some questions that this study would initially attempt to answer related to HIV⁺ Hispanic women, their health practices, and folklore:

1. What are the folk care activities that HIV⁺ Hispanic women incorporate into their everyday lives?
2. How do HIV⁺ Hispanic women incorporate traditional Western medical practices with their folk care activities?

In a qualitative study, research questions are posed at the beginning however, the final questions are written from the findings after the data are analyzed (Leininger, 1985).

The research questions are broad, and specific variables are not identified as these will come from the data.

Summary

The purpose of this study was to explore folk health practices of HIV⁺ Hispanic women. The design was based on the grounded theory methodology as described by Glaser and Strauss (1967). This method is used when a researcher is interested in providing a study of the processes that occur as individuals interact with others in a social setting in response to life circumstances. Grounded theory employs an inductive, from the ground-up approach. Findings are analyzed using the logic of grounded theory. The results of this study may assist nurses to understand from the perspective of the HIV⁺ Hispanic woman, how they incorporate folkcare activities and traditional Western medicine into their daily lives as they live with this disease. This information may assist nurses to develop healthcare with this population in mind so as to decrease the rate of HIV transmission and improve the quality of life for Hispanic women who are HIV infected.

CHAPTER 2

REVIEW OF THE LITERATURE

Women, the minority population in the HIV pandemic, are fast becoming one of the highest subgroups to be infected and affected by the disease (Pizzi, 1992). HIV infection in women is a problem of growing magnitude and concern in the United States. Women constitute the fastest growing group of people with AIDS, a disproportionate number being poor minority women, with Hispanic women leading in those cases (National Center for Health Statistics, 1995; Peragallo, 1996; Phillips, 1997; Wortley & Fleming, 1997). This review of the literature includes Hispanic culture and beliefs, access and quality of healthcare, women with HIV, and Hispanic women with HIV.

Hispanic Culture and Beliefs

Culture functions as a guiding framework and assists individuals to interpret their life experiences. "Culture refers to a way of life belonging to a designated group of people; it may be viewed as a blueprinting for living which guides a particular group's thoughts, actions, and sentiments; it is a product of current responses to various life problems" (Leininger, 1970, p. 48-49). A complex system of beliefs, customs, and traditions persists among Hispanics. These customs have remained in large part because of the difficulties encountered in becoming a part of American society. As an impoverished, illiterate, immigrant, and minority group with a rural, agrarian

background, they have been isolated from the mainstream of modern life and have developed their own subcultural world with many features of the culture of poverty. These beliefs persist because they "make sense" in term of Hispanic values, attitudes, personality, and conflict.

Several early studies (Clark, 1959, 1970; Gonzalez-Swofford & Gutierrez, 1983; Leininger, 1977; Maduro, 1983) of the Mexican-American culture reported that Mexican-Americans believe in certain fundamental holistic concepts that integrate the body, mind, and spirit to form the basis of many cultural health/illness beliefs. Clark (1959) first described the folk health practices of Mexican-Americans in Sal Si Pudes, California, a community of seventy families. Clark and a team of researchers conducted open-ended interviews of persons with representative characteristics of the Mexican-American population and conducted informal but intensive observations of family and community life. Sixty-five percent of the families ($n=46$) were surveyed in the ethnographic census, and 20% ($n=14$) were interviewed intensively. The results of these interviews and observations led to the classification of folk-health beliefs of the Mexican-American community.

Although the barrio people had no clear cut classifications of pathologies, diseases well known to them were grouped for the purpose of organization into the following categories: (a) diseases of "hot and cold" imbalance, (b) diseases of dislocation of internal organs, (c) diseases of magical origin, (d) diseases of emotional origin, (e) other folk-defined diseases, and (f) "standard scientific" diseases. Beliefs and

customs regarding pregnancy, childbirth, and infant care directly influenced maternal and child health practices. Customs and beliefs about food affected nutrition. Family authority and attitudes toward the aged determined when one was free to seek and receive medical attention. Furthermore, family relationships were thought to influence personal adjustment and mental health (Clark, 1959, 1970).

Some sources (e.g., Kay, 1981; Welch, Comer, & Steinman, 1973) maintained that health is considered to be purely the result of "good luck" and that people will lose their good health if their luck changes. Health is described as a reward for good behavior. Health is a gift from God and should not be taken for granted. People are expected to maintain their own equilibrium in the universe by performing in the proper way, eating the proper foods, and working the proper amount of time. The prevention of illness is an accepted practice that is accomplished with prayer, the wearing of religious medals or amulets, and keeping relics in the home. Herbs and spices can be used to enhance this form of prevention, as can exemplary behavior.

Illness is seen as an imbalance in an individual's body or as punishment for some wrongdoing. The causes of illness can be grouped into five categories: (1) body imbalance (diseases of hot and cold imbalances), (2) dislocation of body parts or internal organs, (3) diseases of magic or supernatural causes, (4) diseases of emotional origin, and (5) envidia (envy) (Spector, 1991, 1996). Knowledge about these imbalances may provide information to cure.

The body's imbalance may exist between "hot" and "cold" or "wet" and "dry."

The theory was brought to Mexico by Spanish priests and fused with Aztec beliefs. The concept dates back to the early Hippocratic theory of disease and the four body humors. The disrupted relationship among these humors often is mentioned as the cause of illness. There are four body fluids of humors: (1) blood - hot and wet, (2) yellow bile - hot and dry, (3) phlegm - cold and wet, and (4) black bile - cold and dry. When all four humors are balanced, the body is healthy. When an imbalance occurs, an illness is manifested. These concepts may therefore provide a way of determining the remedy for a particular illness. Illnesses believed to be "hot" are treated with "cold" remedies, while "cold" illnesses are treated with "hot" remedies (Clark, 1959; Currier, 1966; Spector, 1991).

In dislocation of body parts, the disease state is attributed to malposition of internal parts. Varicosities, ganglions, "empacho," and "caida de la mollera" (fallen fontanelle) are in this category. The most common of these disorders is "caida de la mollera" (fallen fontanelle). This is a serious illness that occurs in infants and young children most often under the age of one year who are dehydrated for some reason (usually because of diarrhea or severe vomiting) and whose anterior fontanelle is depressed below the contour of the skull (Arenas, Cross, & Willard, 1980; Clark, 1970; Spector, 1991; Trotter & Chavira, 1980). "Empacho" is an infirmity of both children and adults that occurs when a bolus of poorly digested or uncooked food becomes lodged in the wall of the stomach or the intestinal tract and causes sharp pains. Treatment of this illness includes pinching and lifting the skin while listening for a snap from the abdominal region. This is repeated several times in hopes of unseating the offending

material (Gonzalez-Swofford & Gutierrez, 1983; Martinez & Martin, 1978).

Witchcraft or possession is considered to be culturally patterned role-playing, a safe vehicle for restoring oneself. Witchcraft or possession (*mal puesto* or *embrujo*) refers to illness or evil that is inflicted purposefully by someone. Acting out bizarre behavior or engaging in incoherent speech are legitimized by witchcraft possession. "Mal aire" (bad air) is a cultural belief that evil spirits or other forces are in the air and that under certain conditions are able to possess an unsuspecting victim. A disease that is caused from outside the body is "mal ojo." "Mal ojo" or evil eye is believed to result from excessive admiration on the part of another. The folk treatment is to find the person who has caused the illness by casting the "bad eye" and have he/she care for the afflicted person. Mal ojo can be prevented if the admirer will touch the person after admiring. A person wearing an amulet "ojo de venado" or eye of the deer can ward off "mal ojo" (Clark, 1970; Gonzalez-Swofford & Gutierrez, 1983; Kay, 1981; Maduro, 1983; Rubel, 1964; Spector, 1991).

In diseases of emotional state, "susto" (fright) is described as an illness arising from fright. It involves soul loss---the soul is able to leave the body and wander freely. "Susto" can occur while a person is dreaming or when a person experiences a particularly traumatic event. The symptoms of the disease are: (a) restless while sleeping, (b) listless, anorexic, and disinterested in personal appearance, which includes both clothing and personal hygiene, and (c) loss of strength, depression, and introversion. The person is treated by a *curandero* (a folk healer) who coaxes the soul back into the body (Clark,

1983; Gonzalez-Swofford & Gutierrez, 1983; Maduro, 1983; Rubel, 1964; Spector, 1991).

"Envidia," or envy, is considered to be a cause of illness and bad luck. Many people believe that to succeed is to fail. That is, when success provokes the envy of friends and neighbors, misfortune to self and family can occur. There are a number of social scientists who, after much research, conclude that the "low" economic and success rates of the Mexican-Americans can ostensibly be attributed to belief in "envidia" (Kiev, 1968; Maduro, 1983; Spector, 1991, 1996).

Magico-religious practices are common among the Hispanic population. The more severe an illness, the more likely that these practices will be observed. There are four types of practices: (1) making promises, (2) visiting shrines, (3) offering medals and candles, and (4) offering prayers (Martinez, 1978; Nall & Speilberg, 1967). The spiritual beliefs of Hispanics are rooted primarily in the Catholic tradition. These beliefs include the importance of prayer and participation in Mass. Yamamoto & Acosta (1982) found that this belief related to the view that: (a) sacrifice in this world will lead to salvation, (b) charity is a virtue, and (c) one should endure wrongs done against them.

The belief in the Virgen de Guadalupe, has a major influence on Hispanic families and is a source of comfort in times of stress. Promises to saints and/or the Virgen de Guadalupe are made for curing of illness or relief of family problems. Shrines to the Virgen de Guadalupe and other saints are devoted to commemorating the miracles resulting from these promises (Krippner, & Villaldo, 1976, Spector, 1996).

Curanderismo is defined as a medical system. It is a coherent view with historical roots that combine Aztec, Spanish, spiritualistic, homeopathic, and scientific elements (Edgerton, Karno, & Fernandez, 1978; Madsen, 1970; Maduro, 1983; Slesinger & Richards, 1981). There are no specific rules for knowing who uses the services of folk healers. Not all Hispanics do, and not all Hispanics believe in their precepts. Initially, it was thought that only the poor used a folk healer, or curandero, because they were unable to get treatment from the larger, institutionalized healthcare establishments. However, it now appears that the use of healers occurs widely throughout the Hispanic population. The people who seek help from healers do so for social, physical, and psychological purposes. Some people try to use healers exclusively, whereas others use them along with institutionalized care (Spector, 1991, 1996).

The most popular form of treatment used by folk healers involves herbs, especially when used as teas. Massage is used in illnesses of body imbalance. Cleanings, or limpias, are done by passing an unbroken egg, or herbs tied in a bunch, over the body of the ill person. In contrast to the depersonalized care a Hispanic expects to receive in medical institutions, the relationship with and care by the folk healers are uniquely personal.

A strong belief in family, spirituality, and the importance of interpersonal relationships is common among Hispanics (Adams, Briones, & Rentfro, 1992; Caudle, 1993; Simoni & Perez, 1995). The extended family includes not only blood relatives but also non-blood relatives such as the best man or godfather (padrino), maid of honor or

godmother (*madrina*) and co-parents (*compadre* and *comadre*) (Marin, 1989). The extended family often is seen as a resource, and care is not always sought until advice is obtained from the extended family and friends (Valdez et al., 1991). Family problems including health issues are resolved within the family with the Hispanic woman, usually the mother, as the primary care giver. She usually decides when care should be sought (Gonzalez-Swofford & Gutierrez, 1983). When she cannot treat the illness she seeks outside advice.

The traditional role of the Hispanic woman is to be submissive to the male, self-sacrificing, and restrained. Gil and Vasquez (1996) defined this role of the Hispanic woman by the term "*marianismo*" which means virgin-like, using the Virgin Mary as the ideal role model. *Marianismo* is about sacred duty, self-sacrifice, and chastity. This role is handed down from generation to generation. "The Maria Paradox," a phrase termed by Gil and Vasquez (1996), further defines *marianismo* whereby women feel obligated to sacrifice self for family. The positive attribute sees this self-sacrificing role as empowering the Hispanic woman to seek services for the family and speak up for her children in school settings. The negative attribute centers around self-sacrificing to the point of not caring for self, prolonging healthcare, and enduring abuse by spouse, relatives, and/or community (Williams, 1990; Williams, Shahryaninejad, Andrews, & Alcabes, 1997).

Machismo, the other side of *marianismo*, defines the Hispanic male. *Machismo* also has both positive and negative attributes. The positive attribute sees the male in the

family as a courageous, honorable provider for his family. The negative attribute centers around absolute power in the form of exploitation, self-centeredness, and violence used to maintain power through fear (Gil & Vasquez, 1996; Tamez, 1981).

Cultural influences play a major part in how Hispanics make decisions about healthcare. Their decisions are guided by beliefs in holistic concepts that integrate the body, mind, and spirit. While the traditional role of the Hispanic woman is to be submissive to the male, the Hispanic woman is the primary care giver and resolves most of the family problems, including health issues. The primary caregiver, usually the mother, decides when to seek care and outside advice is sought only when she can not treat the illness. Depersonalized care is a major reason why Hispanics delay seeking or receiving medical care.

Access and Quality of Healthcare

Even though Hispanics have a shorter life expectancy, higher mortality, and more infectious and parasitic disease than white non-Hispanics, conventional medicine in the United States cannot win over the confidence that is needed to achieve quality patient care in the Hispanic culture (Caudle, 1993; Kraut, 1990; Naranjo & Dirksen, 1998). Kraut (1990) noted that the lack of communication and poor understanding between client and doctor led to decreased confidence in prescribed treatment modalities. Others expressed dissatisfaction because the physician's definition of their illness did not correspond with their definition; still others felt that their expectations of the doctor's contribution to recovery from the illness were not met.

Continuity of care is important as Hispanics often prefer, sometimes vehemently, to have the same physician/nurse/therapist provide their care over time (Cornelius, 1997). A consequence of the respect afforded to healthcare providers by many Hispanic individuals is the hesitancy to ask questions, express doubts about the treatment provided, or disagree with the healthcare professional. Many avoid admitting confusion regarding instructions of treatment regimen. In addition, there is a taboo regarding the direct expression of negative feelings. As a result, the individual may withhold information, be noncompliant, or terminate medical care (COSSMHO, 1988). Simoni & Perez (1995) found that Hispanics with a strong traditional orientation had difficulty being open and self-disclosing during counseling. This may be one reason for the level of secrecy in a family towards a disease such as HIV/AIDS.

Ray (1990) studied 3,600 Mexican-Americans needing medical attention and found that 4.2% ($n=151$) consulted a provider of folk medicine and/or used natural herbs and spiritual practices before attempting to access a health facility. Access to a public facility for healthcare was considered as a last resort. This was related to cultural orientation and dissatisfaction with Western medical care, not income and availability of services. Thereby, Hispanics will continue to view medicine as their ancestors did, that illness is nothing more than a spiritual existence that arises in threatening times (Beltran, 1980).

People of various cultures have different beliefs about causes, diagnosis, and treatment of illness (Jackson, 1993). Based on the teachings of their culture, women

have reasons for their health practices. Once Hispanics determine the illness resulted from natural causes, the condition is seen as curable and harmless. The concept is reinforced by the belief that disease is the will of God. If the disease is thought to be incurable, the cure rests outside the natural world in the supernatural realm (Spector, 1991, 1996).

Hispanic women think in terms of one of three kinds of treatment: (1) home remedies, prescribed by either knowledgeable housewives or curanderos(as), (2) over the counter medicines available at drug stores, and (3) prescriptions for antibiotics and other medications provided by healthcare professionals. Ground herbs or vegetables are used in home remedies to ward off illness, while over the counter medicines are used to treat mild illnesses (Gonzalez-Swofford & Gutierrez, 1983).

The health beliefs of some ethnic groups can be distinct from, and conflict with those of most American healthcare providers (Flack et al., 1995). Nurses base their teachings on their culture of origin with superimposed professional "scientific" culture beliefs. Nurses enter the healthcare arena with expectations of health behaviors. When the nurses' expectations and Hispanics' practices clash, culture shock occurs, leads to power struggles, and withdrawal from care on the part of the client (Stern & Harris, 1985).

Women with HIV

According to the National Center for Health Statistics (1995) women are fast becoming the highest subgroups to be infected. During the second decade of the AIDS

epidemic the number of women infected with HIV dramatically increased. The CDC (1997b) reported that the number of United States AIDS cases occurring among women from 1985-1996 increased nearly threefold from 7% to 20%.

Minority women are dramatically over-represented among the AIDS cases reported to the CDC in 1996. Most women infected with HIV were women of African American or Hispanic-American descent (Bunting, 1996; Rogers, 1997, Ward & Duchin, 1997). Black and Hispanic women accounted for 21% of all women in the United States. They made up 45% and 20% of cumulative AIDS cases among women respectively (CDC, 1997b).

The median age of women with AIDS was 35 years, with women ages 15 to 44 accounting for 84% of the cases (CDC, 1997a). AIDS is a leading cause of death for women 25 to 44. AIDS related deaths reported in the United States accounted for twelve times as many black women than whites in 1992 and ranked third as the cause of death for Hispanic women age 25 to 44 (Levy, 1995). According to the CDC (1997b), in 1996, AIDS death cases declined in men by 15% and increased among women by 3%.

Heterosexual contact was reported as the greatest source (66%) of infection among women with AIDS (CDC, 1995). Thirty-six percent of women with AIDS reported heterosexual contact with a partner who had or was at risk for HIV/AIDS. Sexual contact constituted an even greater risk for young women. Fifty three percent of young women 13 to 19 and 50% of women 20 to 24 reported heterosexual contact as their risk factor.

Many of these women had poor access to health care and often sought care late in their diagnosis of AIDS. Sowell et al. (1996) in a focus group study of 46 women with HIV, identified eight distinct categories of perceived barriers to care. These were: (1) lack of knowledge on the part of health care providers, (2) fear of negative treatment, (3) insensitivity of health care providers, (4) fear by providers, (5) lack of patient education, (6) lack of confidentiality, (7) lack of honesty, and (8) blaming the victim. Because of these access problems many of the women often received misinformation about HIV/AIDS and underestimated personal risk (Amaro, 1995; Kalichman, Hunter, & Kelly, 1992; Kline et al., 1992).

The majority of these women were single heads of households with dependent children. Their roles as family caregivers often resulted in delayed attention to their own health. They frequently were stigmatized for drug use, race, and poverty (Cohen & Nehring, 1994; Weiner, 1991). These behaviors impacted on the women's willingness to accept or continue treatment for HIV infection.

Cohen & Nehring (1994) noted that single HIV⁺ women, heads of households, often avoided planning for their children due to denial or stressors of the illness. Due to this lack of planning many children were left in foster care when there was no extended family network to assume care of these children when orphaned. Many of these children were HIV-infected. They also reported that there were 1,149 HIV⁺ children in foster care in 1991, and the numbers were estimated to increase dramatically.

The impact of HIV/AIDS is particularly great on women for four reasons: (1)

Stereotypes related to HIV/AIDS have meant that women are either blamed for the spread or not recognized as potential patients with the disease; (2) women are at an increased risk of exposure to HIV infection for reasons related indirectly and directly to their gender; (3) the psychological and social burdens are greater for women than for men in a similar situation; and (4) women's frequently low socioeconomic status and lack of power make it difficult for them to undertake prevention measures (Vera, 1996). The consequences can be: (a) delayed diagnosis and treatment, (b) stigmatization, (c) loss of income, and (d) violation of human rights. Problems related to pregnancy and motherhood, rejection as marital partners, loss of security and income, and greater demands to cope with the effects of the epidemic are experienced by HIV⁺ women.

Women, increasingly affected and infected by HIV, reported heterosexual contact as the greatest source of infection. Stigmatization, race, and poverty impacted women's willingness to accept or continue treatment for HIV infection. Misinformation and underestimated personal risk were primary in women delaying care after their diagnosis. AIDS has become the leading cause of death for women 25 to 44.

Hispanic Women with HIV

Hispanic women are believed to be at greatest risk for HIV infection and AIDS (Barken et al, 1998). Behavioral, cultural, and environmental factors have been suggested as sources for the higher risk of heterosexual transmission of the disease (Diaz et al., 1993; Weeks, Schensul, Williams, Singer, & Grier, 1995). Hispanic women have cultural beliefs and values that place their family's health over their own. Hispanic

women compared to white women also differ in having lower condom use (Deren, Shedlin, & Beardsley, 1996; Marin et al., 1993), greater reluctance to suggest condom use to male partner (Amaro, 1995; Anastasio, McMahan, Daniels, Nicholas, & Paul-Simon, 1995; Organista, Organista, & Soloff, 1998), and less confidence about avoiding HIV (Hines, & Graves, 1998; Marin et al.).

The high incidence of bisexuality found among Hispanic men (CDC, 1993) puts Hispanic women at greater risk for HIV transmission. Salgado de Snyder et al. (1996) in a study of migrant workers, found that Hispanic men who engage in male-to-male sex do not regard themselves as homosexual, or even bisexual. Acceptance of this practice is dependent on the man assuming the dominant role (insertive v.s. receptive). Fulfilling his "masculine," i.e., heterosexual role and providing for his family and home, overshadows the stigma that could be attached to such behaviors and practices. Furthermore, extramarital sexual activity among Hispanic males is sanctioned culturally.

Simoni, Mason, Marks, Ruiz, & Richardson (1995) in a survey of 65 ethnically diverse women who were HIV⁺ found that Spanish-speaking Hispanics were less likely to disclose their serostatus or discuss HIV-related worries with others than were English-speaking Hispanics, African-Americans, and Anglo-Americans. Participants uniformly expressed concern about disclosing their HIV status because of the expected and feared negative responses from others. Their concerns included discrimination and loss of confidentiality.

Hispanic women face many factors that put them at greater risk for HIV infection

and AIDS. Heterosexual transmission is reported as the greatest source of infection due to behavioral, cultural, and environmental factors. Placement of family's needs over her own and fear of disclosure are reported as factors for delaying care. As a rising group affected by this disease, Hispanic women's access to care must be improved.

Summary

Findings of the research studies presented demonstrated that there is a need for continued research in the area of women with HIV/AIDS but most importantly Hispanic women with HIV/AIDS. Much of the research has been related to the prevention of HIV/AIDS and very little has been devoted to those affected. Furthermore, very little research was found related to cultural influences and folk health practices of women affected by HIV. For many, this disease represents an overwhelming disruptive emotional experience. When efforts to cope with new threats and challenges lead to failure, individuals naturally turned to those sources that provided comfort and "made sense." Research needs to tap into these sources to help "make sense" of this disease and assist women to obtain the healthcare they need.

CHAPTER 3

METHODOLOGICAL APPROACH

The purpose of this study was to explore folk health practices of HIV⁺ Hispanic women. The design was based on the grounded theory methodology as described by Glaser and Strauss (1967). Grounded theory is appropriate in "investigations of relatively uncharted waters, or to gain a fresh perspective in a familiar situation" (Stern, 1980, p. 20). This qualitative method is used when there is an interest in social processes from the perspective of human interactions. The aim of the grounded theory approach is to discover underlying social forces that shape human behavior and to discover the meanings of these situations to generalize responses and integrate categories of responses into theory grounded in data (Glaser & Strauss, 1967).

Following the grounded theory method, data were obtained through interviews and observations of individuals interacting in a social setting. The major feature of the grounded theory method was that data collection and analysis occurred simultaneously. This process required systematic detailed record keeping using transcribed interview tapes and field notes. Hunches about emerging patterns in the data were notes in memos, and the researcher directed activities in the field by pursuing these hunches. The technique for the selection of the population was theoretical sampling (Glaser & Strauss, 1967). The interest was in gathering data about what persons do or do not do to identify,

develop, and relate concepts that proved theoretical relevance to the evolving theory.

The women were interviewed individually and the interviews audiotaped. The researcher made notes before, during, and after the interview to record observations and impressions of the social context. Data were analyzed prior to subsequent interviews. The researcher left open the option to return to the interviewee for clarification of data after analysis. The researcher also clarified data with an expert researcher and an expert in the area of study.

Symbolic interactionism (SI), described by sociologists Mead (1934) and Blumer (1969), provided the philosophical foundations for grounded theory and guided the research questions, interview questions, data collection, strategies, and methods of data analysis (Stern, 1980, 1985; Stern, Allen, & Moxley, 1982; Hutchinson, 1993). SI, a social-psychological theory of social action, is organized around the self, the world, and social action, and suggests that individuals order their world by use of symbols to interpret and identify meaning in situations. The self and the world are socially constructed, and as such, they are ever changing through processes of social interaction. Thus SI focuses on the acting individual (the actor) whose social self is emerging through interaction with society. Individuals share meanings and create them to make sense of their world. The meanings communicated, individuals and their actions cannot be understood out of the social context being studied. Within SI, society includes persons, organizations, events, and objects and is described as ordered, unified, and evolving. Interactions and symbols that describe stages and phases within an experience can change

over time (Blumer, 1969).

Grounded theory, an inductive, descriptive research method, was used to find meaning in social and psychological processes. Grounded theory research is aimed at understanding how a group of people define their reality via social interactions (Stern, 1980). Through relationships to self and society, reality is co-constructed. Reality is not static, but is in evolution as the person interrelates with self and society (Chenitz & Swanson, 1986). The goal of grounded theory is to discover meaning in situations and to generalize responses. Interpreting and extracting meanings in situations allows people to make sense of the world and share meanings with others (Glaser & Strauss, 1967).

In spite of the increasing reliance in physicians and traditional Western medicine, significant barriers to utilization of healthcare still exist. Hispanics are known to turn to the family first then to the healthcare system. When they do seek healthcare, their feelings about the system are usually negative (Valdez et al., 1991). Analyzing the symbols that the HIV⁺ Hispanic women use and how they are used within the social context of the experience may help understand the nature of the problem.

Many valid reasons exist for doing qualitative research. One reason is the conviction of the researcher based on experience. Another is the nature of the research problem. Some areas naturally lend themselves more to qualitative types of research, for example, research that attempts to uncover the nature of a person's experiences with phenomena, such as illness, religious conversion, or addiction. Qualitative methods can be used to uncover and understand what lies behind any phenomenon about which little is

yet known or it can be used to gain novel and fresh slants on things about which quite a bit is already known.

Grounded theorists search for social processes present in human interaction. Grounded theories may be formal or substantive. Formal theories address a conceptual level of inquiry, such as status passage, negotiations, socialization, or stigma. Substantive theories are generated for a specific, circumscribed, and empirical area of inquiry, such as patients in an alternative treatment setting, pre-hospital care, patients recovering from a heart attack, or dying patients (Hutchinson, 1993).

Since this study was to identify folkways and health practices of HIV⁺ Hispanic women to assist healthcare providers build healthcare with them in mind and to decrease the risk of HIV transmission, the grounded theory method was most appropriate. The incorporation of folkways with traditional Western medicine by HIV⁺ Hispanic women in response to their serostatus and impacted by their pregnancy emerged as a substantive theory. A conceptual explanation of how the HIV⁺ Hispanic woman chooses to use folkways and live her life after the affirmation of her status emerged to explain the basic sociological process.

Setting

Participants were selected from clients of an outreach center in a large metropolitan city. A prevention and education organization focusing on HIV/AIDS, reproductive rights, family planning, and other health issues, the center was opened in 1992. The city is estimated to be 56% Hispanic, while Hispanic women comprise 30%

of the state's total female population (Texas Department of Health and Human Services, 1996). According to the Texas Department of Health (1997), Hispanics comprised 46% of the total AIDS cases in that county, with 7.6 AIDS cases reported and 5.8 diagnosed in the city weekly.

Population and Sample

HIV⁺ Hispanic women attending the support group and/or the alternative therapy group sessions at the center comprised the sample. For the purpose of this study, Hispanic was defined as Mexican-American, Mexican-national, and/or Puerto Rican. Theoretical sampling (Glaser & Strauss, 1967) was used to identify respondents from those present at the meetings. Theoretical sampling is a method of selecting "the best informant who is able to meet the informational needs of the study" for the purpose of generating new theory (Morse, 1989, p. 117). Respondents chosen in this way are "theoretically representative of the culture, role or position needed for the study" (Brink, 1989, p. 157).

Potential respondents were selected from those present at the weekly group sessions. Selection criteria were that respondents be HIV⁺ Hispanic women and willing to participate in the interviews. The women chosen communicated with the researcher by responding to open-ended questions and by completing the written informed consents. All the women who were approached and that consistently attended the group and/or alternative therapy session, agreed to be in the study. Some of the women however, put off the interview for as long as 4-6 weeks. One respondent rescheduled three times

before she made the interview. Two respondents requested to be interviewed at home. Ten women who did not come to the sessions consistently, but were part of the agency's case load were approached via phone. All declined, stating they feared loss of confidentiality or disclosure.

According to Glaser & Strauss (1967), the number and types of groups from which to collect data cannot be cited. Selection of samples continued until theoretical saturation (Hutchinson, 1993) occurred. Saturation refers to completeness: a code is saturated if the researcher can answer, via the data, questions regarding the cause, context, and consequences of the particular code. No new conceptual information is available to indicate new codes or the expansion of existing ones. One can fit the code in the theory. "Fit" as described by Glaser & Strauss (1967) means that the categories must be readily (not forcibly) applicable to the data under study.

Data collection was guided by theoretical sampling (Glaser & Strauss, 1967). Theoretical sampling was driven by emerging categories from results of data collection and analysis. The researcher used flexibility when planning the sampling methods for consecutive interviews to enable the generation of as many categories as possible to explain the phenomenon (Glaser, 1978). Theoretical sampling continued until the researcher could specify with confidence that no new categories emerged and the categories were dense in grounded data (Strauss & Corbin, 1990). When the researcher discovered no new data or emerging categories, the data collection ceased.

A final sample of nine was chosen to examine this phenomenon. Theoretical

sensitivity (Glaser, 1978) was used to make the final decision on sample size.

Theoretical sensitivity refers to the researcher's awareness of the data. This awareness comes from experience and the literature. During the analytical process, insight and understanding increase about the phenomenon as the researcher interacts with the data.

Theoretical sensitivity is the ability to recognize what is important in data, give it meaning, and helps formulate theory that is faithful to the reality of the phenomena under study.

Data Collection

Approval for this study was obtained from Texas Woman's University Human Subjects Review Committee (Appendix A) and from the outreach center (Appendix B). The respondents were protected from breach of confidentiality (all data, tapes, and transcripts were identified by a code known only to the researcher and kept in a locked cabinet). The respondents were protected from potential physical or psychological harm (informed consent, consent to audiotape, privacy during interview). Written consent forms to participate in research (Appendix C) and permit to audiotape (Appendix D) were obtained from each respondent prior to the interview. Consents were obtained in English or Spanish, the respondents choice of language. The interview was also conducted in the language of their choice. Two respondents chose to be interviewed in Spanish. All were given the name and phone number of the researcher.

After approval was obtained from both the University and the outreach center, meetings were conducted with the staff to explain the purpose and methodology of the

study. The center was visited and the support and alternative therapies group sessions were attended to become familiar with the conditions of this specific social situation. Continued attendance at the sessions helped gain the women's confidence, win their trust, and make observations.

The women identified through theoretical sampling were approached on an individual basis in private and asked to participate in the study. They were told the interview would last 45 minutes to an hour. Participation was voluntary and there was no penalty for choosing not to participate. They could terminate the interview at any time. They could also refuse to answer any of the questions. The women were interviewed in private rooms. The women signed consents prior to the onset of the data collection. Code numbers were recorded on all forms and audiotapes.

An Interview Guide (Appendix E) was used to obtain demographic data and to structure the interview. Data collection proceeded as follows: (1) Sociodemographics such as age, marital status, and ethnicity were collected. (2) The tape recording was started. (3) The semi-structured interview was begun with a general world view question such as: "Tell me, What did you do today to stay healthy?" (4) Probes were used to collect further data on the topics introduced by the respondents. (5) Observations were recorded as field notes. (6) Audiotapes were transcribed verbatim within 24 hours. And (7) interviews were analyzed within 24 hours of the transcription.

Data Analysis

Each audiotaped interview was transcribed verbatim by the researcher within 24

hours and content of the field notes were added. Using the logic of grounded theory (Glaser & Strauss, 1967), transcripts were coded and categorized, then analyzed as interviews were completed. Sociodemographics were reviewed and listed in chart form to reveal similarities and differences. These data were descriptive and reported by mean and range. The entire verbatim transcript was reviewed by reading the transcript while listening to the audiocassette. Common themes were identified and recorded in the respondent's own words in theoretical memos. Themes and statements were grouped together. Field note data were used to compare observed with verbalized data. Transcripts were recoded several days later and the results compared with the first coding. Repeated coding, yielding the same results, supported the reliability of the study. Reliability refers to consistency in the data. If another researcher with the same background were to interview HIV⁺ Hispanic women, the data analysis should show same or similar content and yield the same codes and categories.

Using the constant comparative technique consistent with the grounded theory approach (Glaser & Strauss, 1967), categories were identified with examples to support each category. Interviewing continued until all categories and subcategories were saturated and no new data emerged from the interviews. Patton (1980) stated that saturation occurs when the categories appear to be complete and analysis shows that data extend beyond the boundaries of the study; the linkages between categories should tell a story.

Credibility, plausibility, and trustworthiness are terms used by Glaser & Strauss

(1967) to describe the outcomes of research. Since the outcome of grounded theory research is dependent upon the entire process, reliability and validity were involved not only during data collection but also during analysis as well. To obtain credibility, fit was established. Fit was attained by the researcher by making sure that the respondents added additional data to the emerging theories by doing mental checks. Data analysis and emerging categories were checked with another researcher as well as experts in the area of study such as caseworkers, therapists, and the curandero(a) to avoid bias.

Generativity was established by use of theoretical sensitivity. Saturation of emerging categories was a way of guaranteeing the applicability of the theory into other areas. The more categories identified, the more generality can be insured. When the theory can be applied and adjusted to many situations with sufficient exactitude to guide thinking, understanding, and research, it is said to be plausible (Glaser & Strauss, 1967). Control of consequences or changes toward the outcome of the study can and is established once actions can be guided by the theory (Strauss & Corbin, 1990).

Convinced that the theory was a reasonably accurate statement of the matters studied, and that it was in a form possible for others to use in studying a similar area, then the research ended. Trustworthiness was demonstrated as special pains were taken to discover the data, the data were believable, and there was no reason to change that belief. Further mining of the data is of little value when core categories are saturated (Glaser & Strauss, 1967).

Summary

An exploratory, qualitative study was conducted to identify folklore and health practices of HIV⁺ Hispanic women. Grounded theory was used to investigate social processes present in human interaction in an attempt to identify folkways and health practices of HIV⁺ Hispanic women. Data obtained may assist healthcare providers to develop healthcare for HIV⁺ Hispanic women and help to decrease the transmission of HIV.

Theoretical sampling was used to select the best informants to meet the informational needs of the study. Selection of samples continued until theoretical saturation occurred. All respondents were protected from potential physical or psychological harm. Using the logic of grounded theory, data analysis was completed. The goal of this analysis was to discover the behaviors and social processes involved as HIV⁺ women attempted to care for themselves.

CHAPTER 4

ANALYSIS OF DATA

Culture functions as a guiding framework and assists individuals to interpret their life experiences. People of various cultures have different beliefs about cause, diagnosis and treatment of illness. Women, themselves a culture, have reasons for their health practices. Hispanic women guided by a complex system of beliefs, customs and traditions, and the driving force of being a woman have distinct reasons for their health practices. This chapter explores and describes the way cultural influences and folk health practices of Hispanic women affected with HIV/AIDS are used to live with the disease. Nine Hispanic women participated in this study. Demographics collected of study participants included age, marital status, educational level, number of children, and ethnic background (see Table 1). All of the participants were in a heterosexual relationship at the time of affirmation of HIV diagnosis. Most participants related HIV transmission from husband or long-term partner. One participant was the victim of date rape. Most of the participants identified Supplemental Security Income (SSI) as their means of support. One participant was working part-time while waiting approval of her SSI application. Another participant had been denied SSI but was in the process of asking for an appeal. Her husband worked odd jobs and received SSI to support the family. All of the participants had access to healthcare. Most of the participants had

Table 1

Demographics of Study Participants

N = 9

Age:

M = 31 years
Range: 19 - 41 years

Educational level:

M = 11th grade
Range: 6th grade - College graduate

Children at home*:

M = 3 children
Age Range: 2.5 months - 18 years

Marital status:

Married	Single	Divorced	Widowed**
3	2	2	2

Ethnic background:

Mexican-American	Mexican-National	Puerto Rican
4	2	3

Note:

* One participant had 3 older children not living at home ages 17, 20, and 22.
Two participants had lost a child to AIDS.
One participant lost both her husband and child to AIDS.

** Husbands died of AIDS

their status revealed to them during pregnancy. One participant was being treated for a long term gynecological problem. None of the participants described having extended family members living with them. The findings are organized around the core variable of La Protectora (The Protectress). For purposes of maintaining privacy and confidentiality, all names are pseudonyms, and minor identifying details have been changed for this report.

Findings: La Protectora

The traditional role of the Hispanic woman is to be submissive to the male, self-sacrificing, and restrained. Gil and Vasquez (1996) defined this role of the Hispanic woman by the term "marianismo" which means virgin-like, using the Virgin Mary as the ideal role model. Marianismo is about sacred duty, self-sacrifice, and chastity. "The Maria Paradox," a phrase also termed by Gil and Vasquez, further defines marianismo whereby women feel obligated to sacrifice self for family. The self-sacrificing role is a positive attribute empowering the Hispanic woman to seek services for the family and to speak up for her children. The negative attribute centers around self-sacrificing to the point of not caring for self, prolonging healthcare, and enduring abuse by the spouse, relatives, and/or community.

Response to the affirmation of HIV⁺ status becomes a process by which the Hispanic woman unfolds into what could be considered a positive attribute of marianismo, La Protectora (The Protectress). Five main categories emerged that describe how the Hispanic woman deals with life after the revelation of her HIV⁺ status. These

categories were: (1) The Revelation of Death, (2) Ofrecer (which means "to offer" according to the Larouse Diccionario Moderno (1983)), (3) Living, (4) Revealing, and (5) Duality. Two subcategories emerged from each of the three categories Living, Revealing, and Duality. The subcategories Dealing and Surviving emerged from Living. Protecting and Advocating emerged from Revealing. And Intensifying and Actualizing emerged from Duality.

The conceptual framework, La Protectora, is depicted in the model La Protectora [The Protectress] (Figure 1). The model consists of blocks and a circle representing the categories and subcategories. Single-ended arrows identify triggers that promote the progression of the HIV⁺ Hispanic woman's upward unfoldment to La Protectora. The model begins with two blocks ordered on top of each other separated by an arrow to depict the beginning of unfoldment. The relative sizes are a conceptual representation and not an accurate statistical representation. The first category, Revelation of Death is the catalyst of the conceptual framework and represents the affirmation of HIV⁺ status. A single-ended arrow connects the next block Ofrecer. This category is representative of the negotiating and "an offer to change" that occurs between the Hispanic woman and her God as she struggles with her mortality and the possibility of her child's positive status. An arrow emerges from Ofrecer and splits to connect the categories Living, Revealing, and Duality. Being Motivated runs along this arrow to depict the outcome of Ofrecer and the triggering of these three main categories, the next level of unfoldment to La Protectora. This process represents the Hispanic woman's new found enlightenment, her

La Protectora

(The Protectress)

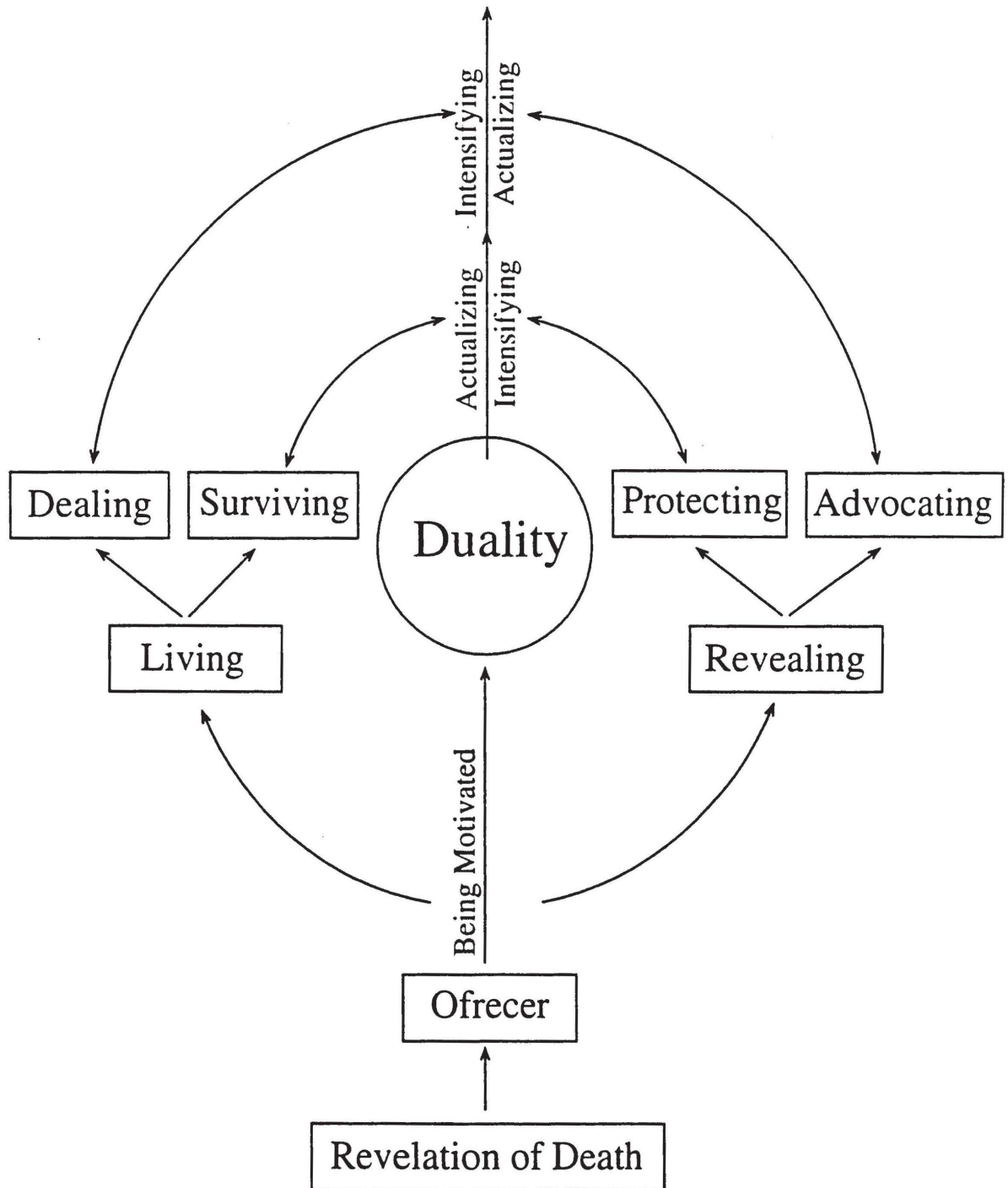


Figure 1. La Protectora

motivation to live with HIV, and the acceptance of her mortality. The arrow emerges from the center of the block and splits into three single-ended arrows. The arrows to the left and right point to two blocks, Living and Revealing, while the central arrow points to a circle, Duality. Living depicts the choices the Hispanic woman makes as she chooses to live her life as a woman with HIV/AIDS. Revealing depicts the struggles and fears she faces with the revelation of her status to others. Two single-ended arrows emerge from the Living block and point to two subcategories, Dealing and Surviving. The Dealing subcategory indicates how the Hispanic woman deals, struggles with, and uses traditional and Western healthcare. The Surviving subcategory depicts how the Hispanic woman survives day-to-day and looks to the future. Two single-ended arrows emerge from the Revealing block and point to two subcategories Protecting and Advocating. Protecting depicts how the Hispanic woman struggles to choose whom and when to reveal her status, for fear of how it may affect her family. Advocating depicts the empowerment she demonstrates as she reveals her status for the purpose of reaching, teaching, and empowering other women faced with this disease. A central arrow points to a circle, the category Duality. A circle was chosen to show the embodiment of woman, her womb (*vientre*) and the dual empowerment that arises, the fruit of her womb (*el fruto de su vientre*) as she progresses towards La Protectora. A single-ended arrow climbs out and gives birth to two subcategories Intensifying and Actualizing. Intensifying and Actualizing sit on both sides of the arrow above and next to each other to demonstrate a union, a bond, a strengthening, and equality between them. For it is the

culmination of these categories that moves the Hispanic woman toward her ultimate role as La Protectora. Intensifying depicts the intensification of the mother or mothering role, while Actualizing depicts the Hispanic woman's actualization in her role as a woman with HIV/AIDS. A double-ended arrow connects Protecting and Intensifying to depict a mutual strengthening of one category by the other. A second double-ended arrow connects Surviving with Actualizing to portray the mutual enhancement of these categories. The meeting of the double-ended arrows completes an inner circling around Duality, which demonstrates closure and strength in her decisions to live for herself and her family. Double-ended arrows connect Dealing with Intensifying and Advocating with Actualizing to depict mutual strengthening of one category by the other. The meeting of this second set of double-ended arrows completes an outer circling around Duality significant of attaining higher level needs. La Protectora unfolds as the Hispanic woman moves from a subservient self-sacrificing role to an emancipated self-sacrificing role for the benefit of herself and other HIV⁺ women.

Revelation of Death

This variable is the catalyst to the unfoldment of La Protectora. This category is characterized by behaviors experienced by Hispanic women with the revelation of HIV⁺ status. The majority of the participants discovered their positive status during pregnancy. The participants described responding to the revelation of their status with behaviors similar to Kubler-Ross' (1973) Stages of Dying. Kubler-Ross (1975) stated that the Stages of Dying are only a guideline to understand the different phases a dying person

may face. The stages are: (1) Denial, (2) Rage and Anger, (3) Bargaining, (4) Depression, and (5) Acceptance. They are not absolute; not everyone goes through every stage, in this exact sequence, or at some predictable pace. Hispanic women, upon revelation of their HIV⁺ status, described similar progression through the stages of dying. Anna, a 41-year-old widow, mother of one, who lost her second child to AIDS at 6 months of age, said, "I wanted to go crazy." Janie, a 36-year-old mother of four, who has been living with her HIV⁺ status for approximately three years described her reaction to the revelation of her status:

I wanted to go into a little closet and hide in there and cry all day. The first thing I did was call my sister and told her I wanted to die. My husband and I kept repeating, "maybe they...you know... they'll take another test...maybe it's not true."

Olivia, a 30-year-old mother of three, who had been living with the disease for five years described her reaction, "I became very depressed. My mother came and took care of me and my children. I couldn't even wash my face. I didn't get out of bed."

While Judy, 36 years old and a mother of three, who had been living with the disease for only eight months summed up her reaction to the revelation and acceptance of her status:

I feel like I've been given a life sentence. I feel like a prisoner given a life sentence, waiting to die. Just like a prisoner who has been given a life sentence, but he knows why he's going to die. And he knows he did a crime. But, I didn't have a crime but yet, I was given the same sentence. But I don't have to wait in a jail cell.

All of the women experienced some or all of the Stages of Dying at their own pace and in their own sequence. However, since most of these women were pregnant at diagnosis or chose to get pregnant knowing their positive status, there was not the typical

self-involvement as with other terminal diseases. The Hispanic woman was faced with the prognosis of her pregnancy and ultimately the life of her child. The pregnancy and ultimately the child became the impetus that appeared to take the women to what is considered the next step of this framework, Ofreecer.

Ofreecer (an offer to change)

For the purpose of this study, Ofreecer was defined as "an offer to change." This category is characterized by the woman's negotiating with her God on behalf of her child. Negotiating is similar to Kubler-Ross' Bargaining stage, in Stages of Dying, where the person accepts the fact of death but bargains for more time. The person promises to do good or do something in exchange for another week or two. The Hispanic woman during the Ofreecer stage promises to do good, namely live for her child and reveal her status to benefit others. Her exchange is not for herself nor for more time but, for the life of her child. She prays and implores her God to spare her child of a positive status and ultimately the same death sentence. Yolanda, a 19-year-old mother of a 2½ month old infant described her experience:

I wasn't thinking like that until I had my baby....the test results came back and said that he was negative. Then I kept thinking if my baby's negative, I can make it then...I can tell others. And I will make it. I told God that I would tell people of my status if He let my son be OK. God has really blessed me and answered my prayers.

Maria, a 40-year-old mother of five, living with the disease for six years summed up her life and relation with God since diagnosis :

I have lived six years since my baby was born and this makes me happy but, I want to live more. I want to live as long as I can for my children. You know we do so much for our children. They are the ones that give me strength in the morning to get up. Of course, the Man up there helps too. Without Him, nothing would be possible.

Being Motivated

Being Motivated is the result of Ofreecer. It is a triggering to the next level of unfoldment. This subcategory is depicted by an arrow that splits and divides into three categories, Living, Revealing, and Duality. These three categories describe the Hispanic women's new found awareness. Some life event that occurred during Ofreecer motivated the woman to see her life with HIV/AIDS differently. Having a family and needing to live for them, the affirmation of their child's negative status, and having lived longer with the illness than presumed are examples of some of the life events. They feel that God has listened, accepted, and granted their offer to change. The Hispanic woman is now motivated and has the impetus to live her life as fully as possible for herself, her child, and her family. She finds the strength to reveal her status to others. She grows within herself into a strong woman and mother able to care for herself, her family, and wanting to help others as well.

Living

Living encompasses the Hispanic woman's choice and struggles to live with HIV/AIDS. This category is subdivided into Surviving and Dealing. These two subcategories depict how the Hispanic woman faces life as she lives with this disease,

caring for herself and her family by meeting basic and ultimately higher level needs. Her life was challenged prior to diagnosis by concerns for food, clothing, and shelter for her family. Now her life is further taxed by the pressures of living with this disease. Her physical self is compromised by the effects of the disease and the treatments while her total self must learn to juggle and keep strict medication schedules, doctor appointments, and group meetings in her already stressed life. Olga, a 27-year-old mother of three, living with this disease for two years expressed it as such:

More of the stress is put on women because we're left to raise the children ultimately. Even if he was here, I would still raise them. You know, it's all put on the women...whether you have HIV or not...you know that to be true. But having HIV, that's just more stress. And stress is the thing that takes you. Stress is what takes you with HIV.

Surviving

Surviving depicts the ways the Hispanic woman's life changed, the means by which she deals and struggles day-to-day with her physical and emotional well-being, and where she sees herself futuristically. Day-to-day she provides and cares for her family while struggling with her own physical and emotional well-being. For everyone of the respondents "getting up" was in itself the biggest daily struggle they faced. Getting up was an effort both physically and emotionally. Once that major hurdle was overcome, usual day-to-day routines unfolded. Meeting basic needs for self and family were dependent on each woman's overall well-being on any particular day. Basic survival mode was either heightened or lessened by each woman's well-being and her

success at getting up in the morning.

One could almost feel Yolanda's exhaustion as she described her effort in getting up in the morning, "I just...so tired that I can't get up in the day and I just don't seem to wake up. And sometimes even carrying my baby is hard for me sometimes. He's too heavy. It makes me tired." Judy, who was diagnosed when she was six months pregnant summarized how she met each morning:

Huh, Just woke up! Waking up to me is a challenge. Especially when you only have two to three hours of sleep at night because you have trouble sleeping. I... I ... bear it ... I just grin and bear it. It's mind over matter. I just get up and deal with it.

Her trouble sleeping was compounded from having a 6-month-old child at home who did not sleep through the night and her own poor health. She suffered from constant pain due to diabetic neuropathy that was intensified by the neuro-toxicity of her HIV medications. Her body language was that of one who was in some apparent pain, both physically and emotionally. However she seemed to find levity in expressing even her most difficult times.

Olivia, a 30-year-old mother of three who has been HIV⁺ for five years summarized how she started her day by imploring for assistance, "Well before anything, pray to be able to get up because I could not get up; prayed to get strength; got up like not fast." While Janie, a 36-year-old mother of four who has been living with HIV for three years summarized how her getting up involved first her family then herself. Her morning ritual eventually lead to needing to go back to bed and attempting to get up again:

First of all I get up, take my shower, put makeup on...I try to put

makeup on to help me feel OK. But actually in the beginning first I get up and give my little girl a bath and make sure my boys are ready for school by 0705. Then I sit down for a while and look at papers I was supposed to see yesterday from school and then I either eat a bowl of cereal and take my medication and then I go back to sleep for about an hour or so and then I get up and take a shower.

Despite the Hispanic woman's constant hardship to get out of bed each morning and periodic inability to look forward to another day, most of them had a very good outlook of the future. Judy attributed her quest for living to her baby girl:

She's the girl I always wanted...but sometimes you see, I think God was punishing me by giving me a girl because He knows I'm not going to live long enough to see her grow....Then my mom told me there's meaning for this. You were meant to have a little girl so you could live a little bit longer...to see her grow up. He's testing you. He gave you this little girl so you would take that medication because if it wasn't for that little girl you wouldn't even know you were HIV⁺. I want her to be a Folklorico dancer and I want to see her dance at the Market Square during the parade and all that. I feel that if I had had a boy, I wouldn't have to live as long because I've already seen two of my sons grow up and I know those sons would take care of my little boy. But she's a little girl.....

Yolanda having chosen to get pregnant despite her diagnosis was very optimistic about the future. She attributed her determination to her son and the new medications available. Her explanation follows:

My goal is to see my baby get married. To see at least my first grandchild. It will happen....It will happen. Those medications will keep me alive. I wasn't thinking like that until I had my baby...then the test results came baby and said that he was negative. I can make it then. And I will make it.

Dealing

Surviving dealt with the impact of the physical and emotional well-being of the HIV⁺ Hispanic women on themselves and their families while Dealing involved the hurdles the Hispanic women faced and had to overcome to obtain healthcare as they lived with this disease. The Hispanic women who sought healthcare were faced doubly with prejudice not only for being women of lower socioeconomic status (SES), but now for being HIV⁺. This prejudice was demonstrated by healthcare professionals to the HIV⁺ Hispanic women by their language, their demeanor, and the services or lack of services provided them. Their lack of support for these women lead some of them to forego healthcare, others to gain strength in acquiring healthcare for themselves and their families, and others to seek comfort in traditional folkways. Some of the women combined both traditional folkways with Western medicine to ease the problems of living and dealing with this disease.

Healthcare provided to these HIV⁺ Hispanic women was funded primarily by Ryan White monies. The women voiced a need for change in the treatment provided them and their families. The centers were run primarily by a gay male population for the gay male population. A disparate bias on the distribution of funds existed. Funds were seen as readily available for gay men but lacking for women, their children, or family. Judy, apparently in need of dental care, chose to forego dental care at a Ryan White dental clinic rather than deal with the lack of professionalism and rudeness by the dentist. She described her experience as follows:

See, I think most of the funding will go to gays before they go to females or to the parents. See that's why I don't get my teeth fixed because the man he's real rude with women. He is. He's some doctor, dentist at the Ryan White clinic....I've seen gay guys go in there with the ugliest teeth and he treats them with the utmost respect. And when I go he's always rude, he goes...you're never gonna take care of your teeth, we're not gonna fix them. But yet, he'll fix those guys teeth....no questions asked. I told him I was born into this world naked and toothless and I will leave this world naked and toothless...so just go to hell....and I walked out. And I haven't been back since. I complained to whoever there is to complain to but...sometimes I think you're better off being gay...you're better funded...than you are being a single Hispanic woman.

Despite this poor experience, Judy did have the utmost praise for the university-run pediatric clinic at which she and her child received most of their HIV care. She described these healthcare providers as caring and willing to listen.

Yolanda and her husband, both HIV⁺, chose to get pregnant and have a child despite their diagnosis. Yolanda and her husband read about the latest interventions and treatments during pregnancy and made an informed decision to get pregnant. They sought early treatment at a local university-run obstetrical (OB) clinic. Yolanda's experience was one of total disappointment with this part of the healthcare system. She blamed her poor experience to lack of information and education on the part of the healthcare providers. Her experience follows:

Even doctors turn their backs on us. They're educated and even though like that they're afraid of the HIV. Because I know when I was pregnant, they changed my doctor like nine times. Because they just came in and when they read the chart and they read the HIV positive, they just turned and got out of the room. Later the nurse came to release me...she didn't even check my belly or nothing. Another doctor just came in with gown, gloves, mask. I just told him, "don't touch me....you're dumb, you're stupid."

They just kicked me out of the clinic.....Yes, I had to go back for my baby. Most of the time after that, I took care of my pregnancy in the Emergency room. That doctor didn't want to see me around. If doctor's are not educated, it would be hard to educate all the people too.

Despite her disappointment and disgust with the healthcare providers at this particular clinic she continued her prenatal care for the safety of her pregnancy and ultimately her child. Her child was born HIV⁻ and has continued testing negative which brings much comfort to Yolanda and her husband. Yolanda has since been diagnosed with AIDS and has had a satisfactory experience at the university-run pediatric clinic where she and her family now receive care.

Olga, a 27-year-old mother of three, described how disparate services were for the HIV⁺ woman with a family:

With these agencies it's all politics. [] is mostly gay men. [] won the grant for transportation. No one else can have taxi service or any kind of van service because they won the grant. Providence Home is an agency provided for HIV affected children.....Providence Home needs another van. The van is old, it breaks down a lot, it smells...it smells like piss...it smells like little kids, because little kids are in there all the time. But look, [] got three brand new vans with cellular phones. There's another thing, when a man becomes homeless, oh, hell they can get him into a hotel/motel in no time. Yeah, but if we become homeless, Hey, SOL....we don't have a place for you. And you have kids....Oh, we really don't have a place for you. Even if they put you in a hotel or motel how are you gonna keep your kids in one room. And I mean one room. Have you ever been in a motel/hotel...one room and a bathroom. And then they'll tell you it's against fire code.

Despite the inadequacies of services and incongruities of care, all of the women took responsibility for their healthcare. They all found it important to follow their medical regimens. In response to the question "What did you do to stay healthy today?"

most of the respondents said taking their medicine. They knew how many they took, how many times a day, and at what intervals. They could name each drug, its strength, type, and effect. Taking their medications was a major topic of conversation among the women at the meetings. They compared notes on strengths, amounts, and times taken. They shared responses to previously taken medications and reasons for change. They were very aware of their t-cell count and viral loads and could give rationale for taking various medications based on their particular laboratory values. They also made taking their medications part of their meeting. All carried water bottles that facilitated taking their medications when their watches buzzed to indicate the time.

However, some of the women still found it necessary or wanted to seek alternative modalities of care for alleviating various side effects and symptomology brought on by this disease. The women in this study used teas and herbs to manage some of their side effects and/or symptoms (see Table 2). The selection of these herbs and teas came from past experience; encouragement or recommendation of family or friends, the curandero/a, and/or through personal research. Some women described long term experience with the use of teas and herbs while others had just begun to experiment and explore. Some of the women used them daily while others only when symptomatic. The herbs and teas were more for palliative than curative use. They were described as soothing, calming, relaxing, and refreshing.

Many of the women described "taking a bath" as a therapeutic regimen. Some used particular herbs and oils in their baths and after their baths to calm, soothe, or relax

Table 2
Herbs Used To Alleviate Side Effects and Symptomology

Herb	Use
Chamomile (Manzanilla)	Treat gastrointestinal disturbance diarrhea, and calm aches and pains
Cinnamon (Canela)	Calms the body
Garlic (Ajo)	Gives strength and removes impurities
Lavender (Alhucema)	Intestinal flu and soothes the body and makes everything fresh
Spearmint (Yerba buena)	Calming effects to the body
Rosemary (Romero)	Alleviates cramps and menstrual problems

them. Some of the women occasionally took time from their weekly routines to get a massage provided by one of the agencies. Herbs used for massage therapy were selected for their aromatic and therapeutic effect on the body and soul. They described rubbing oils on their hair and bodies and using them as perfumes. Some women described non-conventional use of substances to alleviate or treat particular ailments (see Table 3). These were old folkways and were noted more frequently by the respondents that were

Table 3
Non-conventional Substance Use

Substance	Use
Agua de Arroz (rice water)	Diarrhea, dehydration, and fever
Coffee	Calming
Mango	Cleanse the body
Mulberry (mora) juice	Calm gastrointestinal disturbance
Sprite/7up with starch*	Diarrhea
Tuna de nopal (Prickly pear)	Alleviate sore eruption and decrease blood sugars

Note:

* Starch was described as starch used in laundering and found in a "blue box".

older, had less education, and/or were first generation in the United States. This information was obtained through group observation and participation, and/or informal conversations with the respondents. The use of teas, herbs, and non-conventional treatments were used more commonly by these same respondents. However, a greater interest in herbs and teas was shared among all the women in the group as they came to know each other and discussed some of their ailments. The non-conventional use of substances was not shared as openly among the women.

The diagnosis and affirmation of status for some of the women in this study were such a devastation and burden that they sought comfort from a higher source. Some turned to prayer, others to the Bible, and yet others to the Church. Some of the women in this study sought the services of a curandero/a to "heal" them both physically and spiritually. For some, their beliefs and bond with a higher being were strengthened Olivia explained it as such:

In my opinion, one thing that can help is the principles in the Bible. I'm not talking about any specific religion but rather using the principles found in the bible....the principles in the Bible can be a great protection. It tells us how to live, how to be, still yet how to protect ourselves from illness. If one is guided by these biblical principles...like a couple, if he's faithful to his wife and she to him, one to the other then there's less percentage that they will be ill.

Maria, a 40-year-old mother of five, who has been living with the disease for six years incorporated prayer, church, and spiritual healing with her medical regimen. She described her day:

After all the children are up, I walk to the church for morning Mass. There I pray the rosary and light my daily candle to St. Jude. After Mass, I walk home. By this time, the children are ready for school and I walk the three youngest to school. Walking is very good for me. It helps me keep my strength. When I get back from taking the kids to school, I clean my house and do all the things around the house that need to be done. I also make time to sit and pray to Our Lady of Guadalupe (shrine in the corner of living room).

Maria's whole life was guided by the philosophy that "God takes care of those who take care of themselves" and that "idle minds are the workplace of the Devil." This philosophy guided her daily activities and the way she made it through her day. She elaborated:

I believe that natural things are better and that God is Almighty. God will take care of us if we take care of ourselves. Work and activity are good. If we are lazy and we do not do anything then the Devil will take over our minds and bodies and then we will be ill. When we have a lot of time on our hand, our minds wander and we think of bad things and then we can get into trouble. We become dirty in mind and soul and then we get sick.

But despite Maria's guiding philosophy and religious rituals she still found moments that she needed something more. She sought out a "Holy One," a healer, a curandero:

If I just don't feel good, I would go to Don Jesus, down the road and let him tell me what was wrong with me. He would probably then give me some of his tea and pray with me or over me. Don Jesus is a "viejito—an old one, a curandero." He can pray with me or over me. Sometimes we need someone to channel our prayers to God and so the Holy One prays over us so that we can get better faster, especially if someone has tried to bring harm to us. You know with powders, the evil eye, or witchcraft. Since I have this "virus," I go at least once a week. I can't always get to the clinic so I go to him to help me pray. This gives me strength. He is also good just to talk to. He is very wise and just gives me strength with his living. He is very old and yet he is so strong. Sometimes, I get so tired waiting at the clinic, that I just hate to go, but I do go because Don Jesus says God will help us if we help ourselves. So, I feel that I must try to keep my visits at the clinic and take the medicine. Sometimes, I think that medicines just makes me feel worse. But I take it and go see Don Jesus a little more. Talking with Don Jesus, praying and drinking tea with him, usually yerba buena (spearmint), helps calm me and make me feel good the rest of the day.

While most of the women did not have such strong convictions to any form of religion, prayer, or spiritual healing, most described some change in their lives regarding prayer and/or spiritual needs. Janie noted some of the changes in her life:

I'll lay down and get the Bible and read it. I'm one of those who refused to read the Bible before when I was younger. And ever

since my operation, my sister in law brought me this Bible...it's got...the wording is good for me to read, I mean it's not too difficult words or nothing. And I can really read real easily. I'm not a reader, so for me it's something new. It helps me when I read the Bible. It helps me...it helps me understand things that I didn't when I was younger. Because when I used to go to church I really didn't understand what I was doing in church. I knew that I was there to pray for God and pray for our families and stuff. But I didn't know...I was just following what everyone else was doing. And when I started reading the Bible, I realized the things that they were saying up there made sense you know. It's important for me to read the Bible. When I'm feeling depressed or down, I think negative things ahhh.....I read the bible and I start thinking I could be worse...worse than other people. There's a lot other people that are going through more different things worse than... There's some people that are a lot poorer than I am. And I give God thanks for that. Something that I didn't do before....give God thanks for nothing. Or say thank-you God for this or that. Now I can do it without being ...you know being a teenager you kind of get embarrassed or don't want to say it out loud or...but now it doesn't matter. I've always been pushed to go to church, pushed to do this or that. I have to want to go. I have to be the one that makes a choice. It's very important...and I realize a lot of things that I didn't before so it help me a lot.

Janie further described how her personal life had changed. Where she described herself as naive, afraid to talk, and bring attention to herself, she had developed a new interest in attending counseling sessions, support groups, the curandera group, and sessions with a psychiatrist for her own mental welfare. She described how these groups have helped her grow and feel better about herself:

On Mondays, I come to the support groups. I come to the curandera's group too. I like to hear what she has to say and I like to hear the different things, things I didn't know. And when I leave here, I leave here real good because I know things that I didn't before. Growing up I was very naive you know, and yes I am still now but not as much as I used to be. That's one thing that I did learn. I also go to counseling. You

know, I go every other week on Wednesday or Thursday. And ah, I also go to a psychiatrist. He's really helped me out. I had one time when I was feeling real depressed and I'm thinking back on the past, when I was growing up and I wanted it to stop. I didn't want to go to the past and think about it. Mary Jane (curandera) did some healing on me and believe it or not I don't go to the past and think about it. Not like I used to. When she did the healing on me, I didn't think about anything in the past for at least a whole month. And I was glad because it was something that was always there. And now I don't really think much about it anymore. Whatever she did...whatever healing she did, it helped. And I'm grateful for that. I also went to my counselor...and I told her, "God it felt so good" because I used to go to her and I use to cry about it and everything.....it would help that day but then it was another day and I was still thinking about it. And after Mary Jane took care of me, I haven't had to go as often to the counselor.

Some women discussed other rituals as being important in their living with HIV.

One woman described not cutting her hair for fear of "strength loss." Several of the women found "walking" or "just moving" as necessary to live with HIV. Others found activities like "taking time for oneself" just as important. While many felt that survival with HIV was just "mind over matter."

Living in an already complicated world compounded by the devastation of this disease, these Hispanic women found order in their lives by making the most of each day and by making the best of their available resources. They dealt with their lives as best they could by meeting each day face on and drawing from their inner strengths, their faith, and their families.

Revealing

Revealing is characterized by the struggles and fears the Hispanic woman

experienced and faced with the revelation of her status to others. The initial revelation to herself was one primarily of devastation and disbelief. Most of the women expressed being victim to their husbands' or partners' exposure. Some denied knowing who had first exposure and claiming possible responsibility for primary exposure. One respondent was the victim of a date rape.

Most of the women had faced the initial revelation and dealt with the revelation to their husbands and/or partners. They all expressed progression through some or all of the Stages of Dying as they processed and dealt with the news of their status and their mortality. They had all come to accept the revelation of their status and had begun to piece their lives together with the help of family and friends. Initially, most of the women sought solace and refuge by disclosing their status to their mothers. A couple claimed having told an eldest sister first. The revelation of their status to other family members was left to this person. Most expressed strong support from their families following revelation. Others expressed denial and distancing on the part of some family members.

Most of the women had not told their children. A couple told their children that they were ill and they needed to be cautious around mother's body fluids such as blood should she hurt herself. However, they could not bring themselves to tell their children they had HIV/AIDS. Despite lack of disclosure to their children, most had made arrangements for their children after their death. Most left significant family members with detailed instructions on the disposition of the children. Others wrote lengthy letters

to each of their children, to be given to them upon their death. And yet others hoped that they would live long enough to let their children grow to more of an acceptable age to tolerate the news.

Two subcategories emerged from the Revealing category. They were Protecting and Advocating. These subcategories depict how the Hispanic woman makes her decisions to disclose her status to others. Protecting encompasses her decision based on the effects on herself and her family while Advocating depicts her empowerment to reach other women and educate them about this disease.

Protecting

This subcategory depicts how the Hispanic woman struggles to make decisions to reveal her status to others. Decision to reveal her status is guided by the stigma she faces with being HIV⁺. Judy who expressed exposure from her boyfriend and father of her child described this accordingly:

You gotta keep it to yourself. One minute it's like they think that women shouldn't have HIV/AIDS. But they do. The reason why you gotta keep it to yourself because they think only women who do drugs or who are prostitutes have HIV, not a normal, ordinary citizen like me have HIV and AIDS. That's why it's just so hard for women to have "it," because they'll think wrong of you..... Like she's dirty, she did drugs, she's a whore.....Your daughter's not that way. She's supposed to be nice, neat.

Yolanda described how she and her husband have been treated because they chose to have a baby:

Well some people look at us like, "look at them with AIDS and creating children, they don't think about it.....they just think of

themselves. They don't think about the children." Sometimes they don't want to look at us. They think we're breeding children to make them suffer. They have said it to our face. They have said, "Why do you have to bring children to the world, if you have AIDS, you're dying." That's what they say.

The women facing this kind of prejudice and stigma feared disclosing their status to others. Despite personal fear, some of the women expressed more fear for their children and families. One respondent Olga, based her fears to disclose on the possible effect on her eldest son's life. He was only 9-years-old. She feared retribution on his life similar to that of Ryan White. She explained:

And I'm not afraid to....but I am afraid for my son. You know if I didn't have my nine year old son...shit...you know, there would be no obstacles. But because I have a nine year old son, you know I think about Ryan White. And I live in an apartment complex. You know, I have people on top of me, adjacent to me, across from me, you know. I can't just have them all know and I don't know how they'd all react. And then I don't know how they would react with my son. And a lot of their kids go to school with my son. And how would that make my son feel? You know, something's wrong with me. You know, I can't have that.

Even with the apparent acceptance by others of their revelation, some of the women expressed a necessity to change their lives to make family and friends more comfortable with the disclosure of their status. Changes were as drastic as not playing, touching, or being alone with nieces and nephews. While other changes meant not participating in any food preparation for gathered family or friends. The women understood that they could not transmit the disease in these fashions; however, for peace of mind on behalf of their family and friends they conceded. Olivia expressed her desire

to be compassionate of other's feelings as such:

All the congregation knows. I can't complain about my brothers, they have treated me well, they don't turn me away. In fact, they come to my home for dinner. I however, do not prepare anything because I try to be considerate of their feelings. I know that you don't catch it that way, but to ease their minds, and for them to see how considerate I am, my mother cooks most of the things. But they're at my home, with me having a good time. They don't forsake me. I have only been turned away once, by a sister, because "he who doesn't read is lost." Even though society provides us with an abundance of literature, we have good information, but he who doesn't read stays behind. And that is what happened.....

Faced with many reasons to fear disclosure the women of this study all seemed to grow within themselves and expressed a desire to disclose and reach out to other women for the purpose of educating and empowering other women faced with this disease to do the same.

Advocating

This subcategory depicts the empowerment the Hispanic woman demonstrated as she revealed her status for the purpose of reaching, teaching, and empowering other women faced with this disease. Most of the women expressed that this was no longer a "gay" disease but rather one of families. Some of the women expressed surprise that they themselves did not know to what extent this disease affected families. Some of the women further expressed the need to "speak out" about the disparate services available to women, children and families. Judy, vocal in her conviction about changes in the system expressed herself as such:

Just not to be afraid to speak. They don't have to speak openly just to let them know what's going through their minds. I speak when they ask me to speak. They all want me to go to Washington. So that funding will go to better places. I think most of the funding will go to gays before they go to females or to the parents. It is no longer a gay disease. It's an every person disease now.

Olga, also expressed her views on how to try and change the system:

Doing the things that we're doing right now. This is how it's done. This is how it begins. We've got to network to everyone. I have to network and I do a lot of it. I try to do as much as I can...Now it's our turn to get out there and fight for it. And I want to go out there and fight for it. We can't just sit back and complain. We're fighting for more than ourselves. We're fighting for our children. We need money too. We need the focus put on us now....

The women expressed a disbelief in the number of families affected by the disease. Some had been privileged to attend a retreat for HIV/AIDS affected families sponsored by another agency. There they met other families experiencing similar problems as they lived with their disease. The women talked about networking with other families about available resources. There was a mutual exchange of information among those present at the retreat. They readily shared this new found information made available at the retreat with those that could not attend. They even shared future plans to meet with some of these families socially, to network, and to share ideas. Some of the women verbalized that the retreat had opened their eyes to see a bigger picture of people affected by this disease. They were not alone. They also verbalized that attending one agency limited their introduction to other families and the ability to recognize the magnitude of the disease.

Duality

This category is characterized by changes in the Hispanic woman as she lived with HIV. She changed by her willingness to live and work toward accomplishing identified goals. Some basic goals were necessary for personal and family survival. Other goals were indicative of the empowerment that she displayed. The circle was chosen to depict the woman's womb while a single-ended arrow climbs out and gives birth to the two subcategories Intensifying and Actualizing. These two subcategories are characteristic of the dual strength that helped the Hispanic woman rise to her ultimate level, La Protectora. Intensifying her mother role and Actualizing in her role as a Hispanic woman with HIV, moves her along toward that final attainment.

Intensifying

This subcategory, Intensifying, is characterized by those things that help the Hispanic woman intensify her mother role. The Hispanic woman unfolded into La Protectora by first deciding to live for herself and her family. Her strength to live came not only from being a woman but a mother. As she struggled in her decision-making, she drew from this maternal strength. She replenished that strength as she made positive decisions for herself and her family. She drew from this same maternal strength as she protected and provided for her family. She mothered herself and her family. This same maternal strength moved her towards wanting to help and empower other women to live with this disease for the sake of their children. Positive in her convictions she found ways to reach out to other women.

Actualizing

Maslow (1970) described his hierarchy of needs. Basic physiological needs such as air, food, water, and sleep must be met before the higher ones of safety and security, love and belonging, self-esteem, and self actualization can be met. Maslow further described self-actualization as a person's need to be and do that which the person was born to do. It is his "calling." Maslow (1968) redefined self-actualization as episodic. That is, for the time, persons become self-actualizers. These are not only their happiest and most thrilling moments, but also moments of greatest maturity, individuation, fulfilment---in a word, their healthiest moments.

This subcategory, Actualizing, is characterized by those behaviors that "call" the HIV⁺ Hispanic woman to do more than just exist. For example, she was called to reveal her status, to educate, and encourage other women to seek early treatment. She told her story to groups in hope of bringing about change. The Hispanic woman may not achieve all higher level needs and reach self-actualization as originally professed by Maslow but, in her quest to live with this disease she "self-actualizes" in her own right as a woman with HIV. She struggles to learn more about her disease to make informed decisions about her own care. She seeks out ways to provide for her family. She attends groups to network with other women, social workers, case managers, and traditional and Western healthcare providers, to share ideas, and for personal growth. Once she feels that she is strong in herself she finds that inner strength to reach out, educate, and empower other women. She continues to get stronger in her role as a woman with HIV.

Double-ended arrows connect Dealing with Intensifying, and Advocating with Actualizing to depict mutual strengthening of one category by the other. As the Hispanic woman makes a positive move or choice related to any of the categories she enhances the corresponding category. These double-ended arrows complete an inner and outer circling around Duality to represent strength and conviction in her decisions. This culmination of attributes, her growing inner strength as a woman, a mother, and a woman with HIV move her toward La Protectora.

Summary

This study was designed to provide the perspective of how HIV⁺ Hispanic women were guided by cultural influences and used folk health practices to cope with their disease. The core variable La Protectora [The Protectress] (a woman strong in her convictions to live for and protect her family) was identified. Five main categories emerged: (1) Revelation of Death (affirmation of status), (2) Ofrecer (an offer to change in exchange for her child's life), (3) Living (dealing and surviving with this disease), (4) Revealing (cautiously and eventually openly), and (5) Duality (gaining strength as a mother, a woman, and ultimately a woman with HIV). Being Motivated, Dealing, Surviving, Protecting, Advocating, Intensifying, and Actualizing emerged as subcategories to represent the behavioral patterns of La Protectora.

Respondents saw their lives as important because they had to care for their children and their families. When faced with this revelation of death, they chose the path of living for their child rather than accepting to die. They became pro-active in their

choices. They spoke out about the inequalities of services for their families. They found a purpose in life by going to support groups. Their decision to live and emerge as La Protectora was influenced by the birth of their child and the revelation of the child's negative status.

CHAPTER 5

SUMMARY, CONCLUSIONS, IMPLICATIONS AND RECOMMENDATIONS

The purpose of this study was to identify folkways and health practices of HIV⁺ Hispanic women. Grounded theory methodology was used to explore this new area. Through analysis of interviews and observations of HIV⁺ Hispanic women attending HIV clinic appointments, support and alternative therapy group sessions, and in their homes, the core variable La Protectora (The Protectress) emerged. The category, Revelation of Death, emerged as the catalyst to the sociological process that unfolded into La Protectora. Other main categories, Ofrecer (an offer to change), Living, Revealing, and Duality were identified and characterized the Hispanic woman's journey towards her ultimate achievement. The subcategory Being Motivated emerged to depict the outcome of the category Ofrecer and triggering of the other main categories. Subcategories Dealing and Surviving emerged from the category Living. Protecting and Advocating emerged from the category Revealing. And Intensifying and Actualizing emerged from Duality. These subcategories described behavioral patterns of the HIV⁺ Hispanic women. While folk health practices were not used overwhelmingly by the women, cultural influence was apparent in their decision-making and health practices.

La Protectora emerged as the conceptual framework to explain the basic sociological process as HIV⁺ Hispanic women accept their illness, face their mortality,

and manage their lives in the midst of this disease. Since most of the women were pregnant at diagnosis, the pregnancy became the impetus for the progression of the process. For the women who were not pregnant at diagnosis, their families played a part in their unfoldment; however, it was somewhat different.

Previous research has identified that Hispanic women delay their own medical care because their families come first. Hispanic women with HIV/AIDS have been known to miss their own appointments because it is more important to them to ensure that their spouse and/or children keep their appointments (Piette, Fleishman, Stein, Mor & Mayer, 1993; Rose & Clark-Alexander, 1996). A study by Williams et al., (1997) indicated that HIV mothers frequently delayed seeking medical care after a positive HIV antibody test. Chu, Hanson, & Jones (1996) concluded that high rates of pregnancy were found at entry to medical care among HIV infected women. While Raveis, Siegel, & Gorey (1998), in a study of 31 women who exhibited significant delay in seeking a physician after testing positive for HIV antibodies, concluded that the women's psychological responses to learning their serostatus were the most pervasive factors associated with delaying seeking care. No studies have addressed the struggles, fears, and issues Hispanic women face as they deal with the affirmation of their status, their mortality, and the birth of a child.

This study contributes to the literature of HIV/AIDS, Hispanic women's health-seeking behaviors, and minority women's issues. The findings of this study enrich the understanding of HIV/AIDS as a life-altering chronic disease. This study adds richness

to the research on health-seeking behaviors of HIV⁺ Hispanic women and the field of obstetrical nursing by presenting informant's descriptions of their behaviors as impacted by their pregnancy. This study also contributes to the research on Hispanic women by depicting the Hispanic woman differently from that previously presented. The findings of this study revealed a woman strong in her convictions and taking control of her life. Descriptions of her experiences and beliefs as she struggles to live with HIV/AIDS richly contribute to the research.

Discussion of the Findings

Affirmation of HIV⁺ status for the Hispanic woman becomes the spring board for the process that unfolds. The diagnosis of HIV infection creates a state of crisis in the woman and her family (Moneyham et al., 1996; Seals et al., 1995). When women lack housing, food, and transportation their situation becomes more complicated as multiple needs arise after diagnosis. The well-being of the women and their children becomes dependent on how well these women seek care. In this study, the infant became the driving force for the women's desire to live.

Ofrecer: An offer to change

With the infant as the driving force, the Hispanic woman was motivated and sought out and participated in activities to promote her own well-being. Her life had purpose amidst a life sentence of death. That purpose was to live for her child and her family. This new-found purpose promoted a positive environment for the child and

family.

The Hispanic woman's new found purpose evolved from her negotiations with her God for the purpose of sparing her child of a positive HIV status. Similar to Kubler-Ross' (1973) *Bargaining in her Stages of Dying*, the Hispanic woman offers to change her life for the purpose of sparing her child's life from the same life sentence of death. This was similar to the Hispanic cultural practice of making a "promesa" or promise to overcome a punishment for wrongdoing. HIV/AIDS is seen as a "castigo" or punishment for some wrongdoing (Martinez, 1978). However, most of these Hispanic women did not follow one of the traditional cultural beliefs of turning to religious practices such as making promises to a saint, visiting shrines, or offering candles to a patron saint. Their offer to change was with their God. Their offer was altruistic in nature and twofold: (1) she would live for her child and (2) she would reveal her story to other women for the purpose of reaching, educating, and possibly changing the lives of other women facing the impact of this disease. Her "living" meant caring for self to be able to provide, care for, and protect her child. Her living meant revealing her status by telling her story to others with the hope of making a difference in some other woman's life.

The Hispanic woman's focus on herself and participation in activities to promote her personal well-being and living was different from findings in previous research (Amaro, 1995; Anastasio et al., 1995). Historically, women felt a greater responsibility for the life and well-being of their partners and family. Many women living with HIV put partner and family needs before their own, taking care of them while neglecting their

own health (Williams et al., 1997). With Hispanic women this self-sacrificing orientation has been a way of life. However, in this study, the child, who is the reason for this trajectory of events, motivated Hispanic women to change their self-sacrificing orientation. Hispanic women tended to their own needs (i.e., seeking and obtaining adequate healthcare, attending support groups to promote physical and emotional well-being) for the purpose of "living" for this child.

The use of support groups outside the family to cope with stressful events has been viewed as inappropriate or unnecessary by some Latino family members (Simoni & Perez, 1995). In this study, Hispanic women shared mixed emotions about attending support groups. Some stated benefitting from the sessions by claiming "learning more," "finding peace," and recognizing that there were other women who were in the same situation and/or who had bigger problems. Others saw little to no benefit from the support groups other than the camaraderie that was shared. Meetings became a pastime, a social hour for some. However, most of them verbalized the primary reason for attending groups despite their personal benefit, was to receive a voucher from the agencies for attendance. Five dollar vouchers from a local grocery store and drawings for gift certificates to local restaurants were their incentive. Some of these women verbalized they wished they could make their husbands come to the groups to receive a second voucher and increase their chance of "winning" a gift certificate. Vouchers were given per person and one name was drawn from those in attendance for the gift certificate. Some of these women expressed traveling one to two hours by bus from

opposite ends of town to make it to the group sessions. At times they missed connections, stood in the rain, and just ran into obstacles in getting to the groups on time. However, no matter what obstacles they encountered, the trip was well worth the trouble if solely for the purpose of getting the voucher.

Their getting to group was seen as a great accomplishment to themselves and to the other members of the group. They supported one another's efforts to get to the group. Camaraderie was evident by the group's interest in each member's attendance. They questioned the whereabouts of a member when not present. They questioned whether they had called to excuse themselves and inquired about their health and well-being. They welcomed the latecomer with a hug, a handshake, and words of praise for getting to the meeting. Then they informed the member of where they were in the meeting and continued.

La Protectora: Strength in role as mother and woman with HIV

The Hispanic woman demonstrated a strength not previously depicted in the research. She took control of her life, expressed strong conviction in her decision-making and took ownership of her disease; thus not assuming a victim's role. Her story was one of power, strength, and of overcoming obstacles. She recognized disparate inadequacies in the system and advocated change. These women spoke out about the inadequacies of support services for themselves and their children. They recognized the need for change in the appropriation of services. Though research findings (e.g., CDC, 1997b; Neal et al.) offered that HIV/AIDS was no longer a gay disease but rather a

family disease due to the increased heterosexual transmission in this population, government funding has not increased in proportion to the needs of the women and their children.

These women offered suggestions for change. They commented that too many agencies were vying for the same monies and offering duplicate services. They felt that having so many agencies controlling different aspects of services promoted bad feelings among the agencies and the clients they served. This affected them because some agencies used their services to try and coerce them to change their case management site. Distribution of grants to a particular agency for a particular service sometimes was seen as not having availability of that service again. Their contention was that funds still were appropriated to the gay community first.

They advocated change by speaking to visiting dignitaries, going to Washington with focus groups, and speaking out about problems encountered when seeking services. Some went to correctional institutions and schools, and appeared on television programs to speak about "living" with HIV. Their living with this disease opened their eyes to a new-found awareness of strength and power within themselves. They advocated and proposed appropriate and relevant ideas for change. Their ideas were creative, such as proposing having one large agency in the city controlling funding, with satellite sites strategically placed in areas of town accessible to the clients. This central agency would be responsible for intake and tracking of clients thus cutting down on the vying for clients by individual agencies and the dissension among them. They also proposed the

initiation of a national controlling agency for the purpose of standardizing appropriation of funds and care of clients in all states. This would ensure uninterrupted services to all affected clients in any city or state to which they might move. The local power and control element of some agencies would no longer exist and clients would be served better.

Nursing and the HIV⁺ Hispanic Woman

Education of nurses and healthcare professionals is relevant even now, twenty-five years later, as we continue to deal with this disease. In a healthcare society claiming sophistication and advancement in treatment of this disease, healthcare professionals are still lacking the education and finesse to provide adequate unbiased care to HIV⁺ Hispanic women. Some of these women expressed ineffective and inhumane care while others expressed lack of respect and dignity while receiving care. The Hispanic women in this study were educated and well versed on their own disease. They took ownership of it and could explain mode of transmission and universal precautions. They were very cognizant of others' feelings and safety. Despite their concern and respect for others, they felt that these feelings were not reciprocated by the healthcare society.

Some women walked out of healthcare settings rather than be subjected to rudeness by physicians and nurses. Women were treated as if they had "the plague". Physicians and nurses either refused to care for the women altogether or put on the entire protective garb from head to toe for a simple visit. The women claimed that they were hardly talked to, much less touched. This was true only at some clinics. Despite their

poor experiences at some clinics, the women sought care elsewhere and continued to receive care for their pregnancies and ultimately their babies. Since the most prominent feeling about pregnancy is a sense of responsibility for the safe development of the fetus (Jensen, Bensen, & Bobak, 1977), this continued care was not surprising.

The metaphor, *La Protectora*, emerged to describe HIV⁺ Hispanic women as they faced their mortality and struggled with the psychological responses to the affirmation of their status. Pregnancy and family acted as an impetus and motivated them to live and look to the future rather than just wait to die. The HIV⁺ Hispanic woman moved through the categories of Living, Revealing, and Duality at various times. Since these categories were indicative of her response to everyday stressors and how she dealt with them, this process was fluid and not static. She shifted through these categories as she faced them in her everyday living. *La Protectora* emerged as she gained strength by her decision and conviction to live as a woman with HIV. *La Protectora* depicts a Hispanic woman different from the victim and stereotype typically represented in previous research. Planning care using stereotyped and pre-conceived notions about Hispanic women will not be effective in caring for the HIV⁺ Hispanic woman. The unfoldment of the HIV⁺ Hispanic woman into *La Protectora* makes her interested in her own healthcare and that of her family's, wanting to make informed decisions for both herself and her family.

Conclusions and Implications

This study provides information that is relevant for nurses caring for HIV⁺ Hispanic women and their families. The following conclusions and implications are

derived from the findings of this study:

HIV⁺ Hispanic women see themselves as women first. The inequalities they face are recognized as "women issues" rather than cultural issues. How they live their lives, care for their families, and face the prejudice of being HIV⁺ are based on being women. They assume a pro-active role as they live with and take responsibility for their disease.

HIV⁺ Hispanic women who are pregnant take a more active role in their care to assure the safe development of the fetus. They continue care despite the obstacles they encounter. They bear the verbal and emotional abuse by healthcare professionals as they receive care. They change healthcare settings to obtain optimum care, and they lash out and demand equal care when necessary. Consequently, the Hispanic woman seeks, obtains, and continues with her own healthcare for the purpose of "living" for her child.

HIV⁺ Hispanic women choose cautiously when and to whom to reveal their status. They seek the confidence of their mothers first, then an eldest sister if the mother is not available. The revelation to other family members is left to the discretion of this person. The women take great measures in protecting their children from the truth of their disease. Most inform their children of "being sick" and the precautions they have to take; however, they can not bring themselves to reveal the true reality of the disease. All of the women have made provisions for their children since their affirmation of status.

Surprisingly, these Hispanic women do not use traditional folk health practices often. The women's ages, length of time in the United States, and education all seem to impact the extent to which they use or are willing to use traditional folkways in their

healthcare regimen. The practices most commonly used (teas, herbs) are more palliative than curative. They are used primarily for experienced symptomology and not necessarily specific to HIV. Most of the women express belief in a higher power, the use of prayer, reading of the Bible, and going to Church as measures helpful in finding comfort as they deal with this disease.

Group sessions are seen as an important walk of life for the HIV⁺ Hispanic woman. Incentives, however small, are a main reason the women attend the groups. The group also provides the women an avenue in which to discuss their feelings, their fears, and share information about misfortunes with people they have come to trust. They learn from each other. They share any and all information about the politics of being HIV⁺. They help each other fill out forms. They share information about who to see for assistance with a particular matter. They offer suggestions and advice based on their own previous experiences in certain situations. They help each other with any problem that they as individuals can solve. The women find strength to guide their decision making by attending the group. The group is powerful by virtue of the information and experience each member brings to the group. Each individual member is important and plays an important part. Absence from group is noted by those in attendance.

Recommendations

The following recommendations for further research are derived from the findings of this study:

Collaborative models that utilize the knowledge and skills of Hispanic women,

nurses, and healthcare professionals should be developed for cultural assessment, decision making assessment, management, education, and support of the HIV⁺ Hispanic woman. HIV⁺ Hispanic women have a rich cultural background on which they base their decision-making. Tapping into the Hispanic woman's knowledge and skills may assist healthcare professionals to move away from the stereotyping and pre-conceived notions about Hispanic women and develop programs, protocols, and policies that may be effective in caring not only for the Hispanic woman but for the HIV⁺ Hispanic woman.

Research protocols should be developed to include women, especially minority women. Women have diverse and specific needs that impact their health status. Minority women have specific social, cultural, and welfare needs that further impact their health status. Inclusion of minority women in research protocols may enrich current data by providing information on the impact of such diverse needs on current health conditions and research.

HIV⁺ Hispanic women who wish to "tell their stories" should be supported. Programs should be formed to help these women with information, guidance, and support. However, telling of their own stories is primary. The provision of opportunities to tell their stories should be made available by such programs in the hope of reaching and educating other women.

Incentives were motivating for HIV⁺ Hispanic women. The implementation of incentive programs with other groups and/or programs could be helpful in motivating clients to keep their doctor/clinic appointments, encourage participation in support

groups and/or research studies. Incentives could be small, such as food vouchers, taxi vouchers, gift certificates, etc. Funding for such a program could be government-based and/or donations from local merchants.

Taking medications on time was important for HIV⁺ Hispanic women. Offering watches or timepieces that "buzzed", water bottles, pill cases and carrying bags could help remind the women to take their medications. The donation of these items could be proposed as a funding source. Donations could be asked of a watch company, a medical supply house, or pharmaceutical company.

The Hispanic population in this study was of Mexican or Puerto Rican descent. This study should be duplicated in a different geographical area of the United States to see if acculturation in these study populations impacts their dealing with HIV/AIDS. The study should also be duplicated with other Hispanic populations (Columbian, Honduran, etc.) to see if they deal differently with HIV/AIDS. The study then could be expanded further to study acculturation of these other Hispanic populations in different geographical areas of the United States and its impact on dealing with HIV/AIDS.

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APPENDICES

APPENDIX A

University Human Subjects Review Committee Approval

HSRC APPROVAL FORM

Name of Investigator(s) Maria del Rosario ValdezName of Research Advisor(s) Dr. Diane RagsdaleAddress: 303 CosgroveSan Antonio, TX 78210Dear: Maria del Rosario,Your study entitled: Folklore and Health Practices of HIV(+) Hispanic Women*(The applicant must complete the top portion of this form.)*

has been reviewed by the Human Subjects Review Committee - Houston Center and it appears to meet our requirements in regard to protection of the individual's rights

Please be reminded that both the University and the Department of Health and Human Services regulations typically require that signatures indicating informed consent be obtained from all human subjects in your study. These are to be filed with the Human Subjects Review Committee Chairman. Any exception to this requirement is noted below. Furthermore, according to HHS regulations, another review by the HSRC is required if your project changes or if it extends beyond one year from this date of approval.

Any special provisions pertaining to your study are noted below:

 The filing of signatures of subjects with the Human Subjects Review Committee is not required.

 Other: see attached sheet.

 ✓ No special provisions apply.

Sincerely,

Gayle Hensch
Gayle Hensch, Ph.D.
Co-Chairperson, HSRC - Houston Center

8-3-98
Date

TEXAS WOMAN'S UNIVERSITY

DENTON DALLAS HOUSTON

HUMAN SUBJECTS REVIEW COMMITTEE

1130 M. D. Anderson Blvd., Houston, Texas 77030 713/794-2114

MEMORANDUM

TO: Maria del Rosario Valdez

FROM: HSRC

DATE: August 3, 1998

SUBJECT: HSRC Application

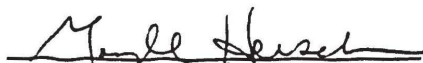
Proposal Title: Folklore and health practices of HIV (+) Hispanic women.

Your application to the HSRC has been reviewed and approved.

This approval lasts for 1 year. If your study extends beyond that time you must notify the Human Subjects Review Committee.

REMEMBER TO PROVIDE COPIES OF THE SIGNED INFORMED CONSENT TO ME WHEN THE STUDY HAS BEEN COMPLETED. GRADUATION MAY BE BLOCKED UNLESS CONSENTS ARE RETURNED.

Thank you for your patience in awaiting the committee's decision. The committee extends its best wishes for a productive and very successful project. Should you have any further questions about your application, please contact me at 794-2153.



Gayle Hersch, Ph.D.
CoChairperson

APPENDIX B

Agency Approval

TEXAS WOMAN'S UNIVERSITY
COLLEGE OF NURSING
1130 M.D. ANDERSON BLVD.
HOUSTON, TEXAS 77030-2897

AGENCY PERMISSION FOR CONDUCTING STUDY*

THE _____

GRANTS TO Maria del Rosario Valdez
a student enrolled in a program of nursing leading to a Ph.D. in nursing at Texas Woman's University, the privilege of its facilities in order to study the following problem:

Folklore and Health Practices of HIV(+) Hispanic Women

The conditions mutually agreed upon are as follows:

1. The agency (_____) (may not) be identified in the final report.
2. The names of consultative or administrative personnel in the agency (_____) (may not) be identified in the final report.
3. The agency (wants) (_____) a conference with the student when the report is completed.
4. The agency is (_____) (unwilling) to allow the completed report to be circulated through interlibrary loan.
5. Other _____

Date: 3-16-98

Maria del Rosario Valdez
Signature of Student

Dr. Linda Ragsdale
Signature of Agency Personnel
Signature of Faculty Advisor

*Fill out and sign three copies to be distributed as follows: Original-Student; First copy - agency; Second copy - TWU College of Nursing.

DR:lt
1/13/92

APPENDIX C

Consents to Participate in Research

TEXAS WOMAN'S UNIVERSITY

DENTON / DALLAS / HOUSTON

COLLEGE OF NURSING
Houston Center
1130 M.D. Anderson Blvd.
Houston, TX 77030-2897
Phone: 713/794-2100

Consent to Participate in Research FOLKLORE AND HEALTH PRACTICES OF HIV⁺ HISPANIC WOMEN

I am being asked to take part in a research study called, "Folklore and health practices of HIV⁺ Hispanic women". The study is being done by Maria del Rosario (Rosie) Valdez, doctoral nursing student at Texas Woman's University. The purpose of the study is to explore folk health practices of HIV⁺ Hispanic women.

1. I understand that I will be interviewed and that the interview will be audio taped. The interview will take approximately one hour. Additional interviews may be requested for more information. These additional interviews will probably last between 15 minutes and one hour. Total interview time can take approximately two hours.
2. I understand that the interview(s) may tire me. I can stop the interview at any time to rest or to say I do not want to be in the study any more.
3. I understand that some questions may be sensitive and I do not have to answer them. I can stop the interview at any time if I become uncomfortable or anxious with any of the questions.
4. I understand that there will be no cost to me to participate in this study. Participation in this study will not affect my enrollment in the _____ support group.
5. I understand that there is a risk that I may be identified and being HIV⁺ through my participation in this study. This risk will be reduced by a code number used instead of my name, which will be known only to the researcher. I understand that the researcher will keep the research forms under lock and when the study is over, the forms will be destroyed.
6. I understand that I am unlikely to receive any direct benefits from participating in this study. The findings of this study may help health care professionals understand and plan care for other HIV⁺ Hispanic women.
7. The researcher will try to prevent any problem that could happen because of this research. I should let the researchers know at once if there is a problem and they will help me. I understand, however, that in the event of physical injury resulting from this research, Texas Woman's University and the _____ does not

Consent to Participate in Research
Folklore and Health Practices of HIV⁺ Hispanic Women
(Page 2 of 2)

provide medical services or financial assistance.

8. If I have any questions about the research or about my rights as a subject, I should ask the researchers. Their phone number is at the top of this form. If I have any questions later, or if I wish to report a problem, I may call the researchers or the Office of Research and Grants Administration at 940-898-3375. My questions have been answered to my satisfaction by the researcher.

I voluntarily agree to take part in this research study with the understanding that I may withdraw my consent or stop my participation at any time. I understand that this study has been approved by the Human Subjects Review Committee of Texas Woman's University and the, I acknowledge that I have received a copy of my signed consent form.

Participant signature

Date

Witness signature

Date

TEXAS WOMAN'S UNIVERSITY

DENTON/DALLAS/HOUSTON

COLLEGE OF NURSING
Houston Center
1130 M.D. Anderson Blvd.
Houston, TX 77030-2897
Phone: 713/794-2100

Consentimiento para Participar en Investigacion FOLKLORE Y PRACTICAS DE SALUD DE MUJERES HISPANAS CON VIH*

Se me solicita qu participe en un estudio de investigacion llamado "Folklore y practicas de salud de mujeres hispanas con VIH*". Este esta siendo hecho por Maria del Rosario (Rosie) Valdez, estudiante de doctorado de enfermeria en Texas Woman's University. El proposito del estudio es ver como las mujeres hispanas con VIH* usan el folklore y practicas de salud caseras en sus vidas.

1. Yo entiendo que sere entrevistada y que la entrevista sera grabada en cinta. La entrevista tomara aproximadamente una hora. Entrevistas adicionales seran solicitadas para mas informacion. Estas entrevistas adicionales probablemente duraran entre 15 minutos y una hora. Las entrevistas probablemente duraran dos horas total.
2. Yo entiendo qu la entrevista(s) me puede cansar. Yo puedo suspender la entrevista en cualquier momento para descansar o decir que no quiero seguir mas en el estudio.
3. Yo entiendo que algunas preguntas pueden ser sensitivas y yo no tengo que contestarlas. Yo puedo suspender la entrevista en cualquier momento si me sieto incomoda o con ansiedad con algunas de las preguntas.
4. Yo entiendo qu no tengo que pagar nada para participar en este estudio. Participacion en este estudio de investigacion no affectara mi relacion con el .
5. Yo entiendo que hay el riesgo de que yo sea identificada y ser VIH* por mi participacion en este estudio. Este riesgo se reducira mediante el uso de un numero clave en lugar de mi nombre el cual lo sabra solamente el investigador. Yo entiendo que el investigador guardara los formularios de la investigacion bajo llave y cuando el estudio haya terminado, estos seran destruidos.
6. Yo entiendo que no voy a recibir ningun beneficio directo de la participacion en este estudio. Los resultados de este estudio podran ayudar a los profesionales del cuidado de la sallud a entender y planear la atencion para otras mujeres hispanas con VIH*

Consentimiento para Participar en Investigacion
Folklore y Practicas de Salud de Mujeres Hispanas con VIH⁺
(Pagina 2 de 2)

7. Yo entiendo que si a caso me lastimo o me ocurre algun dano con participar en esta investigacion, yo tengo que decirle a los investigadores inmediatamente. Yo entiendo que Texas Woman's University o el [] no son responsables por los gastos medicos.
8. Si tengo preguntas sobre esta investigacion o mis derechos como participante en este estudio, debo preguntarles a los investigadores. Su numero de telefono esta al principio de esta pagina. Si tengo algun problema o mas preguntas acerca de este estudio podre comunicarme con la Oficina de Investigacions en el numero 940-898-3375. Mis preguntas han sido contestadas a mi satisfaccion por el investigador.

Yo voluntariamente acepto participar en este estudio de investigacion con el entendimiento de que puedo retirar mi consentimiento o suspender mi participacion en cualquier momento. Yo entiendo que este estudio ha sido aprobado por el comite de Texas Woman's University y de el [] que revisa las investigaciones en sujetos humanos (Institutional Review Board). Yo compruebo que he recibido una copia de el formulario de mi consentimiento firmado.

Firma del Participante

Fecha

Firma del Testigo

Fecha

APPENDIX D

Consents to Audiotape

TEXAS WOMAN'S UNIVERSITY

DENTON/DALLAS/HOUSTON

COLLEGE OF NURSING
Houston Center
1130 M.D. Anderson Blvd.
Houston, TX 77030-2897
Phone: 713/794-2100

Consent to Audiotape FOLKLORE AND HEALTH PRACTICES OF HIV⁺ HISPANIC WOMEN

I consent to the recording of my voice by Maria del Rosario (Rosie) Valdez acting under the authority of the Texas Woman's University and the _____ for the purpose of this research project. I understand that the material recorded for this research will be made available for research purposes, and I hereby consent to such use:

Participant Date _____
(Guardian or nearest relative must sign
if participant is a minor).

The above form was read, discussed, and signed in my presence. In my opinion, the person signing said consent form, did so freely and with full knowledge and understanding of its contents.

Authorized representative
of the Texas Woman's University

Date

TEXAS WOMAN'S
UNIVERSITY

DENTON/DALLAS/HOUSTON

COLLEGE OF NURSING
Houston Center
1130 M.D. Anderson Blvd.
Houston, TX 77030-2897
Phone: 713/794-2100

Consentimiento para grabacion de voz
FOLKLORE Y PRACTICAS DE SALUD DE
MUJERES HISPANAS CON VIH*

Yo consiento a la grabacion de mi voz por Maria del Rosario (Rosie) Valdez actuando bajo la autoridad de Texas Woman's University y el _____, para el proposito de este proyecto de investigacion. Yo entiendo que el material grabado para esta investigacion podra estar disponible para propositos de investigacion, y yo por este medio doy mi consentimiento para tales usos:

Participante
(Custodio o pariente mas cercano
debe firmar si el participante es menor
de edad)

Fecha

El formulario que precede fue leído, discutido y firmado en mi presencia. En mi opinion, la persona que firmo este formulario de consentimiento, lo hizo libremente y con pleno conocimiento y entendimiento de su contenido.

Representante autorizado
de Texas Woman's University

Fecha

APPENDIX E

Interview Guides

INTERVIEW GUIDE
Demographic Data

CODE _____ DATE _____

(1) Age _____ (2) Marital Status _____ (3) # of children _____ (4) Ages of children _____

(5) Educational level _____ (6) Means of support _____

(7) Household size _____ (8) Other family members living at home

(9) Ages of family members living at home

(10) Healthcare access: yes () no ()

(11) Type _____

Ethnic Background:

Mexican National _____ Mexican-American _____ Puerto-Rican _____

INTERVIEW GUIDE
Semi-structured Questions

* Tell me, "What did you do today to stay healthy?"

* What do you usually do to take care of yourself?

Some probes could be:

* What home remedies do you use in your daily living to stay healthy?

* What medicines or herbs do you use in your daily living to stay healthy?

* What other folk practices do you use in your daily living to stay healthy?

* What do you do to stay healthy and live with HIV/AIDS?

* What is it like being a Hispanic woman living with HIV/AIDS?