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Disclosing experience of Latinas living with HIV/AIDS

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Dedication

I dedicate this dissertation to my parents,

Elena and Jessie J. Ortiz

Acknowledgments

I have been privileged to study in the doctoral program in the School of Nursing at the University of California, San Francisco. Several grants and fellowships supported my studies: AIDS Clinical Research Center Fellowship, Universitywide AIDS Research Program, Grant T-32, University of California President's Health Science Fellowship from the University of California, San Francisco, and Century Club Funds from the University of California, San Francisco School of Nursing.

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Abstract

DISCLOSING EXPERIENCES OF LATINAS LIVING WITH HIV/AIDS

by

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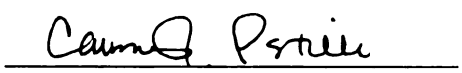
University of California, San Francisco, 2000

Deciding to disclose their HIV/AIDS status affects the lives of Latinas and their relationships and interactions with partners, family members, peers, and the community. Limited information is available on the disclosing processes, situations and consequences of the growing numbers of women, especially Latinas, living with HIV/AIDS. The purpose of this study is to describe the disclosing experiences of Latinas living with HIV/AIDS in the San Francisco Bay Area. This research explores the interactions, consequences, and social contexts of Latinas disclosing their seropositive status.

The research design was a cross-sectional descriptive study of HIV-positive or AIDS diagnosed Latinas. A convenient purposeful sample of 19 Latinas, 18 years old or older living in the San Francisco Bay Area, were interviewed using semi-structured interviews at a mutually agreed upon location. Content analysis was used to analyze the data by identifying code words and related concepts that were developed into categories representative of the disclosing experiences of the participants. Deciding to disclose was identified as the core category, denotes the internal and external factors that influenced each Latina when they decided to tell partners, family members, friends, employers, and health professionals about their seropositive status. From the data emerged four major categories: timing disclosures, needing to disclose, controlling disclosures, and supportive disclosing. Strategies and actions used by the Latinas when deciding to disclose included selective telling, postponing, and seeking help. The strategies were used

to assist with the planning and choosing to whom, when and how the seropositive Latinas would tell. As a result of disclosing their HIV/AIDS status, the women encountered negative and positive consequences. Positive consequences were described as being accepted and receiving support from those who had been told. Negative consequences were described as being rejected and blamed by others. The study increases knowledge of the social cultural context of Latinas' lives and how they disclose their HIV/AIDS diagnosis. Nurses can incorporate that knowledge into care plans that also address the consequences of disclosing.



Carmen Portillo, PhD, RN, FAAN
Chairperson of Committee

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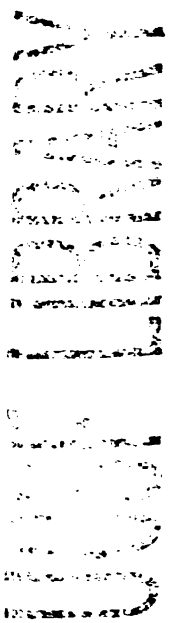

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CHAPTER ONE

STUDY PROBLEM

Background of the Problem

Disclosing an illness or disease, such as human immunodeficiency virus (HIV) or acquired immune deficiency syndrome (AIDS), has many potential and real consequences for Latinas. Latinas diagnosed with HIV/AIDS encounter psychological distress, diminishing physical and social resources, stigma, discrimination, and social isolation (Romero, Arguelles, & Rivero, 1993; Saunders, 1989). The psychosocial stresses of uncertainty about future health and life expectancy, starting or maintaining intimate relationships, and emotional sequelae such as anxiety, fear and depression are ever present (Buckingham, 1987; Ostrow et al., 1989). Discrimination in housing, employment, and health resources are known to be associated with the HIV/AIDS diagnosis (Bayer & Oppenheimer, 1986; Ginsburg & Gostin, 1986). The fear of stigmatization and the subsequent discrimination results in a reluctance to disclose and obtain health care for people living with HIV/AIDS and social services for their families (Gentry, 1993; Moneyham et al., 1996; Sabo & Carwein, 1994). These issues continue to be present as the numbers of HIV/AIDS cases unfold.

The Centers for Disease Control (CDC) reported infection among United States (US) women has increased significantly over the last decade, especially in communities of color. The CDC reported that the majority of AIDS cases of women through 1998, were among African-Americans (56%), Latinas (20%), and whites (22%) (CDC, 1998). Women comprised 16% of the total AIDS cases while Latinas (20%) comprise a disproportionate number of the AIDS cases among all women. The majority of Latinas with the AIDS diagnosis are between the ages of 25 to 44 years (CDC, 1998).

As the third decade of the HIV pandemic begins, Latinas living with HIV/AIDS continue to struggle with economic, medical, social, psychological and behavioral issues. Disclosing is a behavioral issue that is often filled with anxiety, tension, societal fear of HIV/AIDS and the potential for stigma, discrimination (Christ & Weiner, 1988; Chung & Magraw, 1992; Herek & Capitano, 1993; Herek & Glunt, 1988), and blame attached to the diagnosis (McGrath, 1992).

Women of color and injection drug users (IDUs) face additional cultural and social stigma and discrimination because of their association with these identified social groups and diagnosis of HIV/AIDS. Segments of these populations live in turmoil because of poverty and social status. Additional burdens of stigma, isolation and discrimination exist for people living with HIV/AIDS because of unrealistic fears of contracting the virus by members of society (Lawrence, Husfeldt, Kelly, Hood, & Smith, 1990) and health care professionals (Gerbert, Maguire, Badner, Altman, & Stone, 1988; Siminoff, Erlen, & Lidz, 1991). These issues are likely to precipitate caution and fear of disclosing HIV/AIDS status to family, friends, employers, and health care professionals.

A central issue that causes concern for women living with HIV/AIDS is how they view themselves with this illness. Women have expressed feelings of shame, anger and blame toward themselves in response to learning their diagnosis (Kurt & Hutchinson, 1989; McCain & Gramling, 1992). People define themselves and their lives by influencing factors throughout a lifetime (Gergen, 1971). Influencing factors such as family, culture, illness experiences, and society contribute to the roles and identities that define the person (Gecas, 1982). These influencing factors are internalized as the person identifies with them and contribute to a person's overall self-concept and influence the disclosure process.

When a change in health occurs due to an illness, such as HIV/AIDS, there may be a change in the self-concept of wellness of a person. The resulting change in self-concept may cause fear of loss of family or peer support, mutilation of the body due to surgery or treatment, uncertainty of future health or reoccurrence of illness, and feelings of potential stigmatization with disclosure of an illness to others (Charmaz, 1986; 1987; 1991). Disclosing a potential stigmatizing condition or illness may cause the person to lose control over their emotions, be unable to handle others' responses, and be rejected for telling others and for being ill (Ponse, 1976).

The complexities of the disclosing experiences have not been fully described by nursing research regarding Latinas. Identification of the problems, strategies and interactions that influence the Latina's disclosing and not disclosing patterns is a key factor to providing health care by nurses. Understanding the impact of HIV/AIDS on Latinas is necessary to assist them with decreasing their fears of disclosing and facilitate early intervention to health care and emotional support.

There is a paucity of research on Latinas living with HIV/AIDS that describes the psychosocial and cultural factors that may influence the disclosure experiences (Friedman et al., 1987; Jimenez & Jimenez, 1992; Moneyham et al., 1996). Latinas living with HIV/AIDS are concerned about deciding how, when, what, and to whom to disclose their status because of the threat of social stigma, rejection, and discrimination. The HIV/AIDS diagnosis carries the threat of severance from traditional sociopsychological support systems and the fear that disclosure of HIV/AIDS that can bring "shame" on the family and the community (Romero, Arguelles, & Rivero, 1993; Worth, 1990). The effect of HIV/AIDS on the lives of Latinas is influenced by the presence of stereotypes, stigma,

and discrimination toward persons living with HIV/AIDS. In turn, these factors influence the decision of whether or not to disclose one's HIV/AIDS status (Weitz, 1992).

Statement of the Problem

Deciding to disclose their HIV/AIDS status affects the lives of Latinas: their relationships and interactions with partners, family members, peers, and the community. Limited information is available on the disclosing processes, situations and consequences of the growing numbers of women, especially Latinas, living with HIV/AIDS (Moneyham et al., 1996; Simoni et al., 1995; Sobo, 1995). Nursing research is needed to describe the experiences of Latinas within the context of environment, which includes culture, previous experiences, situations and interactions influencing the decision to disclose or not disclose.

Purpose of the Study

The purpose of this study is to describe the disclosing experiences of Latinas living with HIV/AIDS in the San Francisco Bay Area. This research explores the interactions, consequences, and social contexts of Latinas disclosing their seropositive status.

Significance of the Study

Understanding the problems of disclosure and outcomes of disclosure is imperative if nurses are to intervene effectively in the lives of Latinas living with HIV/AIDS (Simoni et al., 1995). Present knowledge does not describe and explain the social relationships and situations experienced by Latinas disclosing their HIV/AIDS status. This study allowed Latinas to describe how HIV/AIDS impacted their decision-making process of choosing to whom, when, and why and under what circumstances the women disclosed their status.

The knowledge generated from this study described the contextual factors that influenced Latinas disclosing their seropositive status. The contextual factors of

disclosing were related to the timing of disclosure, the needing to disclose based on the relationship to a person, and the seeking of support for themselves or others. Strategies described how the women evaluated situations and people when deciding to disclose. The positive and negative consequences perceived or encountered by Latinas influenced their disclosing to others.

Findings from this study will assist nurses in addressing the needs of Latinas living with HIV/AIDS. Becoming aware of these factors will assist nurses with advising Latinas to develop strategies for disclosing and seeking early health care and counseling in community programs that incorporate supportive services and relevant resources pertinent to Latinas with this devastating diagnosis. Understanding the issues of disclosing by Latinas will enhance the nurses' ability to refer Latinas to early interventions that can assist with addressing health problems.

CHAPTER TWO

RESEARCH LITERATURE

Disclosing an illness is a complex phenomenon that involves interactions between people. Persons who decide to disclose information about their illness realize that their lives may change as others become aware. People who disclose realize that they may encounter changes in their relationships and interactions with partners, family members, and community after disclosure.

Literature on self-disclosure of a life-threatening or chronic illness indicates that there may be many factors that influence disclosing. Factors such as trust, a person's relationship, social situation, perceptions of stigma, discrimination, and the interactions among people influence when, why, and to whom a person may share personal information (Charmaz, 1986; Durham, 1994). While the factors of disclosing an HIV/AIDS status have been recognized (Limandri, 1989; Mason et al, 1995; Moneyham et al, 1996; Simoni et al, 1995; Simoni, Mason, & Marks, 1997; Sobo, 1995; Sowell et al, 1997), the experiences of Latinas living with HIV/AIDS have not been fully explored.

The relevant disclosing literature is presented in two major sections: (a) Charmaz's conceptual framework of self-disclosing a chronic illness and (b) self-disclosure HIV/AIDS research.

Charmaz's Conceptualization of Self-Disclosing and Chronic Illness

Charmaz's relevant conceptualization of self-disclosure of chronic illness has developed over the past 15 years. She describes how a chronic illness poses moral and social dilemmas for persons who decide to disclose (Charmaz, 1986). The chronically ill person must decide when and how to disclose and risks the possibility of being rejected by others.

Her conceptualization of disclosing is based on Jourard's (1971) definition of self-disclosing. Ill persons elicit their emotions by self-disclosing information about themselves. Disclosing means revealing thoughts and feelings while stating crucial facts about the self (Charmaz, 1986).

The ill person assesses and interprets information, and conveys their interpretations to others about the ill self. This conveyance of information of the self is done in a non-threatening manner to preserve the self or present the new self to others. With the telling, the ill person is unable to ignore, minimize, or avoid acknowledging the implications of illness for self-concept. In disclosing facts about the illness, people teach themselves about their altered selves. For some people who are ill, disclosing marks the beginning of their own death. That is, even when faced with death, people continue to make choices, design plans, manage interactions, and ultimately construct their lives to meet their priorities, perspectives, and possibilities (Charmaz, 1986).

Making the decision to disclose to another is difficult. The internal struggle and decision-making process of presenting the ill self occurs with evaluating the perceptions and potential responses of the person. The ill person uses previous experiences to assist with the decision-making process of disclosing (Charmaz, 1986, 1991). Evaluating the potential responses and decision-making assists the ill person with developing the strategies of disclosing to whom, when, how much, and what to tell.

Two types of disclosure are described by Charmaz (1991): protective disclosure and spontaneous disclosure. Protective disclosing controls how, what, when, and to whom people reveal their illness. This form of telling is planned and is intended to protect others and themselves from shock, anger, and fear about the illness and future ramifications (Charmaz, 1986; 1991). For protective disclosing to be effective, the ill person controls

the form and timing of information, softens its potential harshness, and attempts to buffer everyone's emotions about the information.

Structuring protective disclosures includes using four strategies (a) invoking the assistance of others, (b) setting the stage, (c) providing progressive clues, and (d) selective informing (Charmaz, 1991). Invoking the assistance of others involves participation of family members, friends, or health professionals with the disclosure of information. These assistants help keep the scene together and reflect a unified view and a statement of their shared relationship. Assistance from a health professional makes the information real and legitimate to others.

Setting the stage offers the opportunity to plan and create an atmosphere in which to tell others. Planning allows the setting of the atmosphere to ease a relative or friend into the disclosure. For example, telling can be done face-to-face privately to see the person's response rather than telling them with a telephone call.

Progressive clues are given over time by the ill person to give warnings and information to others. This strategy allows the ill person to hint, inform and warn over time. The other person has limited knowledge of the severity of the illness. The ill person can use this strategy to build on the seriousness of the illness. Progressive clues also bring reality to the present and future of the illness (Charmaz, 1991). For example, an ill person may have a history of illness and does not show physical signs. Friends and family members may ignore or forget the residual effects of illnesses and need reminders. These hints and warnings define the illness as part of the present and future.

Providing progressive clues to others frequently depends on selective informing. Ill people use selective informing when they believe others need to know something about their illness (Charmaz, 1991). The progressive clues allow the person to reveal selected

aspects of their illness in order to protect their friends and themselves.

The final strategy selective informing allows the person to preserve the previous relationship with the person, maintain autonomy and independence by revealing a few problems encountered with the illness. This strategy enables the ill person to believe that they are easing the other person's strain and assumes that there will be future opportunities to address concerns or request assistance from the other person (Charmaz, 1991).

The second type of disclosing described by Charmaz is spontaneous disclosure, which occurs when the person overtly and openly reveals thoughts and feelings about an illness without planning. The person disclosing shows little regard for the social situations that they find themselves. This disclosing includes full expression of feelings, exposing the self with very little or no control over how, when, where, what, and whom to tell (Schneider & Conrad, 1980).

A final form of disclosing is strategic announcing. The ill person controls and directs interactions when disclosing to others. It must be noted that repeated strategic disclosures assist to protect the ill person from the others' demands, expectations, and assumptions when the "illness remains unacknowledged, ignored, or minimized by others and the ill person must have help or reduce previous obligations" (Charmaz, 1991, p. 122).

Just as strategic announcing is used for self-protection or to control certain reactions, strategic non-disclosure is used in the same manner. However, this non-disclosing can cause the other person to misinterpret the action of not being told and exacerbate a previous conflict. For instance, an ill person may not disclose a condition to a family member with whom there is a history of conflict. When that family member learns that other family members knew before them, there is the feeling of being cheated (Charmaz,

1986).

Charmaz's work provides an understanding of the disclosure process. Her research (1986, 1991) revealed a process of how, when, why, and to whom men and women with a chronic illness disclosed. However, her research does not identify influencing factors of culture and how culture may influence a person's perception of an illness and hinder disclosing to others. Consequently, understanding how these cultural perceptions affect the self-concept and how they influence disclosures needs further investigation. Understanding the disclosing interactions among diverse populations will broaden the perspectives of previous disclosing research (Charmaz, 1986).

Self-Disclosure in HIV/AIDS: Review of Research Literature

The majority of HIV/AIDS disclosing research literature has centered on the gay and bisexual experience. Research identified persons with HIV did not disclose their status because of perceived fears and concerns of how people would respond to the information (Huggins, Elman, Baker, Forrester, & Lyter, 1991; Kegeles, Catania, Coates, 1988; Marks, Bundek, Richardson, Ruiz, Maldonado, & Mason, 1992; Marks, Richardson, & Maldonado, 1991; Stempel, Moulton, Bacchetti, Moss, 1995). Limited research has expanded to include women (Barnes, 1992; Chervenak & Weiss, 1989; Limandri, 1989; Moneyham et al., 1996; Simoni et al., 1995; Sowell et al., 1997) and mothers telling their children (Pliskin, Farrell, Crandles, & DeHovitz, 1994).

The literature revealed that some HIV infected persons who disclose to their partners, family members, close friends, or health care experienced different responses. For example, negative responses involve rejection, stigma, and discrimination. Positive responses involving support, education, and acceptance are contingent on the timing and staging of the illness.

The purpose of this section is to review and critique relevant research literature related to adults living with HIV/AIDS who self-disclosed their status. The review will present HIV/AIDS research that examined self-disclosure experiences of heterosexuals, gays, bisexuals, and women. The following section of the review of the literature is divided into three sections: Heterosexuals, gays and bisexuals; persons who disclose to health care professionals; and women who disclosed their status. Study descriptions summarizing the purpose, design, sample, methodology, and findings are provided in Appendix A: Heterosexuals, Gays and Bisexuals Disclosing Status, Appendix B: Disclosing to Health Care Providers, and Appendix C: Women Disclosing HIV/AIDS Status.

Heterosexuals, Gays, and Bisexuals Disclosing Status

Mitchell and Smith (1987) presented a case study of the development of strategies by hospital staff nurses that enabled an HIV infected hemophiliac male to disclose his status while maintaining patient privacy and confidentiality. Fearing that disclosure of his HIV status to his family and a visiting home nurse would cause rejection by his wife and isolation for his children in the small community, the patient refused to share any information regarding his HIV infected status except with the hospital staff. The patient also felt his children would be more harmed than helped by the knowledge. The nurses considered the negative impacts of rejection, stigma and discrimination with the obligation to tell his wife and fellow nurses. Strategies of providing education and emotional support were employed with the patient deciding to first tell his wife and then the home care nurse. When he told his wife, there was a positive, supportive response toward her husband.

This research revealed three important factors that influenced the person with

HIV/AIDS to make the decision to disclose his status: fear of rejection, stigma and discrimination. This case study presented as a single experience that cannot be generalized to other populations. It is likely that other HIV-positive persons may have different views and reasons for not disclosing their status.

Kegeles, Catania, and Coates (1988) investigated sexual practices, number of sexual partners in preceding month, and intentions to communicate HIV-positive test results to sex partners. The sample included gay and bisexual men who were sexually active during the previous month and in mutually monogamous relationships. Data collection was obtained with a self-administered questionnaire prior to receiving their HIV test results at two testing centers in Alameda County, California. Total number of participants was not presented.

Individuals were categorized according to the previous month's sexual activities: low-risk sex, somewhat risky sex, and high-risk sex. Overall, a majority of the respondents (88%) intended to communicate a seropositive status to their sexual partners, while 12% would not tell their primary sexual partner, and 26.8% would not tell their non-primary partners. Subjects who did not intend to tell their seropositive status to their primary partner had not engaged in high-risk sex with their partner, although 8% had engaged in somewhat risky activities. Nineteen and a half percent did not intend to tell their non-primary partners they were seropositive and had engaged in high-risk sex with multiple partners. Some subjects (7.3%) did not intend to reveal their positive antibody status to their non-primary partners and had also engaged in somewhat risky activities with multiple partners. Sixty percent of the participants engaging in high risk sex practices reported they would tell their primary sex partners, but only 43.9% would tell their non-primary sex partners. Those who had engaged in somewhat risky (8%) or low-

risk (4%) sex behaviors did not intend to tell their primary sexual partner.

O'Dell's (1988) study investigated whether patients knew what their illness was and if they disclosed their illness to their family and, if not, why they did not tell. A questionnaire was used to gather data from 30 patients at a clinic in Central Africa. In the sample, two respondents had AIDS - related complex (ARC), 28 had full-blown AIDS and three were unaware of their illness. Patients with new, tentative, or unconfirmed HIV-positive diagnosis were excluded. Gender was not reported. Participants responded to the questions: (a) have you told anyone in your immediate family about your HIV infection? (b) have you told anyone in your family about your HIV infection? and (c) if not, why have you not told anyone?

Fifteen patients did not tell their diagnosis to their spouse or immediate family, twelve participants told their spouse while three participants did not answer the questions. These results supported the researcher's assumption that a significant number of patients may fail to disclose their illness following the HIV diagnosis. Patients who did not reveal their status cited that fear of rejection (12) or lack of importance (1) as reasons for not telling. Patients, who feared rejection, feared that their families would refuse to care for them.

Marks, Richardson, and Maldonado (1991) reported findings from an ongoing study of self-disclosure of HIV/AIDS status in relation to the specific sexual activities performed. Results from 138 adult males (104 Hispanics, 21 non-Hispanic Whites, 11 Blacks, and two Asians) that tested positive for HIV in the previous 18 months were reported. Ninety-one percent of the participants self-identified as homosexuals or bisexuals. Each subject completed a self-administered confidential questionnaire. Sexual activity and disclosure were collected with a matrix checklist. All subjects were requested

to recall all partners, including intimate lovers, casual partners, and spouse if married, and for each, to identify types of sexual activities. Further, the participants indicated whether they disclosed HIV infection before the activity and whether the partner was known to be infected with HIV. Subjects who did not have sexual relations were also identified.

Researchers reported that 62 of the 138 (45%) subjects had been sexually active since learning of their seropositive status. Four of the 62 men were excluded due to missing data on relevant questionnaire items. Thirty of the remaining 58 men kept their infection secret from one or more partners. Disclosure did not differ significantly by ethnicity. Of the men who only had one sexual partner since diagnosis (n = 36), 69% disclosed their seropositive status to that partner of those with two to four partners (n = 11), 36% disclosed to at least one partner; of those with five or more partners (n = 11), 18% disclosed to at least one partner. This significant trend indicated that the likelihood of disclosure of positive HIV status decreased in direct proportion to the increased number of partners. The difference was larger among the informed partners rather than for uninformed partners, indicating that subjects tended to reveal their infection to those already known to be seropositive. When the sexual activity involved insertive and receptive anal intercourse, disclosure to seropositive partners occurred in combination with unprotected contact. The disclosure to seronegative partners occurred in combination with protected contact.

This study, consisting primarily of lower socioeconomic homosexual and bisexual Hispanic men, revealed a high prevalence of nondisclosure of HIV infection to current sexual partners participating in unsafe sexual activity. Nondisclosure was not due entirely to lack of knowledge about sexual transmission of HIV as 94% of subjects were aware of transmission risk through unprotected sexual intercourse.

Huggins, Elman, Baker, Forrester, & Lyter (1991) examined the affective and behavioral responses to HIV testing and over time for gay and bisexual men. The researchers compared the responses of men who chose not to learn the test results (NOT LEARN), those who chose to learn that they tested positive (POS), and those who chose to learn they tested negative (NEG). The cohort included 155 men: 121 NEG, 22 POS, and 12 NOT LEARN. To control for the effect of subgroup size, 22 NEG subjects were randomly selected.

The three groups were compared on measures of general anxiety, depression, and AIDS anxiety one week after HIV testing, and at six months to one year later. Changes in sexual behavior and disclosure to sexual partners of HIV status were compared. Subjects were gay and bisexual men in the Pitt Men's Study and the AIDS Prevention Project at the University of Pittsburgh. Subjects completed questionnaires one to two weeks after HIV antibody testing before learning the test results.

Five instruments were used to measure anxiety, depression, AIDS anxiety inventory, telling partners, and sexual behavior change. Anxiety was measured with the State Anxiety Scale, 12-item scale, with instructions modified to focus on reactions to HIV antibody testing. The Beck Depression Inventory (12-item scale) was used to measure depression and AIDS anxiety was measured using a 12-item scale developed by the researchers. Subjects were asked whether they intended to tell partners their test results, and later, whether they told their partners. Sexual behavior was defined as the total number of partners with whom a subject had engaged in passive anal intercourse.

The one week and six months results for anxiety had main effects for group and time. Regardless of the group, anxiety decreased from one week to six months after testing. Subjects choosing not to know their results were more anxious over time than those

testing negative and learning their results.

Results of whether the subjects intended to disclose the test results or told their lover, regular sexual partners or partners revealed 87% (26 of 30) of the subjects intended to tell lovers, 89% (17 of 19) intended to tell regular sexual partners, and 31% (5 of 16) intended to tell paid sexual partners. The more emotionally invested a subject was with their sexual partner, the more likely they would tell that partner their test results. Subjects told lovers 96% (22 of 23) more often than regular sex partners 44% (8 of 18) and no one told paid sexual partners. Data revealed that the POS group had increased anxiety, depression, and increased disclosing to partners than the NEG or NOT LEARN groups. There was no data to show that anxiety and depression influence to whom and when others were told.

Marks et al. (1992) investigated self-disclosure among a Latino sample. The researchers examined five hypotheses concerning men's self-disclosure of HIV status. They were: (a) those with HIV are more likely to disclose their seropositive status to significant others such as parents, friends, and lovers than to less significant others such as employers, landlords, and religious leaders; (b) gay and bisexual men with HIV are likely to reveal their medical condition to homosexuals or bisexuals rather than to heterosexuals; (c) gay or bisexual men are more likely to disclose their HIV status to others who are aware of their sexual orientation than to others who are not; (d) the number of people to whom the men disclose is likely to increase with the length of time since testing seropositive; and (e) disclosure was likely to increase with the severity of disease.

Study subjects of 101 Latino men with HIV infection were recruited at a public HIV clinic located in a predominantly Latino section of Los Angeles. Seventy-four percent of

the sample tested seropositive within 8 months of their participation in the study. Sixty percent of the participants were homosexual, 29% bisexual, and 11% heterosexual. Ages ranged from 18 to 57 years. Data were collected with a self-administered confidential questionnaire, English or Spanish, in a private section of the clinic waiting area, with 80% of the subjects using a Spanish questionnaire.

Measures for data collection were diagnostic categories, severity of physical symptoms, physical appearance, self-disclosure of HIV infection, sexual orientation of specific targets, HIV status of close male friend, target's awareness of subject's sexual orientation, and time since testing seropositive. Diagnostic categories were self-identified by the subject. Sixty-five percent reported being asymptomatic or having minimal symptoms short of AIDS related complex (ARC), 14% having ARC, and 21% having AIDS, as defined by the CDC case revisions (CDC, 1987). Eighty-seven percent of the subjects' reported diagnoses that matched the diagnostic category obtained from medical charts.

To measure self-disclosure of HIV infection, subjects indicated (yes or no) whether they had disclosed their HIV status to significant others such as: mother, father, sister, brother, a lover (intimate in the past 12 months), spouse (if married), close male friend (no sexual contact), or a close female friend (no sexual contact). Less significant others were identified as current, most recent employer since testing seropositive, doctor/dentist other than those treating subject for HIV, landlord, religious leader, and professional counselor. Individuals not within the above categories were excluded from the statistical analysis. If a third party revealed the HIV status, the disclosure was coded as non-self-disclosure.

The results revealed that there was a high prevalence to disclose to the mother, sibling, and friend. There was a much higher prevalence to disclose to an intimate lover or spouse. A father, employer, religious leader, and landlord had a lower prevalence for being told of the seropositivity. There was a relatively high rate of disclosure (75%) to doctors/dentists who were not treating subjects for HIV infection. Six subjects reported a third party informant disclosed to their father; although each of the six had disclosed to their mother. Two subjects reported that someone else informed their mother and four reported that someone else informed their best male friend. Overall, subjects disclosed to 38% of the significant others and to 24% of the less significant others.

It was hypothesized that gay and bisexual Latinos would be more likely to reveal their HIV infection to homosexual or bisexual others than to heterosexuals. The gay and bisexual subjects disclosed to gay or bisexual male friends more often if friends were seropositive than if friends were seronegative (77.8% versus 65.9%). The effect was stronger when heterosexual subjects and heterosexual male friends were included in the analysis (77.8% versus 52.7%). Gay and bisexual subjects were likely to self-disclose their HIV infection to others who were aware of their sexual orientation.

Overall severity of physical symptoms correlated directly with disclosure to significant and less significant others; that is, when severity of illness increased, disclosure increased. Participants with ARC/AIDS disclosed to a greater number of people than did those with asymptomatic infection. A few of the correlations between disease severity and disclosure may be attributed to the length of time since testing seropositive. Subsequent examinations of disclosure to significant and less significant others revealed that symptom severity of illness was associated with disclosure to significant and less significant others after statistically controlling for time since testing

seropositive.

This research revealed that persons infected with HIV/AIDS were selective in choosing to whom they would disclose their seropositive status. The Latinos tended to inform significant others instead of less significant others. Furthermore, gay and bisexual Latinos revealed their HIV seropositive status to more homosexual or bisexual persons than to heterosexual persons and informed those who were aware of their sexual orientation. No results were provided about the heterosexual participants disclosure patterns.

Schnell et al., (1992) evaluated disclosure of HIV status to main sex partner and the impact on the relationship among homosexuals. The data was obtained at 6 month intervals from cohorts recruited from AIDS Community Demonstration Project sites in California, Washington, Texas, and Colorado from 1987 through 1990. The median age was 32 years. The ethnic background of the participants were identified as white (86%) and Latino (10%). A questionnaire was used to gather data.

Results revealed that seropositive (82%) and seronegative (70%) participants elected to disclose to their main sexual partner. Those who did disclose to their main sexual partner reported the relationship was strong as ever. Among the seronegative men, a change in relationship status was found between those who did and those who did not disclose their HIV test results ($p < .001$). Those who did not inform their main sex partner were more likely to be single at the return visit. A pattern of a change in partner status was identified to be the same among men who tested seropositive, but there was insufficient data for a reliable statistical determination.

Hays, et al. (1993) examined the patterns of gay men self-disclosing their HIV seropositive status to friends, lovers, relatives and colleagues; assessed the effects of

disclosure; and to identified reasons for not disclosing. Data were obtained from the AIDS Behavioral Research Project (ABRP), an ongoing survey in San Francisco of gay men who have been followed since 1984. The 163 subjects were from the annual data collection in November 1990.

Six variables were used for analyses. The six variables were: HIV status, relationship status, disclosure, helpfulness ratings, reasons for not disclosing, and anxiety and depression. HIV status information was requested from each respondent as well as identifying any physical symptoms commonly associated with HIV infection during the previous 12 months (for at least two weeks) and whether they had been diagnosed as having AIDS. The sample was then divided into three mutually exclusive groups: AIDS-diagnoses, symptomatic HIV-positive and asymptomatic HIV-positive. Relationship status included questions related to whether they were currently involved in a primary gay relationship and the HIV status of the partner. Disclosure was measured by using a list of nine relationship categories of those individuals to whom they had disclosed their HIV seropositivity. Those who did not have anyone within a particular relationship category circled 'not applicable' for the relationship. Helpfulness ratings for each individual that disclosed rated how helpful that individual's response had been on a five-point Likert scale. An overall mean of helpfulness score of the respondent's significant others were computed by summing the helpfulness ratings of all individuals to whom the respondent had disclosed and dividing by the number of individuals told.

Reasons for not disclosing were identified using open-ended questions. Four questions asked were: (a) To whom were HIV-positive gay men likely to disclose their HIV status? (b) At what point in the development of HIV illness is disclosure likely? (c) What are the effects of disclosure to various individuals? (d) What are the reasons for

not disclosing to particular individuals?

The patterns of disclosure were that the majority of the men disclosed their seropositive status to their lover/partner (98%) and to their closest gay friend (95%). The closest heterosexual friends were told less often (77%), but were still relatively likely to be told. Patterns of disclosure did not differ for men at different stages of HIV infection. Disclosure to colleagues and relatives was less common. Fathers were the least likely to be told (40%). Asymptomatic men were significantly less likely to disclose their status to relatives and colleagues (54%) than men experiencing HIV symptoms (66%) or those diagnosed with AIDS (85%).

Results revealed that various relationship categories were not perceived to be equally helpful. Planned comparisons indicated that the closest gay friends, lovers and heterosexual friends were perceived to be more helpful than relatives and colleagues. There were no significant differences in helpfulness ratings between men at different stages of HIV infection.

Reasons for not disclosing a seropositive status were obtained through the use of open-ended questions. The most frequently mentioned reasons for not disclosing were not wanting to worry or upset others, fear of discrimination, fear of disrupting relationships, emotional self-protection, feeling that the person would offer little help, lack of intimacy with individual, and desire to conceal one's homosexuality. Many of the men felt disclosure would cause unnecessary emotional distress to others, especially family members. They also expressed the concern that knowledge of their HIV status would strain their relationship with others or negatively affect how others interact with them. There was fear of being misunderstood, rejected, and distanced from others.

Fears of discriminatory treatment from coworkers and employers and issues such as losing health insurance or opportunities for advancement were identified. Some of the participants felt that there was no benefit in telling certain people because it would not be helpful as they were unfamiliar with the problems of HIV/AIDS. Others did not wish to disclose because they did not have an emotional tie or did not discuss personal issues with the other person. Finally, participants who had not previously revealed themselves as being gay were more reluctant to reveal their seropositive status, believing that HIV and homosexuality were closely associated by many people. Many participants planned to disclose to most people, but felt the time was not yet right.

Laryea and Gien (1993) examined the stigma and rejection experienced by persons with HIV in Newfoundland. The findings are from a larger study that explored the impact of HIV-positive status on 25 women and men. A grounded theory approach was used to analyze the data. The sample consisted of 19 males and six females recruited from a large health care facility. The subjects described the effects of the HIV-positive status on self-disclosing interactions with others, on their attitudes toward themselves and others, and on their social and working lives.

Results indicated that an HIV-positive diagnosis had profound impact on psychosocial interactions with others. The majority of the interviewees told family members, friends, co-workers, employers about their diagnosis. When the participants disclosed to a family member, their reactions were either positive or negative. The positive reactions were identified as family members becoming closer, spending more time together, and maintaining contact. Negative reactions consisted of the family deliberately severing contact and the relationship with the seropositive person. When friends and employers were told, responses included being rejected by friends and being

laid off or fired by an employer. The participants who had negative responses also had feelings of being stigmatized.

A major concern identified by the participants was the fear that the public would become aware of their HIV-positive diagnosis. The fear was intensified when a family member threatened disclosure of the diagnosis. The knowledge of the diagnosis could be used as a weapon by others.

A majority of the respondents mentioned that their social life was curtailed due to fatigue, fear of disclosure, fear of infecting others, or fear of contracting others' infections, such as the flu. Psychosocial and physical changes were mentioned as reasons for changes in lifestyle. If the person was symptomatic, they attempted to maintain their usual social and leisure activities.

Changes of attitude toward themselves and others were noted. Attitudes toward themselves changed after the person learned of their diagnosis. The attitude changes were feeling ashamed, feeling guilty, depression, anger and loneliness, and loss of self-respect. Participants expressed anger and bitterness because of rejection by others, fear that others would become aware of their diagnosis, suspicion that others were talking about them, and envy of people who were HIV-negative.

Mason, Marks, Simoni, Ruiz, and Richardson (1995) examined cultural differences between white and Latino males in disclosing their HIV status. Four hypotheses were investigated by the researchers. First, after statistically controlling for sociodemographic and medical variables, the researchers expected seropositive Latinos to be less likely than white seropositive males to disclose their diagnosis to family members, friends, and lovers. Second, it was predicted that among gay and bisexual men, Latinos would be less likely than whites to disclose their sexual orientation to family members. Third, Latinos

and white males who had disclosed their HIV infection to a particular person would be more likely to have disclosed their sexual orientation to that person. Fourth, researchers anticipated that lower rates of both types of disclosures among less acculturated Latinos would be more strongly attached to traditional cultural values than their more acculturated counterparts. Additionally, subjective questions were asked to investigate reasons for disclosing and not disclosing their HIV status to specific persons.

The sample (398) was randomly selected at two HIV outpatient clinics in Los Angeles between 1991 and 1992. Eligibility criteria for the study included HIV-positive status for more than 2 months, English or Spanish speaking, at least 18 years of age, and identified by medical providers at the clinics to be physically and mentally able to provide reliable responses.

The questionnaire was written in English, translated into Spanish, and then back translated into English. The participants were given a choice of questionnaire, English or Spanish version. The questionnaire was self-administrated and returned to the research assistant at the site. Questions were related to disclosure of HIV infection to significant others, acculturation variables, distance from parents, another person's awareness of participant's sexual orientation, sociodemographic variables, medical variables, and open-ended questions relating to reasons for disclosing and not disclosing HIV infection.

As hypothesized, a greater percentage of Latinos (12%) than whites (3.9%) reported that they had not informed significant others about their HIV status. Whites (38.8%) disclosed to a greater percentage of targets than Latinos (24.5%). Latinos and whites did not disclose their HIV status to their mothers and fathers because they wanted to protect their parents. Other protective reasons for not telling were more prevalent among Latinos than whites. Both Latinos and whites were more likely to express other focused reasons

("she has a right to know") than self-focused reasons ("I need her emotional support") (p. 10) for informing their mothers, fathers and lovers. The participants cited positive quality of the relationship and self-focused needs as the primary reasons for informing their friends.

To examine the association between acculturation and disclosure, the sample was divided into three groups, Spanish-speaking Latinos, English-speaking Latinos and English-speaking whites. White participants disclosed to a significantly larger percentage of significant others than did Spanish-speaking Latinos. There were no significant differences in disclosure between whites and English-speaking Latinos or between the two Latino language subgroups. Spanish-speaking Latinos were significantly less likely than English-speaking Latinos to inform their mother, sister, or lover about their HIV status.

Disclosure of their gay or bisexual orientation to parents was reported among whites (76.6%), English-speaking Latinos (64.7%), and Spanish-speaking Latinos (54.2%). The gay and bisexual men who had disclosed their HIV status to a specific target were more likely to have disclosed their sexual orientation to that person.

Sobo (1995) reported data from a preliminary study involving a focus group of HIV-positive persons discussing issues of self-disclosure. The data were collected in Southern New Mexico through a local agency that served as the research site for persons living with HIV/AIDS. The focus group consisted of four people: Three women and one man. Two of the participants had an AIDS diagnosis.

Five basic topics were discussed by the focus group. They were the other person's need to know, nondisclosure conjoined with safer sex practice, disbelief and denial among the seronegative, strategies for evaluating the potential person to be told, and

rejection or acceptance by the person. All three women reported that disclosure was necessary to sexual partners, especially to long-term partners. They agreed that the person's need to know was to protect the monogamous sex partner.

Nondisclosure was described as a strategy used with casual partners. The participants perceived that since they used condoms with casual partners there was no reason to disclose their status. No other reasons for not disclosing were presented in the data.

Participants described how seronegative partners did not believe the possibility of the person being HIV-positive. The partners made the choice of not using safety measures during sexual intimacy, as one participant stated, "that decision is totally up to them" (p. 24).

Strategies for evaluating potential disclosure to others were used with deciding when and how to disclose. The participants reported listening for negative or positive responses from people during conversations. As one woman described, "You can spot narrow minds and closed minds." Another subject reported "I would not disclose at first to anybody ... until that relationship had time to build ..." (p. 24).

Participants reported not seeking assistance with disclosing status from counseling because they had negative experiences when they were initially diagnosed. Because of these negative experiences, the participants relied on themselves rather than professional care providers when seeking advice about coping.

The participants all felt that disclosing put them at risk for rejection from family members, friends and partners. None of the participants were partnered with known seropositive individuals. But the fear of rejection by their seronegative or untested partners was of great concern for the participants.

The final topic described conditional and unconditional acceptance. When others accepted the person after telling, the participants agreed that the acceptance was conditional. The conditional acceptance by the person told could be revoked or the person could threaten to revoke it later. This may be due to the person's own HIV/AIDS related fears. Children were identified as displaying unconditional acceptance after they became aware of the person's seropositive diagnosis.

Stempel, Moulton, and Moss (1995) investigated patterns of self-disclosure of HIV-1 antibody test results by gay and bisexual men to their sexual partners, social contacts, and family members. The study examined self-disclosure patterns of 93 subjects after one year following notification of their HIV test results. The data included the reactions and concerns of the person who was told about the test results.

Subjects were recruited from the San Francisco General Hospital Cohort groups. The majority of the sample was white (97%). All subjects were notified of their test results in individual counseling sessions. Sixty-three percent of the 93 subjects were seropositive.

The subjects completed a modified self-administered questionnaire measuring certain psychological and behavioral responses to antibody testing. Questionnaires were administered at two weeks prior to notification of the HIV-1 antibody test results and subjects were asked to whom they intended to disclose their status results. At two weeks, three, six and 12 months following notification, questionnaires were re-administered and subjects indicated whether they had disclosed their seropositive status to others. Participants who had shared their test results were asked to rate the reaction to the diagnosis as favorable or unfavorable.

Responses related to intent to disclose. Actual disclosure about test results revealed that subjects were more likely to disclose their status results to all categories of people

during the 12 months post-notification except to doctors and dentists. The exception was due to high anticipation of disclosing to their primary care physicians and dentists than to other categories.

Test results were disclosed to 82% of lovers and 60% of other sexual partners. There were more negative disclosure results (77%) than positive (66%), and less often (56%) to a new sexual partner than a previous partner (67%). Close friends were more than twice as likely to be told than family members (85% to 36%). There was less self-disclosure to fathers (30%) and brothers (28%) than to mothers (45%) and sisters (50%). Seropositive subjects were more likely to tell primary care physicians (71%) and dentists (37%) than seronegative subjects (44% to 25%). Co-workers and employers were about half as likely to be told test results as friends (41% and 83%).

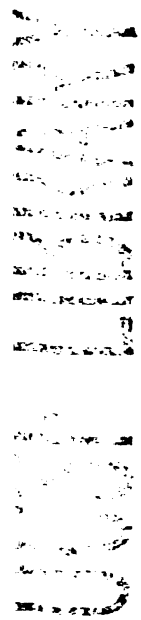
The subjects labeled each reaction to disclosure as either favorable or unfavorable. Relatively few unfavorable reactions (10%) were noted from friends and health professionals. Family members, lovers, new sexual partners, and co-workers were most likely to respond unfavorably. Unfavorable reactions occurred more frequently with fathers (25%) and brothers (33%) than mothers (7%) and sisters (0%).

Concerns regarding disclosure to people of the test results of each group were identified as important or very important at two weeks, three, six, and 12 months following notification. Participants were concerned with loss of health insurance (82% at 6 months), income (64% at 6 months) and housing (47% initially, 36% at 12 months), and fear of being perceived as an "AIDS carrier" (61% at 3 months and fell to 36% at 12 months) (p. 120). Reports of adverse effects on relationships with family members (39% initially and at 12 months), sexual partners (25% initially and 21% at 12 months) and steady lovers (22% initially, falling to 17% at 12 months) were cited. Some subjects were

least worried about the reactions from friends (18% initially, falling to 7% and 10% at 6 and 12 months).

Simoni, Mason & Marks (1997) examined the prevalence and correlates of disclosure of sexual orientation and HIV infection to employers among gay and bisexual employed men. The sample was composed of 389 Latino, white, African American and other males at two HIV outpatient clinics in Los Angeles. The researchers used a bilingual questionnaire to gather data.

Disclosure of HIV-positive status to employers was reported among 35% of the men. Men whose employers were non-heterosexual were more likely to disclose their seropositive status than men whose employers were heterosexual. White men were more likely to disclose than Latinos or African Americans. Latinos born in the US disclosed more than foreign born men. Men who had been diagnosed seropositive for more than 4 years were more likely to disclose their positive status than men recently diagnosed. Men experiencing HIV-related symptoms disclosed more than men not experiencing symptoms.



The men reported not disclosing their status because of anticipated consequences. Sixty percent of the participants who did not disclose their HIV status thought things at work would stay almost the same after telling while 24% thought they would be fired after telling. Twelve percent of the men thought they would not be terminated but would be asked to do a different type of work. Four percent of the men did not know the consequences of disclosing. The belief they would be fired was more prevalent among Latinos than white males. Latinos born outside the US (51%) and those who spoke Spanish (58%) rather than English expected to be fired if they disclosed their status.

The actual consequences experienced by the men who disclosed to their employers were less negative than the anticipated consequences reported by those who had not disclosed. Three percent of the men were fired. Six percent were asked to do a different type of work, and 88% reported things at work stayed almost the same.

Stein et al. in 1998 reported the factors associated with disclosure of HIV-positive status to sexual partners. One hundred twenty-nine men (n=89) and women (n=40) were recruited from two hospitals. The sample reported they had sexual partners during the previous 6 months. Interviews were conducted in English, Spanish and Haitian Creole. Interpreters working with research associates interviewed the participants in Spanish and Haitian Creole.

Findings revealed that 60% of the sample disclosed their HIV status to all sexual partners. Those participants with one sexual partner or a person with high spousal support disclosed more than those with more than one sexual partner and those who did not have spousal support. Whites and Latinos disclosed more that African Americans.

Forty percent chose not to disclose their status. Among 99 participants who had a spouse or significant other, 12% did not disclose. Common reasons for nondisclosure were "too stressful," "partner will leave," "need to deal with my own emotions first," and "partner could not handle it" (p. 255).

Disclosing to Health Care Providers

Limandri (1989) investigated the circumstances under which persons with stigmatizing conditions disclosed their conditions to potential health care providers. A grounded theory approach was used to analyze how people with conditions such as woman abuse, herpes, or HIV/AIDS infection disclosed to health care providers and how health care providers facilitated or in inhibited the disclosure. Specific questions were:

(a) under what sociopsychological circumstances people with stigmatizing conditions disclose their condition, (b) how people with stigmatizing conditions disclose their condition to potential helpers, (c) what contextual factors influence the conditions under which the disclosure occurs, and (d) how do helpers respond to the disclosure of stigmatizing conditions.

Results described the process of disclosure from 29 individuals (13 males and 16 females) with stigmatizing conditions, such as family violence (5), AIDS (8), and herpes (13) and other (3). They shared feelings of shame and the wish to conceal or hide. The majority of the participants were white (26), Native American (two), and one Latino. The results identified and described an interactive process between stigmatization and disclosure of a condition to a confidant or respondent. The process of disclosure consisted of three subprocesses of stigmatization, disclosure, and response.

The first subprocess was identified as stigmatization. The majority of the disclosers acknowledged feelings of stigma or shame about their condition. Some of the participants noted that the stigma they bore made it more obvious that they had a condition. One man commented, "There are the tell-tale signs that you could see the person was diseased (AIDS). You can just look at them and see it. They can't hide it" (p. 72). A significant issue for the participant was the ability to hide the condition in order to pass or appear to be normal and not feel the stigma.

The second subprocess, disclosure includes three categories: (a) nondisclosure, (b) open disclosure, and (c) over disclosure. Nondisclosure was described as a behavior in which secrets were kept to oneself. The respondents did anything possible to keep the condition a secret, including lying. Some nondisclosers had disclosed to a minimal degree with negative outcomes, such as rejection.

The second category was identified as open disclosing and described a venting, explosive or compulsive telling attributed to the stress of being informed of AIDS or HIV status or the need to tell someone out of concern for the welfare of others. The researcher identified a small group of participants who described a subtype of open disclosure in which people who were told in confidence broke the confidence and told other people.

The third category was overdisclosure in which people indiscriminately told many people without feeling comforted from the disclosure. The researchers revealed that this category was not fully developed and needed further exploration.

The third subprocess involved the confidant's response to disclosure. In this process, the disclosers considered the risks and benefits of telling their secrets. They tried to anticipate the other person's response in order to decide whether to disclose.

Limandri compared groups with stigmatizing conditions. The majority of the respondents identified similar feelings of stigma and discrimination. Those persons that anticipated responses as being too negative decided not to risk disclosing their condition. When disclosure did take place, the responses were negative, positive, or neutral.

Negative disclosures were identified among people with HIV/AIDS more often than positive or neutral responses. These images may have persisted because the responses were more memorable and painful. Among the family members and friends, positive responses tended to focus on empathy or support. Negative responses tended to be rejection and distancing or accusatory. Neutral responses tended to be self-protective or ambiguous.

Positive responses from professionals tended to be reassuring or providing information that instilled confidence and expressed acceptance. Negative responses of professionals included rudeness, mistreatment, non-acceptance, uncaring, unsympathetic,

or rejection toward the person. Neutral responses tended to be noncommittal. The disclosers revealed that they wanted people to treat them with compassion, understanding, and give information. Another important response for disclosers was acknowledgment of what was told rather than leaving the discloser to guess what would be the reaction of the respondent.

Barnes (1992) investigated the processes, patterns and consequences of asymptomatic patient's disclosure of HIV status to health care professionals. Twenty-five persons with HIV were interviewed. The sample included gays, drug users, female heterosexual drug users, sexual partners of drug users, and recipients of blood transfusions. A grounded theory approach was used to analyze data.

The researcher identified "balancing" as a core concept of self-disclosing. Balancing describes how people living with HIV/AIDS handle potentially damaging information. Participants balance the consequences of disclosing against the perceived risks of transmission to health care professionals. Barnes reported the participants used their perceptions, past life experiences of disclosure and discrimination, and assumptions and knowledge about social contexts in the balancing processes.

Identified patterns of intentional direct or intentional indirect disclosure and intentional non-disclosure were described within the social context of people disclosing their seropositive status to health care professionals. The majority of disclosure experiences involved intentional direct disclosures. Intentional indirect disclosures were categorized as a more passive form of direct disclosure. Intentional non-disclosure was characterized primarily by silence or occasional false written information. These patterns of disclosure depended upon the perceived or actual conditions and reflection of the dynamic and interactive processes of balancing potentially damaging information.

Non-disclosure experiences were reported by heterosexual men and women of color, as opposed to gay white men who report direct and indirect disclosures. Several health care providers did discover the patient's HIV status. The majority of participants experienced a variety of problematic encounters with providers' discriminatory actions to their HIV disclosure.

Barnes identified non-discriminatory and discriminatory consequences experienced by the majority of the participants. Discriminatory consequences were characterized by actions ranging from blatant (refusal to treat), subtle (suspicious referral), and possible (delayed care). Non-discriminatory consequences were characterized by lack of negative responses.

Women Disclosing Status

The following section reviews the literature related to women with HIV/AIDS disclosing their status.

Chervenak and Weiss's (1989) survey investigated the attitudes of 25 HIV-positive women toward sexual partner notification and concerns for future pregnancy. Interviews of the women were completed at AIDS clinics during July and August in 1988. Questions related to disclosure included: (a) should the Health Department be involved in confidentially assisting in the notification of sexual partners of HIV-positive women, (b) would you be willing to confidentially provide the names of your sexual partners to the New Jersey Health Department, (c) would you agree to health department disclosure of your name to sexual partners, (d) have you informed all male sexual partners you had previous to your HIV-positive diagnosis that you are now infected with HIV, (e) have you informed all male sexual partners you had since your HIV-positive diagnosis, and (f) do you wish to become pregnant.

Results revealed that 64% of the women agreed that the Health Department should be involved in confidentially assisting in the notification of their sexual partners. Sixty-eight percent were agreeable to confidentially providing names of their sexual partners to the New Jersey Health Department. Twenty percent agreed that the Health Department could assist with disclosing their name to sexual partners. Twenty-four percent of the women informed all male sexual partners prior to becoming aware of their HIV-positive status. Fifty percent informed all male partners they had sexual contact since their seropositive diagnosis. One woman stated she wished to become pregnant.

These results revealed that women who were interested in the Health Department's involvement tended to be willing to disclose sexual partners names. Nine women who had not notified all sexual partners' did not desire the Health Department involvement.

Pliskin, Farrell, Crandles, and DeHovitz (1994) presented data that examined the factors which influenced 50 mothers' decisions to disclose their HIV status to their non-infected children. The mothers were recruited from an HIV clinic. Participants were interviewed using open and closed ended questions.

Results revealed that 45% of the women did not disclose their HIV status to their children. Of the 55% who did disclose, approximately half told their children immediately upon diagnosis. Factors influencing disclosure were the mothers' opposition to family secrets, their wish to psychologically prepare their children, their wish for greater intimacy, and their wish to prevent them from learning the diagnosis from a source outside the family. Factors influencing non-disclosure were mothers' fears their children would be psychologically harmed (poor school performance, ostracism and excessive worry), wish to preserve their childhood, belief that children lack the capacity to understand, and fear their children would reject them. Forty percent of the mothers

indicated they would never tell their children. Results also indicated that women who had lost an immediate family member to AIDS were twice as likely to disclose their diagnosis to the child.

Simoni et al., (1995) surveyed an ethnically diverse sample of 65 HIV-positive women to assess: a) rates of self-disclosure of HIV infection to friends, lovers, and family members, b) reasons for disclosure and nondisclosure, and c) reactions of individuals informed. Potential sources of HIV-related social support were also identified. The sample of women were recruited from two HIV outpatient clinics in Los Angeles during 1991-1992. The sample consisted of 65 women (41 Latinas, 13 African-Americans, and 11 white females). Heterosexual sexual behavior was reported by 87% of the sample. Twenty-three percent of the sample was in a committed relationship.

Data were collected with a questionnaire written in English and translated into Spanish. The Spanish version was back-translated to identify potential ambiguities of meanings. The questionnaire was completed independently by the participants.

The respondents disclosed to 44.9% of the identified targets: Lover, friend, mother, sister, brother, father, cousin, grandparents, aunt or uncle. Thirteen percent of the sample did not disclose, and 30% had disclosed to only one person. Sixty-two percent of the participants reported talking with doctors or nurses about their HIV-related worries and concerns. Approximately half identified family members (49%), social workers (46%), and friends (44%) as sources of HIV-related support. Younger respondents were more likely to disclose than older respondents. English-speaking participants were also more likely to disclose than Spanish-speaking participants. Spanish-speaking Latinas disclosed to fewer targets and talked with fewer people about their HIV-related concerns.

Reasons for disclosing differed according to the target and were identified as other-focused or self-focused. Other-focused centered on lovers for ethical responsibility and concern for their health. Self-focused emphasized a desire for support from parents and friends instead of a lover. Additionally, medical reasons related to disease progression were used to disclose to parents and friends but not to lovers.

Reasons for nondisclosure were self-focused toward lovers and friends because of a desire to avoid personal rejection or to maintain secrecy. Not telling parents was identified as other-focused to prevent worry or cause them problems. Stigma and ignorance were identified as reasons for nondisclosure.

Reactions to disclosure from others included positive and negative responses. Mothers, fathers, and friends frequently reacted by providing emotional support and rarely responded by becoming angry or withdrawing. Lovers appeared to be supportive, but the data suggested that they were more likely to become angry and withdraw on learning of the respondent's seropositive status. Six of the lovers left the respondent after learning of their diagnosis.

Moneyham, et al. (1996) explored the concern related to disclosure for HIV-positive women. The sample included 19 women who participated in one of four focus groups. Participants were recruited from two HIV/AIDS service organizations in two Southeastern cities in the United States. The sample was composed of 12 African-Americans and 7 white women. Data were collected by a moderator using a semistructured interview guide that consisted of open-ended questions about the experience of living with HIV. Content analysis was used to analyze data.

Findings revealed three themes of concerns about negative responses from others: Discrimination, confidentiality, and context of disclosure. Fear of discrimination was

reported when disclosing to people with power over some aspect of the women's lives, such as work or needed resources. The fears were based on the participants' previous experiences after disclosing their HIV-positive status.

Another major theme of concern for the women was confidentiality after telling. Loss of confidentiality increased the potential for exposure to discrimination. Concerns about confidentiality often kept participants from using community resources and services.

The third theme identified was the context of disclosure. The concerns about disclosing varied according to the situation and person involved. Three groups of people who caused concern for the women when disclosing were: a) health care professionals, b) sex partners, and c) their children. In disclosing to a health care professional, the women considered the health care provider's ability to give appropriate care, potential discrimination or negative responses from the provider, and protection of others from exposure to the HIV virus during a procedure. In disclosing to sexual partners, the women were unwilling to disclose because of their inability to predict the response and their fear that the partner would leave after being told the seropositive status. In disclosing to their children, many of the women were afraid that the children would be negatively affected or would not be able to maintain confidentiality or that someone else might tell the children.

The seropositive women perceived the impact of nondisclosure toward them would be negative, and, thus, they would experience isolation and loneliness. Researchers reported that the women lacked a safe, supportive environment where they could talk about their experiences without fear of negative responses from others.

Sowell et al. (1997) examined patterns of disclosing among women with HIV infection living in rural communities. Needed resources and perceptions of stigmatization were also examined. Rural women were defined as those women who resided in towns of fewer than 50,000 not abutting a major urban epicenter, were required to travel significant distances for health, lacked public transportation, and had a common identity of living in a rural community rather than urban or suburban communities. A sample of 82 rural women were recruited from urban centers and from areas of Georgia designated as primarily rural in nature. The sample consisted of 56 African-Americans and 26 white women.

Data were collected during the first of five face-to-face interviews as part of a larger study using questions primarily developed from focus groups and available literature. The questions were reviewed by participants in the first four focus groups and assessed for validity to ensure the relevance to the life experiences and cultural of the women.

When the women were asked if they felt stigma, 40 women responded yes and 42 women responded no. Thirty-three women felt they experienced stigma after becoming HIV-positive. Forty-eight women reported feeling ashamed of their illness at least some of the time. A majority of the respondents (82%) indicated they would not avoid getting treatment because someone would disclose their status, and 73% felt they would receive good health care if people learned of their status. The results revealed that the youngest (81%) and the oldest (61%) participants feared losing friends if they became aware of the women's status. African-American (41%) and white (19%) women felt they would be rejected by their families if they told.

The majority of women disclosed to health care providers (72), sexual partners (46), and family members. The family members informed were parents (56), brother and sisters

(58), children (32), and other relatives (40). When analyzed by stage of illness, the women disclosed more to sexual partners than other groups. Of the 67 women who told sexual partners, 13 were asymptomatic, 15 were symptomatic, and 28 had a diagnosis of AIDS.

Sherr et al. (1997) examined ethnicity, relationship, health, and mental health factors for a cohort of women with HIV infection receiving treatment at an inner London, England clinic. A chart audit was performed on 100 women consecutively seen in the HIV clinic. Medical and counseling service data were collected systematically from current case notes on health, medical, and psychological needs (which included disclosure of HIV status) of all women with HIV attending the hospital clinic. Ethnic background of the women included Whites (51), Sub-Sahara Africa (44), Asian (1), Indian (1), South American (1), and West Indian (1). Immigrant status of the women was not present in the report.

Researchers reported disclosure of HIV status to others was a key issue in counseling and determined the ability to gather social or family support for the women. Ninety-eight of the women disclosed to others. Eighteen of the women had only told one person. Two women had not disclosed their status to anyone. Ethnic women were reported to be significantly more likely to restrict disclosure to family members and only tell one person. By only disclosing to their family members or one person, the ethnic women may limit access to social support resources within the family and health care support.

Limitations and Significance of Current Research Literature

This review included research studies from several disciplines, including nursing, medicine, social science and psychology. Limitations and significance of the studies are noted.

The majority of disclosing research literature has centered on gay and bisexual populations living with HIV/AIDS (Hays et al., 1993; Huggins, Elman, Baker, Forrester, & Lyter, 1991; Kegeles, Catania, & Coates, 1988; O'Dell, 1988; Marks, Richardson, & Maldonado, 1991; Marks et al., 1992; Mason, Marks, Simoni, Ruiz, & Richardson, 1995; Mitchell & Smith, 1987; Schell et al., 1992; Simoni, Mason, & Marks, 1997; and Stempel, Moulton, & Moss, 1995). The twelve articles described issues of disclosing to a significant other, partners, employers, and family members.

Several studies were composed of men and women (Barnes, 1992; Laryea & Gien, 1993; Limandri, 1989; Sobo, 1995; Stein, 1998). These studies did not compare the disclosing differences between women and men who participated in the research. Five research studies centered on women disclosing their status. Five studies included women with diverse ethnic backgrounds who disclosed their HIV/AIDS status (Moneyham et al., 1996; Pliskin, Farrell, Crandles, & DeHovitz, 1994; Sherr et al., 1997; Simoni et al., 1995; Sowell et al., 1997). However, only three studies included Latinas (Pliskin, Farrell, Crandles, & DeHovitz, 1994; Simoni et al., 1995; Sobo, 1995).

These studies may not reflect the central issues or concerns of women, and especially Latinas, disclosing their HIV/AIDS status. The research studies do provide information on certain population groups, but do not address the diversity within groups or give insight into the lives of the Latinas who disclose. Only one study described the experiences and possible reasons for disclosing by Latinas, but it did not assess acculturation or cultural values (Simoni et al., 1995). Generalizability of the results is difficult because of the small convenient sampling used by the researchers. These sampling issues and the lack of research make it difficult to determine if the findings can be appropriately generalized to Latinas.

CHAPTER THREE

METHODOLOGY

This chapter presents the qualitative research methodology used to explore and describe the disclosing experiences of Latinas with HIV/AIDS. This chapter will discuss: (a) research design, (b) sample, (c) data collection, (d) data analysis, and (e) trustworthiness.

Research Design

The research design was a cross-sectional descriptive study of HIV-positive or AIDS diagnosed Latinas. A convenient purposeful sample of Latinas living in the San Francisco Bay Area were interviewed during April of 1996 through June of 1997. Data collection consisted of semi-structured interviews at a mutually agreed upon location. Content analysis was used to analyze the data by identifying code words and related concepts that were developed into categories representative of the disclosing experiences of the participants.

Sample

The sample consisted of 19 Latinas living with HIV/AIDS in the San Francisco Bay Area. A purposive convenient sampling of Latinas who self-identified themselves as having HIV/AIDS were targeted for inclusion in this study. Participants were 18 years old or older. The participants were recruited through advertising in a local newsletter for HIV-positive women and distributing flyers in the community. Flyers explaining the research and criteria were distributed to clinics, support groups, and community agencies in the San Francisco Bay Area. Recruitment was enhanced through snowball sampling.

Sample Size

Sample sizes in qualitative research are typically small because of the large volume

of verbal data that is analyzed. Qualitative research also tends to emphasize intensive and prolonged contacts with a small number of subjects. Sandelowski (1986) stated, "research subjects are initially selected because they could illuminate the phenomenon being studied, but the continued selection of subjects is related to the findings that emerge in the course of the study." Therefore, sample size could not be predetermined because sample size depended on the nature of the data collected and how the data guided the researcher during the analysis process.

Credibility of Informants

Criteria for this study were that the women were Latinas and self-reported as being positive for HIV/AIDS status. No personal medical records were reviewed in the study, consequently the women self-identified as Latinas with a seropositive or AIDS status. During the initial telephone screening process, the participants were asked questions related to how and when they were diagnosed with HIV or AIDS. To validate the participant's ethnic background, each woman was asked the ethnic origin of family members. At the time of the face-to-face interview, follow-up questions related to HIV/AIDS status and ethnicity were asked at the beginning and during the interview to assist the researcher with confirming HIV/AIDS status and cultural background of the participants. Using this approach the researcher was able to receive consistent and knowledgeable responses to confirm the HIV/AIDS status and ethnic background of the women.

Data Collection

For this study, a qualitative approach of interviewing was used to generate and analyze data. Demographic data related to age, family ethnic background, education, income, employment or disability, and other descriptors of the women were collected

using a structured format. Data related to disclosing, consequences of disclosing, and nondisclosing followed a semi-structured interview format of open-ended questions.

Procedures

Prior to conducting research, approval from the Committee of Human Research (CHR) at the University of California, San Francisco was obtained. Upon approval by the CHR, subjects were recruited from various community clinics, organizations, and through snowball sampling.

To maintain confidentiality, the potential subject contacted the researcher by phone. Information regarding the study was provided, and the women were asked questions related to criteria of inclusion, such as the date of diagnosis, age, and residency. At the time of the face-to-face interview, the purpose of the research was presented again. Informed consent (Appendix D) was obtained from all participants prior to beginning the interview. Each woman received a copy of the consent. The women received a cash payment of $25.00 prior to the interview.

After obtaining a signed consent, a semi-structured, audiotaped interview in English was conducted. The interviewer used a format (Appendix D) of structured and semi-structured open-ended questions from a pilot study of women living with HIV/AIDS disclosing their status. The interviews lasted from one to two hours.

The interviews were transcribed verbatim. Transcriptions were numerically coded. No individual identities were used in any demographics, interviews, or transcriptions resulting from the study. After completion of the study the tapes were destroyed. At all times data were kept in a locked confidential file not accessible to anyone except the researcher.

Protection of Human Subjects

To protect the Latinas from feeling uncomfortable during the interview, the women were informed of the content of the questions during the initial phone contact and prior to initiating the interview. The women were also informed that they could voluntarily refuse to answer any question asked and terminate the interview at anytime. The majority of the women expressed a desire to share their stories to help others understand the problems of disclosing their status and living with HIV/AIDS.

Data Analysis

Qualitative content analysis was used to analyze and describe the disclosing experiences of Latinas living with HIV/AIDS. A descriptive analytical approach was used to organize, structure, and bring meaning to the collected data. Data analysis of the transcribed interviews was done using the constant comparative method.

Coding data represents the procedures through which data were broken down, conceptualized, and reconstructed (Strauss & Corbin, 1990). Several layers of coding procedures were used during the analysis procedure. Initially, the coding process identified words, phrases, and paragraphs related to the disclosing experiences of the participants. Memos were written to document the process used during the analysis progress.

The second layer of coding is called axial coding. This level of coding reconstructs the data. The codes were organized into themes. The themes were examined and developed into related concepts. The related concepts were then compared to other related themes and concepts and categorized into major categories of disclosing, consequences of disclosing, and nondisclosing. The categories were further examined to elucidate their properties and dimensions. Properties identified the attributes or characteristics of the

related concepts of disclosing. Dimensions identified the location of properties along a continuum. The categories, related concepts, properties, and dimensions were compared among other categories to examine and identify the patterns of disclosing, consequences of disclosing, and nondisclosing.

This analytical approach was useful with organizing and identifying to whom, how, and why the women disclosed, and the effects of disclosing. A core category, deciding to disclose, was identified.

Trustworthiness

The substantive issues of rigor or trustworthiness of qualitative research has been discussed in the literature (Burns, 1989; Guba, 1981; Kahn, 1993; Sandelowski, 1989). One major obstacle is that quantitative criteria of testing have been applied to qualitative method. The most familiar form of these quantitative criteria is validity and reliability as presented by Campbell and Stanley (1966) and later modified by Cook and Campbell (1979). These rigor criteria were developed using assumptions that are appropriate for the critique of quantitative studies but not for qualitative studies (Burns, 1988; Guba, 1981). Qualitative research is trustworthy when it accurately represents the experiences of the study participants (Sandelowski, 1986). Four factors were used to maintain the trustworthiness of this study. The four factors were truth value, applicability, consistency, and neutrality.

Truth Value

Truth value is concerned with establishing credibility of the findings and interpretations with various resources. In qualitative research credibility resides in the discovery of human phenomena or experiences as they are lived and perceived by subjects, rather than in the verification of a priori conceptions of those experiences. A

qualitative study is credible when it presents fruitful descriptions of human experiences that the subject recognizes as their own (Sandelowski, 1986).

To establish truth value, the techniques used were audiotaping all interviews, peer debriefing, audit trail, and member checking. All interviews were audio taped for referential adequacy and later examined for themes. Peer debriefing was accomplished through the use of a knowledgeable faculty member and fellow peer researchers during the analysis process. An audit trail was maintained to assist with describing and tracking the disclosing experiences of the women. Member checking was used to verify the themes during data analysis. Interpretations were discussed with participants during the interview process to clarify statements, listen for variations, and expand on the analysis of the data.

Applicability

Applicability of findings is determined by the ability to transfer or fit into similar contexts. In qualitative studies, the emphasis is on the study of the phenomena in their natural settings with few controlling conditions. To achieve applicability, thick description and purposeful sampling were used. Thick description of the data includes the widest range of contextual information that can be obtained using purposeful sampling. Purposeful sampling includes individuals that have first-hand experiences with a social interaction or phenomenon.

Thick descriptions of the contextual experiences of Latinas disclosing their HIV/AIDS status were included during data collection and analysis process. The descriptions included a wide range of experiences of disclosing information from Latinas who identified themselves as wives, mothers, sisters, and/or aunts living with HIV/AIDS. Several participants had diverse and complex backgrounds of drug abuse, physical or

mental abuse, incarceration, and poverty. Purposeful sampling was used to obtain maximum representativeness of data through the widest possible range of Latina participants diagnosed with HIV/AIDS.

Consistency

The underlying issue with the concept of consistency is dependability. The researcher must consider whether the process of the study is consistent, reasonably stable over time, and consistent across researchers and method (Miles & Huberman, 1994). A study and its findings are auditable when another researcher can follow the "audit trail" used by the investigator in the study (Lincoln & Guba, 1985). Auditability assists fellow researchers to reconstruct the process of data analysis and arrive at comparable conclusions from the original raw data, perspective, and situation.

To achieve consistency, an audit trail notes and memos were maintained to describe the data collection and data analysis process. The audit consisted of maintaining accurate records of all raw data generated and records of the process of theme and category development that described the disclosing phenomenon. The memos consisted of field and theoretical notes. The memos also described reflective personal notes describing interactions with participants.

Neutrality

Neutrality refers to the freedom from researcher bias during the research process. Guba and Lincoln (1981) suggest that confirmability be the criterion in qualitative research. Confirmability refers to the research findings, not to the subjective or objective stance of the researcher. Achieving confirmability occurs when truth value, auditability, and applicability are established (Sandelowski, 1986). Each technique was previously presented in the discussions to establish trustworthiness.

To maintain neutrality a confirmability audit and reflexive journal were used. The confirmability audit refers to the audit trail of research procedures. A reflexive journal was maintained to track the researcher's views, feelings, thinking, and conduct during the data collection and analysis process. The researcher acknowledged the natural subjectivity that existed throughout the study, initially, as empathy for the HIV-positive women as one learned about their world, and, later, as understanding of their experiences emerged.

This chapter presented the qualitative method used to analyze and describe the experiences of Latinas disclosing their HIV/AIDS status. Qualitative content analysis was used to organize and analyze the data to identify the themes and categories of disclosing, consequences of disclosing, and nondisclosing. Qualitative techniques of truth value, applicability, consistency, and neutrality were used to maintain the trustworthiness of the research study.

CHAPTER FOUR

RESULTS

Sample Demographics

The women who participated in the study have very dynamic and challenging lives. The information obtained presents the participants' dramatic backgrounds. During the interviews a mutual respect and trust developed between the investigator and the women. They expressed gratitude for having an opportunity to share stories of their life events and feelings about living with the disease.

This section presents demographics of the 19 Latina participants inducted into the study. Data were gathered from interviews between 1996 and 1997. The women were from different geographic origins, including Mexico, El Salvador, Nicaragua, New York, Nebraska, Oklahoma, Texas, New Mexico, Colorado, and California. The women identified their generations living in the United States as first to fourth. The majority are second (7) and third (8) generation. Ethnicity, age, partner status, education, annual income, and number of children of the Latina participants are presented in Table 1. The participants' living arrangements, transmission risk factors, HIV diagnosis, primary medical care, abuse, and incarceration are presented in additional sections and tables.

Ethnicity

Sixteen Latinas self-identified their ethnic background as Mexican-American and one each as Nicaraguan, Puerto Rican, and Salvadorian. It must be noted that four of the Latinas who identified themselves as Mexican-Americans also identified themselves as multi-ethnic. Their multi-ethnic backgrounds included black, Native American, Italian, and white.

Age

The women's ages ranged between 25 and 60 years. More than half of the group was between the ages of 30 to 39 years. The mean age was 37.6 years.

Partner Status

At the time of the interview, 12 women identified themselves as single. Nine had never been married, while three were divorced. Five were married, and two women were widows.

Education

Ten women reported they had not finished high school. Six women reported completing high school education. Only three Latinas had attended one-two years of college.

Annual Income

All of the women were receiving disability insurance, Supplemental Security Insurance, and/or Aid to Families with Dependent Children. One woman had a small pension. Annual income ranged between $4,128 to 20,000 per year. Over 73 per cent of the women earned less that $8,000 a year. One woman continued to be self-employed as a child care provider in her home at the time of the interview. Seventeen of the Latinas were unable to continue working because of health problems.

Number of Children

The majority of the Latinas had children. Of the women who had children, the majority were not living with them. Six women did not have children. The age range of children living in the home with the woman was from one to three years old. Children who were not living with the mother were identified as living with family members, friends, in foster care, or in juvenile hall at the time of the interview.

Table 1

Demographic Descriptions of Participants (n = 19)

Characteristics		Number	%
Ethnic Background	Mexican-American	16	84.1
	Nicaraguan	1	5.3
	Puerto Rican	1	5.3
	Salvadorian	1	5.3
Age (mean = 37.63)			
	20-29	2	10.5
	30-39	11	57.9
	40-49	3	15.8
	50-59	2	10.5
	60	1	5.3
Partner Status	Single	12	63.2
	Married	5	26.3
	Widow	2	10.5
Education Level	7th grade	2	10.5
	8th grade	1	5.3
	9th grade	3	15.8
	10th grade	2	10.5
	11th grade	2	10.5
	high school	6	31.6
	College (1-2 years)	3	15.8
Annual Income (mean = $7,971.00)			
	4,000-8,000	14	73.7
	8,001-12,000	4	21.0
	12,001-16,000	0	0
	16,001-20,000	1	5.3
Number of Children	1	2	10.5
	2	4[1]	21.0
	3	1	5.3
	4	3	15.8
	5	3	15.8

[1]Includes 3 stepchildren

Living Arrangements

At the time of the interview, eight Latinas were living with family members. One woman was living in a homeless shelter, and another woman was living with a friend. Three women were living in a drug treatment residence in San Francisco. Living arrangements are presented in Table 2.

Table 2
Living Arrangements

	n	%
Lives alone	6	31.6
Lives with family member/s (husband, mother, children, or a niece)	8	42.1
Lives with friend	1	5.3
Lives in homeless shelter	1	5.3
Lives in drug treatment residence	3	15.7

Transmission Risk Factors

Ten women identified injection drug use as the risk factor for contracting HIV. Five women identified having risk factors of injection drug use and multiple sex partners. Two women identified heterosexual contact as the mode of contracting the virus. One woman identified sexual contact with her hemophiliac husband as the mode, while another woman identified receiving multiple blood transfusions in 1982 after an automobile accident as the mode. Transmission risk factors are presented in Table 3.

Table 3

Transmission Risk Factors

	n	%
Injection drug use	10	52.6
Injection drug use and multiple sex partners	5	26.3
Heterosexual contact	2	10.5
Sex with person with hemophilia	1	5.3
Receipt of blood transfusion	1	5.3

HIV/AIDS Diagnosis

The 19 participants tested positive for HIV (n = 17) or were diagnosed with AIDS (n = 2) between the years of 1986 and 1994 for various reasons (Table 4). The women were tested at clinics, hospitals, while in prison, an outreach program, or at a blood bank. Fourteen Latinas stated reasons for testing were requests or recommendations by a husband or a potential partner, medical staff when hospitalized or in prison, at a clinic, applying for insurance, or trying to donate blood. Five women agreed to be tested because they realized they were at risk for contracting HIV.

Table 4

Year tested positive and reasons for testing

	n	%
Year tested positive		
1985 - 1989	10	52.6
1990 - 1995	9	47.4
Reasons for testing		
Requested/recommended health care professional hospital (4) prison (5) husband (1) insurance co. (1) potential partner (1) counselor (1) blood bank (1)	14	73.7
Realized self at risk	5	26.3

Health Problems

During the interview process, the women described health problems in response to the question, "How has the disease changed your life?" At the time of the interview, 12 women identified having one or more health problems. Four women identified having fatigue. One woman had toxoplasmosis and memory problems. One woman had folliculitis. Four women had neuropathy to their lower extremities. Another woman complained of nausea and anorexia related to medications. One woman stated she had wasting syndrome. Two women had chronic depression.

Primary Medical Care

Thirteen (68.4%) women identified physicians as their primary health care provider, while six women identified nurse practitioners as their provider at the time of the interview. Thirteen of the women had T-cell counts less than 500. Five of the women were taking different antiretrovirals (AZT, ddI, ddC, 3TC, d4T). Eight of the women used

a combination of antiretrovirals and a protease inhibitor (Crixivan or Saquinavir). Two women chose only to be treated with acupuncture and herbs, while one woman used only herbs. Three women chose no treatment at the time of the interview. T-cell counts and treatments are presented in Table 5.

Table 5

Health care provider, T-cell count, and treatments

	n	%
T-cell count		
0 - 500	13	68.4
501 - 1,000	4	21.0
1,001 - 1,500	1	5.3
Unknown	1	5.3
Treatments		
Antiretrovirals	5	26.3
Antiretrovirals with Protease Inhibitor	8	42.1
Acupuncture/herbs	3	15.8
No treatment	3	15.8

Additional Self-Reported Information

During the course of the interview, several women shared personal information regarding their experiences of abuse and being incarcerated. Nine of the participants identified themselves as victims of abuse. The abuses ranged from mental and verbal abuse to sexual abuse (including rape) and battery. The abuses were committed during childhood and adulthood by fathers, brothers, boyfriends, or strangers.

Ten (52.6%) of the participants stated they had been incarcerated. The women had histories of being in city and/or county jails and/or California State prison. Reported incarcerations were due to prostitution, indecent exposure, selling or use of illegal drugs, or theft.

In summary, the demographic descriptions of the Latinas living with HIV/AIDS were obtained during the interviews. The information presented in this section provides a dynamic view of the participants. The Latinas self-identified their ethnic background as Mexican-American, Nicaraguan, Puerto Rican, and Salvadorian. The mean age of the women was 37.6 years. Twelve (63.2%) of the women were single. Six (31.6%) graduated from high school and three (15.8%) had attended college for one to two years. The mean annual income was $7,971.00 per year. Thirteen of the women had one to five children. Eight (42.1%) of the women lived with one or more family members and six (31.6%) lived alone.

Over half of the women were infected with HIV by injection drug use. The majority of the women were tested for HIV after being recommended by health care professionals at clinics. The majority of the women saw a physician for care. Thirteen (68.4%) had T-cell counts less than 500 and were taking antiretrovirals or a combination of antiretrovirals and protease inhibitors. Eight participants identified a history of being abused physically, mentally, or verbally by fathers, brothers, boyfriends or a stranger. Ten (52.6%) of the women had been incarcerated for prostitution, indecent exposure, selling or using illegal drugs, or theft.

Findings

Latinas were continually faced with the decision to disclose their HIV/AIDS status to family members, partners or spouses, friends and others. This section presents the self-reported experiences of 19 Latinas living in the San Francisco Bay Area who disclosed their HIV/AIDS status. From the data emerged a core category, major categories, strategies, and consequences the women experienced when deciding to disclose.

Core Category: Deciding to Disclose

After the Latinas were notified of their HIV/AIDS diagnosis the women began the process of deciding to disclose. Internal and external factors influenced each Latina when they decided to tell partners, family members, friends, employers, and health professionals about their seropositive status. The internal factors were the women's perceptions and previous experiences that influenced their decision to disclose. Others disclosing the Latinas' HIV/AIDS diagnosis represented the external factors.

From the data emerged four major categories: timing disclosures, needing to disclose, controlling disclosures, and supportive disclosing. The disclosing was influenced by the Latina's relationship with others, the perceived risks to the woman and others, the need to disclose, and/or wish to give support to themselves or others by disclosing. The decision to disclose was also influenced by the woman's wish to control who should know and when they should disclose.

Strategies and actions used by the Latinas when deciding to disclose included selective telling, postponing, and seeking help. The strategies were used to assist with the planning and choosing to whom, when and how the seropositive Latinas would tell.

As a result of disclosing their HIV/AIDS status, the women encountered negative and positive consequences. Positive consequences were described as being accepted and

receiving support from those who had been told. Negative consequences were described as being rejected and blamed by others.

Major Categories

This section will present the major categories, properties, and dimensions of deciding to disclose. The four categories are timing of disclosure, needing to disclose, controlling disclosures, and supportive disclosing. These categories describe how, when, why, and to whom the Latinas decided to disclose their status.

Timing of Disclosure

The timing of disclosure is an integral part of deciding to disclose. The timing of disclosure is interactive with all of the other major categories when deciding to disclose. All of the Latinas chose different points in time to disclose their status. Timing of disclosure varied as each Latina evaluated the situation and the person being told or the person she was going to tell.

This category of deciding to disclose describes the influencing factors of when Latinas disclose. The influencing factors are described within the properties of the relationship with others and ability to care for self. Table 6 describes the properties and dimensions of timing of disclosure.

Table 6

Major Category, Properties, and Dimensions of Timing of Disclosure

Major Category	Properties	Dimensions
Timing of disclosure	relationship with others	potential . . . . . established
	ability to care for self	low . . . . . high

The majority of the Latinas told a family member (mother, father, husband or partner, brother, sister, and/or children) or a friend of their HIV/AIDS status within a few days after being diagnosed. Half of the women expanded the disclosures to friends and others during the first year. Gradually over time, all of the Latinas continued to disclose to others.

Relationship with others. The relationship with others influenced the women's timing of disclosing as the women evaluated their present, potential and past relationships with others. All of the women decided to disclose to people with whom they had an established relationship such as a family member or close friend. The women included people who had been in their lives for an extended period of time. Potential friends, whom the Latinas had known for a short time, were also chosen and told at different intervals of time. People from past relationships of the women were not always told initially.

Typically, the first persons told were close family members and friends.

12: I told her [mother] right when the doctor told me in prison. I called her. ... I always run to her.

6: The first person I told was my mother.

17: Yes, [mother was the first one told]. To tell you the truth, she's my sun ray, my mother. The best mother in the world, best friend. ... I told my mom after a little while, a month.

10: I told them immediately when I found out. I think I called our parents [in the Midwest] right away to let them know because both of our families ... had a close relationship. I really never hold anything back.

5: I only told one person. That was my partner. He was the only one who knew from 1987 to 1992. ... I was still healthy .... We both felt we should come back to California so my parents could see me doing good and at the same time to tell them. ... I just told my daughter in 1992. [Woman was diagnosed in 1987].

2: He [partner] and my mother were the only two I told when I first found out. I kept it that way until probably about 1988, 1989. Then I started telling other people. ... I

> finally told him [my father] in 1988. ... I came out about 1988 with all the kids and let them all know. ...
>
> 7: I think I told [a friend] that same evening because I wanted to talk to someone. ... I told my niece. [She] was the first one of my family members. ... I must have told her about a month or two later [after being notified].
>
> 1: When I went out on State disability I just told my manager [because] I had some health problems. [She is] the only person who I can trust [fellow Mexican-American].

Women, over time, became more open with their disclosing. The Latinas expanded their disclosing to other friends and even strangers after initial disclosing to their family members. Disclosing to the important people in their lives lessened their fears of telling other people about their seropositive status.

Some women had no problem telling others about their seropositive status. Three women described how they were unafraid and would not hesitate to disclose their status to friends and family members. One woman, who was in prison, disclosed her status to a group of seropositive inmates.

> 2: All my friends, anybody that I've gotten high with since 1988, know that I have it. People that come visiting at home, I tell them. I don't have a problem with it anymore. I am very out of the closet. ... I guess I am real open.
>
> 15: Everybody I see, out of my family, everyone knows. Whenever I see a friend, I let them know. They say how are you doing?, and I say I have the virus. I am HIV positive. I always tell people because I might be on a poster or something. ... I am real open, I don't have a problem [about telling people]. Now [that] my family knows, I don't care about the rest.
>
> 14: But we [inmates] are out there, we weren't scared. At first, it was like all of us [in prison] were like in the closet [with being HIV positive]. Then we said, forget this, we are not in the closet anymore. ... We [started] talking to people and ... I think that is when I overcame being in denial.

Latinas disclosed to people with whom they wanted to establish a relationship. The Latinas disclosed to the potential friend to allow the friend to assess the situation to see if they wanted to continue or end the relationship. This process helped the women decrease

the risk of rejection.

> 11: If I'm going to make a friend and I need somebody to talk to them, I will tell them [my diagnosis]. I tell these people [potential friends] straight out first. They can accept me or they can just go about their business. ...That way ... I am not going to get hurt very much; still it's going to hurt me to be rejected.

> 9: Let me tell you so you can leave and get out of my way. ... I think a lot of that rejection [when] telling somebody. I [have] gotten to the point where I feel I am not going to put up with their BS and dance around a little square for them and not tell them .... No, I [would] rather tell them so they can leave if they are going to leave.

> 18: Friends, there's not one person who do[es] not know that I am positive. Not one. I feel that if they're going to be a part of my life, they need to know. People outside of my life, my everyday living, that's different. If it comes up, [I will tell]. If it does not, [I will not tell].

> 14: Prison really helped me. In 1995. I started [feeling], if they stay with me when I tell them I have it .... If they leave me, well then they were never my friends anyway.

Thirteen women in the study had children. The majority of children were told at different intervals and by a variety of means. Two women told their children soon after being notified about their diagnosis. Six women chose to disclose to their children after the first year of being diagnosed. Two women were advised to delay disclosing to their child by family members; however, the family member eventually told the child before the HIV-positive women had an opportunity to disclose.

> 3: I told them [sister and brother-law] right away. They were telling me not to tell my daughter. After a few years went by, my sister told her.

Three women decided not to disclose their status to their children. Latinas delayed telling their children at the time of the interview because they perceived the children to be too young and lacking the ability to understand the disease. They stated that after the child turned ten years old, they would tell.

Ability to care for oneself. There were perceptions of risks among the women when timing their disclosures. The women would find it necessary to disclose their diagnosis if

the women perceived a change in health status or when there was a noticeable physical change that would affect their everyday functioning or care taking ability.

> 8: The one that knows is M..., the one [foster mother] who is taking care of them. I had to tell her because I got very sick one day and little V... was acting up. He drained me completely and I got sick. I had to call her to come and ... pick-up the kids. ... She is a very understanding person, she helps me.

> 13: [When] we see things are serious [disease progression], then he [son] needs to know.

> 9: ... I really worry that if I do really get sick [I will have to tell my mother].

> 7: [If I become ill] then I will have to tell. Because they [brother and sister] will notice [I am ill], but I see no reason [to tell them now because] the last ten years I've been healthy.

Needing to Disclose

This major category of deciding to disclose describes that under certain conditions the women felt it necessary or wished to disclose their status. Women disclosed when they perceived a risk of being exposed by others. The women also felt the need to disclose when they wished to reconcile with family members, or they felt obligated to disclose to family members or sexual partners, or wished to share knowledge with others. The properties and dimensions are presented in Table 7.

Table 7

Major Category, Properties, and Dimensions of Needing to Disclose

Major Category	Properties	Dimensions
Needing to disclose	perceived risk of exposure	low ..... high
	reconciliation with family	low ..... high
	obligation to disclose	low ..... high
	sharing knowledge	little ..... a lot

Perceived risk of exposure. Women stated they had a need to disclose because they perceived a risk of others disclosing their status. The risk was perceived to be potentially damaging towards them if they did not disclose to friends, neighbors, or family members. Data revealed that the source of exposure could be people who were present during public presentations, an ex-boyfriend, or was unknown.

> 1: ... he (friend from work) should know because one day someone is going to tell him.
>
> 3: I figured sooner or later it's going to get out. Look, we go to the clinic .... So, I told them. Some people went and got tested. Some never did. ... I just wanted them to ... make sure for themselves and so they can never say that I never told them.
>
> 17: I had to tell them (parents) because I ... didn't want them to hear [it] from [someone] else.
>
> 10: They (parents) knew from day [one] ... because I didn't want, especially in a small town where we lived, some[one else to tell them] ....
>
> 7: ... He (ex-boyfriend) threatened to go to the newspaper. So, I was kind of afraid that he would blast if off [to] the neighbors .... I realized that the situation was not getting any better and it was going to get worse. It was up to me to do something about it. ... I had to tell the parents of the children that I was taking care of at that time. I had to tell my son because he [boyfriend] even threatened to tell my son. So, I thought it was only right that I tell him.
>
> 6: I was speaking to these kids. They were ten years old. ... I went in the room and they asked, are you our HIV speaker? I said, yes I am. So, I guess you can imagine what happened. I was in the room and I was speaking, and [I realized] they were [my children's] friends. They asked does J... and M... know? I said no, they don't know that I am HIV. ... [I told my children that] weekend [after my presentation] because I didn't want them [her children] to go to school and the kids tell them what happened.
>
> 10: When I came back [to Nebraska] in March, the second week I knew the media had gotten a hold of me. I knew the thing was going to come out. Well, I better go tell these [friends]. So, ... I called them together and I had to tell them.

Reconciliation with family. Another property was disclosing in order to reconcile a relationship with family members. The seropositive women decided to disclose because they desired to bring parents and siblings back into their lives. These women had strained relationships and poor communication with family members because of their history of

IDU, prostitution, or incarceration. The women felt a need to disclose to family members despite having a strained relationship because they perceived that being diagnosed HIV positive changed the context of the relationship. Disclosing their terminal diagnosis, the women hoped to be reconnected to the family to share their lives and reacquaint themselves with the family members.

> 17: Because I need to, I want to see my children. I want to see my grandchildren. I [want to] ... share some of their lives. They are wonderful kids, my whole family is.

> 5: ... I guess [I told them] because we [step-brothers and step-sisters] went through a lot ... in [our] relationships. I want to be closer. I want to put the bad stuff behind us. ... I was very selfish, not very emotional with people, and I wanted to change all that. I wanted to hug them and say, I love you, whenever I see them and joke around with them, not like before just argue and fight. I just want to show a different side. To show them I've changed, that I am not a spoiled brat, and I just want to be close.

Obligation to disclose. Several women reported feeling a duty or a responsibility to disclose to family members or to sexual partners, past and new acquaintances. For some women, the obligating role of being a daughter was the basis for disclosing to their mothers. The women continued to tell their mothers important information because that was what they had done previously in the daughter role.

> 2: My mother was the first person I told. [She] was the first person I thought of telling. She's my mom, I always tell my mom everything, I guess since I was little. When something happens to me or when I hurt myself ... I always tell my mom everything, I told her everything.

The Latinas also felt an obligation to disclose to people with whom they had or might have a sexual relationship. The women wanted to warn others of the potential risk of transmission of HIV. The Latinas who told their past sexual partners did not want to be responsible for them not knowing they were at risk for HIV and not having the choice to be tested for the virus.

> 3: [I told] everybody that I worked [with] and [had] contact with. ... I wanted them to go [and be] test[ed for the virus], to make sure that they were all right.

> 7: I was going with this fellow, he was up in Alaska so they had to send him home because I didn't want to tell him over the phone. ... I was afraid that maybe I infected him. He was checked twice and he's making it. ...

> 4: Because ... if [there was a chance] I infected someone, I want them to get tested. I want them to know. I just don't want to keep it a secret, I wasn't sure [if I infected someone]. For me, ah, I don't know why because if I have anything to do with someone getting sick, or anything, then I would want to tell.

Latinas also disclosed to potential sexual partners so they could make the choice to continue with the relationship and possibly have sexual intercourse.

> 5: I said, look, I got something I've got to tell you, because he tried to kiss me and stuff but I wouldn't let him. I'll tell you as a friend because I want you to know this. Then I told him that I was HIV. He was fine with it.

> 10: So I had to tell. In a ... way I had told him two weeks before I got out there. I was kind of telling him, what would you do if I tell you I am HIV-positive, so that type of stuff, he would tell me, oh well I really care about you, I think we could work it through. So, I had been building him up to that point. When I saw him I had to tell. By that time, we were ready to go to a motel. I told him I was HIV-positive when we got to the motel. I had gotten to the point that I wanted to have sex so bad, he was doing all the right things for me that I really wanted it so bad that I didn't want to tell him. But, I had to tell; my conscience just won't let it go. So I told him.

> 7: If I become involved then I would have to reveal it.

All of the participants reported at the time of the interview that they had attended some type of AIDS support group or women's support group sessions. During the group sessions, the women revealed that there were discussions of whether women should disclose their seropositive status to potential partners. Over half of the Latinas who attended support group sessions reported that they, along with most of the women in the groups, felt an obligation to disclose their status to their sexual partner.

> 6: I talked about that in W... H..., would you tell your partner that you are HIV positive or do you tell him? We thought about it in a [support] group and everybody agreed that it's better to tell the person ASAP.

Sharing knowledge. Five Latinas reported that sharing knowledge was an on-going important process because they were able to exchange AIDS prevention and health

information with others. The relationship of timing disclosure and sharing knowledge varied from a little to a lot for each of the women. Each of the women chose a time when they felt ready to be open with their lives and to share information with the community.

By sharing HIV/AIDS related information the women also learned from others. The women also felt that the exchange of information enlightened and assisted the seropositive women with dealing with the fear of living with the disease.

> 2: To be open, talking about it, and I guess when I came out of the closet and the more people I told, the easier it became to tell people. Then I noticed a lot of people asked me questions about it [HIV/AIDS] and this helped me because if I did not know the answer to something, I try to find out. Then I am learning more in the same process. ... It makes me feel better about myself. It makes me feel I can deal with it. Not in denial like I see so many people that won't tell anybody. They are afraid to tell. The more people I tell the less afraid of the virus I get.

> 16: Because ... I am not sitting there hiding anything. It makes me feel comfortable [to tell]. I get to share my story, what's going on with me and maybe I can reach somebody else. Maybe somebody else can learn [from my experience] or what's going on with me. But, it is no problem for me coming out and saying, I am HIV positive ....

> 9: I kind of feel like the more you are open about it, the more information that you're going to get. You might find out about something that can really make a difference.

> 18: It is time for the Latinos to know that one of their own [is HIV positive]. The sad part is that a lot of the Latinas that are infected are heterosexual women that got infected through their husbands, their mates, or their boyfriends, not through IV drug use.

> 8: I start[ed] that because first I had my illness, the trauma, the things that I went [through] with my illness, and then the more I got to know about my illness, I said, I cannot just keep my mouth shut. I cannot just put up learning. I just cannot keep [it] to myself. I want to help the community in a different way. ... it's in my heart to reach out to these poor people who are in denial about this. ... I am going to tell it and I am going to repeat it. At the same time that I am telling my story, I get healed.

Controlling Disclosures

Latinas regulated the flow of information to whom, when, and where they would disclose their HIV/AIDS status by controlling the disclosures. This allowed the women to maintain control of private information and prevent exposure. The women attempted to

control disclosures in all situations but were not always successful because of others disclosing. Table 8 describes the property and dimension of controlling disclosures.

Table 8

Major Category, Property, and Dimension of Controlling Disclosures

Major Category	Property	Dimension
Controlling disclosures	degree of control	low . . . . . high

One woman felt that information about her status should originate from her.

14: I would rather tell somebody I have it, than somebody else telling.

Two Latinas described how they were able maintain control of who would be told by selecting specific times to disclose. The women disclosed to selected groups that included family members or screened audiences prior to giving presentations.

> 8: Well, I got all the family together. All my sisters [and brother] were here, [including] two sisters [from] Missouri. They came down for the family reunion ... [in] August of [1996]. I had to tell them because ... I [was] speaking to people [who] might be their friends.

> 6: I always find out when, where, and who [is in the audience, before I go and speak]. Because I don't want my kids' friends to find out. Unless they want to tell their friends. I don't want them [children's friends] to find out.

One Latina described how she was unable to disclose until she was ready to tell her family. The delaying of disclosure assisted her to control who and when she would tell. The delay also gave the woman time to cope with living with the virus and the stigma involved with being HIV-positive.

> 18: But my family was a different story. I just didn't want to [tell them right away]. I had to be ready to tell them. Because I had to deal with a lot, for myself first, before I told them. Again that was in 1988, it was so different than it is now.

In contrast, Latinas reported they did not have control of disclosures when others revealed their status. One woman experienced her brother telling others about her seropositive diagnosis without her permission.

> 14: My brother gets me upset all the time. ... He always says, 'This is my sister and she has AIDS.' I felt dirty and like people were scared of us. Let me be the one [to tell], because I don't want somebody to judge me before they even get to know me.

Four Latinas with 11 children also described situations where they lost control of disclosing their status. One child from each of the women was told by other family members or by reading a document that reported the parent's diagnosis.

> 3: They were telling me not to tell her [daughter], and after a few years went by, my sister went and told her. It's like, I wanted to tell her and you went and told her, and now she knows.

> 9: They [in-laws] told her [daughter].

> 17: My son found out. I guess from my mom speaking. I don't know and then I told him myself.

> 13: My oldest daughter knows (big sigh). Actually I am not the one who told her. She found out reading some papers that my husband left lying around and she goes, 'why do you guys have that?' I told her.

The Latinas experienced other situations where they were unable to control the transmission of information. The incidents occurred while being booked in a police station or being incarcerated. The women felt a loss of control while in prison because they were identified as being seropositive by being assigned to designated areas, the medical doctor they saw, the tagging of documents for identification, or the color of the food trays.

> 2: I was on parole at that time. I got arrested ... at somebody's house they raided. My parole officer arrested me. ... I worked at Casper hotdog. ... and no one but cops go in there. So, when they saw me arrested and they [over]heard my HIV status, they went back and told my boss.

> 4: They told me [when] I was having like a little birthday party downstairs in the prison with my friends. They didn't even have a doctor tell me. They just told me to

roll my stuff up and go to R and R, that I was leaving the prison. So no one really told me the test came back HIV-positive. [I didn't] talk to a counselor. They said it on the loud speaker.

12: ... Everyone [county jail] knows what they said. Oh, it is confidential, but everyone knows. That doctor is the only AIDS doctor. No one else sees him except people who have AIDS. They know the people go to see him, and they call you in front and then they see the room where you go. Everybody knows or if you have HIV they change your diet. I think they don't want people to eat on the same tray. They want us only to have certain [trays], because they're different color plates, trays. We only get the same ones, brown ones and everyone else get a tan ones. There are a lot of things that are fucked up in the county jail.

Supportive Disclosing

Supportive disclosing describes the targets for support and the type of support used by several seropositive women. The targets for supportive disclosing were defined as the seropositive woman or another person. Participants described how they disclosed to gain support for themselves or give emotional support to others. When the seropositive women did decide to disclose they sought different types of assistance, such as professional individuals or agencies or used friends or family members to assist with the disclosing. The properties and dimensions of supportive disclosing are presented in Table 9.

Table 9

Major Category, Properties, and Dimensions of Supportive Disclosing

Major Category	Properties	Dimensions
Supportive Disclosing	targets for support	self . . . . . others
	type of assistance	nonprofessional . . . . . professional

Targets for support. The Latinas described how they disclosed to gain emotional support for themselves and others. The targets for support focused on seropositive women or on people who needed support. Disclosing to obtain support was important because it

assisted the Latinas and others with coping in dealing with the disease and decreased feelings of isolation.

One Latina, in the first quote, decided to disclose her status to two of her sisters so they could provide emotional support to the one sister who knew of the status. This action allowed the three sisters to discuss among themselves and to update each other about the changing condition of their seropositive sister. Other Latinas also disclosed for self support and to increase communication among family members.

> 1: A year later [I told my two other sisters]. Because it was hard for my sister. She wanted to talk to them for support. ... Since we're so close, I think she wanted to talk about how she felt and if like I had bad days she could tell them .... I think she just didn't want to keep it a secret.

> 17: Oh, you know what helps a lot [to tell] is my family. Well, we sit and discuss it just like this. Oh yes, and then as time [passes], coming out of that denial, makes it possible [for] me to share something with other people who I have known for a long time or whatever the situation.

> 5: Oh, I just told my daughter in 1992 also. Because I felt like, when I was in Kentucky, I felt really alone because I had no one to talk to about it.

Latinas disclosed to support themselves by increasing their telling to others. The women maintained an inner comfort with telling and felt uninhibited with ongoing disclosures. The women continued this action of supporting oneself with ongoing disclosures over time.

> 16: I am not sitting there hiding anything. It makes me feel comfortable [to tell].

> 2: To be open, talking about it, and I guess when I came out of the closet and the more people I told, the easier it became to tell people. ... [telling] helps me because if I don't know the answer to something, I try to find out and then I am learning more in the same process.

Two Latinas sought emotional support from community agencies. The women had previous experiences with agencies. They perceived community agencies were the only resource that could assist them with discussing their emotional concerns about being HIV

positive.

> 5: When I was in Kentucky, I felt really alone because I had no one to talk to about it. Because if you live in Fort Knox, they are not open-minded. I had no one to talk to. So, whenever I really felt like crying or something I had to let it out and call the AIDS Hotline. The lady says I'm not a counselor. I just explained to them I did not have anyone to talk to, because the only one I could talk to was my boyfriend. He was over the road driving, he was always on the road. So, they helped a lot.

> 18: That very night I found out, [I told]. I called a friend and told her what happened and then I said I have to go to an Alcoholic Anonymous meeting right now. I said, not that I want to go out and use or anything like that at this moment, but I want a meeting. She came over and drove over to San Pedro. We went to the meeting and it had like 30, 40 guys and just me and my friend.

Another woman who had been in the California Correctional Institute for Women (CIW) numerous times, decided to disclose to prison personnel so she could join a support group for seropositive inmates. Prior to the CIW support group, the woman chose not to disclose her status in prison because of the lack of support services for inmates diagnosed with HIV/AIDS.

> 2: Just recently in 1992 or 1991, they just unsegregated them. We're not locked up anymore. We are with the main population now, but they do have us in one yard and basically in one unit. They keep all the HIV/AIDS people in C yard .... So, I came out of the closet this time. They have a very good support group for women now.

Type of assistance. The Latinas sought assistance and the presence of certain people to help them with disclosing to others. When a Latina wanted to disclose to family members or employers, she used a trusted counselor, another family member or a friend to assist her. A counselor or friend was used to assist with answering questions about the disease process. Help from a knowledgeable person ensured assistance for the Latina with disclosing if she had problems with clinical questions. The act of seeking help from others would also give insights to the women on how to disclose to family members.

> 15: [I told] my two nieces because they told me that they were having sex and stuff. ... They gave me the opportunity [to tell]. I need to tell you guys something, I am HIV-positive. I haven't told your mom, my sister. ... they were with me when I told [my sister]. They stayed with me. They supported me. ... It was like if I couldn't

handle something that they could. ... I needed them to tell me, what would you guys suggest for me to do because they know their mom and I told them that I wanted them to be with me.

7: So, I told one of the women, [who was an RN], ... She helped me tell the other parents [of the children I do child care for].

16: Yeah, I took her [daughter] to the clinic and we had a meeting. The counselors helped me [tell her].

18: When I went back and told my bosses about two weeks later because I was so depressed. ... They sent me home because they didn't know how to deal with it. So, K... [counselor] talked to my bosses and sent them literature .... So, he helped me and it only lasted three days and then I went back [to work]. He has been very helpful to me.

One woman planned to disclose with the support from a counselor to her children when she had finished a drug rehabilitation program.

11: I have to do this [drug rehabilitation] first. Then, I am going to bring them in and tell them. ... Then ... we're going to have an appointment for a family counseling right then and there. Because I know there are probably going to be a lot of questions and stuff that I won't be able to answer. I will not do that alone. I'll have a counselor, someone who I trust. Naturally, knowledgeable and answer their questions for a kid's mind.

Strategies Used When Deciding to Disclose

The Latinas used strategies when deciding to disclose. The strategies were used as purposeful or potential actions to choose who, where, and when to tell. The disclosures were made before or during the course of the verbal interaction with another person.

Selective telling, postponing, and seeking help were strategies used to assist the women with making their decisions to tell or not tell. Table 10 describes the strategies, objectives, and actions used by Latinas when deciding to disclose.

Table 10

Strategies, Objectives, and Actions Used by Latinas When Deciding to Disclose

Strategies and Objectives	Actions
Selective Telling	
• To control the telling	14: I would rather tell somebody I have it, then somebody else telling. ... Let me be the one [to tell], because I don't want somebody to judge me.
• To inform others	16: If something I have is going to hurt somebody else, I have to [tell]. If [I] knew that I had something and I didn't tell somebody and they end[ed] up getting sick because of me, I couldn't live [with] that.
• To assess receptiveness	14: I'll feel them out [by telling a story] to see how they would accept it [HIV/AIDS]. If I feel that ... [they] got too excited about somebody with AIDS then I won't tell [them].
• To preserve confidentiality	1: I did not want to tell [human resource] personnel because they do not keep things confidential.
• To maintain privacy	13: I don't have that many friends anymore ... and I don't like to tell the people my business.
	3: It's really none of their business unless I am going to be involved with them.

	1: I get to thinking about, maybe we [Mexican manager and woman] are just very private people. We just don't like our business out. Not on the streets.
• To protect from negative responses	7: There's too much in jeopardy. I am sure that if they found out, I couldn't live here. ... They will probably burn the house down. ... All they have to find out is that I have it [AIDS]. I am sure they'd burn the house. I just don't feel safe.
	16: Because in jail ... they made you feel like you're a disease. ... They kept them segregated from the rest of the prison.
	8: She is the only one that has a good job, works with lawyers in a law firm. She was the one that I would try not to tell. [I do not want] her or co-workers or her friends to [find out]. ... I am afraid that maybe they will reject her.
• To prevent being shamed	
Self	12: I still have I have a lot of shame, I don't like people to know, and I still feel ashamed. ... I feel dirty. I feel I don't want anyone to know.
Other person	I don't want to tell my son because I feel [he will] feel shame, and I don't ever want him [to feel that]. ... I don't want him to feel ashamed ... of his mother.
From community	Latinas, I guess have more ... shame. ... We tend to be very proud and HIV to a lot of people, it's a dirty thing, a bad thing. ... they think of it as a stamp of disgrace on somebody.
<u>Postponing</u>	
• Readiness to understand	6: My son [nine years old] doesn't know. I am going to tell him when he turns ten.
	13: We do not want to tell him because it is really not for him to know just yet. He is still too young.

Seeking Help

• To manage the telling	15: I brought everybody [family members] in the house. Yeah, everybody needed to give me some feedback. I was scared to death. ... We told her [grandmother].
	18: I asked [my friend] to sit with me while I told my family. I knew my family wouldn't desert me. That wasn't even a thought in my head. My feeling was that they would need more explanation and maybe more support.
	6: ... I didn't tell them alone. I had somebody [from work] with me. ... [They were] working with people who are infected. They helped me explain to a ten year old. I knew I couldn't do it alone.

Selective Telling

The Latinas used selective telling as a strategy to determine whom, when, what and how they disclosed their HIV/AIDS status. Selective telling was a strategy used by women that included seven objectives for telling. The objectives of selective telling were to control the telling, inform others, assess receptiveness, preserve confidentiality, maintain privacy, protect from negative responses, and prevent being shamed.

To control the telling. The Latinas controlled disclosures of their HIV/AIDS status by selecting to whom, when, and where they would disclose their seropositive or AIDS status. The women wanted to be the primary informant when disclosing their status. Using this approach ensured that the women's diagnosis would not be revealed to people she did not wish to have the information.

In order to keep control of the telling, a few of the women needed to know the very specific circumstances or the individuals who would be present while disclosing their status. For instance, one woman was invited to speak to elementary school children. If there were people in the audience who knew her children, she would decline the

invitation. The woman perceived there was a danger that the children at the presentation would tell her children.

To inform others. Women chose to disclose their status to inform past or potential sexual partners of the risk of transmission of the HIV virus. The women told past sexual partners of their potential exposure to HIV so that they could get tested. Likewise, by informing future partners, the women ensured that they would be receptive to taking precautionary measures to prevent transmission of the virus. In both cases, the women reported they had met their obligation by informing past and potential sexual partners. The women used this strategy to ease their conscience.

To assess receptiveness. In selecting who to tell, Latinas told HIV/AIDS related stories to explore and evaluate the person's overall reaction to people diagnosed with HIV/AIDS. The women used this technique in social situations with people who did not know their HIV positive status. By presenting the stories face-to-face, the women were able to observe the person's response and make the decision whether to disclose to that person.

To preserve confidentiality. In this objective of selective telling, the women disclosed when they felt assured the information would be kept confidential. Conversely, women desired to preserve confidentiality by not telling. The concern of confidentiality related specifically to the legal notification of employers and their insurance company. The women felt that the people managing the information could not be trusted to keep their status confidential. Therefore, most of the women selectively chose not to disclose their status to human resources departments, their employers, or anyone that would jeopardize their job or medical insurance.

To maintain privacy. Women chose to maintain a level of privacy by selecting to whom to tell their diagnosis. Latinas, in this study, generally selected not to share their diagnosis with casual acquaintances. When the women did not have a professional relationship with the person, they selected not to tell. Specifically, the Latinas did not disclose to people who were not providing direct physical care or community services.

For example, several women described how a mutual acquaintance confronted her on the street and he asked her if she had AIDS. Because he was only a mutual acquaintance, the woman did want to disclose her diagnosis and selected not to tell him.

To protect from negative responses. The objective of selecting not to tell people was to protect them from negative responses. The women would protect themselves, their children or parents from negative responses by not telling neighbors or people that might harm them. In this way, they would not be at risk of experiencing negative responses, such as physical or psychological harm, isolation, or rejection.

For example, one woman decided not to tell because she believed her neighbors would destroy her home. She had experienced previous problems with the neighbors and felt she was not safe. So, to prevent physical harm, she made concerted efforts not to tell anyone in the neighborhood.

Women who were incarcerated reported the risk of isolation. They decided not to tell other inmates or the prison authorities because they perceived they would be segregated if their status became known. Not disclosing would also protect the incarcerated Latinas from possible stigmatization from fellow inmates and correctional officers.

Some of the Latinas chose not disclose to protect children or a parent. The women did not want their family members to be treated 'differently' or rejected by their friends or their community. For example, one mother chose not to disclose to her daughter, the

daughter's co-workers or friends because the woman feared she would lose a 'good job' in a law office. The woman also did not disclose because she did not want to risk rejection by her daughter.

To prevent being shamed. Latinas also selected not to disclose to prevent being shamed, either for themselves or for others. Latinas who experienced shame as a result of their HIV diagnosis described that, in the Latino culture, women with HIV/AIDS are thought to be 'dirty' and bring 'disgrace' to the family and the Latino community. The Latinas believed that women diagnosed with HIV/AIDS would be treated as outcasts if the community became aware of their diagnosis.

> 16: They [Latinas with HIV/AIDS] are outcasts. ... They [Latino community] have this thing, like [if] Mexican girls [are] sick or if people know that there is something wrong with them, they won't be wanted anymore.

A fourth of the Latinas described feeling ashamed because they were HIV-positive. They felt their shame came from not following the inculcated role of the woman in Latino culture, which according to the women, was to stay home, serve their families and not be sexual active.

> 16: Because Mexican girls or Latinas are supposed to be the type of girls that always stay home and [care] for their husbands. You're not supposed to be out on the street tramping or whatever.

> 10: I think it is the custom. I think it is the Latino Native-American custom. Most women are brought up that way to take care of their husbands, kids and the house. ... That is the way it has always been.

Latinas also selected not to disclose because of the family rule of not disclosing private family matters. The Latinas described that family pride must be maintained by not disclosing private family information that had the potential to bring shame to the family.

> 1: [My parents said,] be quiet. What's in the house, is in the house. When you go out, you don't talk about what goes on in this house. So, maybe that is what it is. I'm not ready to tell.

Therefore, given the stigma associated with HIV/AIDS, the women felt revealing their diagnosis of HIV/AIDS would bring shame to themselves, family members, and the community.

Postponing

Postponing the disclosure was a strategy used only by mothers with minor children. The central concern of the mothers related to the children's readiness to understand the physiological and psychological impact of the disease.

Readiness to understand. Mothers were concerned about the ability of the child to understand the physiological and psychological implications of living with HIV. The objective of postponing disclosure was to ensure that the child would be old enough to cognitively understand their mother's disease. The mothers believed their child would be ready to understand when they reached ten years of age. The mothers felt that ten years old was a proper age for the child to understand and comprehend the gravity of being told the seropositive status.

Seeking Help

When women used the strategy of seeking help, it was primarily to manage the telling to family members. Women planned to disclose to family members by seeking help from a fellow family member or health professional. The goal of the strategy was to facilitate disclosures when the women wanted to reconnect or rejoin the family.

To manage the telling. To facilitate disclosure to the family, Latinas sought help from trusted family members, friends, or health educators because they were afraid of telling their family by themselves. The women felt that if they asked for help they would be able to overcome their fear of telling their family. The women chose family members or friends who would give insight about how to tell family members. Health educators

were selected to assist with answering health issues related to HIV/AIDS. Despite who assisted in the telling, the ultimate goal was to rejoin the family.

Consequences of Disclosing

This section describes the consequences Latinas experienced when disclosing their HIV status to others. The consequences were reported as positive and negative experiences from family members, friends, healthcare personnel, or employers. Positive consequences included being accepted and receiving support after disclosing. The negative consequences were identified as rejection by others and blame by others.

Positive Consequences

The women experienced positive consequences of being accepted by others and receiving support from others. Being accepted by others describes how the women were reconnected into social environments among the family unit or among friends at different times. Receiving support included both emotional and physical support from family members, friends, fellow inmates, or support groups. The positive consequences and related actions are presented in table 11.

Table 11

Positive Consequences and Actions After Disclosing

Consequences	Actions
Accepted by Others	
• Continued relationship	15: Everyone came around at a different time. Did it separately. Accepted it [my diagnosis] separately. My brother accepted it first right away.

Received Support • Emotional	7: They [friends] have all been very supportive, very understanding. … not rejected in any form. ... They gave me hope that I won't get sick. 18: One of the guys [at the Alcoholic Anonymous meeting] got up and just gave me this big hug, and just told me, you'll never be alone.
• Physical	12: He got involved and he always gave me my pills, makes me be healthy, he got really more involved. Instead of backing away, he got closer to me. 15: We lived together. He [brother] didn't put me out. … He did everything he could to make me comfortable.

Accepted by Others

Acceptance by others involved social reconnection with family members, friends or employers. There were circumstances where the women experienced positive consequences of disclosing which had elements of temporality. Being accepted by others occurred immediately or was delayed after disclosing.

Continued relationship. When an intact relationship preceded the diagnosis, then the relationship continued despite the HIV diagnosis. That included relationships with immediate family members, extended family members, friends, and an employer. The women experienced acceptance by family when they were allowed to engage in their daily and social activities after they disclosed their HIV/AIDS status.

Latinas who had strained relationships with family members because of their history of IDU or being in an abusive relationship valued the importance of continuing a relationship. Even though the relationships were strained, the women maintained a distant contact with family members prior to disclosing their diagnosis. Over time, after

disclosing their status, the women were accepted and allowed to reintegrate into the various social roles. The women were restoring or expanding roles that included being a family member, a sister, a daughter, or a godmother.

> 8: Since I have this illness, they have been closer. My brother brings my mom [to visit]. I think my illness has gotten my family closer to me .... They didn't reject me.

> 12: No rejection at all, like he [husband] just embraced me with it more. He didn't back out on me, he just loved me more.

A friend honored one HIV-positive woman, who was estranged from her family, by making the woman a godparent to her child. This action is significant in the Latino culture because the woman is not only responsible for the child's religious upbringing but also assumes responsibility for the child should the parent die. The new role pleased and reassured the HIV-positive Latina of her friend's acceptance of her.

> 5: They're there for me. One of my girlfriends, was in the same lifestyle [as me, IDU], but she was lucky and didn't get the virus. ... She made me the godmother to her son. I was shocked (laughs). I was never godmother before to anybody's kids.

The women described their experiences of being accepted at different times by family members. After being told the woman's diagnosis, some people needed to 'step back' and absorb and deal with the information. Once the person was able to deal with the information, the women experienced acceptance from family members or an employer.

> 18: One of my nieces ... would not talk. She stepped back for a while. I didn't hear from her for a while. ... When we finally talked, [she said] she needed to step back to be able to deal with it, and then I said that's fine. I said, that is why I 'm a great believer in and when you tell somebody allowing them the space to deal with it.

> 15: Everybody came around at a different time. Did it separately. Accepted it separately. My brother accepted it first right away.

One woman reported that when she told her boss, the employment relationship continued because the woman was allowed to keep her job. The employer took about a

year to accept her as just another employee. The relationship was considered continued because she did not lose her job.

> 18: They [employer] had a hard time with it at first, but it took about a year before they really settled down with it, feeling better as time went by.

Received Support

Latinas described receiving emotional and physical support from family and friends. Women received emotional support in the form of understanding and people being there for the seropositive women. The Latinas reported experiencing friendship and protection from family members, friends, and even a stranger. Physical support was given when the women received physical care or environment from another person, such as a partner or family member.

Emotional. Women received emotional support from many sources, such as family members, friends, neighbors, a stranger, and an inmate who was not HIV positive. The support was in the form of comforting, listening, and 'being there' for the women.

> 8: My sister M... is one who has given me more support. When she comes, [she] checks on me and we go out.

> 5: [A friend] told me she would always be there no matter what [after she made me godmother to her child].

One woman who had been incarcerated reported receiving support from a fellow prison inmate. The woman described the fellow inmate as her sole support who gave her comfort and protection while in prison.

> 16: She [fellow inmate] was the only one I told. She was the only support I had in there [prison]. She comforted me. She gave me support. She just watched out for me.

Physical. The physical support the women received occurred when the women were ill or needed a place to live. One woman received support from her husband when he cared for her while she was ill. He assisted her by administrating her medication and

giving physical care. Another seropositive woman described how her brother supported her by not asking her to leave his residence after she disclosed her status.

Negative Consequences

The participants reported experiences of being rejected or being blamed for contracting the virus. Rejection was characterized by the lose of social interaction, being treated as an outcast, and contradicting behaviors from others after disclosing. The Latinas reported that family members, friends, and society implied that the women were to blame for their infection because of their history of IDU and previous prostitution activities. Table 12 presents the negative consequences and actions after disclosing.

Table 12

Negative Consequences and Actions after Disclosing

Consequences	Actions
Rejected by others	
• Loss of social interaction	15: ... I took her [stepsister] kids to the rodeo, and then when I got back, I told her I had the virus. So, when I called her, to see if I could take the kids the next week, she told me no. She said, I [could not] take the kids out anymore.
• Treated as outcasts	16: There was nothing I could say because I am not [liked]. I am an outcast. It is like I do not even exist. My family does not like me and when they found out I was using [drugs] ... and now that I am HIV it is even worse.
• Contradictory behaviors	10: He said he had no problem with that [my seropositive status]. But he did have a problem with it, because the body language [became] totally different.
Blamed by others	

• Family	8: [My children] are blaming me [for contracting the virus]. Everybody [says], no you have it, but my dad does not have it mom. You fool[ed] around mom, ... you were with Tom, Dick, and Harry, the time you were separated with him.
• Society	15: They look at you a certain [way], not all of society, but it is like you got the plague. If you tell them you got it from a blood transfusion, [they say], oh poor you. If you tell them you are a dope fiend, you deserve it.

Rejected by Others

The Latinas reported experiencing rejection from family members, friends, prison inmates or personnel, health professionals, and law enforcement officers. They experienced losing social interactions, being treated as outcasts, and receiving contradicting messages after disclosing their status.

Regardless of the women's previous lifestyles and recognition of unacceptable behaviors, the rejection was always devastating to the women.

Loss of social interaction. After disclosing their diagnosis, several of the women described how they were denied further contact with family members or friends. Women experienced a loss of social interaction because people were fearful of exposing themselves and family members to the virus. As a result of rejecting the women, family members isolated the women and lessened support for the women.

> 2: He [father] throws it [in] my face, ... He said, you've got that AIDS and I don't want the kids around you.

Latinas in prison also experienced rejection when fellow inmates and staff would not allow contact with other inmates. The women were separated from the general population in certain areas of the prison. The rejection in all incidents was due to the ongoing fear of

contagion by the inmates and personnel.

Treated as an outcast. Women reported they were treated like outcasts after disclosing. As an outcast, the women are not included in the general community and are treated differently because of their diagnosis or illness. The seropositive women were rejected by family members, friends, medical personnel, an employer, and police officers.

> 2: They [family] didn't really like it [AIDS status]. They treated me [like an] outcast ....
>
> 8: Oh, I have gone through a lot of rejection. Yes. My kids turned their back on me. ... Up to this day, every time that I get sick I am by myself. My kids don't care that I don't have [anyone].
>
> 18: I've lost friends [after I disclosed my status]. They didn't call back and I never saw them again. I've lost like two or three friends that way.
>
> 4: Then they [prison personnel] get scared and they send you to the infirmary until they can send you to another place. ... When we were segregated, [it] made me feel like, God, all kinds of different feelings.

Two women reported experiencing rejection from medical personnel and policemen after they disclosed. Being rejected by the medical personnel caused the first woman to isolate herself and to be cautious with further disclosures, which delayed or affected the continuity of medical care as the woman searched for another medical doctor. The second woman reported being fired after policemen told the employer of the restaurant where she worked about her seropositive status. The police officers threatened to discontinue patronizing the establishment if the woman continued working at the restaurant.

> 7: I was rejected from my doctor. I was rejected from my dentist and it's not a good feeling. ... When I told my doctor he stood across the room, and it was the day after that I found out that I was positive. ... You tend to isolate yourself. Now, I don't reveal my status unless it's absolutely necessary.
>
> 2: They [policemen] weren't going to go there anymore and eat if they had me working there. So, I lost my job [in] 1990.

Contradictory Behaviors. The women also experienced rejection when people's attitudes changed after the learning of the diagnosis. When a person was told of the Latina's diagnosis, the initial response appeared to be positive but the person's actions in body language and attitudes communicated the opposite. The women described experiencing incidents of contradictory behaviors after disclosing to friends and sexual partners. Women initially perceived that the person accepted them after disclosing their seropositive status. However, within a short time span the people changed their attitude and physical contact with the women.

> 10: [After disclosing my status to my friend], I invited her to the [presentation]. ... she said she could deal [with it], but she couldn't. ... I always thought my friend would not leave me no matter what, but it took something like this [HIV] to tear us apart.

> 7: After a while he seemed very understanding, as far as the disease, but there was no sexual contact after that.

Blamed by Others

Latinas reported experiencing blame from family members or society after disclosing. Being blamed was a result of others faulting the women for their seropositive conversion. The women perceived they were blamed for contracting the virus because others believed they engaged in behavior that caused them to contract the virus.

Familial. When their family members blamed the women for contracting the virus, the women experienced blame. One woman contracted the virus from her husband, but her children did not believe her when she told them. They believed it was her actions that were associated with wrongdoing, therefore it was her fault she was HIV-positive.

Societal. One woman perceived that society blames certain groups of women after learning how they contract the virus. As the woman stated, "My friend got it from a transfusion and she says people say poor thing. The day I said how I got it [AIDS

because] I was a drug user and a prostitute. [They said,] what did you expect?" Because of the woman's past lifestyle of drug use and prostitution, the woman was blamed for contracting the virus.

In summary, the core category of deciding to disclose and four major categories were identified and are not mutually exclusive but, rather, are relational. The four categories identified were timing of disclosure, needing to disclose, controlling disclosures, and supportive disclosing. The Latinas began the process of deciding to disclose after being diagnosed with HIV/AIDS. The women used strategies to assist them with making the decision to whom, when, where, and how they would tell. As a result of their decision to disclose, all of the women encountered positive and negative consequences.

The first major category, timing of disclosures, varied among the women in regard to the relationship they had with others, the ability to care for themselves, or the wish to share knowledge with others. The women chose to disclose to people with whom they had an established relationship such as their parents, other family members, and friends. The women also chose to disclose to people with whom they were developing a relationship. When the women perceived that they were unable to care for themselves, they would choose to tell people. Sharing knowledge was also related to timing of disclosures because it did not occur unless the women were ready to speak to people about their status. When the women did disclose they shared their experiences and knowledge with others and also were recipients of information from others.

The Latinas felt a need to disclose if they perceived there were risks of others exposing their status, wanted to reconcile with family members, or felt an obligation to disclose. If the women perceived there was a risk of others exposing their status to partners, family members, friends, or neighbors the women chose to disclose. The women

who had a strained relationship with family members also felt a need to disclose to reconcile with them. Additionally, there was a need to disclose when they felt an obligation toward family members, past and potential sexual partners. The obligation was to fulfill a role as a daughter or to warn sexual partners so they could be tested for the virus.

In the third major category, controlling disclosures, the women decided they should be the ones to disclose their status. As a result, the seropositive women directed and regulated their disclosures. Conversely, when the women were unsuccessful in controlling the information, others disclosed their status.

The Latinas made decisions to disclose when they wished to obtain support for themselves and others. The support assisted the women with decreasing their feelings of isolation and living with the seropositive diagnosis. Disclosing also assisted with sharing information about the women's health status and giving emotional support to family members. The seropositive women sought assistance with disclosing from family members or health professionals and educators.

The strategies used when deciding to disclose were selective telling, postponing, and seeking help. Selective telling was the predominant strategy used to control the telling, inform others, assess receptiveness, preserve confidentiality, maintain privacy, protect the women from negative responses, and prevent being shamed. By using selective telling, the women were able to control to whom, when, where, and how to disclose. The women would inform others when they felt an obligation to tell past or potential sexual partners. Conversely, women selected not to disclose to preserve confidentiality and maintain privacy. To assess the receptiveness of others, the women would examine the person's overall reaction to a discussion of people living with HIV/AIDS. Depending on the

reaction observed the women selected to tell or not tell. By not telling, the women were able to protect themselves from negative responses such as harm, isolation, rejection, and stigmatization or shame.

The seropositive mothers of minor children used the strategy of postponing disclosure. The women postponed telling their children until they perceived they were old enough to understand the gravity of the disease.

Seeking help was a strategy used to assist the women to manage telling family members. To manage the telling, a health educator, family member, or friend was used to facilitate disclosures. The women used this strategy when they desired to reconnect with the family unit.

As a result of disclosing, the women encountered positive and negative consequences. Positive consequences were identified as being accepted and receiving support from others. The acceptance by others was expressed by the family's continued relationship with the women. The continued relationship was demonstrated when the family included the women in social activities and by the family's contributions to AIDS related community events. A second positive response was characterized by the women receiving emotional and physical support from partners, family members, or friends.

The negative consequences experienced by the Latinas were rejection and blame from others. Women were rejected when they experienced a loss of social interactions, were treated as outcasts, or when they observed contradictory behaviors from family members and friends. Being blamed for contracting their disease was a second negative consequence experienced by the women. The women experienced blame from family members and society. For example, one of the women perceived that society judges and blames a woman for contracting the virus via IDU or prostitution.

CHAPTER FIVE

DISCUSSION

This study described the factors that influenced the Latinas' decision to disclose their HIV seropositive status. From this research of Latinas living with a HIV/AIDS diagnosis emerged a core category, deciding to disclose, with major categories of: timing of disclosure, needing to disclose, controlling disclosures, supportive disclosing. The strategies and actions used by the Latinas are presented. Positive and negative consequences of disclosing as well as the limitations and implications for nursing are discussed.

Deciding to Disclose

For the Latinas living with HIV/AIDS, deciding to disclose denotes a complex process of interactions between the women and their family members, partners, friends, health care providers, employers, and public audiences. This interactive process involved the Latinas making choices of when and how to tell others about their seropositive status. In addition, decisions to disclose were influenced by multiple factors related to the risks of others disclosing the status or encountering negative responses. Strategies used to manage disclosures by the women included selective telling, postponing, and seeking help.

From the data, four categories were identified: timing of disclosure, needing to disclose, controlling disclosure, and supportive disclosing. The following section discusses the categories, properties and dimensions.

Timing of Disclosure

Timing of disclosure is an ongoing process that describes different moments and situations that made the Latinas disclose to a person or a group. The Latinas initiated

disclosures after being notified of their seropositive status. Disclosing at different times was influenced by the women's relationship with others, ability to care for themselves, or wishing to share knowledge about HIV/AIDS disease process. Initial disclosures were to family members, partners, and close friends. Subsequent disclosures expanded to a fellow inmate or friends. After one year, the Latinas disclosed to other family members, support groups (in and out of prison), and persons at public presentations.

Relationship with others. The Latinas in this study disclosed to people with whom they had a trusting relationship, generally family members, partners, or close friends. A few women who did not tell family members reported they were not ready to tell the family because they had to 'deal with' living with the virus and the stigma attached to the diagnosis. Five of the Latinas decided to delay telling their children after being advised not to tell or because the women perceived the children were too young to understand.

Over time, some Latinas disclosed to acquaintances with whom they had a history of using drugs or being inmates while in prison. Latinas also disclosed to people with whom they might wish to establish a relationship. After disclosing, the women allowed the potential friend to make a choice of whether to continue the relationship.

Seropositive Latinas with children in this study supports similar concerns and experiences of disclosing reported by mothers living with HIV/AIDS (Moneyham et al., 1996; Pliskin, Farrell, Crandles, & DeHovitz, 1994), primarily with the child's cognitive level of understanding at the time of the interview. Overall, the women decided to delay disclosing until the child was ten years of age and judged old enough to comprehend.

Findings from previous studies reported that the majority of the respondents living with HIV/AIDS disclosed their status to family members, sexual partners, friends, or health care providers (Laryea & Gien, 1993; Simoni et al., 1995; Sowell et al., 1997;

Stein et al., 1998) rather than employers and casual acquaintances. Studies focusing on homosexual and bisexual men have reported similar findings of disclosing (Hays et al., 1993; Huggins, Elman, Baker, Forrester, and Lyter, 1991; Marks, Richardson, & Maldonado, 1991; Mason, Marks, Simoni, Ruiz, & Richardson, 1995; Schnell et al., 1992; Stempel, Moulton, & Moss, 1995). The findings suggest that persons living with HIV/AIDS are likely to disclose to their close, established relationships. The relationship between who was told and choosing when they were told is influenced by multiple factors and needs further investigation for Latina women infected with HIV/AIDS.

Ability to care for oneself. When the women perceived they were unable to care for themselves because of their disease progression, they would disclose to people who could assist them. Those most likely told were family members, such as mother, sister, brother, or even a child.

The ability to care for themselves as an influence on timing of disclosure is similar to results reported by respondents living with HIV/AIDS who also indicated they would disclose if their disease progressed (Marks et al., 1992; Simoni, Mason, & Marks 1997; Simoni, Mason, Marks, Ruiz, et al., 1995). Consequently, the impact of caring for oneself may supersede the relationship with the person and hasten the timing of disclosure. That is, if the person is able to care for herself the primary disclosure may be to the person with whom she has a close, established relationship. However, if the person living with HIV/AIDS is unable to care for herself, then whether or not the person has a close, established relationship may not be significant. Perceptions of disease progression by persons living with HIV/AIDS may precipitate disclosing due to the need for assistance.

Needing to Disclose

Latinas decided to disclose when they wished to tell others about being seropositive.

The women felt a need to disclose when they perceived there was danger of another person disclosing their diagnosis. Latinas also felt a need to disclose when they wished to reconcile with family members, or if they felt an obligation to disclose to past or potential sexual partners, or felt an urgency to share their personal knowledge of living with the virus.

Perceived risk of exposure. A few Latinas felt a need to disclose when they perceived there was a risk of others revealing their HIV/AIDS status. The risk was perceived as threatening and potentially damaging toward the women. The Latinas perceived there was a risk of negative responses from people who knew or would know the diagnosis after the women told them or heard from the media or others.

One woman perceived a risk of exposure by an ex-boyfriend when he threatened to tell a newspaper or neighbors. Another woman who spoke at public presentations, perceived a risk from certain people in the audience who knew family members. The other women disclosed to parents, children, and friends to prevent people in the community exposing their status. These incidents reveal that when the seropositive women perceived a risk of being exposed they disclosed.

Reconciliation. Another reason the women felt a need to disclose was their desire to reconnect with family members. Maintaining family ties among Latinos is perceived as a coveted bond that provides support among family members. Mindel (1980) reported that Latinos migrate toward kin networks. Latinos use family networks as a resource for solving problems and support (Keefe, 1984).

The women described the relationships prior to disclosing to family members as being strained and distant because of the women's previous lifestyle or history of IDU. The Latinas chose to tell family members, partners, and friends after being notified of

their seropositive status when the women wanted to reestablish relationships and 'share' their life with them. The need to reconcile as the impetus to disclose was not present in previous disclosing research of women living with HIV/AIDS. Further investigation is needed among different populations living with HIV/AIDS.

Obligation to disclose. Latinas in this study disclosed out of duty to family members or concern for another person's health. For example, a Latina told her mother out of obligation because she always had done so in the past. This may be due to her learned familial role and duty as a daughter.

Cultural factors that influenced the Latina to disclose may be related to familialism. Familialism describes a deep identification and attachment of individuals to their families and the strong emotions of loyalty, reciprocity, and solidarity among members (Sabogal, Marin, Otero-Sabogal, VanOss Marin, & Perez-Stable, 1987). The attachment and loyalty leads to membership in a supportive extended network of relationships, which usually provides a sense of security and social cohesiveness.

Over half of the women also expressed an obligation to disclose to sexual partners. The women felt an obligation to disclose to previous sexual partners as well as current or potential sexual partners. By disclosing, the women felt they were warning the partners about the potential risk of contracting the virus. Prior research supports these findings of disclosing to sexual partners because of the seropositive respondent's concern for the other persons' health (Moneyham, et al., 1996; Simoni et al., 1995; Sobo, 1995). Conversely, researchers also reported that seropositive individuals did feel it was necessary to disclose if they used prophylactic measures during sexual intercourse (Moneyham, et al., 1996; Sobo, 1995).

Sharing knowledge. Another aspect of needing to disclose was sharing knowledge.

Five Latinas, who felt open about telling people about their diagnosis, disclosed when they desired to share knowledge and educate others about HIV/AIDS. By disclosing, the women also gained knowledge from members of the audience during the presentations about living with the disease. The women who shared knowledge with others in this study felt 'less afraid of the virus' with the presentations.

The women who shared their knowledge had known of their seropositive status for over a year or more and had given previous public presentations. It is unclear if the sequential relationship between length of HIV/AIDS diagnosis, disclosing experiences of sharing knowledge, or need to disclose. Further investigation of sharing knowledge is needed to understand the relationships since this information is not present in previous disclosing research among other populations.

Controlling Disclosure

Disclosing was controlled by the Latinas to regulate the flow of information. The women declared that they wanted to be the person to disclose rather than have another person disclose their status. To maintain such control, the Latinas chose the person, time, and location of disclosure. The Latinas chose family members or certain audiences after determining whom would be present. When they disclosed, most women chose a family gathering setting or public presentations.

This finding is similar to the concept of strategic announcing proposed by Charmaz (1991). People, who are ill, use strategic announcing to control information. Ill people strategically plan to disclose to whom, when and where. This action ensures protection for the person and control over the interaction (Charmaz, 1991; Derlaga & Grzelak, 1979; Goffman, 1975).

The Latinas reported that when they were unable to control the disclosing, they felt

exposed. Being exposed opened the potential for unwelcome opportunities for the women to experience negative responses. The loss of control occurred when the women were identified as recipients of services for people living with HIV/AIDS, prison services, or when family members disclosed to the women's children or others who were unaware of the seropositive status. As a result of not wanting their seropositive status to be made public, the women denied themselves the use of community services for people living with HIV/AIDS. This action places the women in jeopardy for early medical treatment and emotional support from fellow seropositive women who receive assistance from community agencies.

Previous disclosing research also reported issues with loss of control when others disclosed the person's seropositive status. The loss of control of disclosure meant a loss of confidentiality, which represented the potential for exposure to discrimination of seropositive women and their children (Moneyham et al., 1996).

Supportive Disclosing

Seropositive Latinas used supportive disclosing to gain emotional support for themselves and others who know the diagnosis or assist with disclosing to others. Under those conditions, the women in this study disclosed to family members and community resources. This approach assisted the Latinas and the person aware of her diagnosis to cope with the HIV/AIDS diagnosis and decrease feelings of isolation. This finding is similar to self and other focused reasons commonly reported by seropositive persons for disclosing to parents and friends for emotional support (need to talk to someone) and health care personnel for medical reasons (Simoni et al., 1995).

Supportive disclosing included seeking professional (counselors) or nonprofessional (family members or friends) assistance with disclosing. Invoking the assistance of

professional assistance with disclosing makes the information real and legitimate to others (Charmaz, 1991). By using the support of a trusted person, the women diminished concerns of disclosing and presented accurate information to others.

Targets for support. Two groups were identified as targets for support. The targets needing support were identified as the seropositive woman or another person who was aware of the women's status. Both groups required emotional support from family members, peers, or community resources.

Type of Assistance. The Latinas disclosed to obtain support for themselves. The support was either from professionals or nonprofessionals to assist the women with disclosing to others. The majority of the Latinas disclosed using nonprofessional support systems among friends, family members and among members within the Latino community. By requesting the assistance from different family members, the women were using their familial connection to disclose. Boldt and Ray (1986) reported that the family is the dominant source of advice and assistance. Family members were trusted and could be relied on to assist the women.

The seropositive women requested professional support from counselors or educators from clinics when they did not use family members to assist with the disclosing. The professionals were able to make the medical information real and legitimate (Charmaz, 1991) and give emotional support to the women and the family members while disclosing.

Previous disclosing research reported a reason for disclosing was to generate support for the seropositive person and obtain needed community resources (Moneyham et al., 1996). Findings from this study are similar because the Latinas disclosed to obtain emotional support for themselves by disclosing to family members and community

agencies. But what is significant is the women in this study also reported that they disclosed to help others receive emotional support as well as requested others to assist them with the disclosing. This finding expanded the concept of supportive disclosing that was not only supportive of the seropositive Latina but also supportive of others.

Strategies Used to Disclose

The Latinas used strategies to assist them during the process of deciding to disclose. Depending on the situation, the women chose different strategies. The women used selective telling, postponing, and seeking help with disclosing. These strategies were used to select whom they would tell, when they would tell, and who would be able to assist with the disclosing.

Selective Telling

When deciding to disclose the women selectively choose people they could trust with personal information. Initially, partners, family members, and close friends were told. Over time the women expanded their disclosing selection to other family members and public forums. One woman would inquire who the audience was before she presented. This strategy would ensure who would be informed of her status and the possible consequences of disclosing.

Assessing receptiveness was another objective described by four Latinas. The Latinas attempted to evaluate others' reactions to HIV/AIDS. The women used HIV/AIDS related stories to test the other person for a positive or negative reaction. If the women felt comfortable and safe with the reaction, they decided to disclose. Sobo (1995) presented similar findings in deciding to disclose such as the seropositive person listening for cue words or observing for signs of a potential reaction to the information. If the person did not act negatively toward them, they would disclose.

The Latinas also selected not to disclose their status. Although this was not the primary focus of this descriptive analysis, data was collected to discover and describe the women's experience of not telling others. The women decided not to disclose to preserve confidentiality, maintain privacy, protect themselves from negative responses and prevent being shamed. The women chose not to disclose when they perceived the risks of encountering negative responses to be greater than the benefits of disclosure.

A few Latinas in the study perceived risks of rejection by the Latino community if their status were to become known by going to community HIV/AIDS services. It was unknown how many Latinas living with HIV/AIDS did not use services because they feared they would be discovered by community members and family members.

Previous studies reported similar findings that Latinos may create a tendency to withhold disclosing their diagnosis to avoid discrimination and stigmatization. These factors are especially true for immigrant Latinos who also have a fear of deportation (Keefe & Padilla, 1989; Madiros, 1984). Further research is needed to investigate the possibility of a generational relationship of not disclosing a seropositive status among Latino immigrants and Latinos born in the US. The findings would assist with identifying the similarities and differences of who is selected among Latinos when disclosing or not disclosing a seropositive status.

For the Latinas in the study, their social relationship with the family and close friends would be further strained or ended if the women disclosed their status. To maintain a relationship and connection with family and friends, the women living with HIV/AIDS decided to not tell. Latinas feared that disclosure of their HIV status would shame and disappoint their parents and blemish the honor and reputation of the family in the community (Diaz, 1993; Kaminsky et al., 1990). Latinas in this study reported

avoiding disclosure to prevent shame, which they described as feelings of being dirty and bringing disgrace to the family and/or the Latino community. By avoiding disclosure, the women felt they would not be an outcast in the family and in the Latino community.

Therefore Latinas maintained their privacy by not disclosing. They avoided disclosing to anyone they were unable to trust or would not be of help to them. This action of maintaining privacy was a result of the Latinas being taught by their parents to preserve the privacy and prevent shame on the family. As one Latina stated, "you don't hang your laundry out for other people to see." By not disclosing, the women would be protected but also may suffer from a self-imposed atmosphere of isolation and loneliness (Moneyham et al., 1996). If the women continued to avoid disclosure, the risk for them would be loss of support from family and friends or support groups and access to medical care and community services. Though, the literature is replete on the concept of shame, further investigation is required to explore the relationship of experiencing shame and disclosing and not disclosing a seropositive status among Latinos.

In summary, there are complex issues related with avoiding disclosure among Latinas. The women chose not to disclose because of their wish to protect them from rejection, to maintain privacy, and to prevent shame. While these elements emerged from the data, the research literature is limited in describing the multiple conditions, which HIV positive Latinas selected not to tell.

A major area for investigation is the issue of not disclosing a seropositive status by incarcerated Latinas in California. Demographic information reveals that Latinas compose 24% of the California population of incarcerated women (Ruiz & Mikanda, 2000). The Department of Health Services (DHS) reported that the seroprevalence of HIV among Latina inmates entering the California correctional system was 4.7%, while whites

were 1.3% and African American women were 4.2 (DHS, 1996).

Incarcerated Latinas in this study support similar concerns and experiences of not disclosing a seropositive status. In California, seropositive inmates continue to be segregated in 10 California prisons and each prison administers the HIV/AIDS unit (or none) and services differently. The practice of segregation causes inmates to refuse coming forward and disclosing their status, even when they are symptomatic (Greenspan, 1996). The finding is similar described by the women in the present study. Similar to the Latinas in this study with a history of being incarcerated, disclosing may also be avoided by inmates if they could be identified seropositive by receiving HIV-related medication; participating in HIV or infectious disease clinics or support groups; or exhibiting physical manifestations of HIV/AIDS. Inmates do not disclose because they perceive they will be at risk for losing confidentiality and subsequent stigmatization from fellow inmates and correctional officers (DeGroot, Hammett, & Scheib, 1996). As a result of not disclosing, the women place themselves at risk of not receiving medical treatment and social support from fellow seropositive inmates and the correctional institution.

The seropositive mothers, who had not disclosed to their adult children, in this study share similar finding with previous research. Like the mothers in this study, issue of protecting their children from experiencing negative responses was a main concern. For example, one mother did not disclose to her adult daughter to protect her from potential loss of her job or discrimination. Previous research described reasons for not telling young children were to preserve childhood and prevent frightening (Moneyham et al., 1996) or harming the child (Pliskin, Farrell, Crandles, & DeHovitz, 1994). Further investigation in needed among Latinas and women to further describe the concerns of not disclosing to their minor and adult children.

Latinas in this study also chose not to tell family members. Not disclosing was used to protect others from worrying, such as parents. Similar to other findings, the women also did not disclose to protect others from experiencing stigma (Hays et al., 1993; Mason, Marks, Simoni, Ruiz, and Richardson, 1995; Simoni et al., 1995).

Postponing

The mothers in this study also used postponing as a strategy disclosing their diagnosis to their children. In this instance, postponing meant delaying disclosure to allow time for the child to mature and become of an age to prevent harm to the child. The estimation of ten years as a marker for disclosing coincides with the child's transition from concrete operational thinking to formal operational thinking (Wong, 1995). The thought processes of children at this age become more socialized and less self-centered. The ten year old becomes more flexible and considers other points of view and the impact on others.

Seeking Help

The results of the present study revealed that a few of the Latinas sought assistance from professionals and nonprofessionals when deciding to disclose. Seeking help by the Latinas in this study was similar to Charmaz's (1991) concept of structuring protective disclosure of invoking assistance from others and setting the stage. Asking for assistance of professionals to disclose a diagnosis assists with making the information real and legitimate to others (Charmaz, 1991). Additionally, the Latinas sought help from nonprofessionals such as nieces, brothers, or friends who could assist with disclosing to family members and friends. By seeking help, the Latinas set the stage of when and where to disclose with the assistance of people they trusted.

The Latinas in this study described the strategies of selective telling, postponing, and

seeking help as a part of the process of deciding to disclose. The strategies allowed the women to time their disclosures, decide to whom they would disclose their status, and request assistance with the disclosing. As a result using the strategies, the women would prevent themselves from experiencing negative responses.

Consequences with Disclosing

Latinas encountered many types of consequences as they disclosed. The consequences are the responses or reactions experienced by the women. Positive consequences were identified as another person's reactions or actions interpreted by the women as being supportive and receptive toward the women. Negative consequences were described as others rejecting or blaming the women because of their diagnosis. The following section will present the positive and negative response after disclosing.

Positive Consequences

All of the Latinas reported that they experienced positive consequences. From the data, two general positive consequences emerged. The women reported they experienced being accepted by others or receiving support after disclosing.

Accepted by Others

The women experienced positive consequences from family members and friends when they were 'pulling me back home' and 'there for me'. These positive responses allowed the women to become socially involved by being accepted by family members and friends immediately or over time after disclosing. Family and friends demonstrated their acceptance by reintegrating the seropositive women in the social structure of the family or among friends. These findings are similar to previous research of seropositive people maintaining contact with family members and friends (Laryea & Gien, 1993; Siminoni et al., 1995; Sobo, 1995).

The Latinas in this study who reported feeling accepted by others experienced reintegration when they were allowed to return into the family structure. As the family became more educated, fears of the contagion diminished and the women returned to the roles of sister, daughter or took up a new role, such as godmother. One woman reported that she felt accepted by a friend when she was entrusted to be a godparent to a child. Further investigation is needed to explore the post disclosing responses encountered by larger populations of women as they related to continued relationships and reintegration with family and familial roles.

When the response was not positive immediately following disclosure, a few women described how the person's feelings changed and acceptance followed over time. The delay in accepting the women in this study by the person may be attributed to the fear of contagion or uncertainty of whether the relationship should continue which is supported by previous disclosing research (Limandri, 1989).

Received Support

Another positive response reported by the women was receiving support after disclosing. Sources of this support were from family members, friends, and even strangers. Parents and friends reacted positively toward the Latinas by providing emotional support to the participants. The women described experiencing emotional support from others by 'being there' for the women. The Latinas were able to rely and depend on those persons that showed emotional support toward them.

Previous research described responses to disclosure as being positive and supportive among other women living with HIV/AIDS (Simoni et al., 1995) or wishes for others to be part of their support system (Moneyham et al., 1996). Similar findings or receiving support were present among other research of persons living with HIV/AIDS (Limandri,

1989). Further research is needed not only to identify additional types and sources of support experienced after disclosing but what type of support or resource is needed and from whom the women thought they needed with disclosing.

Negative Consequences

After disclosing, seventeen Latinas in this study reported experiencing negative consequences. The Latinas experienced negative responses, such as being stigmatized and being blamed, from family members and friends, partners, and society. As a result of experiencing blame and stigma the women reported rejection.

Rejected by Others

The characteristics of rejection described by the Latinas in the present study support findings of participants being rejected by family member and friends (Laryea & Gien, 1993). Simoni et al., (1995) also reported that 20% of the participants experienced rejection from lovers who became angry and withdrew from the relationship after learning the diagnosis. Rejection of the Latinas in the current study was characterized by contradicting behaviors from others and the loss of social interaction. The women experienced rejection from family members, friends, medical personnel, an employer and members of a police department. The women perceived themselves as being outcasts because of the manner others treated them.

Another characteristic or rejection reported by the women was the contradicting behavior by others. The women reported that the contradiction was between what others said and what they did. For example, some of the Latinas were initially allowed to remain in the relationship with a sexual partner or family, but as time passed the women noticed signs of rejection from friends and sexual partners. The rejection was demonstrated by a change in their attitude or physical contact, such as not wanting to engage in sexual

contact with the women or discontinue a friendship. Another incident reported was when a woman told an ex-lover about her seropositive status. They resumed their friendly relationship but ultimately the ex-lover threatened to use the information to blackmail her.

Loss of social interaction was a result of others distancing themselves from the Latinas. After disclosing, the women encountered others not wanting to have contact with them. Therefore the women lost social connections with others and experienced stigmatization and rejection.

Stigma is defined as the perception and acceptance of what another person within an accepted social group views or describes as non-acceptable (Goffman, 1963). HIV/AIDS related stigma is a socially constructed reaction to a lethal illness that has been most prevalent among groups that already were targets of prejudice (Herek and Glunt, 1988). AIDS related stigma evokes complex responses that include a personal threat, moral indignation and disapproval, anger, anxiety, and prejudice. Social stigma against persons with HIV/AIDS results in rejection and scapegoat of people with HIV/AIDS and persons who are most affected, gays, bisexual men, women of color, and IDUs (Hall & Stevens, 1988). The Latinas experienced stigmatization resulting in rejection was present in previous disclosing research and was a major concern of persons living with HIV/AIDS (Limandri, 1989; Moneyham et al., 1996; Simoni, 1965; Sowell et al., 1997).

Literature is replete regarding disclosure and stigma. Current literature does not offer sufficient data to construct a comprehensive view of Latina's perceived and lived experiences of disclosing a HIV positive status and stigma. This present study of disclosing presents new insights and information regarding the conditions and consequences that occur with disclosing potentially stigmatizing information of Latinas

living with HIV/AIDS.

Blamed by Others

Blame has been identified as a major emotional and psychological concern for seropositive individuals. Being blamed has been directed towards groups already stigmatized, such as homosexuals, injection drug users, prostitutes, and people of color. Persons diagnosed with HIV/AIDS not associated with any of the groups have been described by society as innocent victims, such as hemophiliacs, persons who received transfusions, or unsuspecting women who contracted HIV from a sexual partner (Herek & Capitano, 1993).

Similar finding of being blamed by others was experienced by two Latinas in the current study. To these Latinas, being blamed meant that it was their fault, whether due to their own behavior or lifestyle, that they had become infected with the HIV virus. The women reported being blamed by two groups, from family members and from society at large because of the perceptions by others in the manner in which the Latinas contracted the virus.

The experiences of the women in the current study are congruent with previous research with mixed samples that identify blame as a significant part of the seropositive individual's experiences (McGrath, 1992; Herek & Capitano, 1993). This study provides evidence that a few Latinas experienced being blamed for contracting the virus after disclosing their status from close relationships or from society. Further research can explore whether the experiences of the Latinas are unique to them or to all women disclosing their HIV/AIDS status.

Limitations

Several limitations of the study should be noted. Findings are limited to an English-

speaking sample of Latinas who participated in the study. The findings cannot be generalized to the diverse Latina communities in the San Francisco Bay Area. However, this research expanded a previously limited topic of the social processes of disclosure among Latinas living with HIV/AIDS. The findings can enhance awareness of the complexities of the disclosing processes of Latinas and identify areas for future research in this substantive area.

Implications for Nursing

Previous published research provides a limited description of influencing factors and experiences of Latinas disclosing their HIV/AIDS status. The findings from this study described the disclosing experiences of Latinas living with HIV/AIDS. Findings from this study supported previous research as well as describe related topics in regard to the temporality, need, control, and supportive disclosing.

This study will assist nursing professionals by increasing awareness of the need for diverse approaches in communicating and caring for this population of women living with HIV/AIDS. Nurses must become knowledgeable of the social cultural context of Latinas' lives and how they disclose their HIV/AIDS diagnosis so nurses will be able to incorporate that knowledge into comprehensive care plans that also address the concerns of disclosing. Understanding of the reasons for disclosures and nondisclosures should center on the Latinas concerns and perceptions of the real and potential negative consequences from health care professionals, family members, community members, and friends.

Health care professionals should develop and provide safe environments so women can feel comfortable with disclosing their status so they can receive immediate access to appropriate social health care resources (Huggins, Elman, Baker, Forrester, & Lyter,

1991; Simoni et al., 1995; Sowell et al., 1996). By providing a safe environment, nurses can take advantage of the opportunity to educate Latinas on the use of strategies to disclose and expand the Latinas' support system or prepare them to manage potential concerns, such as risking exposure or experiencing negative responses.

Further research will increase the understanding the process used by Latinas and the sociocultural factors that influence the decision to disclose. Expanding disclosing research among Latinas and other diverse communities can increase the understanding of the perspectives and interactions with others as well as the phenomenon of disclosing.

Further investigation is needed to identify and confirm findings of this study among the incarcerated female population diagnosed with HIV/AIDS. Incarcerated women pose a challenge with identifying and providing medical, support groups and educational services with confidentiality because of their fear discrimination and rejection (Siegal, 1997). Additionally, investigation is needed to explore the issues of disclosing when inmates transition from prison to the community so appropriate supportive resources can be assessed. Investigation of the process of disclosing over time will increase understanding of what is acceptable support for women disclosing their seropositive status and how their lifestyles changed after disclosing.

Deciding to disclose has dynamic factors that may be influenced by an individual's perception of the social, psychological and economical consequences of informing others. Nurse caregivers and researchers need to identify and understand the influencing factors of disclosing and if they vary depending on the stage of disease. By identifying and understanding the influencing factors of disclosing, nurses can assist with disclosing interventions and incorporate them into health care programs so as to maximize the utilization of appropriate resources by women living with HIV/AIDS.

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APPENDIX A

Appendix A

Heterosexuals and Gays Disclosing Status: Review of Selected Literature

Author (Date)	Design/Purpose	Sample	Methodology	Findings
Mitchell & Smith (1987)	Case study To describe the decision making process of a patient disclosing status and the ethical problems of staff nurses.	n = 1 Gender Male Ethnicity Not reported	Instrumentation Not reported Analysis Not reported	Reasons for delay or not telling 1. Wanted more information about HIV/AIDS. 2. Did not want to harm children. 3. Feared loss of friends, isolation, and shunning by towns folks. Reactions 1. After the patient told wife, she was supportive. 2. Nursing staff assisted patient with education and were respectful of his decision on who to tell because of perceived social stigma and discrimination.
Kegeles, Catania, & Coates (1988)	Descriptive Investigated sexual practices, number of sexual partners and intentions of disclosing test results to others.	n = Not reported Gender Males Ethnicity Not reported	Instrumentation Self-administered questionnaire Analysis Not reported	Sexual practices Majority engaging in high risk behavior would tell their primary sex partners Disclose test results Majority intended to disclose seropositive status to their sexual partner

Appendix A (Continued)

Author (Date)	Design/Purpose	Sample	Methodology	Findings
O'Dell (1988)	Descriptive To identify if patients knew what their illness was, if they disclosed to their family, and if not, why they did not.	n = 30 Gender Not reported Ethnicity Central African	Instrumentation Questionnaire Analysis Not reported	1. Majority of patients were aware of their illness 2. Majority did not disclose their status to family members, and 3. Identified fear of rejection as a reason for not telling family members.
Huggins, Elman, Baker, Forrester, & Lyter (1991)	Descriptive Examined the affective and behavioral responses to HIV testing over time for gay and bisexual males.	n = 25 Gender Males 155 Negative 121 Positive 22 Not learn 12 Ethnicity Not reported	Instrumentation Questionnaire • State-Trait Anxiety Scale • Beck Depression Inventory • AIDS Anxiety Inventory • Telling Partners • Sexual Behavior Analysis Descriptive statistics, nonparametric statistics	State-Trait Anxiety Scale 1. All three groups had increase anxiety before learning results 2. Positive and not learn groups remained above mean at six months Beck Depression Inventory Difference between groups at 1 and 2 weeks, and 6 months AIDS Anxiety Inventory Increased in the positive group over time and decreased in the negative and not learn groups Telling Partners Majority intended to tell lovers and regular sexual partners Sexual Behavior No significant interaction or group main effect

Appendix A (Continued)

Author (Date)	Design/Purpose	Sample	Methodology	Findings
Marks, Richardson, & Maldonado (1991)	Descriptive Examined self-disclosure of HIV infection to current sexual partners.	n = 138 Gender Males Ethnicity Latinos 104 whites 21 African Americans 11 Asians 2	Instrumentation Self-administered questionnaire Analysis Descriptive statistics	1. Disclosure did not differ significantly by ethnicity. 2. Forty-five percent of the men had sex since learning the positive status. 3. Fifty-two percent kept their status a secret from one or more partners. 4. Disclosure of positive status decreased as the number of partners increased.

Appendix A (Continued)

Author (Date)	Design/Purpose	Sample	Methodology	Findings
Marks, Bundek, Richardson, Ruiz, Maldonado, & Mason (1992)	Descriptive Investigated self-disclosure among Latinos.	n = 101 Gender Males Ethnicity Latinos	Instrumentation Self-administered questionnaire • Diagnostic categories • severity of physical symptoms • physical appearance • self-disclosure of HIV infection • sexual orientation of specific targets • HIV status of close male friend • target's awareness of subject's sexual orientation • time since testing positive Analysis Descriptive statistics, multiple regression	Prevalence of disclosure to significant and less significant others 1. High prevalence to disclose to intimate lover and spouse. 2. High rate of disclosure to doctors and dentists who were not treating subjects for HIV. Sexual orientation and HIV status of others Gay and bisexuals disclosed to other gay and bisexual more often if the person was seropositive. Others' awareness of subjects' sexual orientation Gay and bisexuals disclosed to others more if they were aware of their sexual orientation. Time since seropositive, disease severity, and disclosure When severity of ill increased disclosure increased.

Appendix A (Continued)

Author (Date)	Design/Purpose	Sample	Methodology	Findings
Schnell, Higgins, Wilson, Goldbaum, Cohn, Wolitski (1992)	Descriptive Evaluated disclosure of HIV status to main sex partner and impact on relationship in men who have sex with men.	n = 249 Gender Males Ethnicity white 86% Latino 10% Other 4%	Instrumentation Questionnaire Analysis Descriptive Statistics	1. 89% of those tested disclosed their HIV result status to main sexual partner. - seronegative 70% seropositive 82% 2. Relationship 'strong as ever' - seronegative - 70% seropositive - 82%
Hays, Mckusick, Pollack, Hilliard, Hoff, & Coates (1993)	Descriptive/ Exploratory Examine patterns of gays self-disclosing seropositive status, assess effects of disclosure, and identify reasons for not disclosing.	n = 163 Gender Males Ethnicity white 91%	Instrumentation Longitudinal questionnaire survey with open-ended questions • HIV status • relationship status • disclosure • helpfulness ratings • reasons for not disclosing • anxiety and depression Analysis Descriptive statistics, multiple regression	Disclosure Majority of men disclosed to their lover/partner and to closest gay or heterosexual friend Helpfulness ratings Closest gay friends/lovers and heterosexual friends were perceived to be more helpful than relatives and colleagues Reasons for not disclosing 1. Not wanting to worry or upset others 2. Fear of discrimination 3. Fear of disrupting relationships 4. Emotional self-protection 5. Desire to conceal one's homosexuality Anxiety and depression 1. Participants reported relatively high levels 2. Symptomatic males had more anxiety and depression

Appendix A (Continued)

Author (Date)	Design/Purpose	Sample	Methodology	Findings
Laryea & Gien (1993)	Exploratory/ Descriptive To describe the stigma and rejection experienced by HIV+ persons. Disclosure was part of the study.	n = 25 Gender Males 19 Females 6 Ethnicity Newfoundland	Instrumentation Interview Analysis Grounded Theory	1. The majority had told family members friends, co-workers, employers about their seropositive status. Responses from family after disclosing 1. Negative responses were distancing. 2. Positive responses were maintaining contact. 3. Participants were fearful of others finding out results. Changes in attitudes toward self and others 1. Self changes were feeling ashamed, feeling guilty, depression, anger and loneliness, and loss of self-respect. 2. Changes toward others were suspicion that others were talking about them, envy of people who were HIV negative.

Appendix A (Continued)

Author (Date)	Design/Purpose	Sample	Methodology	Findings
Mason, Marks, Simoni, Ruiz, & Richardson (1995)	Descriptive To examine the cultural differences of disclosing HIV status between whites and Latinos	n = 398 Gender Males Ethnicity Latinos 192 whites 206	Instrumentation Questionnaire • Disclosure of HIV infection to significant others • Open ended reasons for disclosing or not disclosing HIV infection • Acculturation variables • Distance from parents • Target's awareness of participant's sexual orientation • Sociodemographic variables • Medical variables Analysis ANOVA Multiple Regression	Disclosure of HIV infection to significant others 1. Whites informed a larger number of targets than Latinos Reasons for disclosing or not disclosing HIV infection 1. Participants cited positive quality of the relationship and self-focused needs as the primary reasons for disclosing status. 2. Nondisclosure : a) Majority of men gave self-focused reasons for not informing their lovers. b) Latinos and whites did not disclose to parents out of concern for protecting them. This was more prevalent among Latinos than whites. Distance from parents Not significant between whites and Latinos Target's awareness of participant's sexual orientation 1. Disclosing to mother: whites 76.6%, English-speaking Latinos 64.7%, and Spanish-speaking Latinos 54.2%. 2. Disclosing to the father: whites 54%, English-speaking Latinos 50.6%, and Spanish-speaking Latinos 38.5%. 3. Gay and bisexual men who had disclosed their HIV status to a specific target were more likely to have disclosed their sexual orientation to that person.

Appendix A (Continued)

Author (Date)	Design/Purpose	Sample	Methodology	Findings
Sobo (1995)	Exploratory/ Descriptive Examine process of disclosure to sexual partners.	n = 4 Gender Male 1 Females 3 Ethnicity Latina 1 white 3	Instrumentation Interview, focus groups Analysis Not reported	Major topics identified were: 1. Disclosee's need to know. 2. Nondisclosure conjoined with safer sex practice. 3. Disbelief and denial among the seronegative. 4. Strategies for evaluating potential disclosees. 5. Rejection and acceptance.
Stempel, Moulton, & Moss (1995)	Descriptive Investigates patterns of self-disclosure of test results to partners, social contacts, and family members.	n = 93 Gender Males Ethnicity white 97% Other 3%	Instrumentation Questionnaire Analysis Descriptive statistics	Intentions to disclose 1. Majority disclosed to lovers and other sexual partners. 2. More disclosure of negative results than positive results. Reactions to disclosure Majority of reported responses were unfavorable among family members, lovers, new sexual partners and co-workers.

Appendix A (Continued)

Author (Date)	Design/Purpose	Sample	Methodology	Findings
Simoni, Mason, & Marks (1997)	Descriptive Examine the prevalence and correlates of disclosure of sexual orientation and HIV infection to employers among gay and bisexual employed men.	n = 389 Gender Males Ethnicity Latino 33% white 49% African-American 14% Other 4%	Instrumentation Questionnaire Analysis Descriptive statistics	Employer awareness of employee's sexual orientation White gay males were more likely to have employers who were aware of their sexual orientation than Latino or African-American gay men. Disclosure of HIV status 35% of the men told their employer. Whites were more likely to disclose than Latinos or African-Americans. Latinos born in the U.S. disclosed more than foreign born. Gay men were more likely to disclose their status to their bosses if they also knew the sexual orientation. Telling status was related to being symptomatic, length of diagnosis, employer's sexual orientation, and awareness of person's sexual orientation. Consequences of disclosing 3% were fired 6% asked to do a different job 88 % stated things at work stayed almost the same

Appendix A (Continued)

Author (Date)	Design/Purpose	Sample	Methodology	Findings
Stein, Freedberg, Sullivan, Savetsky, Levenson, Hingson, Samet (1998)	Descriptive To determine factors associated with disclosure of HIV positive status to sexual partners.	n = 129 Gender Males 89 Females 40 Ethnicity African-American 59 white 35 Latino 30 Other 4	Instrumentation Interview Analysis Descriptive statistics, multiple logistic regression	1. 60% of disclosed their HIV status to all sexual partners. 2. Of the 40% who did not disclose, half had not disclosed to their one and only partner.

APPENDIX B

Appendix B

Disclosing to Health Care Providers: Review of Selected Literature

Author (Date)	Design/Purpose	Sample	Methodology	Findings
Limandri (1989)	Exploratory/ Descriptive To describe the conditions that persons with stigmatizing conditions disclose.	n = 29 Gender Males 13 Females 16 Ethnicity white 26 Native Amer. 2 Latino 1	Instrumentation Interviews - Open ended questions Analysis Grounded Theory	Process of disclosing occurring under stigmatized conditions consisted of 3 subprocesses. Subprocesses 1. Stigma - enacted or felt 2. Disclosure - nondisclosure - over disclosure 3. Responses (positive - reassuring, provide information) (negative - rudeness, mistreatment, rejection) (neutral - noncommittal, self-protective, ambiguity)
Barnes (1992)	Exploratory/ Descriptive Focus was to investigate the processes, patterns, and consequences of patients' disclosing status.	n = 25 Gender Males 18 Females 7 Ethnicity white 16 African American 5 Latinos 4	Instrumentation Interviews, open ended questions Analysis Grounded Theory	Core concept: Balancing Patterns of disclosing Intentional: Direct or indirect Intentional nondisclosure Consequences of disclosure Discriminatory and nondiscriminatory

APPENDIX C

Appendix C

Women Disclosing HIV/AIDS Status: Review of Selected Literature

Author (Date)	Design/Purpose	Sample	Methodology	Findings
Chervenak & Weiss (1989)	Exploratory/ Descriptive To investigate HIV+ women concerning attitudes toward sexual partner notification or disclosure and feelings concerning future pregnancy.	n = 25 Gender Females Ethnicity Not reported	Instrumentation Survey Analysis Not reported	The majority of the women were interested in Health Department involvement with notification and would be willing to provide names of sexual partners Health Department. The women that did not want the Health Department to be involved did not disclose their status to all sexual partners.

Appendix C (Continued)

Author (Date)	Design/Purpose	Sample	Methodology	Findings
Pliskin, Farrell, Crandles, & DeHovitz (1994)	Exploratory/ Descriptive To examine factors that influence mothers' decisions to disclose status to children.	n = 50 Gender Females Ethnicity African Americans 64% Latinas 21% Caribbean 12% white 3%	Instrumentation Open and closed -ended Interviews Analysis Not reported	Factors influencing centered on family belief systems. Disclosing: 1. Opposition to family secrets 2. Wish to psychologically prepare children 3. Wish to preserve childhood 4. Increased intimacy Nondisclosing: 1. Fear their children would be psychologically harmed 2. Wished to preserve their childhood 3. Belief children lack the capacity to understand 4. Fear of rejection from children 5. 40% of mothers indicated they would not tell children.

Appendix C (Continued)

Author (Date)	Design/Purpose	Sample	Methodology	Findings
Simoni, Mason, Marks, Ruiz, Reed, & Richardson (1995)	Descriptive To assess: 1. Rates of self-disclosure to friends, lovers, and family members. 2. Reasons for disclosure and nondisclosure 3. Reactions of individuals informed.	n = 65 Gender Females Ethnicity Latinas 41 African American 13 white 11	Instrumentation Survey - English and Spanish Analysis Descriptive statistics, multiple regression, analysis of variance	Rates of disclosure and nondisclosure 1. Highest rate (44.9%) of disclosure to lovers and friends. 2. 13% of sample had not disclosed to anyone. Reasons for disclosure - identified as self-focused or other-focused and differed according to target. 1. Other-focused reasons were ethical responsibility and concern for lover's health. 2. Self-focused reasons emphasized desire for support and disease progression as a reason to tell parents and friends but not lovers. Reasons for nondisclosure - also differed according to target. 1. Self-focused - avoid personal rejection or maintain secrecy. 2. Other-focused - prevent worry or cause problems. Reactions to disclosure 1. Mothers, fathers, and friends provided emotional support and rarely responded by becoming angry or withdrawing. 2. Lovers were frequently emotionally supportive but would become angry and withdraw after learning of the woman's positive status. 20% of lovers did leave after learning of status.

Appendix C (Continued)

Author (Date)	Design/Purpose	Sample	Methodology	Findings
Moneyham, Seals, Demi, Sowell, Cohen, & Guillory (1996)	Exploratory/ Descriptive Explore the issues of disclosure for women infected with HIV.	n = 19 Gender Females Ethnicity African American 12 white 7	Instrumentation Interview Focus groups Analysis Content analysis	Identified concerns about disclosure: 1. Discrimination 2. Confidentiality 3. Context of disclosure Concerns influence disclosure decisions and use of supportive services and resources. The decision of nondisclosure posed a negative outcome of isolation and loneliness.
Sowell, Lownstein, Moneyham, Demi, Mizuno, & Seals (1997)	Exploratory/ Descriptive Identify the perceptions of HIV infected rural women related to adequacy of available resources, level of perceived stigma encountered and patterns of disclosure of their HIV serostatus.	n = 82 Gender Females Ethnicity African-American 56 white 26	Instrumentation Questionnaire Analysis Descriptive statistics	Resources 1. 80 women receiving WIC (23), AFDC (34), SSI/SSD (49), food stamps (53), veteran benefits (2). 2. 48 women felt medical resources were inadequate some of the time. Perceptions of stigma 1. Felt stigmatized before HIV+, 40 yes, 42 no 2. After HIV+, 33 yes, 36 no, 13 no answer 3. Women felt they would be blamed by others 27-yes, 55-no Patterns of disclosing 1. Greatest concern of disclosing after HIV+ status 2. Concerns of disclosing: to children, about their health and wellness, and dying. 3. Seventy-two women told all their health providers. Forty-six women told all their sexual partners.

APPENDIX C (Continued)

Author (Date)	Design/purpose	Sample	Methodology	Findings
Sherr, Barnes, Elford, Olaitan, Miller, & Johnson (1997)	Descriptive To examine ethnic, relationship, health, and mental health factors for a cohort of women with HIV infection attending an inner London, England clinic.	n=100 Gender Females Ethnicity White 51 Sub-Sahara Africa 44 Asia 2 India 1 S. America 1 West Indies 1	Instrumentation Chart audit Analysis Descriptive statistics Chi-square comparison	98 women disclosed (18 told one person only) Ethnic minority women were significantly more likely to restrict disclosures only to family members 2 women did not disclose their status

APPENDIX D

Consent Form

Interview Guide

UNIVERSITY OF CALIFORNIA, SAN FRANCISCO
CONSENT TO BE A RESEARCH SUBJECT

Problems and Strategies of Latinas Disclosing HIV/AIDS Status

A. PURPOSE:

Carmen Portillo, Ph.D., RN, Assistant Professor and Christine E. Ortiz, RN, MS, PhDc in the Department of Community Health Systems, School of Nursing, UCSF are conducting a research study to investigate and describe the problems and strategies that Latinas encounter when self-disclosing their seropositive status. I am being asked to participate in this study because I have an HIV/AIDS diagnosis.

B. PROCEDURES:

If I agree to be in the study, the following will occur:

1. I will be interviewed once for one to one and a half hours.
2. The interview will be audio taped.

These procedures will be conducted at a mutually agreed upon location convenient to me in the San Francisco Bay Area.

C. RISKS/DISCOMFORTS
Risks or discomforts in participating in this study may be the potential loss of privacy or confidentiality. Also there may be some discomfort from being asked to think about the difficulties and strategies of telling others about my HIV/AIDS status. Some of the questions may make me uncomfortable or upset, but I am free to refuse to answer any questions or to stop the interview at any time.

The interview materials will be kept as confidential as is possible. I am under no pressure from my doctor or nurse to participate. Whether I do participate or not, it will make no difference in my health care. Records will be kept as confidential as possible. No individual identities will be used in any reports or publication resulting from this study. Only Dr. Portillo and Chris Ortiz will have access to the audio tapes. After completion of the study the tapes will be destroyed. The transcription will be kept at all times in a confidential file not accessible to anyone except to Dr. Portillo and Chris Ortiz.

D. BENEFITS:

There will be no direct benefit to me from participating in this study. However, the information that I provide may help health professionals better understand and identify the stressors and coping strategies of Latinas with HIV/AIDS.

E. COSTS :
There will be no costs to me as a result of taking part in this study.

F. REIMBURSEMENT

I will be reimbursed $25.00 for participating in this study.

G. QUESTIONS:

This study has been explained by Christine E. Ortiz. If I have any further questions about this study, I may contact:

Supervisor/Research: Carmen Portillo, Ph.D., RN, Assistant Professor
Department of Community Health Systems
N511M, BOX 0608
School of Nursing, UCSF
UCSF, San Francisco, CA 94143-0608
Office Telephone (415) 476-1630

Researcher: Christine E. Ortiz, MS, RN, PhDc
Department of Community Health Systems
School of Nursing, UCSF
UCSF, San Francisco, CA 94143-0608
Home Telephone (510) 523-2998

If I have any comments or concerns about participation in this study, I should first talk with the investigators. If for some reason I do not wish to do this, I may contact the Committee on Human Research, which is concerned with the protection of volunteers in research projects. I may reach the committee office between 8:00 and 5:00, Monday through Friday, be calling (415) 476-1814, or by writing: Committee on Human research, Box 0962, University of California, San Francisco, CA 94143. CHR# H7115-125-11-01

H. CONSENT:

I will be given a copy of this consent form to keep.

PARTICIPATION IN RESEARCH IN VOLUNTARY. I am free to decline to be in this study, or to withdraw from it at any point. My decision as to whether or not to participate in this study will have no influence on my present or future status as a patient at UCSF.

If I wish to participate I should sign this form.

Date	Signature of Study Participant
Date	Signature of Researcher

Approved February 8, 1996
Renewed January 30, 1997

Date:

I. Demographic Information

Age:

City of Residence:

How long have you lived in California?

Where were you born?

Where was your mother born? Father? Grandparents?

How do you identify yourself? - Latina, Hispanic, Chicana, etc.

Education: Grade School High School College/University

Yearly Income:

Marital status: Married Divorced Single Partner

Children: Yes/No How many? Ages?

Do they live with you?

Employed? Yes/No

Date last employed?

II. HIV/AIDS Status

When did you decide to be tested? Why?

How did they tell you?

When were you diagnosed HIV+? When were diagnosed with AIDS?

How did you feel after you were told?

Severity of illness:

CD4 count -

What medications are you taking?

Are you under care of a MD or NP?

Are you satisfied with the care you receive?

How has the disease changed your life?

Please tell me what it is like to be living with HIV/AIDS? (harder, easier, etc.)

How do you feel about yourself now?

How has your relationship with your family, friends, and/or partner changed?

III. Self-disclosure and Response

Who was the first person you told?

When did you tell them?

Why did you to tell them?

What were the circumstances (what was happening at the time you decided to tell)?

What did you tell them?

How did you feel after you told?

What was their response? Negative? Positive?

What or who has helped you to tell?

Who else knows your status?

How did they find out?

IV. Nondisclosure

Is there someone you do not want to tell? Who?

Why didn't you tell them?

V. Advice to other Latinas

What would you tell another Latina about telling others about their HIV/AIDS status?

Is there something you would share with others Latinas who have HIV/AIDS?