THE LIVED EXPERIENCE OF WOMEN OF MEXICAN HERITAGE WITH HIV/AIDS

by

Linda María Domínguez

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1996
As members of the Final Examination Committee, we certify that we have read the dissertation prepared by Linda María Dominguez entitled The Lived Experience of Women of Mexican Heritage with HIV/AIDS and recommend that it be accepted as fulfilling the dissertation requirement for the Degree of Doctor of Philosophy/Nursing.

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Date 1/29/96

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Final approval and acceptance of this dissertation is contingent upon the candidate's submission of the final copy of the dissertation to the Graduate College.

I hereby certify that I have read this dissertation prepared under my direction and recommend that it be accepted as fulfilling the dissertation requirement.

Dissertation Director
Date 1/29/96
STATEMENT BY AUTHOR

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SIGNED Linda M. Oronjegerez
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DEDICATION

To

Tony Zigrossi

whose love, sensitivity, and nurturance

made my personal goal possible.

________________________

With Gratitude and Love

________________________
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ABSTRACT

The number of women of Mexican heritage with HIV/AIDS continues to escalate dramatically. Concurrently, salient psycho-social forces in women's environment impede access to health care and affect health outcomes. Yet, nursing's knowledge on the impact of HIV/AIDS on women of Mexican heritage is limited. Lacking in the nursing literature are the voices of women of Mexican heritage who have HIV/AIDS. The purpose of this study was to describe the lived experience of women of Mexican heritage with HIV/AIDS. Rogers' Science of Unitary Human Beings, the philosophy of phenomenology, and feminist perspectives provided the conceptual underpinning for this phenomenological study. The data were analyzed using an adapted procedure from Colaizzi (1978). The essential structure of the lived experience is a process of struggling in despair to endure having a fatal, transmittable, and socially stigmatizing illness which threatens crucial aspects of the woman's own self, being, and existence. Conditional support leaves the woman to suffer in silence as she confronts issues of fear of her own mortality and of transmitting HIV to others. Moreover, the woman experiences shame, blame, concern for children, and changes in normal human relationships.
CHAPTER 1

THE PROBLEM: WOMEN OF MEXICAN HERITAGE WITH HIV INFECTION

Women are the fastest growing risk group for the human immunodeficiency virus (HIV) infection both in the United States and around the world (US Depart. of Health, 1991). Equally scathed by the virulence of HIV are women of Mexican heritage whose numbers with the contagion continue to dramatically increase (AZ. Dept. of Health Services, 1995). Women of Mexican origin are a subgroup of those classified as Hispanics. For Hispanic women aged 25 to 44 years, HIV infection was the third leading cause of death in the United States in 1991 (Morbidity and Mortality Weekly Report, 1994).

The health status of women of Mexican origin with the AIDS virus is further complicated by significant psycho-social forces that impede access to health care and are a detriment to their health (Sue & Sue, 1990). As women of Mexican heritage continuously and mutually interact with their environment, they are influenced by culture, language, low educational attainment, low income, immigration status, high mobility, and discrimination which affects every dimension of their being (Morbidity and Mortality Weekly Report, 1994; Schick & Schick, 1991; Sumaya & Porto, 1989). Nursing has recognized that individuals of different cultures are different, have different needs, and have different
expectations of health care providers (Leininger, 1988). However, no concerted effort has been made by nursing to study women of Mexican heritage with HIV/AIDS.

Women infected with HIV/AIDS have a poorer prognosis and die sooner than men (Smeltzer & Whipple, 1991). Several reasons account for this phenomenon. Until recently the AIDS virus in women was not often suspected. Consequently women were misdiagnosed even when women exhibited symptoms of full blown AIDS (Smeltzer & Whipple, 1991). Current factors accounting for further misdiagnosis include: (a) the criteria for AIDS established by the Centers for Disease Control (Morbidity and Mortality Weekly Report, 1992) are biased to men, and (b) women's symptoms consisting of various, serious, gynecological problems often appear to be different than those of men (Carpenter, Mayer, Fisher, Desai, & Durand, 1989; Minkoff & DeHovitz, 1991; Rhoads, Wright, Redfield, & Burke, 1987; Smeltzer & Whipple, 1991). Nursing research on women in general with HIV/AIDS is especially limited in the care of HIV-infected women and gender specific diseases (Minkoff & DeHovitz, 1991).

Mexican Cultural Influences

The prognosis of women of Mexican heritage with HIV infection is further compromised by cultural influences. The Mexican culture is often paternalistic in that women's role is thought to be submissive to the male, self-sacrificing, and restrained (Sue & Sue, 1990). Women in the Mexican culture depend on the male partner for their
everyday needs and are not empowered to see a physician whenever it is necessary (Gonzalez-Marshall, 1987; Poma, 1987). Further, any extramarital behavior of the man is often interpreted as the woman's inability to satisfy her partner, so women tend not to disclose such information to health care providers (Rapkin & Erickson, 1990).

In the Mexican culture, women are not accustomed to sharing details of their intimate sexual behaviors with people they do not know, even in medical settings (Rapkin & Erickson, 1990). Women of Mexican heritage are traditionally modest, they often defer physical examinations by physicians, and they feel embarrassed discussing sexual problems with male physicians (Espin, 1992; Galanti, 1991; Poma, 1987). Absent from the nursing literature are the experiences of women of Mexican heritage with HIV/AIDS which might reveal other salient forces impacting their health and accelerating their demise.

In the Mexican culture, the mothering role is one of nurturance, support, and self-sacrifice. Women may defer attending to their symptoms when they misinterpret their symptoms, are involved with caretaking responsibilities, do not have medical care, or deny their feelings or fears (Hankins, 1990). Further, the Catholic religion which is the predominant religion in the Mexican culture (Schick & Schick, 1991) also influences women and suggests suffering can lead to spiritual growth, salvation, and joy. One is encouraged to suffer gladly and in imitation of Christ (Kempis, 1993; No Greater Love, 1967). Subsequently, the treatment of women has often been delayed until the progression of the infection is very advanced.
The discipline of nursing values human interaction, subjectivity, and shared experiences to assess and develop mutually acceptable interventions with clients (Munhall, 1994). Nevertheless, missing from the nursing literature are the voices of women of Mexican heritage describing their lived experience with HIV/AIDS. Furthermore, inquiries into the worlds and lived experiences of individuals of different cultures enable nurses to understand the interplay of health and disease causation, language, identity, and relatedness to the world. It is the sociopolitical pattern of knowing in nursing, suggested by White (1995), being allowed to unfold.

Inquiries into women's lived experience with HIV/AIDS would assist nurses to effectively dialogue with these women, plan mutually acceptable interventions in various practice settings, and generate further research to foster theory development. The needs and social concerns of women of Mexican heritage with HIV/AIDS need to be investigated and shared not only with other health care professionals but with the women themselves and others in the community.

**Research Purpose and Objectives**

The purpose of this dissertation was to conduct a phenomenological study to describe the experience of living with HIV/AIDS in women of Mexican heritage. Objectives for this study were to:
1. Describe the essential structure of the lived experience of women of Mexican heritage who have contracted HIV/AIDS.

2. Compare patterns of the lived experience on women of Mexican heritage with HIV/AIDS, with previous findings on patterns of the lived experience in a multicultural group of women with HIV/AIDS.

Significance of the Problem

Women of Mexican heritage are a particular ethnic group vulnerable to contracting HIV/AIDS and having limited access to health care. Several social variables which these women confront also impede preventive measures to avoid contracting the virus, prolong life, and enhance well-being.

Nursing promotes the human betterment of individuals wherever they may be (Rogers, 1992). Yet, there has been no research on the women of Mexican heritage with HIV/AIDS. These women are different by merit of being of Mexican heritage. Women of Mexican origin have particular concerns and needs inherent to the influences of their culture and related to their having HIV/AIDS (Leininger, 1988). If nursing aims to promote appropriate human health and care of these women as unified persons within the context of their worlds, further nursing research into the lived experience of women of Mexican heritage with HIV/AIDS is crucial. If nurses are to dialogue, plan for mutually appropriate interventions in the various practice settings, and generate theory based on the
actual concerns and needs of these women, then these women's voices need to be understood in the context of their lived experience with HIV/AIDS.

**Philosophical Orientation**

Three theoretical perspectives were integrated to provide the theoretical underpinnings that guide this dissertation work: (a) Rogers' (1991) science of unitary human beings, (b) feminist perspectives, and (c) the philosophy of phenomenology. Rogers' (1991) science of unitary human beings provides an appropriate conceptual model for understanding the lived experience of women of Mexican heritage with HIV/AIDS. Rogers' (1992) conceptual model focuses on the individual and the environment which are both viewed as indivisible and irreducible wholes. Moreover, in Rogers' conceptual model health is recognized as being culturally influenced. Therefore, Rogers' conceptual model allows for the examination of human and environmental patterns in their entirety. The narratives of the women describe the context of the lived experience with HIV/AIDS which is interwoven and mutual with the environment.

Feminist perspectives (Chinn & Wheeler, 1985; Comas-Díaz, 1991; MacPherson, 1983; Offen, 1988) include common tenets with Rogers' conceptual model. Feminist theories acknowledge the integrality of individuals and their environments (sociocultural systems) which form an unseparable unity. Furthermore, feminist theories hold a reverence for life, society, and respect for each individual's uniqueness (Chinn, 1992;
Offen, 1988) as do Rogers’ theories. However, a basic feminist tenet is that women are oppressed. Feminist theories, therefore, serve the dual purpose of describing women’s oppression and offering prescriptions for eliminating it. Feminist theories focus on questioning and challenging social imperatives perpetuated in a patriarchal society which create and maintain the oppression of women. Furthermore, feminist research promotes the betterment of women’s lives, adheres to the establishment of horizontal relationships between the researcher and participant(s), and aims to empower women to recognize the sources of their own oppression (Anderson, 1991). Feminist perspectives’ usefulness relative to this research are in lending a critical look at patriarchal relationships and structures which may shape women’s experiences.

The philosophy of phenomenology acknowledges individuals as being conscious of and influenced by their environment (Colaizzi, 1978; Natanson, 1973). An event is not viewed as an isolated occurrence, but as a composite of accumulated past experiences, history, contexts, and social and cultural influences. Further, a tenet of phenomenologists is that human science can be advanced by studying the pre-conscious perspectives of individuals. The philosophy of phenomenology is congruent with nursing’s values of using human senses, feelings, and intuition to understand human experiences. Further, subjects in phenomenology are viewed as participants in the research enterprise as they are in feminist research. These three perspectives are congruent with my personal views that women of Mexican heritage with HIV/AIDS need to be studied within their own distinct
environments, have prominent input in the research process, and benefit from research. To provide more context to this dissertation enterprise, a more in-depth description of the theoretical perspectives are presented in the following section.

Rogers' Science of Unitary Human Beings

This section presents a description of Rogers' conceptual model. Included are the basic elements of the model; Rogers' description of the four concepts recognized in the nursing metaparadigm: person, environment, health, and nursing; and the Principles of Homeodynamics.

**Basic Elements**

Human beings and their environment are the central focus of Rogers' conceptual system of the science of unitary human beings (Rogers, 1992). Martha Rogers' conceptual system incorporates four major concepts: energy fields, universe of open systems, patterns, and pandimensionality (Rogers, 1980; Rogers, 1991).

**Energy fields.**

Energy is the fundamental unit of both the living and the non-living (Rogers 1991). In other words, energy is matter. Energy presents itself in dynamic wave patterns and
extends to infinity as it has no boundaries. Boundaries can be arbitrarily set to assist in studying a phenomenon; however, these boundaries are imaginary.

An energy field is used as a unifying concept possessing unified wholeness and being indivisible. Two fundamental energy fields are the human energy field and the environmental energy field (the environment being anything external to the unitary human being).

**The universe as an open system.**

Openness is the quality exhibited by an open system. Open systems are also energy fields which extend to infinity, and are integral with one another. The universe, therefore, consists of wholes that are all moving towards greater complexity and heterogeneity. Therefore, predictions about the whole cannot be made from parts of the whole.

**Patterns.**

Patterns are the identifiable characteristics of energy fields and are perceived as single waves. Every energy field pattern whether it be a human or an environmental field pattern is unique and integral with the other. Patterns, which are abstractions, are not observable. Only the manifestations of field patterning are observable as they arise from the human-environment field mutual process. Furthermore, the nature of unitary human
field patterning is unpredictable as well as creative (Rogers, 1992). Changes among individuals are continuous, relative, and innovative. Differences among individuals are a reflection of the increasing diversity of field patterning as well as unique individual changing rhythmicities.

**Pandimensionality.**

The concept of pandimensionality characterizes human and environmental fields as non-linear domains without spatial or temporal attributes. Therefore, space and time are not viewed as separate entities. Pandimensionality is analogous to an infinite domain without limit (Rogers, 1992). The pandimensional human field is seen as fluctuating imaginary boundaries. The concept of pandimensionality encompasses the view that any present point is relative to the observer. As such, this concept has implications for the explanation of paranormal events (Rogers, 1992).

**Concepts In The Nursing Metaparadigm**

The four concepts of person, environment, health, and nursing which are recognized in the metaparadigm of nursing are described in the science of unitary human beings. The following is a brief description of these four concepts.
Unitary human beings.

Unitary human beings are seen as irreducible, indivisible, and pandimensional open energy fields. A human energy field is identified by pattern and organization. The characteristics and behaviors of a human energy field cannot be predicted from the knowledge of its parts. Although individuals are characterized by mass, structure, function, and feeling, separately, these characteristics do not describe the individual. Only by being and acting as a totality do these characteristics describe the human being. Therefore, knowledge about the human's particulars does not describe the individual. Rogers (1991) explicitly stated, "human beings are more than and different from the sum of their parts" (p. 46).

What sets a unitary human being apart from earth's other life forms is that the human being is able to perceive and ponder about events in his/her world. Rogers (1991) lists other fundamental attributes to the human being's humanness as the ability for abstraction, imagery, language and thought, sensation, and emotions (Rogers, 1991). Additionally, an individual's feelings are subjective and are responses to the environment. As a sentient being, the individual is able to feel and be expressive to the multitude of phenomena perceived within the world while interacting and coming in contact with the environment. A unitary human being is also capable of rational thought and of making choices.
The environment.

The environment has its own integrity. It is a pandimensional, open system which is irreducible and indivisible (Rogers, 1991). Furthermore, the environment is anything external to the human being. However, the environment is integral with the human field and together the unitary human being and the environment complete the whole.

The relationship of unitary human beings and their environment is such that the two concepts are spoken of together. A unitary human being evolves from continuously and mutually interacting and changing with the environment—this is a life process. The process of life along the space-time continuum is a dynamic, irreversible, non-linear process characterized by increasing complexity of energy field patterning. As the unitary human being is manifested, it is characterized by increasing heterogeneity, diversification, and complexity (Rogers, 1992).

Health.

Health and illness are viewed as expressions of the process of life. Health and illness are value terms derived by society. Rogers (1991) states: "health and illness, ease and dis-ease are dichotomous notions, arbitrarily defined, culturally infused, and value laden" (p. 85). Disease and pathology reflect characteristics manifested by the human field which are viewed as being undesirable (Rogers, 1992).
Rogers (1991) further maintains that whatever meaning health and illness have is derived from an understanding of the life process in its totality.

**Nursing.**

The uniqueness of nursing as a discipline is its central concern for human beings and their environment (Rogers, 1992). Nursing is seen as a learned profession that is a science and an art (Rogers, 1980). Nursing science is an organized body of abstract knowledge about human and environmental fields which is arrived at by scientific research and logical analysis. Multiple methodologies are recognized as appropriate in the quest of new knowledge (Rogers, 1992). The art of nursing entails the creative use of the science of nursing for human betterment (Rogers, 1992). The goal of nursing is to promote human health and well being to individuals wherever they are (Rogers, 1992). Rogers (1992) advocates viewing an individual with compassion and as a unified whole. All goal setting for nurses in regards to patient, family or groups needs to be evolving. Interventions are based on the individual needs of the person and on their perception of health.

**The Principles of Homeodynamics**

Rogers' (1992) conceptual model includes three principles of homeodynamics which postulate the nature and direction of individual and group field changes. Rogers'
(1992) three principles include: (a) Principle of Resonancy which describes continuous change from lower to higher frequency wave patterns in human and environmental fields, (b) Principle of Helicy which describes change as continuous, innovative, unpredictable, and increasing diversity of human and environmental field patterns, and (c) Principle of Integrality which states there is continuous mutual human field and environmental field process.

Rogers (1992) describes the evolution of life as a process characterized as being dynamic, irreducible, non-linear, and increasing in complexity of energy field patterning. Changes in life are viewed as being innovative, diverse, creative, relative, unpredictable, emerge out of nonequilibrium, accelerating, and exhibit punctualism not gradualism (Rogers, 1992).

**Feminist Perspectives**

Feminist perspectives were additionally integrated to provide the theoretical underpinning for the development and implementation of this research on women of Mexican heritage with HIV/AIDS. The purpose of this section is to inform on feminist perspectives by presenting feminist views, feminist theories, historical discourse, issues related to feminists of Color and White feminists as well as viewpoints on feminist research. This section concludes with my own feminist perspectives.
Feminist Views and Values

Feminist perspectives are world views (held by both men and women) that value women. Feminist views reveal and challenge patriarchal and systematic injustices based on gender to which women have been made to endure (Anderson, 1991; Chinn & Wheeler, 1985). Two major assumptions of feminist thinking are that (a) women are oppressed, and (b) women's position in society is directly related to patriarchal dominance and diffused sexism (Chinn & Wheeler, 1985). Feminist thinking challenges the status quo of society and is, therefore, viewed by some as being intimidating and revolutionary. Chinn (1992) provides further insight into feminist views by adding, "feminism values and endorses women, critiques male thinking, challenges patriarchal systems, and focuses on creating self-love and respect for all others and for all forms of life" (p. 128).

Evidence of patriarchal thinking in society is illustrated by merely inquiring for a definition of feminist. Webster's (1991) definition of feminism indicates feminism adheres to the principle that a woman should have the same political, economic and social rights as men. This definition is viewed by feminists as being arrogant and short-sighted since it implies the normal standard of rights is one set by and for men (Offen, 1988).

Feminism is also a social/political movement. As a social/political movement, feminism strives to achieve a balance between men and women within their social, economic, and political world that is humane to all ethnic groups, genders and classes.
(Chinn, 1992; Offen, 1988). The concern in the feminist movement is for respect of all individuals, regardless of their differences.

**Feminist Theories**

Feminist theories function to offer descriptions of women's oppression and prescribe their elimination by advancing new visions of justice and freedom for women (Liaschenko, 1993; MacPherson, 1983). Four major philosophic approaches to feminist theory include: liberal, traditional Marxist, radical, and socialist feminism (Chinn & Wheeler, 1985; MacPherson, 1983).

**Liberal feminist theory.**

Liberal feminist theory stresses equality of opportunity for women and the unequal distribution of wealth, position, and power based on family, race, and sex (Chinn & Wheeler, 1985). Sources of women's oppression lie in the lack of equal civil rights and educational opportunities. From the liberal perspective, oppression can be overcome by attacking sexist discrimination and by providing legal rights and opportunity for women.

**Marxist feminist theory.**

Traditional Marxist feminist theory identifies the origins of women's oppression historically in the introduction of private property (MacPherson, 1983). Women's
oppression stems from the private ownership of land to the industrialization of society and
the instituted class system from which sexism is derived. Women and children as well as
material goods and the means of production have become the property of males. Women's
labor in the family, industry, and marketing is seen as being exploited in a Capitalistic
society which has created a unique social and economic class for women. To liberate
women from oppression there has to be a socialist revolution whereby the means of
production and ownership of property become the property of society as a whole
(MacPherson, 1983).

Socialist feminist theory.

In socialist feminist theory, cultural institutions such as the patriarchal family,
motherhood, housework, and consumerism are viewed as having a major role in the
oppression of women (Chinn & Wheeler, 1985). Socialist feminism brings out the integral
relationship between the private sphere of the family, personal life, and the public sphere
of productive work. The oppression of women and socioeconomic class oppression are
viewed as being equally fundamental and mutually reinforcing. Furthermore, these cultural
institutions are seen as operating differently within different classes such as in the women's
working class and with women of Color. Therefore, socialist feminists reject the
assumption made by earlier feminists that all women are oppressed in similar ways.
According to this view, elimination of the double oppression of a class-focused society
and institutionalized gender discrimination is needed to free women from oppression (MacPherson, 1983).

**Radical feminist theory.**

Radical feminist theory draws not from existing social or economic theories, but from a woman-centered world view. Radical feminist theory insists that the oppression of women is fundamental, existing within all types of economic systems, and cannot be eliminated simply by changing the systems (Chinn & Wheeler, 1985). Radical feminists question existing concepts and language of patriarchal systems, and endeavor to formulate concepts derived from a woman-identified perspective. A distinguishing characteristic of radical feminist theory is its starting point. Radical feminist theory focuses on discovering, analyzing, and valuing women's experience without the standards of male ideology or systems (Chinn & Wheeler, 1985). Radical feminist theory promotes the end of institutionalized gender discrimination and gender roles. In order for these psychosocial changes to take place, woman-defined systems, thought, and cultures need to be developed.

**Historical Discourse**

Two basic and distinct modes of historical discourse used by women and their male allies relating to women's emancipation from Western male-dominated societies are
relational and individualist feminism (Offen, 1988). Relational feminism focuses on women's rights by merit of women's childbearing capabilities and/or nurturing roles. Relational feminists claim rights for women based on their contributions to society as mothers who raised children to serve and better society.

By contrast, individualist feminism centers on more abstract concepts of individual human rights. The individualist feminist endeavors to acquire personal independence in every aspect of life and downplays all socially defined roles, especially sex-linked roles (Offen, 1988). Feminism opposes women's subordination to men and the claims made by men regarding what is right for women without consulting them first.

White Feminists and Feminists of Color

Tension has existed among white feminists and feminists of color (Comas-Díaz, 1991; Hurtado, 1989). White feminists (women of Anglo-Saxon descent) oppose women's oppression and discrimination. The basis for the oppression is viewed by white Feminists as being due to gender differences. Women of color (minority women) contend that focusing on sexism (gender) as the primary oppression negates the oppression experienced by women of color which is due to their race, class, and culture (Comas-Díaz, 1991; Hurtado, 1989). A great chasm exists economically between white women and women of color. Due to white women's relationship to white men (who as a group
have the most power), such as being their wives, their daughters or sisters, white women are at more economic advantage than women of color (Hurtado, 1989).

White women tend to stay in school longer than many women of color who have less money. Therefore, white women earn substantially more money as a group than women of color who stay longer in the labor force without interruption (Hurtado, 1989).

Theories on feminism and feminist psychology have been developed which omit the subordination experiences of women of color. Women feminists are beginning to acknowledge that bridging the gap between white women and women of color entails recognition of each other's differences and diverse forms of oppression.

**Feminist Research**

Feminist perspectives promote critical examination of societal structures that impact and shape women's experiences as well as exploration of the historical context of oppression. Classical feminist research includes those of Belenky, Clinchy, Goldberger, and Tarule (1986), Gilligan (1982), and Hyde (1990).

**Gilligan's research.**

Gilligan (1982) presented an alternative view on women's moral development in her thesis on the ethic of care. The study, based on research using both males and females making moral choices, extracted a different voice. The voice was identified by theme and
found to be empirically, although not absolutely linked with females rather than males. Three stages of moral development were identified, (a) care for one's own survival, (b) care for others, and (c) care for integrity. Central to the ethic of care were responsibility and relationships instead of rights and rules (Gilligan, 1982). The conceptualization of rights and justice, from the perspective of the care ethic, depends on contextual factors, consequences, and the occurrence of the least amount of harm to an individual or to others. The ethic of care diverges from the conventional ethic of justice of Kohlberg (1969), which is based on the intrinsic right of the action without appeal to other consequences.

Hyde's research.

Hyde (1990) probed into studies which had made general claims regarding gender differences in cognitive abilities such as in verbal, mathematical, and spatial abilities. She used the more precise measurement of meta-analysis to evaluate and qualify findings from previous research studies. Results from her meta-analysis indicated gender differences in cognitive abilities were not very different. There was a moderate difference in mathematical and spatial ability performance, with males doing better than females. No general differences were found between genders in verbal ability.
Research by Belenky, Clinchy, Goldberger, and Tarule.

Belenky et al.'s (1986) research on women added insight to the ways women come to know. Five categories identified ways women come to know. The categories included (a) silence, a state where women find themselves as mindless and voiceless, and controlled by external authority, (b) received knowledge, a state where women view themselves able to receive and reproduce the knowledge from external authorities but not capable of producing any knowledge of their own, (c) subjective knowledge, a perspective achieved by women where they are aware of their capability of inner knowing such as knowing by intuition and/or experience, (d) procedural knowledge, a phase reached by women where objectivism and scientific methods of the natural sciences are favored and used, and (e) constructed knowledge, where women come to perceive knowledge as contextual, perceive themselves as creators of knowledge, and appreciate both subjective and objective modes of knowing (Belenky et al., 1986).

Feminist research.

The preceding studies are examples of feminist studies which made it evident that more research on women was needed to expand knowledge in women's development. However, the research process itself has also been the focus of feminist researchers' analyses.
Oppressive research.

Elements of the traditional research process, which is viewed by feminists as a form of oppression is likewise critiqued. Research is oppressive to women when (a) women's voices are curbed, withheld, or edited to conform to scientific discourse, (b) when women's knowledge is appropriated, and (c) when research using women is not used to better women's lives (Anderson, 1991).

Elements of feminist research.

Feminist research centers on women-related inquiry, questions, alternative explanatory hypotheses, and establishment of relationships between the researcher and participant(s) (Campbell & Bunting, 1991). Interest is on examining the status of women's lives, in understanding them, in revealing the influences and consequences of women's oppression, and in improving women's state (MacPherson, 1983).

Feminist research calls for the empowerment of women used in research. Such empowerment commences with the initial research encounter. The inequality and hierarchical power between the researcher and the participant during the interview process is recognized. Measures to equalize the interview process are examined and used to ensure a collaborative approach to the research enterprise (Oakley, 1981).
A feminist researcher is expected to invest his or her own personal identity in the relationship with the participant during the interview process (Oakley, 1981; Tilden & Tilden, 1985). Feminist research rejects the masculine model for interviewing in which the interviewer receives but does not give information, objectifies the interviewee as part of the data, and in which the interaction during the interview is devoid of personal meaning (Oakley, 1981). Feminist researchers engage women participants in open dialogue concerning their lives and their lived experiences, so these women may come to see sources of their oppression. During the interview, the researcher should be able to share information with the women. This information may encourage self-determination and may help the women take control over their lives (Anderson, 1991; MacPherson, 1983; McBride, 1984; Oakley, 1981).

**Research methodologies and critical scholarship.**

Feminist research is more likely to be qualitative than quantitative in nature using such methods as ethnography, grounded theory, and phenomenology (MacPherson, 1983), although other research strategies such as critical multiplism are also promoted (Coward, 1991).

For feminist researchers engaging in the research method of phenomenology, the strategy of "bracketing" may seem problematic (Anderson, 1991). However, the philosophy of phenomenology recognizes the active and reciprocal relationships between
the participant and the researcher. Phenomenology acknowledges the dialectical processes of interaction, and the intersubjective construction of meaning. To "bracket" one's beliefs and biases is the means by which the researcher recognizes his or her own opinions to understand the experience of the other (Anderson, 1991).

Feminist perspectives coincide with critical scholarship, an emerging pattern of work in nursing. Thompson (1987) defines critical scholarship as, "...a pattern of thought and action that challenges institutionalized power relations or relations of domination in the social reality of nursing" (p. 28). As an analytical, intellectual, or methodological approach to nursing phenomena, critical scholarship attempts to make power relations transparent. It is when nurses see through power relations and realize that the established order is only one possible way of constructing reality, that traditional power relations lose their power.

**Research for the betterment of women.**

As stated previously, traditional research is viewed as being oppressive to women, when the findings are not shared with the women or are not used for the betterment of women. Research findings are to be shared with participants and presented as clear as possible in professional and popular journals (MacPherson, 1983).
My stand on feminist views coincides with radical feminists. In taking such a stand it goes without saying that I feel all women are oppressed. However, women’s realities are complex and hold diverse types of oppression. Further, women are reared in oppressive patriarchal social systems that perpetuate gender divisiveness, oppression, and discrimination. Oppressive systems and patriarchal ideologies have been so ingrained among certain individuals/cultures that beliefs and behaviors are usually taken for granted and are not usually questioned. Radical feminists seek to question and challenge everyday concepts and patriarchal language. Examination of the basis for traditional human concepts and behavior assists in informing individuals of the prevalent sexist and oppressive social forces that impact women’s and men’s behaviors and lives. Furthermore, radical feminists seeks to develop concepts from a woman-focused perspective, an endeavor that manifests the value of women-derived knowledge. My view is that women’s experiences need to be acknowledged and valued in their own right and not against male-standards. Furthermore, society needs to be educated and informed of the various types of oppressive structures influencing women’s and men’s lives. By becoming aware and learning of the various oppressive behaviors and patriarchal social systems, social changes which would benefit all humankind may be instituted.
Feminist research is appealing for its women-related focus which attempts to improve women's state. Of concern to this researcher is the processes involved in creating an equal plane between the researcher and participants in this cross-cultural research enterprise. Certain cultures, such as the Mexican culture, have strong hierarchical social systems and hold deference to professionals. Furthermore, feminist research requires the researcher to invest his or her personal identity in the relationship with the participant during the research process. This is also appealing as hopefully both the researcher and the participant will benefit from the interaction.

**The Philosophy and Approach of Phenomenology**

Phenomenology is the third theoretical perspective that guides this dissertation. The use of phenomenology is appropriate for describing the lived experience of women of Mexican heritage with HIV/AIDS and for theory development. The method of phenomenology generates theory or concept development about the lived experience, and may also generate hypotheses related to the phenomenon of interest (Knack, 1984; Smith, 1989). Further, phenomenology may be used to extend, modify or support concept development and findings of other research (Walker & Avant, 1988). This section describes the advent of phenomenology, the development of phenomenology through Edmund Husserl's work, inclusive of key concepts, and phenomenology's access and acceptance into the discipline of nursing. The final section comprises my personal
perspectives and the context within which I ventured on this dissertation and are "bracketed" for this study.

**The Advent of Phenomenology**

Historically, phenomenology arose in Germany in the nineteenth century in response to the dominant position that *the scientific method* or the natural sciences was the only way to universal truth and knowledge. The foundation of the natural sciences was from the dominant empirical-analytic paradigm also known as the positivistic paradigm. Phenomenology was also developed in opposition to the logical positivistic view that only observable data should be used in science (Spiegelberg, 1971). The logical positivist's view, with the goal to predict and control, rejected the use of consciousness or what goes on in the mind because it could not be observed. Studying what goes on in the mind involved subjectivity which went against the dominant epistemological view of objectivity in science. Abstract, context-free, universal generalizations were the products of the natural science which some philosophers viewed as an inadequate method for studying all aspects of human beings (Spiegelberg, 1971). The influence of the seventeenth century with the invention of the scientific experiment by Galileo and the emergence of the Newtonian world view has continued to the present. The Newtonian world view holds that there is a materialistic, deterministic, predictable, and unchanging system that can be known (Ittleson, 1994). Quantification of objects was viewed as
lending greater exactitude and precision as opposed to viewing them experientially. Consequently, the quantification of physical objects swiftly acquired scientific favor over experience which was doubted and distrusted (Colaizzi, 1978).

Several disciplines, including psychology, and later nursing, ascribed to the Newtonian world view and the quantitative approach as a means for developing the knowledge for their discipline. The founding of experimental psychology which is usually credited to Wilhelm Wundt in 1879 (but actually should go to William James), further strengthened the use of the quantitative method as the way to the truth (Boring, 1950; Colaizzi, 1978). The study of human consciousness and human experience was not amenable to the quantitative approach.

**Edmund Husserl and Key Concepts**

Edmund Husserl, a German philosopher, is acknowledged as the founder of the Phenomenological Movement (Spiegelberg, 1971). Phenomenology, a philosophy of the life-world (the world of daily life), is described by Spiegelberg (1971) as a movement as it indicates the philosophy of phenomenology as being dynamic from country to country, across philosophers, and within each philosopher (Cohen, 1987). Husserl was interested in the descriptive analysis of various types of thinking, of the diverse forms and degrees of intuitive consciousness, and of modes of symbolic and direct representation of experiences (Spiegelberg, 1971).
Husserl asserted that individuals were aware of existing with others, and of interacting with others in their life-world, the *Lebenswelt* (Natanson, 1973). Experiencing, therefore, arises from being directly involved with others who also experience in the life-world (Colaizzi, 1978). Additionally, experience which arises from one's perception while interacting and negotiating with others in the life-world is thinking that is directed at or "intended" toward an object. Therefore, every act of thinking denotes an object thought of (Natanson, 1973).

For Husserl, the approach to the phenomenological enterprise was being "free from presuppositions" such as prejudice or prejudgments, the *epoché* (Farber, 1966). Placing presuppositions in abeyance or "bracketing" allows phenomena to come directly into view (Farber, 1966). Freedom from presuppositions did not mean one begins the phenomenological endeavor without values or beliefs. Instead, freedom from presuppositions implied eliminating presuppositions which had not been thoroughly examined or which had not been presented for examination (Spiegelberg, 1971). The strategy of "bracketing" allows the researcher to experience firsthand the process of discovering the phenomenon through direct contact or "intuition" and also through the task of description (Churchill, 1990).

Phenomenology was viewed by Husserl as a descriptive science of experience and the objects of experience, with interest restricted to their essential structures (Farber, 1966). Husserl was interested in investigating essences and not the existence or self-
observation of experiences (Natanson, 1973). Through knowledge of essences and of essential relations, the clarification of empirical knowledge and of all knowledge would become evident (Farber, 1966). Therefore, the phenomenological method provided a strategy for the treatment of "universal" experience (meaning all types of experience) and consequently a foundation for all knowledge (Farber, 1966). Husserl also insisted on the ideal of scientific rigor to which philosophy had to achieve to become scientific (Farber, 1966).

**Other phenomenologists**

Edmund Husserl's work and concepts were influential on succeeding phenomenologists who further transformed phenomenology. The philosophy of phenomenology as Husserl constructed it has since had many divergent transformations. For example, consciousness was central in Husserl's phenomenology. Martin Heidegger's focus was on Being and with time. Being is temporal, and Being and time were viewed as inseparable entities (Cohen, 1987; Spiegelberg, 1971). Heideggerian phenomenology is a method for uncovering the hidden about Being itself, an uncovering of that which is concealed (Spiegelberg, 1971). Further, self-understanding and interpretations depend on certain preliminary understandings and background influences. Background influences are inclusive of interpretations and self-understandings handed down through language and
culture which one may not initially be cognizant of or completely explicit or clear to the individual (Benner, 1985; Leonard, 1989; Munhall, 1994; Spiegelberg, 1971).

For Van Manen (1990), the goal of phenomenology was to transfer the lived experience into a textual expression of its essence. The investigation is into the meaning of the lived experience as it is lived rather than as it is conceptualized (Munhall, 1994; Van Manen, 1990). Further, obtaining experiential descriptions from participants may include interviews, taped interviews, written experiences by participants, and close observations. A phenomenologist may also turn to the literature, poetry, or other story forms such as biographies, autobiographies, personal life histories, diaries, journals, and logs. Visual objects of art may also be used for case material (Van Manen, 1990).

Other phenomenologists include, but are not limited to, Colaizzi (1978), Van Kaam (1966), and Giorgi (1970). Though key concepts of phenomenology are adhered to, these phenomenologists' data analysis are distinct as they seek to capture the meaning of the experience (Munhall, 1994; Omery, 1983).

**Phenomenology In Nursing**

Nursing, like other disciplines striving to develop its discipline into a science, has been fruitful in using the empirical-analytic method borrowed from the natural sciences for the development of its knowledge base. Many nurse investigators, however, were dissatisfied and recognized the limitations of the positivistic method which presumed the
existence of causal relationships through the objectification of subjects. Further, the epistemology of the natural sciences denies the use of one’s senses, feelings, and intuitions as means for determining truth and understanding in human experience. Nurses had long been aware of the value of interacting with clients and using one's senses to assess clients' needs. There was incompatibility between nursing values and the methodology of the natural sciences. Qualitative, interpretive research methods, therefore, appealed to nurses as a means of finding answers to their questions emanating from their interactions and dialogue with clients (Munhall, 1982; Oiler, 1982; Paterson & Zderad, 1976).

**Nursing and qualitative research.**

Nurses became exposed to qualitative methodological approaches from other social disciplines as nursing schools became located in universities and away from teaching hospitals. Nurse researchers receiving their doctoral education in other disciplines such as sociology, anthropology, or psychology were among those exposed to diverse research methods such as grounded theory, ethnography, and phenomenology (Lowenberg, 1993).
**The promotion and discourse of phenomenology in nursing.**

Phenomenological discourse and research studies in nursing began to be seen in the 1970s and continues. The following provides a brief description of the content of nursing discourse in relation to phenomenology.

Phenomenology was promoted in nursing through Paterson and Zderad's (1976) book *Humanistic Nursing* which acknowledged the value of the phenomenological approach in understanding human experience. The seminal works of Oiler (1982), Munhall (1982), and Omery (1983) also explicated phenomenology's congruence with nursing's humanistic and holistic views of individuals. Nursing which focuses on the individual, recognizes and values the individual as a unique, autonomous being, possessing free will, and author of his/her own world (Munhall, 1994; Oiler, 1982). The study of individuals is further believed to be in conjunction with their environment rather than looking at parts of the individual (Munhall (1982).

Oiler (1982) described phenomenology as a philosophy, an approach, and as a method. As a philosophy, phenomenology was explained as being based on the view that individuals are conscious of being-in-the-world. This view is the notion of *intersubjectivity*, inherent in the philosophy of phenomenology. Further, intersubjectivity holds that an individual is conscious of the world through the body and its senses. Perception provides an access to an individual's experience while interacting with the
world. It is through the body that an individual is able to perceive. Individuals are recognized as co-existing with others who share a common world. As participants in the world, individuals are exposed to cultures, languages, and social and historical contexts. The world, which has been experienced and interpreted by others, is also handed down and instructs later generations about reality (Munhall, 1989).

In addition, the value of personal experiences, perceptions (of both nurses and patients), as well as personal meaning linked to responses to health, illness, and situations has been recognized as being significant to nursing knowledge development through research or theory building (Meleis, 1992). The patient's personal meanings are understood in a nursing-patient situation within the context of societal and cultural meanings. Meleis (1992) points out, "patients' experiences are no less significant for knowledge development. Their responses take a different meaning when placed in the context of past life experiences" (p. 123).

The phenomenological strategy of "bracketing" used to approach phenomenon, as promoted by Husserl, has been acknowledged by nurses (Cohen, 1987; Munhall, 1994; Omery, 1983; Smith, 1989). Another important concept in phenomenology is *intuiting*. Oiler (1982) described intuiting as requiring the researcher's complete concentration on the experience as well as becoming absorbed in the phenomenon without being enveloped by it. Intuiting is looking at the experience with wide-open eyes and wonder (Oiler, 1982).
Also appealing to nursing was phenomenology's reconciliation of the mind and body dualism. In phenomenology there is no separation of mind and body. Being-in-the world is life. Consciousness, therefore, is not viewed as existing solely internally, but as co-existing with the body. The subjective and the objective world exist as one. There is no mind/body or consciousness/existence dualism in phenomenology (Cohen, 1987). In this perspective, subjectivity is desirable. Subjectivity is the element that expands and enriches the authenticity of perceptions and understandings of the phenomenon (Munhall, 1989). Nurses continue to promote the value of phenomenology for knowledge development (Carpenter, 1995; Morse, 1994; Munhall, 1994). Descriptions of phenomenology's historical transformations have been presented (Cohen, 1987), as have been problems with rigor (Sandelowski, 1986), and ethical considerations (Munhall, 1988).

**Phenomenological research in nursing.**

The method of phenomenology was recognized for its usefulness in studying the human experience as it is lived and as it appears to the individual (Cohen, 1987; Oiler, 1982; Omery, 1983). Phenomenology provided a strategy for studying individuals in their own context rather than isolating person and situation variables and then trying to reconnect them together (Benner, 1985).
Nursing phenomenological studies began appearing in the 1980s. Research studies such as those of Haase (1987) on the components of courage in chronically ill adolescents, Banonis' (1989) work on recovering from addiction, and Santopinto's (1989) research on the relentless drive to be ever thinner are examples of nurse researchers using phenomenology for theory building. Phenomenology provides a more comprehensive approach for the study of human science.

The Researcher: The Context of My Turning Point

One of the criteria in phenomenology is for the researcher to investigate his or her own presuppositions to the phenomenon at hand, the strategy of "bracketing". The use of "bracketing" allows the researcher to be cognizant of preconceived assumptions and prejudices, and biases are candidly admitted, analyzed, and accounted for (Natanson, 1973). Common notions and biases usually taken for granted about a phenomenon are not denied. Instead these preconceived suppositions are discerned and held at bay or placed "under control" for the researcher to gaze more fully into another's experience (Natanson, 1973; Omery, 1983).

Accordingly with the phenomenological approach, the final section contains my personal account of the path which led me to inquire into the lives of women with HIV/AIDS and other views which are "bracketed" for this study.
The Researcher: Accepting the Journey Into the Lives of Women With HIV/AIDS

My brother's death from AIDS was the main impetus for my interest in inquiring about the impact HIV/AIDS on individuals' lives. Other social forces, as will be explained, came into play which triggered further interest into those with this disease.

The time of my brother's death was very inconvenient for me. I found out he was dying when I arrived at my mother's house where my older sister and I had planned to meet to start our long anticipated vacation together. We had been jubilant for weeks thinking of the fun we would have.

Upon my arrival, I found my mother distraught, crying, and saying my brother was dying. I had known my brother was sick in the hospital due to his diabetes being out of control, but this had not been the first time he had been in the hospital during the last few years. In fact, I felt the previous times he had been in the hospital were due to his self-neglect, which had become part of his life routine.

My mother said she was on her way to the hospital (to a city 100 miles way), alone, because she did not want her husband to come with her because "he tells everybody everything." Looking at my mother, I could see she was immutably determined, but in no emotional condition to navigate herself to a city she had never driven to or was very familiar with. My sister and I could not believe our bad luck! I could not believe my brother's bad timing with his illness, in fact I was angered by him, and the fact that we
could not leave for our vacation knowing our mother would be fending for herself in a big
city, and the possibility that our brother might really die this time. "If our brother died
while we were on vacation we would feel like jerks" was my sister's and my conclusion.
This was not so bad, but we could not let our mother travel alone.

To provide context, I am a first generation Mexican American born in a small
southwestern border town. I lived in this town until I graduated from High School and
left for college at a University in a metropolitan city. So, I grew up in a world having
strong ties to the Mexican culture embedded in an Anglo culture. I was the second child
of five: my brother who developed AIDS was the youngest. I had loved my brother who
was 10 years younger, but when I left for college our distance deepened.

Time, social forces, and choices impacted my relationship with my brother. In his
 teens, my brother was caught in the world of drug addiction. This led to his years of
numerous criminal activities, confrontations with the law, and (what I consider) his abuse
of those around him including my parents (who were divorced and re-married). My
parents always forgave him, and I think this increased my anger and my disregard toward
my brother. So when I heard my brother, a prisoner in a detention ward in a city hospital,
was sick I really did not care.

As my sister and I were trying to convince my mother that he would be all right,
that he was probably not dying, she informed us he had AIDS. We were shocked! I was
shocked! AIDS had been a distant disease for me. I knew homosexuals and drug addicts
contracted the disease, but someone in my family? Further inquiries revealed both my
parents had known for months but had not told their daughters because "your brother
didn't want anyone to know and made us promise not to tell." No one in our family,
except my parents, knew. My parents had kept their anguish a secret, even from their new
spouses.

It is hard to see anyone gasping for each breath, with their face beaded from the
moisture of the oxygen mask, and still feel anger. I still did not like my brother, but I did
not hate him when I saw him. The guard showed us where the gloves were in case we
wanted to touch him. We did not use the gloves. How can you touch your dying brother
with gloves? We were given five minutes to be with him—rules of the jail system. Just
getting to see him had been a long process because we had not been okayed by "someone
in the jail system" and we needed special permission. After several phone calls to the main
prison and talking to several individuals, we were permitted to see him. My mother was
distraught. He died the next day with my sister with him, and my mother, my other sister
and I outside the room, waiting our next turn.

This event led me to look at those with HIV/AIDS and their families/significant
others with a different view. My family's experience with AIDS influenced my further
inquiry into HIV/AIDS during my doctoral program. While reviewing the literature on
those with HIV/AIDS, I found limited information on women with HIV/AIDS. The
sparse literature on women with HIV/AIDS was in relation to their children or as vectors
of transmission. There was little information on women and HIV/AIDS although there were thousands of women in the world with the virus.

I conducted a study during my doctoral program on women with HIV/AIDS. One difficulty encountered after finding these women with HIV/AIDS, was to recruit them to take part in the research. I learned of the stigma associated from HIV/AIDS personally, and I found it in the lives of these women. While interviewing the women, I discovered these women were young, had small children, and usually had limited access to others due to their fear of their family and themselves being stigmatized. I found these women (once they consented to being interviewed) yearning to tell others of their story. It was as if a faucet had been turned on and they were free to share with another their innermost thoughts.

Because I am from a Mexican American culture, I then wondered about women of Mexican heritage with HIV/AIDS. Statistics indicated there were women of Mexican heritage who had contracted the AIDS virus. Feminist issues also enhanced my awareness of the barriers which the Mexican culture and society imposed on women of Mexican origin. I wondered what prominent, discrete or hidden needs or concerns their story of living with HIV/AIDS would disclose that would enhance nursing knowledge, nursing practice, and better the lives of women of Mexican heritage with HIV/AIDS. For me, it became a personal goal to investigate the lives of these women and report on their needs.
and concerns. By articulating the needs of these women with HIV/AIDS, I hoped the process for their and others’ betterment would be advanced.

**Further Views Bracketed**

My own perspectives on women of Mexican heritage with HIV/AIDS were that these women are strong individuals whose center of living is to care for others. The patriarchal Mexican culture can be both a source of comfort and a stifling experience. It is common for women of Mexican origin to suffer in silence. The less educated the woman is, the more vulnerable she is to isolation and social abuses. Women of Mexican heritage are very adept and self-reliant when they are needed by others dear to them.

In addition to the preceding perspectives, the following views were also bracketed. Women of Mexican heritage have particular issues related to having contracted HIV/AIDS because of their:

1. generally lower educational level
2. possible language barriers
3. general lower socioeconomic status
4. possible immigration issues
5. cultural influences
6. limited access to health care
7. stigma of having HIV/AIDS
as addressed by various sources (Morbidity and Mortality Weekly report, 1994; Schick & Schick, 1991; Sumaya & Porto, 1989). This was the context in which I prepared to enter and inquire about the lives of women of Mexican culture with HIV/AIDS.

Summary

Significant psycho-social factors confronted by women of Mexican heritage that impact their lives, impede access to health care, and are detrimental to their health were addressed in this chapter. Women of Mexican origin are different then the general population by merit of being of a different ethnic group. Furthermore, these women of Mexican heritage have particular needs and concerns related to having HIV/AIDS. Yet, review of the nursing literature found the voices of women of Mexican heritage with HIV/AIDS virus absent. Rogers' science of unitary human beings, the philosophy of phenomenology, as well as feminist perspectives were chosen to serve as the theoretical underpinnings to guide this dissertation enterprise. The purpose of this study was to use the narratives of women of Mexican heritage to uncover, explore, and describe their lived experience with HIV/AIDS. The researcher's personal perspectives were also presented.
CHAPTER 2

LITERATURE REVIEW

The following literature review provides the background context of this dissertation. A description of the conceptual orientation for this study is presented. Concepts generated from this author's research on women with HIV/AIDS are examined. The final section presents a comprehensive description of the Mexican culture to provide context and understanding to these women's behaviors.

Conceptual Orientation

The proposed descriptive, phenomenological study used the researcher's previous research findings to provide the conceptual orientation. The researcher's previous study was a phenomenological study of the lived experience of women with HIV/AIDS. The purpose of the study was to examine the essential structure of the lived experience of women with HIV/AIDS. The purposive sample consisted of four women who ranged in age from 24 to 50 years and all of whom were symptomatic. Outlined in Table 2.1 are the pseudonyms of the women whose narratives were privileged as well as their ages, marital status, years of marriage, child(ren), date of diagnosis, approximate years with the virus,
date medication was begun, initial CD4 count, their last CD4 count, and their current symptoms at time of interview.

Table 2.1

Overview of the Participants

<table>
<thead>
<tr>
<th>Participant</th>
<th>Elsa</th>
<th>Carrie *</th>
<th>Chloe *</th>
<th>Diane</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age</td>
<td>24</td>
<td>34</td>
<td>28</td>
<td>50</td>
</tr>
<tr>
<td>Marital status</td>
<td>married</td>
<td>married</td>
<td>separated</td>
<td>single</td>
</tr>
<tr>
<td>Years married</td>
<td>7</td>
<td>9</td>
<td>3</td>
<td>0</td>
</tr>
<tr>
<td>Child(ren)</td>
<td>2 da. (4 &amp; 6 yrs)</td>
<td>1 son (7 yrs)</td>
<td>2 sons (4 &amp; 6 yrs)</td>
<td>unknown</td>
</tr>
<tr>
<td>Years with virus (approx.)</td>
<td>7</td>
<td>&gt; 9</td>
<td>unknown</td>
<td>unknown</td>
</tr>
<tr>
<td>Date medication begun</td>
<td>1/93</td>
<td>1/92</td>
<td>1993</td>
<td>none</td>
</tr>
<tr>
<td>Initial CD4 count</td>
<td>800</td>
<td>39</td>
<td>&lt; 600</td>
<td>~ 800</td>
</tr>
<tr>
<td>Last CD4 count</td>
<td>458</td>
<td>25</td>
<td>464</td>
<td>~ 1300</td>
</tr>
<tr>
<td>Symptoms</td>
<td>fatigue, dysplasia</td>
<td>fatigue, thrush, lymphadenopathy, pneumonia, arthritis, retinitis</td>
<td>fatigue, lymphadenopathy, vaginal yeast infection, endocarditis, hepatitis C</td>
<td>fatigue, lymphadenopathy, vaginal yeast infection, insomnia</td>
</tr>
</tbody>
</table>

* Deceased

Only one woman had AIDS, two had begun treatment for decreased T-cell counts, and one had a normal T-cell count. Two of the women were Caucasians, one was Mexican American, and one was African American. These women were recruited from a southwestern metropolitan county clinic for individuals with HIV/AIDS and from a southwestern city support group for women with HIV/AIDS. All the interviews were audio-tape recorded and transcribed.
The data were analyzed using an eight-step procedure adapted from Colaizzi (1978). Six theme categories emerged from the women's narratives and describe their concerns and experiences of living with the HIV virus. The following describes these six theme categories.

**Discovering the Virus**

The women's description of discovering the virus encompassed distinct phases that included (a) awareness of the illness as it begins to unfold; (b) enigmatic effects of the AIDS virus advance unrecognized, (c) panic stricken by diagnosis; and (d) certain activities and perceptions substantiate reality of the diagnosis.

The category of "Discovering the Virus" was characterized by the traumatic impact in the women's lives when told they had HIV/AIDS. Whether or not the women suspected they had contracted the virus was irrelevant as was their differentiation of having HIV or AIDS. Upon finding out they had the AIDS virus the women believed death was imminent, and they were panic stricken.

**Facing Personal and Social Core Issues**

As the women struggled to live with their diagnosis of having HIV/AIDS they began to face difficult life issues including (a) apprehensiveness for their child(ren)'s well-
being, (b) preparing the family for the future, (c) dealing with HIV's effects on relationships and, (d) social consciousness about the spread of AIDS.

The theme category of "Facing Personal and Social Core Issues" illustrated women's sense of caring and responsibility toward family members and others in their social worlds. For the women with children, there was an urgency to assist the child(ren) in their ability to be independent and care for themselves, to be happy, and to be able to safely interact with others and not be emotionally and/or physically hurt. Likewise, there was concern for the emotional well-being of their significant other.

The focus of women's concern extended to others in their environment. They developed a social consciousness about the spread of HIV/AIDS which led them to diverse journeys in their efforts not to spread the virus.

**Sources of Sustenance**

This theme category described various sources of sustenance found by the women which helped them to endure living with HIV/AIDS: (a) fidelity of significant other, (b) strength from family, (c) solace from guilt, (d) community assistance, and (5) knowledge that positive thinking and beneficial behaviors promoted one's well-being.

Sources of sustenance were explicated by the women. These sources of sustenance varied for the women and were recognized during different periods in their lives.
Awareness of An AIDS Stigmatized Environment

With the diagnosis of having HIV/AIDS, came the awareness of living in an AIDS stigmatized environment. The process of learning about the existence of an AIDS stigmatized environment came from (a) awareness and/or experience of social sentiment towards those with the AIDS virus, (b) media's impact on society's views on AIDS, and (c) prejudiced health care providers who impacted care.

The category "Awareness of An AIDS Stigmatized Environment" exemplified the influences and changes that occurred in women as they continuously interacted with their environment. The environment's (society and culture) dominant moral views in regards to individuals with HIV/AIDS influenced the women's sense of being stigmatized. As the women interacted within their environment, they became aware of an environment intertwined with prejudice and harmful toward those with HIV/AIDS. The women learned to hide their infection to protect their loved ones and themselves.

Seeking Understanding and Meaning to Having HIV

As the women evolved in their struggle of living with HIV, they entered a phase where they were ready to learn about their infection and they attempted to find meaning to having HIV. So, the women began to (a) seek answers about the virus, (b) take the
good with the bad in receiving health care, and (c) use appetite and cell counts as gauges to well-being.

In the theme category, "Seeking Understanding and Meaning to Having HIV", the women emerged as stronger and more active beings, striving to learn more about their infection, and attempting to take control of the infection's progression. They became part of the health care system in which they were exposed to positive and negative interactions and treatments.

**Evolving Life Perspectives Since Contracting the Virus**

Time allowed the women to step back, reflect, and place their life in perspective in a process characterized by (a) self-reflection and living for today, (b) developing attitudes towards the source of HIV, (c) wavering with ability to control despair, and (d) concern and desire to help others in society.

The category "Evolving Life Perspectives Since Contracting the Virus" described the women as setting priorities in their lives. They reflected on their past and present state, and developed attitudes to assist them on their difficult journey. At times the women wavered in their courage, however, they found the strength to look beyond themselves and focus toward their betterment of society. These women were able to transcend their illness.
Phenomenology assists in understanding the lived experience of individuals. These six theme categories reflected an in-depth view into the lives of women with HIV/AIDS as well as enhanced their needs and concerns.

**Concepts Generated**

From the present researcher's first study on the lived experience of women with HIV/AIDS, the concepts of initial crisis, social support, stigma, self-transcendence, and suffering emerged. Table 2.2 presents the concepts generated from the theme categories.

**Table 2.2**

<table>
<thead>
<tr>
<th>Concepts Generated</th>
</tr>
</thead>
<tbody>
<tr>
<td>Discovering the virus</td>
</tr>
<tr>
<td>Facing personal and social core issues</td>
</tr>
<tr>
<td>Sources of sustenance</td>
</tr>
<tr>
<td>Awareness of an AIDS stigmatized environment</td>
</tr>
<tr>
<td>Seeking understanding and meaning to having HIV</td>
</tr>
<tr>
<td>Evolving life perspectives since contracting the virus</td>
</tr>
</tbody>
</table>

The following literature review describes these concepts which may be further developed to expand nursing's knowledge base.
Initial Crisis

In the theme category "Discovering the Virus", the women described a period of time beginning after being informed of their seropositive test result, where they were paralyzed by feelings of shock and panic in response to their sense of imminent death. This phase has been described by Nichols (1985) as "initial crisis". During the initial crisis phase, individuals are said to respond to life-threatening illnesses with alternating responses of acute denial to periods of intense anxiety (Miller, 1990; Nichols, 1985). Denial can be a human adaptive response as it can alleviate internal stress (Miller, 1990). However, intense denial and anxiety may in some individuals lead to dangerous disregard of medical advice or life-threatening behavior (Nichols, 1985). Other responses to being seropositive included guilt, fear, anger, sadness, bargaining, and acceptance. In addition, individuals in the initial crisis stage were also found to have difficulty retaining information with possible distortion of what they were told regarding their illness (Miller, 1990; Nichols, 1985).

The existence of suicidal ideation in individuals with HIV/AIDS was found in the literature. Miller (1990) suggested suicide among individuals with HIV/AIDS could occur during the initial crisis phase. Factors which could heighten the risk of suicidal activity particularly during the initial shock, after diagnosis, and where follow-up support was not offered or available included: (a) HIV testing without consent or pre-counseling, (b) the
manner in which the news of infection or disease was presented, and (c) subsequent social and cultural isolation (Miller, 1990).

Nichols (1985) indicated suicidal thoughts were more prone to occur in the "transitional state", a state following the crisis stage. The transition state is said to begin when alternating waves of anger, guilt, self-pity, and anxiety supersede denial and is further marked by distress, confusion, and disruption (Nichols, 1985). Nichols (1985) suggested possible emotional factors contributing to suicide ideation to include (a) intense guilt, anger, fear, and depression, and (b) changes in self-esteem. Social factors which could promote thoughts of suicide included: (a) social rejections by friends, family, and community, (b) loss of work, income, and one's home, (c) loss of identity, values, and (d) self-devaluation (Nichols, 1985).

Contradictory finding were found in studies related to suicide ideation and suicide rates among individuals with HIV/AIDS. Suicidal ideation was said to be common among individuals with HIV/AIDS but that actual attempts were not as frequent (Faulstich, 1987; Perry, Jacobsberg & Fishman, 1990). Miller (1990), however, reported the risk of suicide was significantly higher among people with AIDS than in the generally healthy population. Evidence suggested individuals who were prone to suicidal ideation or intent were those having more psychosocial characteristics associated with increased vulnerability to psychiatric distress (Dew, Ragni & Nimorwicz, 1990; Perry, Jacobsberg, & Fishman, 1990).
Worth (1990) indicated that women in emotional crisis tended to isolate themselves from others. Women were said to pull back from important relationships with their children and partners for fear of infecting them or having to explain their leaving due to their impending death.

**Social Support**

The literature of the 1970s and mid 1980s raises questions about previous research on social support from which scientists and theorists had based their premises (Cassel, 1974; Coyne & DeLongis, 1986; Heller, Swindle & Dusenbury, 1986; Thoits, 1982). Research on the significance of social support and well-being up to that time, was found to (a) contain discrepancies in the conceptualization and operationalization of social support, (b) lack consistency of measurement methods, (c) contain poorly constructed research designs including methodology, and (d) lack theoretical frameworks (Cassel, 1974; Cobb & Jones, 1984; Coyne & DeLongis, 1986; Thoits, 1982). Further, it was recognized that the processes between social support and social ties were complex and the links between social support and the beneficial effects needed further inquiry. The term social support, itself, needed clarification and its components needed to be disaggregated (Coyne & Delongis, 1986; Heller, Swindle & Dusenbury, 1986).

Recent literature describing human relationships with their environment has focused on concepts such as connecting, connectedness, intimacy, and human relatedness.
Further, the theory of human relatedness (Hagerty, Lynch-Sauer, Patusky & Bouwsema; 1993) has been advanced.

**Theory of Human Relatedness**

The theory of human relatedness (Hagerty et al., 1993) provides a theoretical framework which may assist nurses in understanding, assessing, and developing interventions with clients having problems in relatedness; a core construct of the theory. Within this framework, the concept of relatedness is defined as "an individual's level of involvement with persons, objects, groups or natural environments and the concurrent level of comfort or discomfort associated with that involvement" (Hagerty et al., 1993, p. 292). From the two dimensions of relatedness, involvement-noninvolvement and comfort-discomfort, four states of relatedness emerged: connectedness, disconnectedness, enmeshment, and parallelism. The theory of human relatedness also describes phenomena that contributed and comprised the various states of relatedness. The four major processes influencing the establishment and promotion of relatedness states were a sense of belonging, reciprocity, mutuality, and synchrony (Hagerty et al., 1993).

**Connecting**

Connecting and its linkage to the bereavement process have been found in the nursing literature. Two basic social-psychological processes identified in McGaffic and
Longman's (1993) grounded theory study on the bereavement experiences of gay partners of men who died of AIDS-related complications, were connecting and disconnecting. The process of connecting served to maintain the bereaved survivor's sense of the partner's presence. Connecting also involved activities, thoughts, and behaviors which affirmed the meaningfulness of the relationship.

Longman's (1995) grounded theory study on the bereavement experience of mothers whose sons died of AIDS-related complications also found the basic social-psychological processes of connecting and disconnecting. In this study, connecting was a continuous process to retain connection with the deceased son and to face the son's death. Connecting entailed both mental and physical activities which assisted the mothers to validate their sons' life, reconstruct their lives, and find meaning to their sons' demise.

**Connectedness**

Heifner's (1993) exploratory, descriptive study inquired into elements influencing positive connectedness in psychiatric nurse-patient relationships. Connectedness reflected a sense of union in a client-nurse interaction. Factors positively impacting client-nurse interactions as perceived by the nurses in the study included: (a) patients expressing vulnerability, (b) perception of existing commonalities between client and nurse, (c) reciprocating characteristics in client-nurse interactions, (d) investment of more time by nurse, and (e) nurse feeling valued by the patient.
The work on relatedness by Hagerty, Lynch-Sauer, Patusky, and Bouwsema (1993) which examined the concept of connectedness in part supported Heifner's findings. Hagerty et al. (1993) indicated connectedness was characterized as including active involvement with another person, object, group, or environment. Significant in promoting relatedness was if the involvement led to a sense of comfort, well-being, and anxiety-reduction.

**Intimacy**

Intimacy was described as an interactive process. Reis (1990) described the process of intimacy as beginning when an individual expresses verbally or non-verbally personally revealing feelings or information to another person. The process continues when the listener responds in a supportive or emphatic manner. A key element in intimate relationships is that the disclosure had to feel understood, validated, and cared for by the listener. Further, both behaviors depended on the other's behavior and responses.

Common elements in the above support-related concepts appear to include a particular type of involvement which leads individuals to experience a sense of comfort or feelings of being valued. The concepts of vulnerability and reciprocity add to the complex interplay of establishing positive, supportive relationships.
Stigma From the AIDS Disease

Not only do people with HIV/AIDS have to deal with the sequelae of the disease, but they have to additionally endure the stigma of the disease. Stigma from a disease is extended to individuals close to the person with the stigmatized disease. Individuals, significant others, including family members associated with the person with AIDS virus were also found to be stigmatized (Chekryn, 1989; Kleinman, 1988; Powell-Cope & Brown, 1992; Sowell, Bramlett, Gueldner, Gritzmecher & Martin, 1991; Weitz, 1991).

How individuals view and experience an illness is said to be culturally shaped (Kleinman, 1988). It is from society and from interpersonal communication between the family and society that individuals learn to think about their world and how to interact within their world. The symbolic interactionist perspective additionally supports the view that society and its culture influence the manner in which individuals derive meaning and understanding from their experiences (Mercer, 1989).

Social response to all illnesses is not equal. Those illnesses that evoke the most stigma were those that evoked the greatest blame and dread. Weitz's (1991) ethnographic study addressed six factors found to be associated with higher levels of stigma. These factors included (a) when an illness was linked to an already stigmatized group (such as gays), (b) when an illness was connected to sexual matters, (c) if the illness had no vaccine known and (whether it is true or not) the illness was thought to be contagious, (d)
if the illness resulted in visible, disfiguring, and dehumanizing changes, (e) if the illness led to death or severe disability, and threatened not just a few individuals but an entire society, and (f) if an illness contained a mystery as to its nature. HIV infection includes all of the above factors. Goffman (1962), additionally described three types of stigma as those arising from "abominations to the body", "blemishes of character", and "tribal stigma of race, nation, and religion."

The impact of being stigmatized (shunned, derided, disconfirmed, and degraded) by society leads individuals and their family to experience feelings of being less worthy, degraded, deviant, and shamefully different (Kleinman, 1988). Individuals who internalize the stigma come to expect to be treated differently, and many individuals end up with a frayed self-image.

The influence of religion was intertwined with other societal mores. Stigmatized individuals were also viewed as being sinful, evil, or being punished by God for their evil ways (Weitz, 1991).

Individuals with the AIDS virus, who were not homosexuals, also bear the stigma of the disease. Suspicions may arise from others who wondered what it was in their past that led them to contract AIDS (Weitz, 1991).

The stigma of having the HIV virus was so great, that individuals and their family often choose to keep it a secret (Chekryn, 1989; Kleinman, 1988; Rosenberger & Winburgh, 1992; Sowell, Bramlett, Gueldner, Gritzmacher & Martin, 1991; Weitz, 1991).
Society's assignment to the AIDS disease as a deserved punishment has led many families to reject their ill, afflicted relative. It has also led to the afflicted person being fired from jobs, to being evicted from homes, and to the loss of friendships (Weitz, 1991). Whatever the choice of afflicted individuals and their family regarding disclosure or concealment of the HIV virus, their world is forever changed.

Self-Transcendence

A dominant concept emanating from this researcher's initial study on women with HIV/AIDS was self-transcendence. Reed (1991) defined self-transcendence as, "the expansion of one's conceptual boundaries inwardly through introspective activities, outwardly through concerns about others' welfare, and temporally by integrating perceptions of one's past and future to enhance the present" (p. 5).

Transcendence has been linked in the literature with human mental health. One perspective was the view that individuals possessing intra-psychic mental health (transcendence) used "hierarchical-integrative" thinking, whereby they were able to turn away and detach from the outer world (Maslow, 1968). Detachment enabled one to look within oneself and to listen to one's inner voices for guiding values and rules by which to live. Another function of detachment was that it allowed for a purer, broader look at the natural attributes of objects and others without imposing external biases (Maslow, 1968). Detaching or disengaging from one's surroundings was analogous to finding solitude.
Solitude or isolation was found to be a necessary element to facilitating insight or the process of transformation (Chinen, 1986).

Experience of meaning was a transcendent phenomenon described by Steeves and Kahn (1987) as occurring in terminally ill patients and to those grieving anticipated loss of their own life, or the life of someone close to them. The distinct, all-absorbing experience connected individuals to a force greater than themselves and altered the manner in how they experienced themselves and coped with suffering. Steeves and Kahn (1987) indicated conditions outside the conscious self which facilitated the experience of meaning included (a) having access to and having the ability to perceive objects in the environment, (b) having free time and time alone (solitude), (c) being surrounded by quietness, (d) possessing freedom from constant worry, responsibilities, and decision making activities, (e) having the presence of various objects of interest, and (f) being clean and comfortable (Steeves & Kahn, 1987).

Transcendence was viewed as a powerful resource individuals have to restore their wholeness (Cassell, 1982). Individuals sensing their own mortality or that of a close other tended to respond by opening up their self-boundaries. Patterns of self-transcendence heightening during compromising life events and facilitating emotional well-being was found in women with advanced stages of breast cancer (Coward, 1990), in persons with a terminal illness (Steeves & Kahn, 1987); in those faced with adversity, loss, grieving, and
suffering (Frankl, 1984; Steeves & Kahn, 1987); and in the elderly, some facing the last chapters of their life (Chinen, 1986; Marshall, 1980; Reed, 1991).

Self-transcendence was also viewed as a developmental characteristic representing a "natural resource" in later adulthood to promote or restore one's emotional well-being (Chinen, 1986; Marshall, 1980; Reed, 1989; Reed, 1991; Vaughan, 1985). Beneficial patterns of transcendence undertaken by the elderly included (a) generativity, a form of altruism including concern for others, especially, those in the next generation, (b) body-transcendence, where the individual turns from preoccupation with personal infirmities or physical disabilities to other issues, (c) introjectivity, such as finding solitude to engage in inner-directed activities, self-directed learning, spiritual learning, and reflections, and (d) temporal integration of past and future perspectives to determine present views and activities (Chinen, 1986; Marshall, 1980, Reed, 1991; Vaughan, 1985).

Individuals in the last half of life are faced with the painful reality of old age, disease, and death. Those that open up their self-boundaries, accept life to the fullness, with its richness and adversities, accept death as part of the natural cycle of life. Such an attitude is said to be the product of self-transcendence (Chinen, 1986; Vaughan, 1985).

Another pattern of self-transcendence observed as being beneficial to one's emotional well-being was not only in helping others but in allowing to be helped. Mature individuals possessing wisdom realize the value of reciprocity between individuals interacting with their environments. Reed's (1991) study of self-transcendence and mental
health in oldest-old adults indicated a link between emotional health and reciprocity of social support in elderly persons. The values of youth give way to the value of discovering authentic truths (Chinen, 1986). What was once valued (such as self-sufficiency, independence) gives way to broader perspectives inclusive of others, or a path to knowing oneself.

Lastly, individuals viewed as being emotionally healthy were characterized as being not only authentic, self-governing, and autonomous, but also creative, wise, receptive, intuitive, peaceful, loving, compassionate, possessing humor, and playful (Chinen, 1986; Maslow, 1968; Reed, 1991; Vaughan, 1985).

**Suffering**

Suffering was the over-arching, dominant concept that arose from this researcher’s initial study on women with HIV/AIDS. A review of the nursing literature indicated nursing’s inquiry into human suffering and the suffering experience was limited. Paradoxically, nurses encounter suffering in their everyday interactions with clients, and are expected to recognize and alleviate the suffering of clients, family members, groups, and communities (ANA, 1985). The concept of suffering in the nursing literature has not been very well investigated and not clearly defined.

Travelbee (1971) defined suffering as "an experience which varies in intensity, duration and depth. Basically, suffering is a feeling of displeasure which ranges from
simple transitory mental, physical or spiritual discomfort to extreme anguish, and to those phases beyond anguish, namely, the malignant phase of despairful "not caring", and the terminal phase of apathetic indifference" (p. 62). Kahn and Steeves (1986) presented a more concise and individualized definition, "suffering is experienced when some crucial aspect of one's own self, being, or existence is threatened. The meaningfulness of such a threat is to the integrity of one's own experience of personal identity" (p. 626). A clear definition of suffering is essential in nursing, one which would contain the attributes, antecedents, and consequences.

A review of literature on suffering by this author (unpublished manuscript) evidenced six common themes across the data base using 33 literary sources addressing the concept of suffering. These were: (a) personal meaning in suffering (Battenfield, 1984; Benedict, 1989; Bovet, 1973; Cassell, 1982; Copp, 1974; Gregory & Longman, 1992; Steeves & Kahn, 1987), (b) pain and suffering (Charmaz, 1983; Cope, 1974; Kahn & Steeves, 1986), (c) amelioration of the suffering experience (Chapman & Gavrin, 1993; Charmaz, 1983; Fordyce, 1988; Travelbee, 1971), (d) inferring another's suffering (Davitz, Sameshima & Davitz, 1976; Davitz & Pendleton, 1969; Hinds, 1992; Kahn & Steeves, 1986), (e) suffering and religion (Huebner & Garrod, 1991; Kempis, 1993), and (f) attributes and measurement of suffering (Battenfield, 1984; Benedict, 1989; Ferrell, 1993; Kahn & Steeves, 1986). Perspectives on these themes varied according to the authors' world view. The world view evidenced by the book or article was categorized
into one of Fawcett's (1993) three world views, (a) the reaction world view, (b) the reciprocal interaction world view, or the (c) simultaneous action world view.

The following attributes, antecedents, and consequences were compiled from across the literature database and from the definitions of suffering. The common attributes of suffering were that suffering was part of life. Suffering was viewed both as a negative and as a positive psychological experience. Further, suffering was a personal phenomenon experienced by individuals.

The three antecedents of suffering were (a) desire for eternal youth, material goods, pleasurable sensations, and power, (b) ignorance of the reality that having does not dissipate desire and of the fact that desire leads to increased negative karma and more suffering (Huebner & Garrod, 1991), and (c) a perceived loss or threat to some crucial aspect of the self (Cassell, 1982; Cassell, 1992; Chapman & Gavrin, 1993; Charmaz, 1983; Kahn & Steeves, 1986).

Comprising the consequences of suffering were (a) shattered self-images (Charmaz, 1983; Cassell, 1982; Gregory & English, 1994; Gregory & Longman, 1992; Kahn & Steeves, 1986; Travelbee, 1971), (b) a sense of hopelessness (Travelbee, 1971), (c) social isolation (Charmaz, 1983; Gregory & English, 1994; Gregory & Longman, 1992), (d) guilt (Farmer & Kleinman, 1989; Kristjanson, Gregory, & Kuypers, in press), (e) shame from lack of personal power (Farmer & Kleinman, 1989; Goldberg, 1986), (f) apathetic indifference (loss of will to live), (g) depression, longing, self-pity, and blaming
(Travelbee, 1971), (h) a decrease in negative karma (Huebner & Garrod, 1991), and (i) joy (Kempis, 1993; No Greater Love, 1967).

Other similarities among the literature data base on suffering included a strong desire to know more about the phenomenon of suffering to assist those who suffer. Suffering was viewed as part of life, an occurrence in the lifetime of individuals. Suffering was also recognized as being influenced by an individual's personal meaning which derives from past experiences, values, and sociocultural influences. As such, suffering is partly individual and partly socially derived.

Pain and suffering were acknowledged as being distinct entities. Even so, individuals in pain were readily described as suffering, and suffering could occur without pain. Pain was viewed as causing suffering when an individual had sustained pain, perceived his or her pain to be out of control, was overwhelmed by pain, did not know the source of the pain, or was aware the pain was dire (Bennedict, 1989; Cassell, 1982; Chapman & Gavrin, 1993). Suffering was also recognized as able to occur in anticipation of pain (Copp, 1974).

Individuals were believed to not only be able to infer another's suffering but suffer when others suffer (Hinds, 1992). How well another's suffering was detected depended on multiple factors such as the culture and subculture of the nurse making the inference (Davitz, Sameshima & Davitz, 1976), the patient's diagnosis, age, and socioeconomic status (Davitz & Pendleton, 1969).
Research and further inquiry into the phenomenon of suffering was advocated in the literature data base (Gregory & Longman, 1992; Kahn & Steeves, 1986). There was a desire to know more about the phenomenon of suffering and to assist those who suffer by understanding their suffering experience.

Women of Mexican Heritage and the Mexican Culture

The Mexican culture is a strong thread interwoven in the lives of women of Mexican heritage which influences directly or indirectly their being and patterns of behavior. This section uses analytical works as well as research studies to provide background information and describe the Mexican culture. The following description of the Mexican culture along with a brief history by feminist writers is presented to assist in understanding the context and various social forces which influence the behavior of women of Mexican heritage. Feminist writers lend an enriching and at times a contrasting perspective from that of the traditional descriptions of Mexican women and those in their environment. In describing the Mexican culture, it needs to be kept in mind that regional, generational, socio-economic, and individualistic variances exist among different families and within individuals of the same family.
The Structure of the Mexican Family

The family structure of Mexican and Mexican American families is characterized as being paternalistic as well as a close family unit (Falicov, 1982; Portillo, 1990). In the Mexican culture, the family is connected to its extended family just as much as with its immediate family. The family nucleus typically consists of a husband, wife, and their children (Keefe & Padilla, 1987).

The extended family includes grandparents, cousins, aunts, uncles, godparents, and other close family friends. Great value is placed on the extended family and friends. The extended family is a source of solace and social support, and is expected to be present in stressful situations for the family (Padilla & Ruiz, 1973; Portillo, 1990). Generally, the Mexicans identify themselves as Catholic (Schick & Schick, 1991).

The ties among siblings and cousins are very strong. Competition and fighting among siblings are discouraged, while cooperation, sharing, and even sacrifice for a sibling are encouraged (Falicov, 1982). The needs of the family have more precedence than individual needs (Gonzalez-Marshall, 1987).

The Mexican culture is hierarchically based. An individual's age and sex are important factors. Males are higher in the hierarchy than females. Older males have more control over younger males and others, as well as more power in decision making. Older
females are also higher up in the hierarchy than are younger females, but females as a rule are lower in the hierarchy than males.

**Males of Mexican Origin**

Males are the dominant individuals in the Mexican culture. Padilla and Ruiz (1973) list ideal attributes of Mexican males as proud, dignified, reliable, vengeful when dishonored, and stoic. The role of the father is to provide for the family. Men usually do not take part in household work or take part in raising the children. However, depending on circumstances, Mexican and Mexican American men will change roles to ensure the family's well-being (Deutsch, 1987). When the children are young, the father behaves in a friendly and indulgent manner towards them. It is the mother's role to discipline the children. As the children become older, the father begins to exercise his authority with his children. The discipline of children can be a harsh punishment (Padilla & Ruiz, 1973).

**Values in the Mexican Culture**

Often, the concept of "machismo" is used negatively to denote men's super-ego, their aggressiveness, or their sexuality. Men are expected to show their manhood by exerting sexual prowess and by asserting their dominance over women. Some Mexicans see "machismo" only as a myth, while others see it as a traditional Hispanic value (Espin, 1992). Other values attributed to males who project "machismo" are courageous, loyal,
fair, honorable, responsible, and protectors of their family. Not all Mexican and Mexican American males exert the stereotypical "machismo" behavior. "Machismo" behaviors acted out may be the result of men's reaction to oppressive social conditions that men encounter in society (Espin, 1992).

Certain values of honor came from the Spaniards and have been assimilated among certain individuals within the Mexican culture. Honor was derived by either superior birth or moral integrity (Seed, 1988). Moral integrity for males meant courage and fidelity to promises made. In contrast, moral integrity for females meant premarital chastity and post-marital fidelity. Indians and the poorer Mexicans did not hold virginity in such reverence. The upper classes and individuals who endeavored to improve their social standing adhered more rigidly to this honor system. Espin (1992) explains that a woman's virginity was important because the heir of one's property had to be the father's true child. For both the male and the female, maintaining moral integrity impacted the honor of the family.

The Catholic church influenced and continues to influence the moral integrity of women. The Virgin Mary who was a virgin and a mother is not associated as a sexual being and is held as a role model for all Hispanic women (Espin, 1992).
**Mexican and Mexican American Women**

The females in the Mexican culture are idealized as homemakers and caretakers of the family. Women raise their children to be obedient and well-mannered children. Mexican women begin early to teach their children to help with the work and to prepare for adult life (Dill, 1992). Some Mexican women do not think Mexican American women control their children properly (Pardo, 1993). Complementary roles between males and females are described as the influence of Spanish ancestry (Falicov, 1982).

The messages received by females by others in the Mexican American culture are to be dutiful, faithful, and submissive to their husbands (Gonzalez-Marshall, 1987). The role of the mother is that of being nurturant, supportive, and self-sacrificing. The expectation for women to be self-sacrificing, and sexually pure affects the sexual development of women. Women who enjoy sexual pleasure even in marriage are viewed as lacking virtue. However, if a woman shuns sexual pleasure and sees sexual activity as a disdained obligation necessary only to have children, her behavior manifests a virtue (Espin, 1992). Problems and matters of sexuality are usually only spoken to other women. Older women are usually sought for advice on sexual problems.

The double standards such as infidelity of husbands are tolerated by some women. It is widely believed among Mexican and Mexican American women of all social classes that in general, men cannot and should not be trusted. Even though a man's behavior may
be offensive or abusive, women stay with their man because having a man gives some women a sense of self-worth (Espin, 1992).

**A Historical Perspective By Feminists**

To further augment the preceding description of the Mexican culture, the following is included to provide a feminist, historical description of the social forces impacting the lives of individuals of Mexican heritage. These descriptions are derived from authors' analyses and present the independent views of the people of the society in which they were a part.

Individuals of Mexican descent have populated the United States for hundreds of years. With the 1848 treaty of Guadalupe Hildalgo, Mexico ceded to the United States areas of land that are now California, New Mexico, Arizona, Colorado, Nevada, and Utah (Schick & Schick, 1991). American citizenship was granted to Mexicans living in these Southwestern regions. More land in the Southwest was bought from Mexico with the 1854 Gadsden Purchase.

In 1848, the Mexican people living in the Southwest were mostly peasants existing off the land. The family system was patriarchal and hierarchical by gender and age. Males had more power than females, although elderly females were respected and had a strong say in family matters. Valued norms in males were their ability to work and provide for
their family. Females gained their value from doing household chores such as cooking and growing crops, and maintaining stability in the family (Dill, 1992).

**Changes In Lifestyles**

After 1848, the influx of Anglo immigrants to the Southwest gradually displaced Mexican Americans from their land and used the Mexicans as cheap labor (Dill, 1992). Greedy priests and other men seeking to increase their wealth often succeeded in taking land away from the Mexicans when documentation of property could not be produced. In Mexico, women were allowed to own property separate from their husband. If the woman died, the property would go to the children and relatives, not the husband, unless such stipulations were made in a will. Widowed women or abandoned women were often prey for males wanting to expand their property. California courts later passed a law that allowed the deceased wife's property to revert to her husband. Laws which did not recognize equal ownership of property between husband and wife, ignored and undermined important aspects of the extended family (Dill, 1992). The outcome was that women lost important legal rights (Jameson, 1988).

The economic imbalance that proceeded from the development of retail stores, mining, the building of railroads, the new system of labor, and the transient lifestyle that followed affected the living structure of the Mexicans in the region. Unable to compete with the Anglos and their large production of crops, cattle, and hog ranching, Mexican
peasants living in these southwestern regions were also unable to keep up with food shortages and inflationary prices of commodities (Gonzales, 1990). Money was scarce among the Mexicans. Mexican men were forced into menial work. The men began to leave their families to work in the mines or the railroads which sometimes were hundreds of miles away. The work was long and hard for the meager wages paid and often the work was under unsafe conditions. Consequently, many fathers, husbands, and sons were killed at their jobs. As the men left their family seeking work, many women were left behind and some of the women were abandoned (Gonzales, 1990).

The women who were left alone as heads of households had the daily struggle of survival. Familiar family lifestyles among the Mexicans changed. Women entered the Anglo work force engaging in service work such as domestics, laundering, and sewing clothes for Anglos (Gonzales, 1990). Their wages were the lowest paid and often their children also worked as domestics to help with the family income.

Other families chose to follow the men to mining camps or railroad camps which at first had prohibited families into the camps. Employers, as a means of attempting to stabilize the work-force, later acceded to allowing families to live in the camps. The living conditions in these camps were crowded and unsanitary. Women found themselves tending to sick children and family members stricken with disease (Dill, 1992).
Agricultural work was another option for earning a living. Entire families sometimes worked on seasonal jobs which led to transient lifestyles. After working in the fields, the women still had household work to attend to.

**Women Maintaining Cultural Norms**

There were several factors which contributed to the maintenance of the Mexican culture. The four that are described are (a) the structure of the Mexican family along with its extended family network, (b) poverty, (c) the kinship expansion through godparenting, and (d) the oppression and racism to which the Mexicans were exposed.

**The Family and Extended Family**

Although lifestyle changes occurred among the Mexican and Mexican Americans, the women are credited for preserving the Mexican culture (Dill, 1992; Gonzales, 1990). When women were left by males seeking work, the women usually did not live alone but lived with extended family members (Gonzales, 1990). Living in these large extended families, everyone did their part to maintain the survival and well-being of the family by pooling their resources. Whether the women lived in extended families or in the camps, the women were instrumental in preserving local customs. Mexican traditions were maintained by the celebration of birthdays, baptisms, saints' day, weddings, and funerals in
a manner consistent with the culture. Folklore, songs, and other oral traditions also helped perpetuate the Spanish language (Dill, 1992).

**Poverty and the Mexican Culture**

Poverty assisted in the perpetuation of Mexican cultural norms as the women reached out to each other as sources of sustenance. Crops grown in their villages were used to barter among each other and kept individuals interacting with one another. The women led church services. Traditional meals were cooked and the Mexican style of cooking was retained. The Spanish language was also perpetuated. Usually there were no physicians in the Mexican villages, and many peasants could not afford to see the town physician. Instead, the older women were looked up to for advice and many of the older women served as mind and body healers (Espin, 1992). These healers were called "curanderas", "espiritistas", or "santeras". At times these elderly women were also the village's midwives known as "parteras". The use of varied traditional herbs for medicinal purposes was passed on to others. Padilla and Ruiz (1973) explicate that many Mexicans and Mexican Americans continued to avoid hospitalization which represented exposure to an Anglo institution where many faced rejection, hostility, and prejudice.

In times of need, the roles of women changed as those of the men. Instead of being submissive and subservient, these women were strong leaders and constructed communities that were home for their family and neighbors (Deutsch, 1987).
The Retention of Culture Through Godparenting

Godparenting was another form of extending the family, providing security for individual members, and preserving the Mexican culture. Godparenting "compadrazgo" was a means of connecting family and community through respected friends or authorities. Godparents had a moral duty to assist the child financially in times of need and to substitute as parents in the event of a parent's death. Dill (1992) describes how this tradition cut across class and racial lines as kinship ties were expanded between the rich and the poor, and between individuals of different races (Spanish, mestizo, and Indian).

Racism and Oppression

Racism and oppression were social forces experienced by Mexican and Mexican Americans which helped retain the Mexican culture. For example, in California, deliberate efforts to Americanize Mexican immigrants took place in the early twentieth century. The main purpose of these programs was to eradicate Mexican values and to have the Mexican immigrants assimilate American values so they could fit in American society (Sanchez, 1990). The Americanization programs targeted mothers as it was thought the mothers could instill American values in their children. When this did not work, adolescents were targeted to perpetuate American values. Further, during the mid twentieth century,
schoolchildren in other southwestern regions of the United States, were disciplined in the schools for speaking Spanish.

Another reason for the Americanization of women was to use these women to serve the needs of the Anglos such as for domestic services and also, so that the women could Americanize their men (Deutsch, 1987; Sanchez, 1990). Missionaries in the villages and social workers all tried to Americanize the Mexican women. Americanization programs were a way of offering second-rate citizenship which the Mexicans turned down (Sanchez, 1990).

**Mexican and Mexican American Women and Jobs**

The American economic structure which was changing into a high technology and service structure impacted the growth of income for the poor (Eitzen & Zinn, 1992). The Hispanic population, of which Mexican Americans are a subgroup, were a group of individuals heavily impacted by industrial job loss and by declining manufacturing employment. Mexican and Mexican American women made up a large part of the service work force of which the pay was extremely low and the working conditions were substandard. Both men and women worked in factories and in manufacturing plants, but as a rule men held the power jobs while women did the menial work (Soldatenko, 1993). Women's jobs have been those characterized as non-union affiliation, service sector, and of low-paying wages (Eitzen & Zinn, 1992). Review of the literature described how working
in factories provided women an environment to network (Ruiz, 1990). However, Soldatenko (1993) argued over women's inability to network in factories and garment manufacturing plants due to the large turnover rates, families living great distances from each other, the high level of noise in factories, and the intense competition for work.

Women worked outside the home to supplement their husbands' income, and many women worked because they were the head of household. The results of Romero, Castro, and Cervantes' (1988) study indicated a high level of stress endured by Hispanic women related to losing their jobs. The study found that the women's loss of work negatively impacted family relationships. This study suggested older women had higher levels of stress than younger women from losing their jobs. Racial and gender discrimination in the work arena were forces frequently encountered by the women in the study.

For new Mexican immigrants coming to the United States looking for work and assimilating into communities was not an easy event in Mexican American communities (Pardo, 1993). Mexican Americans saw the new immigrants as backward individuals. The new Mexican immigrants were called pejorative names and Mexican American students in schools segregated themselves from the poorly English speaking immigrants. Consequently, the new Mexican immigrants preferred to reside next to older immigrants (before 1965) than next to the United States born Mexican Americans (Pardo, 1993). It was the women in these communities who bridged the social gap for the new immigrants.
and assisted them to adjust to their new community by teaching them the rules and norms of the community.

The subject of dominant Mexican and Mexican American males not allowing the women to work outside the home was addressed in the literature. Segura's (1993) qualitative study on 30 Mexican and Mexican American women found that Mexican and Mexican American men did not oppose their wives working outside the home as long as the women's employment did not challenge the patriarchal structure of the family. Men were not opposed to women working outside the home as long as the women worked to help the family economically, if the women voiced that housework was a priority, and if the men were not asked to help with the housework or child rearing. This study was further supported by the findings from Flores-Ortiz's (1993) study, whose sample included 40 Mexican and Mexican American families in northern California. Flores-Ortiz's study found marital discord from wives working to occur if, by working, the women became unavailable to the men or to the household responsibilities.

Mexican and Mexican American women's views on working outside the home or staying home to raise and care for the family varied. Segura's (1993) qualitative study indicated the Mexican women came to the United States to find a better way of life and expected to work outside the home. For many of the Mexican women, their work already entailed housework and working outside the home. In contrast, some Mexican American
women had been acculturated in the belief mothers should stay home and raise their children, and expressed guilt when they did work outside the home.

**Educated Mexican American Women and Males**

Formally educated Mexican American women and males recount experiences with their own silence and oppression. Moraga (1992), a poet and playwright, described her good fortune when growing up and passing for an Anglo because of her fair skin inherited from her Anglo father. She told of being spared the oppression her Mexican mother suffered until she acknowledged her lesbianism. She then felt the silence and oppression known to her family and was oppressed for her gender, race, and for her lesbianism.

Trying to survive in an academic setting is also a struggle for those being stereotyped (Madrid, 1992). Mexican Americans come to feel they are the "other" in the American culture. Madrid (1992), a professor of Spanish language and trained as an analyst of literary texts, told of how being the "other" included being highly visible and highly invisible. One was visible because of ethnic features and because of the language accent when speaking. Invisibility came from being left out or from not being considered because one is stereotyped as different or of being incapable. Being the "other" meant being the outsider.

Determined to rise above the poverty of her Mexican family, Castellano (1992), a professor of English, described her rage at others' explicitness in telling her she was
defective and incomplete because of her gender and race. Obstacles were also presented by her own family members who implicitly and explicitly expressed wonder as to why she was not married, or when they questioned her obsession with reading. Castellano (1992) revealed she sensed her family did not believe she could succeed.

Summary

An overview of the literature enhanced the plight of women with HIV/AIDS. Concepts generated from the study of women with HIV/AIDS were examined. Descriptions of the Mexican culture provided the context for the researcher's belief that women of Mexican heritage with HIV/AIDS have particular needs and concerns which need to be examined by nurse researchers.
CHAPTER 3

METHODOLOGY

This chapter, describing the research design and methods consists of five sections. The first section centers on phenomenology as the method of choice for investigating the lived experience of women of Mexican heritage with HIV/AIDS. The research design is described in the second section and includes the sample, interviewing process, data collection procedure, and protection of participants' rights. The third and fourth section expands on the research design by describing the translation method used for the protocols in Spanish and the process of data analysis. The final section addresses the evaluation criteria used in this study.

Phenomenology As A Research Strategy

The number of women of Mexican heritage who contract HIV/AIDS continues to escalate. Along with social-economic pressures, these women are also influenced by the Mexican culture which concurrently influences their health status. The proposed research was to conduct a phenomenological study to describe the experience of living with HIV/AIDS in women of Mexican heritage. The objectives for this study were to:
1. Describe the essential structure of the lived experience of women of Mexican heritage who have HIV/AIDS.

2. Compare patterns of the lived experience of women with HIV/AIDS and the present study which focuses on the lived experience of women of Mexican origin with HIV/AIDS.

Phenomenology is a philosophy, an approach as well as a research method (Munhall, 1994; ). Embedded in the philosophy of phenomenology is the view that individuals are conscious of "being-in-the world". It is through the body that one accesses the environment. Perception, which is enabled by the body, is an individual's access to experience in the world (Munhall, 1994). Hence, the mind/body, subjectivity/objectivity dualism is resolved. The intentionality of consciousness implies individuals are conscious of some object in their environment. Every act of thinking contains an object of thought (Natanson, 1973). Other acts of perception such as remembering, reflecting, imagining, and willing are also directed at some object (Natanson, 1973). As individuals interact and experience others in their environment, they are influenced by society, culture, historical context, and knowledge handed down by previous generations. Individuals are also influenced by their own perceptions of others’ claims and pronouncements (Munhall, 1994; Natanson, 1973). Experiences are, therefore, whatever presents themselves by way of the acts of perception. In phenomenology, the researcher is interested in the meanings ordered and constituted by an individual's appropriate acts of consciousness. For the
phenomenologist, these meanings lead to grasping the essences or unities of meaning found within a phenomena as experienced by one or more individuals (Natanson, 1973).

**The Method of Phenomenology**

Husserl's method of phenomenology was characterized as being reflective and subjective (Ströker, 1993). The method of phenomenology is reflective such that the focus is on the conscious experiencing of the object rather than on the object directly (Farber, 1966; Ströker, 1993). The path to learning the truth was by going to the "roots" or the "beginnings" of all knowledge. Knowledge could be found in the consciousness of the knowing participant who had experienced the phenomenon. The process of digging down to the roots of these phenomena Husserl later called "transcendental subjectivity" and implied "turning to the subject" for knowledge (Spiegelberg, 1982). In the phenomenology of Husserl, only by thorough inquiry into the acts of knowing could logical formations be properly interrogated with respect to their sense and truth (Ströker, 1993).

The phenomenological method is a rigorous process that strives to describe concepts and their meanings to understand the nature or meaning of human experience (Cohen, 1987; Munhall, 1989). The phenomenological method in its rigor goes to the "roots" of knowing the participant's consciousness to extrapolate the experience of the
event or phenomenon in their "life worlds". It attempts to capture by intuiting the meaning of the experience to achieve understanding.

Reasons for choosing the phenomenology method were due to my personal interest in understanding as fully as possible what living with HIV/AIDS meant to women of Mexican heritage. The method of phenomenology provides the way to discovering the essences or concepts that give common understanding to the phenomenon under investigation (Carpenter, 1995). Additionally, the methodology of phenomenology leads to the identification of the phenomenon's fundamental structure, the "essential structure" (Colaizzi, 1978). As a clinician and researcher, I wanted to discover the essence of their experience with HIV/AIDS to learn and understand the impact of the AIDS virus and women's consequent needs and concerns. The use of grounded theory would have led to explaining a social situation by identifying the core and operating subsidiary processes.

An additional aim for using grounded theory would have been to develop theory, which at this time was not my goal (Glaser & Strauss, 1967; Streubert & Carpenter, 1995). Although the purposive sample consisted of women of Mexican heritage, my intent was not to describe the social and cultural worlds of a particular group from the natives' point of view (Spradley, 1980). The use of ethnography would divert this research to discovering the cultural or social knowledge that people use to organize their behavior and understand their life experiences (Omery, 1988). As a feminist researcher, I wanted the women (with little prompting or influence) to be creators, narrators, and
validators of their own story, and to take an active part in this research endeavor. During the explanation of the research purpose, the women were acknowledged as being the experts on this topic.

The Research Process

Sample

The purposive sample of six women was recruited from (a) two AIDS community resource centers, and (b) from two health clinics for individuals with HIV/AIDS in a southwestern metropolitan city after the institutional review board approval for the research was obtained. A sample of 2 to 6 participants is considered adequate for a phenomenological study (Morse, 1994; Parse, 1987). Parse's (1987) criterion of "redundancy" was used to determine actual sample size. Redundancy criteria denote the addition of subjects to the point where no new themes emerge. Criteria eligibility for the study included: women of Mexican heritage needed to be at least 18 years of age, who tested positive for HIV and/or had AIDS, had the ability to speak either English or Spanish, and had to be willing and able to describe the experience of living with HIV/AIDS.

It was the aim of this study to identify the common elements, which describe the essence of the lived experience of women of Mexican heritage living with HIV/AIDS.
Aside from controlling age, gender, and ethnic group, no effort was made to control education, religious preference, socioeconomic status, extent of HIV infection, nor length of time with HIV/AIDS.

**Interview Process**

Each participant was interviewed by the investigator at a time and place convenient to the participant. Locations where the interviews took place included outside a fast-food restaurant, in a park near a participant's home, in a community resource center for individuals with HIV/AIDS, and in participants' homes. The interview sessions were open-ended and audio-tape recorded. Interviews lasted from 35 minutes to 90 minutes each.

The data generating question used for this study was:

"Please describe what it is like for you living with the HIV infection. Tell me all your thoughts, your feelings and your beliefs. Describe your experience of living with HIV until you have fully described it. You can start anywhere you want and end when you have no more to add."

Consistent with phenomenology, detailed descriptions of an experience were elicited using techniques of "interviewing by comment" as described by Snow, Zurcher, and Sjoberg (1982) as well as with minimum number of suggestive or leading questions (Field & Morse, 1985). It was the intent of the researcher to elicit as detailed a
description of the lived experience as possible and to ensure that the participants, not the interviewer, determined the content discussed.

**Data Collection Procedure**

Four different sites were used to recruit the participants: two sites were community resource centers for individuals with HIV/AIDS and two were health clinics for persons with HIV/AIDS. In three of these facilities, the facilitators or health care providers were contacted by the investigator and informed of the research and of the need for participants. One facilitator at a community resource center was contacted by a previously contacted facilitator. Facilitators were informed of the $50 participant compensation. Flyers announcing the research advertised for women of Mexican heritage with HIV/AIDS. The flyers included the researcher's name and a contact telephone number. The flyers (Appendix A) were distributed by employees of these facilities. The fourth site was a community resource center recruited by a facilitator already participating in recruiting women for this study. The facilitator from the fourth site contacted this researcher after being informed of the study and volunteered to assist with recruiting women for this study. Women interested in participating in the research contacted the researcher. Upon contacting the researcher, the purpose of the study along with its objectives were further explained. The women were appraised of risks and benefits to participating in the study. All their questions were answered as honestly as possible. The
data generating question was presented and the women were informed that they would be contacted several times during the data analysis. They were also informed they would be contacted at the completion of the data analysis to validate the findings of the study. The women were informed they had the right to stop the interview session at any point and could withdraw from the research at any point in time. Times and places convenient for the women were scheduled with those agreeing to take part in the research.

At the time of the scheduled interviews, the women were again informed of the study, and an informed consent (Appendix B) was obtained. For those women who could not read English, the researcher (who is bilingual) read and explained the content of the consent to the participant in Spanish. A copy of the consent was mailed to the participants, except one who preferred that it be mailed to the facilitator of the resource center who would then give it to her on her next visit to the center. The interviews lasted between 35 to 90 minutes.

**Protection of Participants' Rights**

This study was approved by the University of Arizona Human Subjects Committee (Appendix C) and the Ethical Review Committee of the College of Nursing (Appendix D). The three sites used for recruitment of participants verified the university's approval prior to granting their approval to assist in recruiting participants. The fourth site (a community
resource center for individuals with HIV/AIDS) granted verbal approval after consulting with a participating site.

Additional activities were directed to ensure protecting the participants and maintaining confidentiality.

1. All consents (Appendix B) signed by the participants were reviewed, read to them when necessary, translated verbally to Spanish, and a copy was mailed to all but one of them.

2. The purpose of the study was explained as clearly as possible.

3. Participants were apprised of the risks and benefits of the study.

4. All participants' questions were answered as honestly as possible.

5. The participants were also informed they had the right to end the interview or their participation in the study at any point in time.

6. Participants' full names were omitted on the audio-tape recordings and on the protocols.

7. Only pseudonyms were used on any documents.

8. All protocols as well as audio-taped recordings were kept locked in this researcher's office.

9. Only this researcher had access to participants' protocols and audio-taped recordings.
Translation of Spanish Protocols

All the interviews were audio-taped recorded and transcribed. Three of the six protocols from the interviews with the women were in Spanish. Prior to conducting data analysis these Spanish transcripts were translated from the source language (SL) which was Spanish to the target language (TL) which was English. An important concern in any translation is to produce the cultural equivalence of the text (Werner & Campbell, 1970).

The translation process had to go beyond finding a denotative (literal) meaning for a word used in the original or source language (SL). The translation process had to convert the word in the SL and provide a connotative meaning equivalent to the target language (TL). Inclusive in a culturally equivalent translation is equivalence in tone, style, syntax, semantics, context, and deep structures (the underlying meaning of a sentence) (González, Vásquez & Mikkelson, 1991).

Back-Translation

The current research used an adapted from of the translation strategy of back-translation which was highly recommended for translating instruments from the original (SL) to the target language (Brislin, 1970; Chapman & Carter, 1979; Cohen & Jones, 1990; Jones & Kay, 1992). Back-translation entails that protocols in the source language (SL) be translated to English or the target language (TL) by one translator. Then the
English translation (TL) is translated back to the source language (SL) by a second translator. The resulting two protocols in the SL are then compared. Table 3.1 depicts the strategy of back-translation used.

Table 3.1

| SL → 1st Translator → TL → 2nd Translator → SL |

For this research, the process of translating the protocols was as follows. Initially, the audio-taped Spanish protocols were hand written in Spanish by a bilingual person who was literate in the Spanish language. These written protocols were double checked with the audio-tape recordings by a professional translator and myself. Any errors were verified and corrected. The majority of the errors were due to portions of the protocols being barely audible. Once the protocols were written and typed, back-translation followed. The resulting two protocols in the SL were compared. Discrepancies and their sources were analyzed. Thereafter, corrections were negotiated by the translators and the best English version was selected.

Description of the Translators Used

Werner and Campbell (1970) emphatically assert that an interpreter-translator is not an *adjunct* to a cross-cultural-cross-language research project, but he or she is crucial
to its success. The translator is to be thought of as a colleague and as a confidant in the research project. Criteria for selecting a translator include language competence, familiarity with the culture, and professional maturity (Marín & Marín, 1991).

All of the three translators used in this study were of Mexican origin. Two of the three translators used in this research were professional translators who worked in a health care facility in a Southwestern city as translators. Of the two professional translators, one was born in Mexico, the other in the United States. The third translator was a lay person of Mexican origin, born in Mexico, and immigrated to the United States as a young woman. Only the two professional translators were proficient in English and Spanish, the third being more proficient in Spanish.

**Types of Errors Found**

Common errors were in the tenses of the translations. Most of the errors in tenses were found as significant statements were pulled from the protocols and compared to the original Spanish protocols. Medical procedures were difficult to translate by translators unfamiliar with medical terminology. When Clara described that the physicians wanted to place her husband on a life-support system, her narratives were translated to signify her husband would be placed in some kind of a chamber. There were a few mismatches in syntactic or in the arrangements of words in a sentence which affected the meaning when the protocols were translated to English. For example, "I look at my life calmly now"
should have been translated to “I look at my life as being more tranquil now.” Only rarely were original narratives missing in the English translations.

**Critiquing Translations**

The translators were candid in that they did not want to meet together and critique each others translations. They felt unable to fairly critique another’s work face to face. Therefore, this researcher had to meet individually with the translators when discrepancies were encountered. Marín and Marín (1991) indicated there were certain factors which could limit translation by committee. These factors included (a) cultural norms which proscribed disagreement with certain individuals such as those who are older or more educated, or (b) the reluctance of individuals to criticize their colleagues.

**Data Analysis and Interpretation**

The data were analyzed using an eight-step procedure adapted from Colaizzi (1978). First, the interviews were listened to several times to obtain a sense of the meaning being disclosed. Then, significant statements were extracted from the data, restated into more general terms and, underlying meanings were identified. Common themes which emerged from the reformulated meanings were next organized into theme categories. A full narrative description of the experiences of living with HIV/AIDS was developed from theme categories. Finally, the common essential structure of the lived
experience was identified. Findings begin to emerge at every step of the data analysis and are described in Chapter 4. The following section is an example of how significant statements evolved to formulated meanings.

Extraction of Significant Statements

The first step in data analysis was the extraction of significant statements. Significant statements are the words, phrases, and sentences that in themselves have an inherent contextual meaning. Repetitions were not excluded since it became obvious during the reading of the protocols that repetitions were used by the participants for emphasis. Significant statements consisted mainly of phrases or complete sentences. The significant statements were reformulated into a generalized form for the purpose of moving from the individual case to a more general language of science. Table 3.2 presents examples of restatements from each protocol.

Formulated Meanings

The formulated meanings were derived through a process of studying significant statements and restatements to arrive at their meaning, the formulated meaning. A goal in developing formulated meanings was to present the meaning within context. Therefore, protocol statements preceding and following the formulated meaning were considered in the development of formulated meanings. Moreover, care was taken to maintain a close
connection between the original statement, restatement, and formulated meaning. Three
doctorally prepared judges knowledgeable in the method of phenomenology and one
"non-involved" person were used to validate this process. Due to the enormous amount
of data analyzed and developed into formulated meanings, Table 3.2 presents only two
examples from each of the protocols which include significant statements (SS),
restatements (RS), and formulated meanings (FM).
Table 3.2

Two Examples of Significant Statements, Restatements, and Formulated Meanings

From Each of the Protocols

Examples Elena’s protocol
SS: There’s no cure for it.
RS: there is no cure for the AIDS virus
FM: knows there is nothing to stop the virulence of the virus
SS: And the more I go to the clinic, the more money, you know, they’re, it’s too much and
RS: the more trips to the clinic the higher the debt becomes
FM: receiving care means becoming deeper in debt

Examples from Chrisy’s protocol
SS: She is like the major support thing in my life
RS: parent is the center of support
FM: parent has been the center of support during ordeal
SS: And my son, he made a big difference in it too.
RS: son has made a big difference in coping with the virus
FM: lives for and gains inner strength from offspring

Examples from Rene’s protocols
SS: He just, he didn’t know what they were
RS: physician didn’t know what they were
FM: changes in body a puzzlement to medical professional
SS: He just kept putting it off, you know, he didn’t want to discuss it and...
RS: physician ignored and didn’t want to discuss body changes
FM: felt abandoned that concerning body changes were ignored by health professional

Examples from Clara’s protocols:
SS: Every little thing tires me out
RS: even small activities cause fatigue

(table continues)
Table 3.2 - Continued

FM: ever persistent the virus saps one’s essence of life
SS: I get fatigued, very fatigued and...
RS: gets fatigued, very fatigued
FM: is left drained of all energy

Example from Alicia’s protocols:

SS: Ah! This began when my daughter became ill
RS: found out had the virus when offspring became ill
FM: awareness of the AIDS virus came through the misfortune of offspring
SS: She is eight years old
RS: offspring is only eight years old
FM: misfortune struck one so young and innocent

Examples from Berta’s protocols:

SS: When I want to caress or touch my husband, I feel afraid
RS: is afraid to caress or touch mate
FM: fears the hurt from mate’s rejection
SS: Sometimes I only touch him and he asks, do you have a cut?
RS: sometimes only touches mate and mate asks if has an open cut
FM: mate fears contracting the virus from wife

The validation of formulated meanings was to make certain of the match between the constructed realities of the participants and those realities represented by the researcher in the formulated meaning. Validation of formulated meanings resulted in minimum changes. Changes that occurred from the process of validation were mainly to
make the meaning clearer by adding precision to the meaning or to expand the meaning and make it more relevant to the context. For example, the term "stable" was changed to "responsible"; "was horrified to think had transmitted the virus to offspring" was expanded to "realizing the serious consequences of the diagnosis, was horrified to think had transmitted the virus to offspring."

**Evaluation Criteria**

For a study to have integrity, it needs to follow standards of rigor which have been acknowledged by the scientific community. Guba and Lincoln's (1989) trustworthiness criteria and the criteria of authenticity was applied to this study in an effort to promote its trustworthiness. These criteria are congruent with the belief system of the constructivist paradigm.

**Credibility**

The criterion of credibility focuses on validating the match between the constructed realities of the participants and those realities as represented by the researcher. This study used four techniques to establish credibility (a) prolonged engagement, (b) persistent observation, (c) progressive subjectivity, and (d) member checks.
**Prolonged Engagement**

This technique requires the researcher to spend sufficient time with the participant to establish a trusting relationship. Such a relationship facilitated discerning useful information such as eliciting misinformation during the researcher's and participants' interactions due to distortions. Furthermore, a trusting relationship enabled the researcher to become immersed, and better understand the context of the situation. Relationships in this phenomenological study were developed during the interview, during calls/meetings with the participants during data analysis, and when validating the constructs with the participant.

**Persistent Observation**

This criterion encompasses that substantial observation or time is spent with the participant so that the researcher is better positioned to identify events/elements in the situation which were relevant to the phenomenon of interest. In this manner, patterns of the phenomenon are more easily perceived. In this study, persistent observation was limited to the time spent with the participant during the interview, while conversing on the telephone, or on repeated encounters. The time spent with the participants never seemed enough. However, that was in part due to my desire to probe further into their
experiences. Member checks were valuable in clarifying the contexts and meanings of unclear significant statements.

Peer Debriefing

In this technique, this researcher engaged several "non-involved" persons in discussing particular findings or in "testing out" certain perspectives or findings. These "non-involved" persons included a close friend and two doctoral student classmates who were asked to opinion on particular constructed formulated meanings or themes.

Progressive Subjectivity

Progressive subjectivity required this researcher to elicit the assistance of someone familiar with the method of phenomenology to monitor the researcher's developing constructions. Colleagues or instructors familiar with phenomenology monitored developed constructs.

Member Checks

Participants were asked to take part in validating exhaustive descriptions which reflected their experiences. Changes were incorporated into a revised description.
Transferability

Transferability is paralleled with external validity or generalizability of the conventional paradigm. The ontological position of the constructivist paradigm embraces the notion of multiple realities, therefore, establishing generalizability is not a concern of constructivists (Guba & Lincoln, 1989).

Thick Descriptions

The burden of proof for claiming transferability is on the receiver. However, to enable other researchers to discern transferability or to compare similarities between this study and others, thick descriptions of the entire research enterprise are provided.

Authenticity

Guba and Lincoln's (1989) criterion of authenticity is based on the constructivist paradigm, unlike that of the credibility and transferability which have roots in the positivist paradigm. The authenticity criterion further enhanced the establishment of trustworthiness.

Fairness

A constructivist paradigm recognizes multiple realities exist and participants may have different value systems, some which may be in conflict with those of the researcher's
own values. Therefore, the strategy of fairness addresses that participant's differing constructions along with their underlying value systems was accounted for in an even handed way. Participants' different or conflicting values were extracted, examined, explained, and equally honored throughout the analysis of the dissertation.

Summary

This chapter presented the method of phenomenology and addressed its appropriateness for investigating the lived experience of women of Mexican heritage with HIV/AIDS. The research design was described including the translation method of back-translation used to translate the Spanish protocols. The evaluation strategies used to establish the trustworthiness of this study were presented.
CHAPTER 4

RESULTS

The research objectives which provided a focus for this research, and which are answered in this chapter are (a) describe the essential structure of the lived experience of women of Mexican heritage who have contracted the HIV virus, and (b) compare the patterns of the lived experience among women of Mexican heritage with the patterns of the lived experience among a multicultural sample of women with HIV/AIDS, the researcher’s previous study.

This chapter is comprised of six sections which (a) provide a description of the participants, (b) describe the findings in each step of data analysis, (c) address validation of the findings, (d) summarize the findings, (e) compare the findings between the two studies on women with HIV/AIDS, and (f) concludes with a summary of the findings.

The Participants

Six women of Mexican heritage were recruited into the study. Outlined in Table 4.1 are the pseudonyms for the participants, age, citizenship, length of time in the United States of America (USA), and type of medical insurance. The women ranged in age from 18 to 36 years; the average age was 23 years. Half of the participants were USA citizens and the other half were Mexican nationals. All the women of Mexican citizenship spoke Spanish only, and their years of being in the USA ranged from 2 to 7 years. The length of time in the USA for one participant (Alicia) is unknown due to the participant valuing
confidentiality and stipulating that any contact with her be made only through her social worker. Since the interview, the AIDS resource facility has lost its funding and staff, and this researcher has been unable to communicate directly with Alicia. All the women in this research had some type of public medical assistance instead of private insurance. Five participants were receiving medical care through the Ryan White Comprehensive AIDS Resources Emergency (C.A.R.E.) Act and one participant was eligible for Arizona Health Care Cost Containment System (AHCCCS).

All the women appeared to be from a lower socio-economic background. The income of the participants was not elicited as this researcher felt uncomfortable asking such a personal question due to (a) the women were initially informed that the researcher was only interested in their description of their lived experience, and (b) it was evident that the participants were not financially well off. Other demographic variables of the participants are outlined in Table 4.2.

Half of the participants were married, the others were divorced (n = 1), single (n = 1), and widowed (n = 1). The number of children ranged from one to four and the children's ages ranged from less than 1 year old to 16 years old. At the time of their interview, three of the women had been diagnosed with AIDS. The length of time since learning of their HIV sero-positive status ranged from 1 to 5 years. Elena was the only woman employed at the time of the interview.
A brief orientation to the participants is provided in advance of the findings to depict the participants as persons. All passages from the participants’ protocols end with the notation [SS followed by the number of the significant statement].
### Table 4.1

**Overview of Participants**

<table>
<thead>
<tr>
<th>Participant</th>
<th>Age in Years</th>
<th>Citizenship</th>
<th>Years in USA</th>
<th>Medical Insurance</th>
</tr>
</thead>
<tbody>
<tr>
<td>Elena</td>
<td>36</td>
<td>USA</td>
<td>N/A</td>
<td>Public</td>
</tr>
<tr>
<td>Chrisy</td>
<td>18</td>
<td>USA</td>
<td>N/A</td>
<td>Public</td>
</tr>
<tr>
<td>Rene</td>
<td>27</td>
<td>USA</td>
<td>N/A</td>
<td>Public</td>
</tr>
<tr>
<td>Clara *</td>
<td>28</td>
<td>Mexican</td>
<td>2 years</td>
<td>Public - AHCCCS</td>
</tr>
<tr>
<td>Alicia *</td>
<td>31</td>
<td>Mexican</td>
<td>Unknown</td>
<td>Public</td>
</tr>
<tr>
<td>Berta *</td>
<td>22</td>
<td>Mexican</td>
<td>7 years</td>
<td>Public</td>
</tr>
</tbody>
</table>

* Spanish speaking only

### Table 4.2.

**Demographic Variables as of 1994**

<table>
<thead>
<tr>
<th>Participant</th>
<th>Marital Status</th>
<th>Children</th>
<th>Cell Count</th>
<th>Year Diagnosed</th>
<th>Occupation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Elena</td>
<td>Divorced</td>
<td>son = 16 yrs. da. = 15 yrs.</td>
<td>500</td>
<td>1993</td>
<td>Maid at a motel</td>
</tr>
<tr>
<td>Chrisy</td>
<td>Single</td>
<td>son = 4 yrs.</td>
<td>1500</td>
<td>1991</td>
<td>Recently quit job at a day care</td>
</tr>
<tr>
<td>Rene *</td>
<td>Married</td>
<td>son = 11 yrs. da. = 9 yrs. da. = 8 yrs. son = 2 yrs.</td>
<td>24</td>
<td>1992</td>
<td>On disability for having AIDS</td>
</tr>
<tr>
<td>Clara *</td>
<td>Widow</td>
<td>da. = 6 yrs.</td>
<td>26</td>
<td>1989</td>
<td>Unemployed</td>
</tr>
<tr>
<td>Alicia *</td>
<td>Married</td>
<td>da. = 8 yrs. son = 6 yrs. son = 5 yrs. infant son</td>
<td>2</td>
<td>1992</td>
<td>Homemaker</td>
</tr>
<tr>
<td>Berta</td>
<td>Married</td>
<td>da. = 3 yrs.</td>
<td>600</td>
<td>1993</td>
<td>Homemaker</td>
</tr>
</tbody>
</table>

* confirmed with AIDS
I first met Elena, a 36 year old single mother, and her two teenage children in the waiting area of an HIV/AIDS health clinic. We had agreed to meet there after her clinic appointment. She wanted to take part in the research but only if we talked further about what the research entailed and only if her children consented. We were both shy upon meeting, and her children were polite as she introduced them to me. It was evident that they were like her body-guards. Elena’s 15 year old daughter and 16 year old son listened quietly as their mother and I discussed the research. Before giving her consent, Elena asked her children how they felt about her giving an interview. Her children consented and a time would be set in the future for the interview. Elena did not own a car. By luck (mine), they had to take a bus home, so I offered to drive them home. During the drive, the tension lessened. Upon arrival, Elena suggested we do the interview that day at her home.

Their home was a small clean wooden apartment in the back of her uncle’s house. It was located in a lower income neighborhood in the south side of a metropolitan city. As I interviewed Elena in her living room, her children left for their rooms. Elena is an attractive woman about 5’3”, about 120 pounds, who has many prominent Native American features mixed in with her Mexican background such as high cheek bones,
tanned-colored skin, and dark black shiny hair which she wore curled and shoulder-length. She smiles easily and her voice is soft and husky-sounding.

**Contraction of the virus.**

Elena contracted the virus from her boyfriend who knew he had AIDS but never told her. She found out from his physician while she was visiting her boyfriend at the hospital. Elena had been with her boyfriend for six months. They had met at a bar. Upon informing her mother that her boyfriend had AIDS and that she too may have contracted the virus, Elena was hurt by her mother, who instead told her it was her fault for going out. When her boyfriend left the hospital, he went back home to Mexico, and Elena has not spoken to him since. Elena becomes angry when she reflects that she was not warned by her boyfriend. Her boyfriend never acknowledged to Elena that he had transmitted the virus to her.

**State of affairs.**

At the time of the interview and one year since learning she was HIV positive, it was evident that Elena was still overwhelmed by the consequences of her diagnosis.

I’m HIV positive. It’s contagious, you know. It is very harmful for your partner, you know, and... It can kill you! You know, it can kill you....[SS 43-46]
Furthermore, she wanted to know more about the AIDS virus because she felt afraid of the disease and did not really understand it. She has her son read about the virus in school and he tries to explain it to her. Her only symptoms are fatigue.

Since she works as a maid in a hotel, earning minimum wage, she is not eligible for AHCCCS and her only source of medical care is through the Ryan White Act. Elena would like to go to a private doctor to be retested for the AIDS virus but says she has no money to do so.

Those who know.

A few friends, her mother who lives in the same city, her sister who lives in another state, her ex-husband who is in prison in another state, and her children, know she has the AIDS virus. Elena does not attend any support groups as she says she is embarrassed about others learning she is HIV positive. The people at work do not know she has the virus. She and her children conceal her secret.

Future outlook.

Elena anticipates re-marrying her ex-husband (the father of her children) who is in jail in another state. He accepts her illness. Furthermore, he tells her he is dying from a damaged liver. Meanwhile, Elena refuses to date any other men (even when her children encourage her to do so) because she is afraid to transmit the virus to others. She has been celibate since learning of her diagnosis, about one year.
One year since the interview.

Telephone contact with Elena has continued throughout the year of data analysis. We met for lunch once during data analysis for validation of the essential structure. All three have moved out of her uncle’s apartment and now live in a small house in a safer part of the city. Her home is small, from the living room which also has the washing machine, a sofa, a few tables, you can see her kitchen which is 15 feet away and a small table against the kitchen wall. The home is clean and straightened up although the furnishings are worn. Elena seems less overwhelmed by thoughts of dying than a year ago, although when thoughts of her death enter her mind, fear emerges. She now thinks about attending a women’s support group but still hesitates. Furthermore, she says she is becoming more comfortable telling others she trusts that she has the AIDS virus.

Ties with her mother have been broken due to her mother telling others about her infection. Elena thinks her mother has invaded her privacy too often. The activities of her teenage children have consumed much of Elena’s thoughts and energy this past year. Both teenagers are more independent and have rebelled against some home rules set by Elena. Still, Elena and her children are very close. Elena’s daughter has verbalized her fear of losing her mother. Elena’s ex-husband was released from jail, broke parole, and is again back in jail in another state. Elena never saw her ex-husband when he was released from jail. Elena still hopes that someday they will marry. Elena’s celibacy continues.
The day of our scheduled interview, I went to Chrisy’s house only to have a young girl say Chrisy was not home. As I was getting in my car, another car with three young women drive up and Chris jumps out. She leads me into the her grandparents’ house, to the kitchen where the interview takes place. On the way we pass by her grandfather who is sleeping in his chair in front of the TV. Her grandmother, who did not come out, is in one of the back rooms.

Chrisy the Person

Chrisy looks very young. She is 5 feet, about 130 pounds, light complexion, brown eyes and has short curly light brown hair. She does not appear to be of Mexican descent nor does she speak with an accent. Chrisy is full of energy and very confident in her thoughts and mannerisms. She seems very mature for 18 years old. Chrisy and her 4 year old son presently live with her grandparents along with a 7 year old young girl whom the grandparents adopted when the child’s mother did not want her.

Chrisy feels she has control of her life. She does not think she suffers from any of the HIV symptoms except frequent vaginal yeast infections. Furthermore, her CD4 count is normal. Chrisy was 16 years old when she discovered she was HIV positive. At that time she was going through an adoption agency when she was pregnant with her second child. She had alienated herself from her family, had been living with her boyfriend, and
could not deal with another child. She remembers being panic-stricken upon learning she was HIV positive. Her boyfriend was out of town at the time and she felt very alone.

**Contraction of the virus.**

Chrisy contracted the virus from her boyfriend. He did not know he had the virus and denied having the virus when Chrisy informed him of her HIV positive status. Chrisy describes her boyfriend as a philanderer.

**State of affairs.**

Positive events have transpired since Chrisy learned she was positive for the AIDS virus. Her second son who was born HIV positive has converted and does not show signs of the AIDS virus in his blood tests. At the time of his birth Chrisy endured great guilt for giving her son the virus. Since her son converted, Chrisy has regained her faith in God. Chrisy’s CD4 counts have also continued to stay normal. She recently quit her job in a day care center because it was a stressful job and has since been feeling better.

Although Chrisy does not see much of a future with her boyfriend, she still occasionally sees him. Chrisy is afraid to meet other men. She fears being rejected by them when they find out she is HIV positive. Once she had sexual intercourse without telling her partner she had the AIDS virus. Even though she used protection she said she felt badly about it and does not want to feel that way again.

I did it one time but it was like with protection and everything, and I still felt so bad for weeks. I felt like I..., I felt like a murderer or something. Because I didn’t tell the
guy before he did it....So that’s why I just choose not to even talk to them. I don’t even like feeling the way I feel after I do, you know. [SS 162-165, SS 169-170]

Chrisy feels as if she is the only teenager in the world with the AIDS virus. She has never met anyone her age with the virus and would like to talk to someone her age who is HIV positive. Chrisy is adamant that teenagers lack education on the AIDS virus. She also thinks the media misrepresents individuals who contract the virus and would like to see adolescents with the virus represented by the media in commercials.

Those who know.

All of Chrisy’s family and friends know she has the HIV virus. Chrisy is now very close to her family who has been very supportive. She believes contracting the virus was God’s only way of uniting her back to her family.

Future outlook.

Since her son converted back to normal from being HIV positive, Chrisy feels there is hope someday she will be rid of the virus. She feels empowered to fight the virus and prolong her life. Chrisy wants to endure the virus in order to see her son grow up.

One year since interview.

Contact with Chrisy has been lost. Her case manager no longer works at the AIDS resource center and there is no new telephone number to contact Chrisy.
Rene

In the southwestern part of a large metropolitan city, I first saw Rene waiting for me outside her apartment complex. It was a two story U-shaped structure in a rough-looking neighborhood. A heavy set teenager, who I later found out was her brother, was hanging over the second story railing watching our encounter. Upon meeting, Rene suggested I drive to a neighborhood park for the interview. I felt uneasy being in such a neighborhood until I saw police cars frequently patrolling around the park. Our interview was often interrupted by low flying airplanes landing and taking off from a nearby airport.

Rene the Person

Rene is about 5 feet tall and about 120 pounds. She indicated she had lost a lot of weight but is happy because she always used to be much heavier. Her face has pretty features and she has dimples on both sides of her mouth. She appears tranquil and she smiles a lot. It would not have surprised this researcher if she had smoked marijuana prior to the interview as she admitted she used it often to increase her appetite and to help her deal with the stresses in her life.

Contraction of the virus.

In her calm candid manner Rene recounted her lived experience. Throughout the interview, I found myself intermittently shocked by her story. She revealed she had led a promiscuous lifestyle, had been a drug addict and sold her body for drugs. She thinks she contracted the virus from a drug dealer who she slept with for drugs. Discovery of having
the AIDS virus occurred because Rene was experiencing symptoms such as weight loss, fever, fatigue, lymphadenopathy, and genital herpes. She suspected she had the AIDS virus and went to a physician who only ignored the symptoms. With symptoms still recurring, Rene again went to her physician and asked to be tested for the AIDS virus. Positive test results confirmed her worst fears, she had AIDS. She ran out of the physician's office after yelling at her physician for lying to her. Overwhelmed by the meaning of her diagnosis she contemplated suicide. After many hours, her family convinced her to come home, and she informed her husband.

State of affairs.

Since she met her husband of seven years, she has been off drugs except for marijuana. She and her husband occasionally fight because he still uses cocaine and goes on drug binges. He tells her she is no better because she smokes marijuana.

Rene has four children ranging in ages from 2 years to 11 years. Her first born is mentally delayed and was by a previous marriage. She finds it ironic that her first born is not normal and that during her pregnancy she did not use any drugs. Her other children are within normal developmental limits for intellect although during her pregnancies, she used illegal drugs. Rene is concerned about her youngest son who has many medical ailments. She wonders if he has the AIDS virus but has not had him tested. She fears not being able to deal with the guilt of transmitting the virus to her child even when she knows
that if he does have the virus, medications could prolong his life. So she chooses not to dwell on that subject.

I still don't know if he's HIV positive because I'm scared to check him. I just...I mean I could barely handle my own and then finding out that he has it. I mean I know I'm doing him wrong by not checking him, you know, because he could be on medication and live a longer life if he does have it, but I'm just scared. [SS 38-43]

Rene's husband is HIV negative. She is relieved he has chosen to stay with her. However, she worries that he refuses to use protection during sexual intercourse. He says if Rene dies he too wants to die. Therefore, Rene worries that her children will be left without parents if her husband also contracts the virus. Rene is concerned because her sexual appetite has waned and her husband would like to have more frequent sexual intercourse. Her husband becomes frustrated, too, because Rene has a poor appetite, does not eat, and does not feel like cooking. He becomes upset because Rene is too tired to do any housework and her mother does everything for her. Rene's husband resents her mother who looks after Rene and the children. He has difficulty coping with Rene's infection, does not want to talk about it, and at times thinks Rene does not have AIDS.

Rene has a good relationship with her mother. Her mother is a devoted Catholic who does not believe Rene has AIDS. Rene acknowledges that she does not know what she would do without the help of her mother. Rene has faith in God. However, she still sees herself as a sinner because she cannot give up smoking marijuana.
Those who know.

Only Rene’s mother who lives in the same apartment complex, her husband, a sister, a couple of girl friends (whom she regrets informing), and a cousin know her secret. Family members on her husband’s side do not know she has the virus.

Future outlook.

Rene thinks her future looks very bleak. She believes she undergoes much stress with her infection, her husband, her children, and life in general. She says the stress is why she also smokes marijuana. She sees her body changing and knows many of the changes are the symptoms of AIDS. She is afraid of dying and at times prefers to ignore reality. Rene is on 7 different medications. Some days she chooses not to take them because they are large pills and they gag her. She knows someday she may regret not taking them, but some days, she just cannot swallow them.

One year later.

Telephone contact with Rene and her mother have continued throughout the year. In that year I have seen Rene three times, once in the emergency room of the health facility where I work, another time at her apartment where I delivered medication for her diarrhea, and the last time was in November of 1995. She was asleep in her mother’s sofa, curled up in a heavy blanket. Rene’s health has continuously deteriorated and she now
weights about 65 pounds and is very weak. She has been hospitalized several times for pneumonia and electrolyte imbalance. Rene's mother still takes care of her and the children.

Clara

I first met Clara outside her aunt's apartment complex located on the west side of a large city. We drove to a nearby fast food restaurant that she thought would be a good place for the interview. Clara seemed happy and excited to take part in a research study.

Clara the Person

Clara is a 28 year old short woman about 5 feet tall weighing about 115 pounds. Her cheerful outlook and her easy laugh belie the suffering she has endured. She has been a single mother since her husband who had hemophilia died of AIDS-related complications two years ago. During her husband's illness she brought him to the USA for medical treatment. She stayed at her husband's bedside for four months. He never left the hospital once he entered it. After he died, she went back to Mexico. There, she could not endure the stigma and the town's gossip that she had contracted AIDS by being promiscuous. She came back to the USA with her 6 year old daughter to live with her aunt. Two years of living with her aunt has created tensions between them. She now plans to return to Mexico where her own family lives.
Contraction of the virus.

Clara's husband contracted the AIDS virus from blood products used to treat his hemophilia. During her husband's last hospitalization, Clara had herself tested and was also found to have AIDS. She holds no one responsible for contracting the virus and feels she was a victim just as was her husband.

State of affairs.

Clara was recently hospitalized for allergic reactions to the medications for the AIDS virus. She knows the virus is invading her body. Clara indicates she does not fear death as she saw her husband die a horrible death and knows what to expect. Her only regret is leaving her daughter.

She has few friends in the USA, mostly her aunt's family, and she does not go out. For Clara, going to her clinic appointments is fun because she likes the physicians and nurses who treat her well. In Mexico, she was treated with aversion by the health care providers. Clara acknowledges her aunt has been very nice, but she thinks it is time to move out as they probably would like their own privacy.

Clara is naturally cheerful, loves music, likes to sing, and dance. When she is overcome with fatigue she tries to just stay in her room and not bother anyone with her problems.

I do not feel well. Yes, sometimes I feel weak. I have noticed this weakness. Every little thing tires me out. I get fatigued, very fatigued and yes, there are times when I
feel very bad inside, from the illness and everything. But I do not show it because I do not want to worry anyone. [SS 95-102]

**Those who know.**

Everyone in Clara's family knows she has AIDS. She is happy that the family does not pity her and she has become closer to her family since her illness. Clara is the youngest of five siblings and feels everyone is very supportive. She misses her own family, and she intends to see them soon.

Clara does not feel ashamed to have AIDS. It is only when she is shunned by others and made to feel ashamed that she becomes angry.

**Future outlook.**

Clara knows her body is succumbing to the virus. She tries to decide which of her family members will raise her daughter. They all are willing. Clara has lost hope in becoming romantically involved with anyone. Once, after her husband died, she met a young man who wanted to become her boyfriend. She revealed her secret and gradually he distanced himself. Having been disappointed, she chooses to focus her energy on caring for her daughter.

**One year after the interview.**

Contact with Clara was lost after she returned to Mexico. While in Mexico, Clara made one phone call to her health clinic here in the USA and told them she was not
allowed to return. In December of 1994, the hospital in Mexico contacted the health clinic asking for Clara’s medical records. Along with their request was a post office box number of a relative of Clara’s. This researcher then sent a letter asking about Clara. Several weeks later, Clara’s sister-in-law called and said Clara was very ill, had surgery, and was not doing well. Furthermore, Clara was down to 70 pounds and was very weak. They were caring for Clara at their home as well as her daughter who was doing well in school. I sent Clara a card with my telephone number but there has been no further communication.

Alicia

Alicia was the most secretive and the one who seemed to be having the most difficulty with her life of all the women interviewed. She chose to be interviewed at an AIDS resource office where her social worker would be nearby. Upon agreeing to take part in the interview, she stipulated that she could only be contacted through her social worker. Her own husband did not know she had AIDS. Alicia was driven to her interview by her social worker. She brought along her 8 year old daughter who has AIDS, her two sons ages 6 and 5 years who are negative for the virus, and she carried her infant son whom she held and fed throughout the interview. Alicia is a thin, young looking 31 year old woman. She is about 5 feet tall and weighs about 110 pounds. Alicia looked very tense but seemed determined to go through the interview. The social worker entertained the other children in another room during the interview. Later, the social
Alicia’s lived experience was filled with despair. She first found out her then 6 year old daughter had AIDS before learning she too had AIDS. Since discovering the virus, Alicia lives with the guilt of transmitting a deadly virus to her daughter. Alicia refuses to take her medication for two reasons (a) she sees having contracted the virus as a punishment for past deeds which must be endured, and (b) she tries to deny that she actually has the virus. Her pressing concerns are for her children’s well-being.

**Contraction of the virus.**

Alicia contracted the virus from her first husband. After the birth of her daughter, her husband revealed that in his past life he had injected drugs. Alicia had always thought of him as a responsible person and was shocked to learn this. She asked him if he had ever been tested for the AIDS virus and he said he had and that he was negative. Consequently, she never gave it anymore thought nor was she ever tested for the virus. They had two more children before they parted. Alicia later married. It is unknown to this researcher when Alicia married her second husband. However, her second husband knows their daughter has AIDS.
State of affairs.

Alicia and her husband do not discuss the AIDS virus. She lets her husband know that their daughter has never had any blood transfusions. Her husband does want to discuss the subject of AIDS in the family. Behind his back Alicia went to be tested for the AIDS virus and discovered she has AIDS. She is fearful to tell her husband. Alicia has tried to coax her husband to be tested but he refuses saying he would rather not know. Alicia fears telling her husband she has AIDS because she is afraid her husband will abandon her or find another to satisfy his sexual needs.

Alicia describes herself as being fastidious about cleanliness at home as she does not want her other children to contract the virus. She recounts how she vigorously lathers her hands with soap and Clorox before preparing her children’s meals. Clorox is used for most cleaning purposes.

There is much anger towards God which stems from her daughter contracting the AIDS virus. Alicia can comprehend that she is being punished for her misdeeds in life, but she can not understand how God could punish innocent children for their parent’s mistakes.

Those who know.

No one in their family knows that Alicia and her daughter have AIDS. Alicia is adamant that her family not know, as she does not want them to be disappointed in her.
She knows her family would be supportive if they knew but refuses to tell them. Alicia is so fearful others will find out she or her daughter has AIDS that she has severed relationships with all acquaintances. The only person Alicia talks to is her social worker.

When something happens to me, or I want to do something, I talk to her, and she helps me. I thank God for having met her. [SS 125-128]

**Future outlook.**

Alicia is aware that having AIDS is deadly and decreases one’s life span. She is filled with guilt and despair that her daughter has AIDS. She would like to run away with her children to a place where no one would know them and forget that they have the virus. However, for her daughter’s sake she makes it a point to attend to all her daughter’s medical needs.

**One year later**

Approximately eight months since the interview, I spoke to Alicia’s social worker. Alicia’s infant son had been hospitalized for several weeks in a city hospital where he almost died. The infant was found to be positive for the AIDS virus. Alicia was said to still be barely coping with her life and that her husband still did not know she had AIDS. Thereafter, contact with Alicia was temporarily lost due to the AIDS resource center losing its funding and unable to contact Alicia’s social worker. Recently, this researcher has found Alicia’s case manager. Alicia is said to still be having difficulty coping with her circumstances. The health of her daughter is failing. A copy of the essential structure was
given to the case manager to present to Alicia for input. There has been no feedback
from the case manager regarding Alicia’s feedback.

**Berta**

Berta chose to be interviewed at her home. She lives in a small white wooden
house with a chain-link fence around it. It is located in a predominately Hispanic
neighborhood. The living room had worn furniture but was clean and straightened-up.
From the living room one could see the kitchen and the doorway to a bedroom where her
6 year old daughter and her sister’s young son were supposed to be taking a nap. The
children were excited to have me as a visitor and it was difficult for Berta to keep them
quiet. At one point her daughter fell, was crying, and we continued the interview as she
rocked and comforted her daughter to sleep. The other child played quietly in the other
room.

**Berta the Person**

Berta is a pleasant, plump looking 22 year old woman. She is about 5 feet tall and
weights about 130 pounds. She has medium brown long hair, brown eyes, and has a light
rosy pink complexion. Berta looks very healthy. She is very courteous, somewhat quiet,
and has a friendly smile. As time passed, and we dealt with the children, she became more
relaxed and appeared relieved to be able to talk to someone.
**Contraction of the virus.**

Berta does not know for sure how she contracted the AIDS virus. During her adolescent years she valued saving herself for her husband and never had sexual intercourse until she married. She also never used drugs. To the best of her knowledge she thinks she contracted the AIDS virus from a friend at church. While at church, she accidentally cut her hand. This male acquaintance offered to help her with her cut. She remembers he had open sores on his hands and that some of his blood fell on her own cut. At that time she thought nothing of it.

Three years later, when Berta was married and had a daughter, she was tested for HIV as a medical work up because she and her husband wanted to have another child. She was shocked to learn she was HIV sero-positive and could not account for it. To her relief, her husband is negative and so is her daughter. Weeks later, she heard that her church friend died, and there was gossip that he died of AIDS. She sought out his brother-in-law who revealed her friend did have AIDS.

**State of affairs.**

Berta has received instructions from her health care providers on how to prevent the transmission of the virus to her husband and daughter. They tell her to continue her normal life. Berta laughs. She says her life is anything but normal and that her life and that of her husband have changed drastically.
There is much fear of transmitting the virus to her family. Furthermore, normal human interactions are affected by having the virus. Berta laments that when she has a cut and her daughter hurts herself, she will not touch her daughter for fear she will transmit the virus.

When I have a cut, she always wants me to hug and pet her and I want to because I love her. But then I see the cuts and I get afraid and.... [SS 359-360]

Berta’s relationship with her husband has also changed:

I try to live a normal life, but sometimes I see that I can’t make it normal. When I want to caress or touch my husband, I feel afraid. Sometimes I only touch him and he asks, “do you have a cut?” I say, no, I have nothing, but when he asks me that, I feel bad and I quit touching him. [SS 329-334]

Berta’s husband is not too willing to discuss the sequelae of the AIDS virus. Initially her husband was tested for the virus and was found to be negative. He refuses to be tested again because he fears someday he will be positive.

Those who know.

All of Berta’s immediate family has been told she has the AIDS virus. However, her parents refuse to believe she has the virus. Her mother becomes angry when Berta tells her she’s been to see her physician as she does not want to acknowledge her daughter has the virus.
Future outlook.

Faith in God helps Berta face her misfortune. She has placed her life in God’s hands and feels a sense of comfort. Berta is also relieved that she has a supportive husband who comforts her whenever she is overcome by fear. She realizes her husband is at times overwhelmed by their misfortune. Berta counts her blessings for every day of life that is given to her.

One year later.

Berta’s CD4 counts are dropping. At the time of the interview, they were 600 and now, a year later, they are down to 400. Furthermore, she was diagnosed with hepatitis B. Recently, she has suffered from extreme fatigue. She appears quieter, more worried, and less willing to talk.

Analysis of Data

This section begins with the presentation of this researcher’s bracketed perspectives. Thereafter, the findings from the lived experience of women of Mexican heritage with HIV/AIDS are described through each step of the data analysis.

Researcher’s Bracketed Perspectives

A list of bracketed perspectives which were presented in Chapter 1 include the following:
1. Women of Mexican heritage are strong individuals whose center of living is to care for others.

2. The patriarchal Mexican culture can be both a source of comfort and a stifling experience.

3. It is common for women of Mexican origin to suffer in silence.

4. The less educated the woman is the more vulnerable she is to isolation and social abuses.

5. Women of Mexican heritage are very adept and self-reliant when they are needed by others dear to them.

Furthermore, it was this researcher's view that women of Mexican heritage have particular issues related to having contracted the HIV/AIDS virus because of their:

1. generally lower educational level
2. possible language barriers
3. general lower socioeconomic status
4. possible immigration issues
5. cultural influences
6. limited access to health care, and
7. stigma to having HIV/AIDS

The limitations in the design of this research prevent making definite statements about the effects of variables such as: a lower educational level, language barriers, lower
socioeconomic status, and immigration issues on the lived experience. These variables were not specifically investigated during the research process.

**Theme Clusters**

The formulated meanings were assembled into themes. A record of all the original, numbered protocol statements under each theme was maintained and referred to in order to maintain a sense of the commonality of the themes (Appendix E). The themes were then organized into theme clusters which depicted the commonality of the themes.

Within the 6 protocols, 2,464 significant statements were identified and reformulated into formulated meanings. These formulated meanings were compiled into 162 themes. The themes were then organized into 22 theme clusters. Seven theme categories emerged from the theme clusters (a) Personal divergent vignettes describe the encounter with the AIDS virus, (b) Unsettledness in familial relationships, (c) Changes in patterns of sexuality, (d) Prevalent emotional turmoil since contracting the virus, (e) Social stigma to the AIDS virus affects the lives of those with the virus and their family, (f) Compassionate and adverse encounters upon entering the health care system, and (g) Struggling to rebuild one's shattered world. Table 4.3 presents the theme categories and clusters. The following section presents the seven theme categories with a description of the subsumed theme clusters. To magnify the findings at each step of the data analysis, a table for each theme cluster is provided which contains a description of corresponding themes as well as actual statements from the participants.
Table 4.3

**Theme Categories and Theme Clusters**

Theme Category 1: Personal Divergent Vignettes Describe the Encounter With the AIDS Virus
- Theme Cluster 1A: Discovering the Virus (Table 4.4)
- Theme Cluster 1B: Panic Stricken by the Diagnosis (Table 4.5)
- Theme Cluster 1C: Doubts Surround the Diagnosis of Having the AIDS Virus (Table 4.6)
- Theme Cluster 1D: Experiencing Shattered Dreams (Table 4.7)

Theme Category 2: Unsettledness in Familial Relationships
- Theme Cluster 2A: Fear of Rejection by Significant Other (Table 4.8)
- Theme Cluster 2B: Child(ren) as a Source of Concern and Strength (Table 4.9)
- Theme Cluster 2C: Does Not Want to Be a Burden to Family (Table 4.10)
- Theme Cluster 2D: Conditional Support (Table 4.11)

Theme Category 3: Changes in Patterns of Sexuality
- Theme Cluster 3A: Development of Social Consciousness (Table 4.12)
- Theme Cluster 3B: Waning Sexual Desire (Table 4.13)

Theme Category 4: Prevalent Emotional Turmoil Since Contracting the Virus
- Theme Cluster 4A: Feelings of Aloneness With No Outlet for Innermost Thoughts (Table 4.14)
- Theme Cluster 4B: Faces Blame for Contracting the AIDS Virus (Table 4.15)
- Theme Cluster 4C: Overcome by Intermittent Pangs of Fear and Despair (Table 4.16)

Theme Category 5: Social Stigma to the AIDS Virus Affects the Lives of Those With the Virus and Their Family
- Theme Cluster 5A: Experiencing Shame to Having the AIDS Virus (Table 4.17)
- Theme Cluster 5B: Fearful of Rejection and Discrimination to Self and Family (Table 4.18)
- Theme Cluster 5C: Awareness of the Widespread Lack of Knowledge Related to the AIDS Virus (Table 4.19)

Theme Category 6: Compassionate and Adverse Encounters Upon Entering the Health Care System
- Theme Cluster 6A: Appreciative for kind and compassionate interactions (Table 4.20)
- Theme Cluster 6B: Learning knowledge to Enhance Well-being (Table 4.21)
- Theme Cluster 6C: Adverse Encounters With Receiving Health Care (Table 4.22)

(table continues)
Theme Category 7: Struggling to Rebuild One's Shattered World

- Theme Cluster 7A: Developing Perspectives Toward the Source of the Virus (Table 4.23)
- Theme Cluster 7B: Hope, Peace, and Conflict With God (Table 4.24)
- Theme Cluster 7C: Effort Made To Transcend Misfortunate Fate and Savor Everyday With Loved Ones (Table 4.25)

**Theme Category # 1: Personal Divergent Vignettes Describe the Encounter With the AIDS Virus**

Theme clusters which emerged and were subsumed under the theme category of Personal Divergent Vignettes Describe the Encounter With the AIDS Virus included (a) discovering the virus, (b) panic stricken by the diagnosis, (c) doubts surrounding the diagnosis of having the AIDS virus, and (d) experiencing shattered dreams. Tables 4.4 through 4.7 include the theme clusters with supporting significant statements. In Discovering the Virus (Table 4.4) an event or suspicions led to the discovery of the virus. Upon reflection, there was an awareness of having limited knowledge about the AIDS virus. Symptoms of the virus for some women either had been perceived, had not been recognized, or were absent.

Themes which comprised the theme cluster Panic Stricken by the Diagnosis (Table 4.5) related to initial responses upon learning of being sero-positive for HIV. Participants described their initial responses as being dumbfounded by the news, perceiving imminent death, feeling devastated, and “acting out”.
Doubts Surround the Diagnosis of Having the AIDS Virus (Table 4.6) was a theme cluster related to doubts of having HIV/AIDS. Doubt was experienced by the women, family members, and health care providers. There was also doubt in the health care provider.

The theme cluster of Experiencing Shattered Dreams (Table 4.7) related to the various aspirations women had which were shattered because of having the AIDS virus. Included in this category were the shattered dreams, shattered social role of being a mother, the questioning of “why me?” as well as feelings of depression, helplessness, and powerlessness.
### Theme Cluster 1A: Discovering the Virus

<table>
<thead>
<tr>
<th>Event or Suspicion for Discovery</th>
<th>Elena</th>
<th>Chrisy</th>
<th>Alicia</th>
<th>Clara</th>
</tr>
</thead>
<tbody>
<tr>
<td>And when the doctor told me he had AIDS, you know what, I cried for days, you know.</td>
<td>And when the doctor told me he had AIDS, you know what, I cried for days, you know.</td>
<td>And when the doctor told me he had AIDS, you know what, I cried for days, you know.</td>
<td>And when the doctor told me he had AIDS, you know what, I cried for days, you know.</td>
<td>And when the doctor told me he had AIDS, you know what, I cried for days, you know.</td>
</tr>
<tr>
<td>I went through an adoption agency, and it was required to take an AIDS test.</td>
<td>I went through an adoption agency, and it was required to take an AIDS test.</td>
<td>I went through an adoption agency, and it was required to take an AIDS test.</td>
<td>I went through an adoption agency, and it was required to take an AIDS test.</td>
<td>I went through an adoption agency, and it was required to take an AIDS test.</td>
</tr>
<tr>
<td>This began when my daughter became ill...a lady doctor told me they had found something, but they were not sure.</td>
<td>This began when my daughter became ill...a lady doctor told me they had found something, but they were not sure.</td>
<td>This began when my daughter became ill...a lady doctor told me they had found something, but they were not sure.</td>
<td>This began when my daughter became ill...a lady doctor told me they had found something, but they were not sure.</td>
<td>This began when my daughter became ill...a lady doctor told me they had found something, but they were not sure.</td>
</tr>
<tr>
<td>I already knew it. I thought so, because living with my husband for so long and he had it.</td>
<td>I already knew it. I thought so, because living with my husband for so long and he had it.</td>
<td>I already knew it. I thought so, because living with my husband for so long and he had it.</td>
<td>I already knew it. I thought so, because living with my husband for so long and he had it.</td>
<td>I already knew it. I thought so, because living with my husband for so long and he had it.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Uneducated about the AIDS Virus</th>
<th>Elena</th>
<th>Chrisy</th>
</tr>
</thead>
<tbody>
<tr>
<td>I didn’t know what it was then. I still don’t know what it is now.</td>
<td>I didn’t know what it was then. I still don’t know what it is now.</td>
<td>I didn’t know what it was then. I still don’t know what it is now.</td>
</tr>
<tr>
<td>Well, I wasn’t educated, none of us were.</td>
<td>Well, I wasn’t educated, none of us were.</td>
<td>Well, I wasn’t educated, none of us were.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Experiencing of Symptoms</th>
<th>Rene</th>
<th>Rene</th>
</tr>
</thead>
<tbody>
<tr>
<td>And I started developing lymph nodes.</td>
<td>And I started developing lymph nodes.</td>
<td>And I started developing lymph nodes.</td>
</tr>
<tr>
<td>I started losing a lot of weight.</td>
<td>I started losing a lot of weight.</td>
<td>I started losing a lot of weight.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Symptoms Unrecognized</th>
<th>Chrisy</th>
<th>Chrisy</th>
<th>Rene</th>
</tr>
</thead>
<tbody>
<tr>
<td>It’s like I noticed that I get a lot of yeast infections.</td>
<td>It’s like I noticed that I get a lot of yeast infections.</td>
<td>It’s like I noticed that I get a lot of yeast infections.</td>
<td>It’s like I noticed that I get a lot of yeast infections.</td>
</tr>
<tr>
<td>My doctors told me maybe I was getting yeast infections by being too clean, you know, like douching too much or something.</td>
<td>My doctors told me maybe I was getting yeast infections by being too clean, you know, like douching too much or something.</td>
<td>My doctors told me maybe I was getting yeast infections by being too clean, you know, like douching too much or something.</td>
<td>My doctors told me maybe I was getting yeast infections by being too clean, you know, like douching too much or something.</td>
</tr>
<tr>
<td>And I started getting lymph nodes, and then you know, he (doctor) just didn’t know what they were.</td>
<td>And I started getting lymph nodes, and then you know, he (doctor) just didn’t know what they were.</td>
<td>And I started getting lymph nodes, and then you know, he (doctor) just didn’t know what they were.</td>
<td>And I started getting lymph nodes, and then you know, he (doctor) just didn’t know what they were.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Symptoms Absent</th>
<th>Alicia</th>
<th>Chrisy</th>
</tr>
</thead>
<tbody>
<tr>
<td>No, not yet (has not noticed any symptoms).</td>
<td>No, not yet (has not noticed any symptoms).</td>
<td>No, not yet (has not noticed any symptoms).</td>
</tr>
<tr>
<td>I have never gotten sick off of it.</td>
<td>I have never gotten sick off of it.</td>
<td>I have never gotten sick off of it.</td>
</tr>
</tbody>
</table>
**Table 4.5**

**Theme Cluster 1B: Panic Stricken by the Diagnosis**

<table>
<thead>
<tr>
<th>Feelings of shock:</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Berta: At that moment I couldn't say a word because I knew, I thought it was negative.</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Perceptions of imminent death:</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Berta: I tell him (husband) that it is true that one feels one has died when they tell you.</td>
<td></td>
</tr>
<tr>
<td>Berta: Because I feel that from the moment they told me I was positive, my life ended, that's it, that’s all I can do here.</td>
<td></td>
</tr>
<tr>
<td>Chrisy: So as soon as they told me that, that night I like wiggled out. I just...I thought I was gonna die like tomorrow or something from it.</td>
<td></td>
</tr>
<tr>
<td>Rene: I just kept saying, 'I don’t want to die, I don’t want to die.’</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Feelings of devastation:</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Clara: And then, well, when they told me, I felt awful.</td>
<td></td>
</tr>
<tr>
<td>Elena: Oh I cried. Yes, I cried for two days.</td>
<td></td>
</tr>
<tr>
<td>Clara: Well, yes it hurt me. Yes, I felt badly and everything.</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Acting out:</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Rene: And then I just started getting crazy and ran out of there.</td>
<td></td>
</tr>
<tr>
<td>Rene: I was gonna kill myself and get it over with and I just didn’t know what to think. I didn’t know what to do.</td>
<td></td>
</tr>
</tbody>
</table>
Table 4.6

**Theme Cluster 1C: Doubt Surrounds the Diagnosis of Having the AIDS Virus**

<table>
<thead>
<tr>
<th>Doubt about the diagnosis:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Clara: I knew I had the illness, you see, because I had it done in Yuma. But I wanted to have it done again. So I had it done there where I live, in Sonora, Mexico.</td>
</tr>
<tr>
<td>Alicia: There are times when I accept myself as being positive, and I say...yes, I am positive, and other times I say, no! I do not have a thing.</td>
</tr>
<tr>
<td>Berta: Then, from there we went to see another doctor. They gave me the test.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Family members doubt the diagnosis:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Rene: It's like my mom and my sister, they say no, it's nothing, it's nothing.</td>
</tr>
<tr>
<td>Berta: But she (mother keeps telling me that it (the fatigue) isn't because I am ill. She (mother) even gets mad when I tell her that I am going to the doctor.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Doubt by Health Care Professionals:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Chrisy: Mine have been between 900 and 1,100, my T-cells. That's good because my doctor was starting to wonder about me. He was like 'are you sure you have HIV?' I'm like, 'yes, I wouldn't joke about that.'</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Doubting the Health Care Professional:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Alicia: Yes, the doctors explained it to me, what it was and how this virus was contracted and everything, but when they told me it was positive, I did not accept it. I thought the doctors were wrong.</td>
</tr>
<tr>
<td>Elena: I want to go see a private doctor, you know, sometimes I wonder if these people were lying to me, if I had this, if I am HIV positive.</td>
</tr>
<tr>
<td>Elena: Just to make sure of another doctor instead of going to a County hospital.</td>
</tr>
</tbody>
</table>
### Table 4.7

**Theme Cluster 1D: Experiencing Shattered Dreams**

<table>
<thead>
<tr>
<th>Dreams never to be fulfilled:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Berta: I was thinking that, well, everything was ending, even though I wanted to do so many things yet.</td>
</tr>
<tr>
<td>Berta: I wanted to have another child.</td>
</tr>
<tr>
<td>Elena: We had plans of getting married and having a relationship. Now I can’t because I got this.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Social role of mother curbed:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Rene: I just don’t want to leave my babies.</td>
</tr>
<tr>
<td>Clara: But I don’t know. It hurts and saddens me to die, like now, this year. I say this because of my daughter, because of her, more than anyone else.</td>
</tr>
<tr>
<td>Alicia: The children are not positive, but my little girl and I, yes. And since then, well, I feel that my life has changed, you see.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>The question of “Why me?”:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Berta: I wondered why me. Why if I hadn’t used drugs or had been with another.</td>
</tr>
<tr>
<td>Alicia: Well, I did not have any risks. I have never done drugs, never in my whole life. Neither was I running around with men.</td>
</tr>
<tr>
<td>Elena: Why me, you know, why didn’t this guy tell me? God, I wish he would have told me and I would have never been with him.</td>
</tr>
<tr>
<td>Clara: Because sometimes I ask myself, why has this happened to me, to my husband, you see.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Feelings of depression:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Alicia: I would like to take my children and...go away where no one would know about us.</td>
</tr>
<tr>
<td>Elena: I get depressed. There are sometimes that I get depressed and I’ll go into my room, turn on the stereo, and cry.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Feelings of helplessness:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Alicia: Because I feel that from the moment they told me I was positive, my life ended, that’s it, that’s all I can do here..</td>
</tr>
<tr>
<td>Elena: I’m afraid of the disease. I don’t know what to do.</td>
</tr>
<tr>
<td>Elena: I’m very, you know, I’m very confused.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Feelings of powerlessness:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Alicia: I believe it (that is going to die), and I still continue to believe it.</td>
</tr>
<tr>
<td>Berta: Life has been very hard, suddenly everything in life changes by force and we have to change our lifestyle.</td>
</tr>
</tbody>
</table>
Theme Category # 2: Unsettledness in Familial Relationships Theme Clusters

Theme clusters composing the theme category of Unsettledness in Familial Relationships which emerged included (a) fear of rejection by significant other, (b) child(ren) as a source of concern and strength, (c) not wanting to be a burden to family, and (d) conditional support. Included in Tables 4.8 through 4.11 are the theme clusters with supporting significant statements. In Fear of Rejection by Significant other (Table 4.8) there was fear of rejection by mate or member of the opposite sex. There was also an awareness that one’s mate was overwhelmed by the consequences of the wife having the AIDS virus, and fear of contracting the virus.

The theme cluster Child(ren) as a Source of Concern and Strength (Table 4.9) related to the women’s perspectives concerning their child(ren). This theme cluster included concerns experienced by the women with child(ren)’s well-being, of issues related to informing the child that their mother has the AIDS virus, fear of transmitting the virus to child(ren), views of the injustice that children contract the virus, and the sources of strength that children are to their mother.

Does Not Want to be a Burden to Family (Table 4.10) related to concerns of the women for other family members. The women did not want to burden their family with their ailments or financial concerns.

Theme cluster Conditional Support (Table 4.11) related to the women’s perceptions about the support from others. Included were themes such as not having contact with other women with the AIDS virus, no one of the same age to talk to, limited
or no support from significant other, and partial support from family. Other themes included family as support and support from community.
### Theme Cluster 2A: Fear of Rejection By Significant Other

#### Fears mate’s rejection:
- **Elena:** I would write it in so many words before he would understand. And he would never tell me, you know, what he suspected, if I had HIV.
- **Rene:** My husband didn’t know. I didn’t know what he was gonna do when I told him...how he was gonna react.
- **Rene:** He’s probably saying why did I ever get mixed up with her.
- **Alicia:** I am afraid...I’m afraid that he might find out that I’ve been tested
- **Berta:** When I want to caress or touch my husband, I feel afraid. Sometimes I only touch him and he asks, do you have a cut?

#### Fear of rejection by the opposite sex:
- **Chrisy:** I don’t want to have to deal with telling somebody that.
- **Chrisy:** It’s changed my way like in meeting guys because I can’t meet guys because I’m too embarrassed to tell them, you know, well hey, before we get involved, I am HIV positive.
- **Clara:** But he began to stay away more and more until he did not come around and he did not call me or anything

#### Partner overwhelmed by consequences:
- **Rene:** I know him and I could see it in him but he just stares at me and stuff and he’s wondering, you know. I think he’s wondering how did I get it, you know.
- **Berta:** I also have seen him crying. And I ask him ‘why are you crying?’ and he says, ‘Oh, nothing, I was just thinking about things that could happen..’

#### Partner worried about contracting the virus from wife:
- **Berta:** And sometimes I detect that he is afraid to find out that he might be like this (with HIV).
- **Berta:** Yeah. It is as if he were afraid. Even though he came back negative, but next time?
- **Rene:** I tell him (to use protection) and he says he doesn’t care. But sometimes I know he does, you know. I could see it in him.
## Theme Cluster 2B: Child(ren) As a Source of Concern and Strength

<table>
<thead>
<tr>
<th>Theme Cluster</th>
<th>Participant</th>
<th>Quote</th>
</tr>
</thead>
<tbody>
<tr>
<td>Child(ren)’s well-being:</td>
<td>Chrisy</td>
<td>I felt like I had just ruined an innocent child’s life forever.</td>
</tr>
<tr>
<td></td>
<td>Rene</td>
<td>I don’t know what’s gonna happen to my baby cause he’s the only one from me and my husband, you know. My other kids, my mom will take them definitely.</td>
</tr>
<tr>
<td></td>
<td>Alicia</td>
<td>And I have been diligent and kept all her doctor’s appointments.</td>
</tr>
<tr>
<td></td>
<td>Berta</td>
<td>What I tell him sometimes is that what I think about most of the time, is not so much about me being sick, and that I’m going to die, but what I’m afraid is to leave my little girl. She is only two years old.</td>
</tr>
<tr>
<td>Informing children:</td>
<td>Clara</td>
<td>I was telling her about the illness, and everything and instantly she started to cry. And I could not tell her.</td>
</tr>
<tr>
<td></td>
<td>Berta</td>
<td>But that I felt an obligation to tell her (daughter), so she’d be aware of it. And when she’ll see me in the hospital and I cannot be with her she’d understand why.</td>
</tr>
<tr>
<td>Fear of transmitting virus to child(ren):</td>
<td>Alicia</td>
<td>But since I found out I am positive I am much more careful. And (people) ask me why do I clean, or over-clean my hands before I handle the food. Because in order to prepare the children’s food I must wash my hands with a lot of soap and Clorox.</td>
</tr>
<tr>
<td></td>
<td>Berta</td>
<td>I am going around constantly watching her so that she does not hurt herself or if I have a cut or something I am careful not to touch her or let her touch me.</td>
</tr>
<tr>
<td>Injustice of children contracting the virus:</td>
<td>Alicia</td>
<td>I think that children are not responsible for the illnesses they inherit from their parents.</td>
</tr>
<tr>
<td></td>
<td>Berta</td>
<td>I said, but you know, the hardest thing for me to see is to see small babies, newborn babies infected.</td>
</tr>
<tr>
<td>Children as a source of strength:</td>
<td>Elena</td>
<td>The only ones I really do trust is my kids. They are my best friends. We are very, very close. You know, they understand. They’re by me. They support me. If I’m down, you know, they pick me up.</td>
</tr>
<tr>
<td></td>
<td>Chrisy</td>
<td>Because I think if, I honestly believe if I wouldn’t have had my son, I probably would have tried to kill myself.</td>
</tr>
<tr>
<td></td>
<td>Chrisy</td>
<td>I have to, you know, outlive it for my son.</td>
</tr>
</tbody>
</table>
**Table 4.10**

**Theme Cluster 2C: Does Not Want to be a Burden to Family**

<table>
<thead>
<tr>
<th>Burdened by well-being concerns:</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Clara: Yes, there are times when I feel very bad, inside, from the illness, and everything. But I do not show it. Because I do not want to worry anyone.</td>
<td></td>
</tr>
<tr>
<td>Clara: I am going to have good days and bad days, up and down, so why make them feel like that too.</td>
<td></td>
</tr>
<tr>
<td>Alicia: It would be very painful for them to know what I am going through.</td>
<td></td>
</tr>
<tr>
<td>Rene: Sometimes I do not show it (how I feel).</td>
<td></td>
</tr>
<tr>
<td>Berta: I go into the bathroom to take a bath and to cry.</td>
<td></td>
</tr>
<tr>
<td>Berta: I would go before a notary public and give him our little girl, because of my illness. And tell him that if he (husband) wanted he could leave me.</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Financial burdens:</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Elena: They’re my bills and I don’t want my family to pay for me.</td>
<td></td>
</tr>
<tr>
<td>Chrisy: I mean I have a lot of bills that we haven’t even paid off yet from when I first found out. But we’re slowly trying to pay those off too.</td>
<td></td>
</tr>
<tr>
<td>Rene: I’m always stressed out as it is. Especially about money. I mean I got so much bills. I got that big hospital bill, over $10,000.</td>
<td></td>
</tr>
</tbody>
</table>
Table 4.11

**Theme Cluster 2D: Conditional Support**

No contact with other women with HIV:
- **Elena:** And I see a lot, but I don’t see women. You don’t hear about women, you know, getting sick. They don’t talk about women, you know.
- **Berta:** I would have liked to go (to a support group), but my husband said that if I went, then they would expect him to go with me.

No one of the same age:
- **Chrisy:** And it’s like I feel, I’ve always felt this way, I feel I’m the only teenager in this whole entire world that has it. That’s how I feel because I’ve never met any kids my age that have it.
- **Chrisy:** And it’s like, am I the only one in Phoenix Arizona who’s got this, that’s this young?

Limited or no support from significant other:
- **Elena:** He is away. Put away. He’s in prison.
- **Chrisy:** I called him and told him and he denied everything.
- **Rene:** My husband hadn’t come to see me (in the hospital) cause he couldn’t handle it either, you know. And I started crying cause my husband hadn’t came to see me in about two days. He was out on a partying streak.
- **Rene:** That’s what gets my husband mad you know, cause I don’t feel like cooking.
- **Clara:** He (husband) died here in Tucson.
- **Alicia:** No, he knows that our little girl is positive and he does not want to know anymore.

Partial support from family:
- **Rene:** But my mom is another person. She understands to a point. It’s like my mom and my sister, they say no, it’s nothing, it’s nothing, you know.
- **Rene:** So I only told my mom, my sister, my husband, and two friends and that’s it.
- **Rene:** His (husband’s) mother doesn’t know.
- **Rene:** But everyone lives in Mexico, my parents, everybody.
- **Berta:** But I do not say anything because I do not want to hurt him.

Family support:
- **Elena:** The lady (health care provider at the clinic) told me, ‘Did you tell anyone? Did you tell your kids and your mom?’ and I go yes.
- **Chrisy:** And as a matter of fact since I’ve gotten it, I’ve gotten real close to all my family.
- **Clara:** On the contrary, I feel them closer to me.
  (table continues)
Table 4.11  -  Continued

Support from community:
Elena: I had a denial on AHCCCS and then they say they have me on some kind of program.
Chrisy: Whatever I needed done, my pills or whatever, I went through my school. And then
when I was finally eligible for AHCCCS, that’s when I started going seeing doctors.
Alicia: The only person I talk to, is with the social worker.

**Theme Category # 3: Changes in Patterns of Sexuality**

Changes in Patterns of Sexuality was a theme category which described various
attitudinal and behavioral changes among the women and included the theme clusters of
(a) development of social consciousness which affect sexuality, and (b) waning sexual
desire. Tables 4.12 and 4.13 include the theme clusters with supporting significant
statements. In the theme cluster Development of Social Consciousness (Table 4.12), the
women described attitudinal changes which affected their sexuality. Social consciousness
included an awareness of having developed definite views and responsibilities toward
others. These attitudes included that they did not want to spread the virus and that the
sexual partner should be informed.

The theme cluster Waned Sexual Desire (Table 4.13) described decreases in the
women’s sexual desire. Furthermore, this theme cluster included themes of sexual
abstinence which was preferred by some of the women.
### Table 4.12

**Theme Cluster 3A: Development of Social Consciousness Which Affects Sexuality**

<table>
<thead>
<tr>
<th>Awareness of changed perspectives:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Chrisy: It really hasn't changed my life much except that I am more like, I don’t know how to put it in words other than I care about...everything matters to me now.</td>
</tr>
<tr>
<td>Elena: I've changed. It's changed me. My sexual activities have changed.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Do not want to spread the virus:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Elena: I’m scared, you know, I don’t want to give it to somebody because someone gave it to me.</td>
</tr>
<tr>
<td>Chrisy: Because I won’t go out and do it with anybody else.</td>
</tr>
<tr>
<td>Berta: I am so afraid of someone catching it, someone I am fond of, and I would think it was because of me.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Sexual partner should informed:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Elena: And, you know, I think that people that have AIDS should tell their partner they have it or their girlfriend, or just one-night stands, you know.</td>
</tr>
<tr>
<td>Chrisy: I felt like I was taking an important choice away from them, you know, by not telling them what I had.</td>
</tr>
<tr>
<td>Clara: And then after a month or two, he asked me to be his girl, but first I told him, I told him what was happening. Yes, about having the virus.</td>
</tr>
</tbody>
</table>
Table 4.13

**Theme Cluster 3B: Waned Sexual Desire**

<table>
<thead>
<tr>
<th>Changes in sexual desire:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Chrisy: It's not a big issue to me anymore, for some reason, I don't know. It's like I prefer just to be like hugged and kissed than actual doing anything.</td>
</tr>
<tr>
<td>Chrisy: I don’t even like feeling the way I feel after I do (has sexual intercourse).</td>
</tr>
<tr>
<td>Berta: We are not together (sexually). Sometimes once in two months. Well the truth is I am afraid. Because if he is not infected yet, I might infect him.</td>
</tr>
<tr>
<td>Rene: Its (AIDS) affecting me so bad that I can’t even make love to my husband. Nothing (no sexual desire)! He has to really arouse me for me to want to but it is like once a month and he’ll be after me and I know he gets tired of, you know, asking me.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Abstinence from sexual activity:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Elena: I stay away, away. Way away, you know. I don’t have sex with anyone. I haven’t been with anyone in two years.</td>
</tr>
<tr>
<td>Elena: Regardless, even the condoms don’t, they’re not 100% proof, you know.</td>
</tr>
<tr>
<td>Clara: I already have been alone 4 years and well, I feel fine, I feel fine. No, I don’t feel that I need a man, and then, well, I think sometimes that I feel alone.</td>
</tr>
</tbody>
</table>

**Theme Category # 4: Prevalent Emotional Turmoil Since Contracting the Virus**

Prevalent Emotional Turmoil Since Contracting the Virus theme clusters included (a) feelings of aloneness with no outlet for innermost thoughts, (b) facing blame for contracting the AIDS virus, and (c) overcome by intermittent pangs of fear and despair.

Tables 4.14 through 4.16 include the theme clusters with supporting significant statements. In Feelings of Aloneness With No Outlet for Innermost Thoughts (Table 4.14), the women described their sense of aloneness in their suffering. Their situation was aggravated by the desire to keep their infection a secret from others. Further, because of
the denial by other family members, there was less opportunity to discuss innermost thoughts and concerns.

   Facing Blame for Contracting the AIDS Virus theme cluster (Table 4.15) was related to blame issues and perspectives about contracting the virus. Blame issues involved self blame and being blamed by others for contracting the virus. Perspectives about contracting the virus involved the women not feeling responsible for contracting the virus and having to defend themselves against other's blame. Moreover, some women viewed having contracted the virus as a punishment by God for past sins.

   The themes subsumed under the theme cluster Overcome By Intermittent Pangs of Fear and Despair (Table 4.14) were related to different perspectives of the women upon viewing their mortality. Fear arose in the women when faced with their mortality. Moreover, pangs of fear were experienced with new and ominous physical changes. However, time was found to abate certain fears, and for some, there was no fear of death. Table 4.16 describes intermittent pangs of fear themes and examples of significant statements.
Table 4.14

**Theme Cluster 4A: Feelings of Aloneness With No Outlet For Innermost Thoughts**

<table>
<thead>
<tr>
<th>Being alone:</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Chrisy: And he wasn't there in Phoenix at the time when I found out.</td>
<td></td>
</tr>
<tr>
<td>Clara: Here no one knows me. I don't know anybody.</td>
<td></td>
</tr>
<tr>
<td>Alicia: I do not have a lot of friends.</td>
<td></td>
</tr>
<tr>
<td>Chrisy: I was going through all this by myself like giving my kid up for adoption, I found out I was HIV positive and all that.</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Keeping infection a secret:</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Alicia: My family does not know anything about it.</td>
<td></td>
</tr>
<tr>
<td>Clara: It is an awful feeling to have to be careful and keep it from other people.</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Unable to discuss infection with family:</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Berta: You are normal, that's their (parent's) response to me.</td>
<td></td>
</tr>
<tr>
<td>Rene: I do not tell him how or what I feel.</td>
<td></td>
</tr>
</tbody>
</table>
Table 4.15

**Theme Cluster 4B: Faces Blame For Contracting the AIDS Virus**

<table>
<thead>
<tr>
<th><strong>Blames self:</strong></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Elena:</strong></td>
<td>I was very unsafe. And I should have used a condom which I didn’t.</td>
</tr>
<tr>
<td><strong>Rene:</strong></td>
<td>I slept with him for drugs.</td>
</tr>
<tr>
<td><strong>Alicia:</strong></td>
<td>Because I feel responsible for what happened to my little girl. Because I think and I say...if I had been more careful, she would not have been infected. I say to myself, I am an adult, and if I have it, I looked for it because I knew the risks. Well, I feel bad because I think that because I was careless in some way.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th><strong>Is blamed by others:</strong></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Elena:</strong></td>
<td>And he is very upset with me because I did some stupid things.</td>
</tr>
<tr>
<td><strong>Elena:</strong></td>
<td>But, she (mother) also tells me, ‘Well it’s your fault. You went out. If you didn’t go out, you wouldn’t have had it.’</td>
</tr>
<tr>
<td><strong>Chrisy:</strong></td>
<td>They made me feel like how could a young girl like you let this happen to you?</td>
</tr>
<tr>
<td><strong>Clara:</strong></td>
<td>Well, there was a lot of talk. Then they were saying that because I was running around with many men.</td>
</tr>
<tr>
<td><strong>Berta:</strong></td>
<td>When someone has what I have, they (husband’s family) say it is because of running around with other men.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th><strong>Defends self as a good woman:</strong></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Elena:</strong></td>
<td>But I’m human. You know, I am a human being. I have needs, you know.</td>
</tr>
<tr>
<td><strong>Rene:</strong></td>
<td>And now I’m married. I’ve been married for going on seven years.</td>
</tr>
<tr>
<td><strong>Clara:</strong></td>
<td>I said, it is not because I am ashamed, because it was not my fault, I told them.</td>
</tr>
<tr>
<td><strong>Clara:</strong></td>
<td>Well, not in my case, because my husband got it from the hemophilia, you see. I do not feel I made any mistakes, you see. It was a misfortune what happened to us.</td>
</tr>
<tr>
<td><strong>Berta:</strong></td>
<td>Because in my past, well I did not have any risks.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th><strong>Being punished for past sins:</strong></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Chrisy:</strong></td>
<td>I felt like He (God) didn’t like me or something. That’s why He (God) was doing that to me.</td>
</tr>
<tr>
<td><strong>Rene:</strong></td>
<td>But, you know, I know I’m still a sinner cause I smoke dope.</td>
</tr>
<tr>
<td><strong>Alicia:</strong></td>
<td>Well, perhaps because I take it as some sort of punishment for myself.</td>
</tr>
</tbody>
</table>
**Theme Cluster 4C: Overcome By Intermittent Pangs of Fear and Despair**

**Fears own mortality:**

Elena: It can kill you! You know, it can kill you. I am very scared. I am so scared. And there is days that I wonder well, what's it going to be like the next day, you know.

Chrisy: I'm not ready to die. I'm too young to die.

Alicia: But I believe that this is one of those illnesses when one does not live long.

**Pangs of fear accompany physical changes:**

Chrisy: I didn't know that a lot, that women (with HIV) get that (vaginal yeast infections)!

Rene: When I was in the hospital, I was laying there one day and I was, I guess I was just massaging my leg like that and I felt one (swollen lymph node) right here on my leg. And I just broke out again (became upset), you know, cause I didn't know, I thought I was gonna die when I was in the hospital.

Clara: I don't even remember (she laughs) until now that the symptoms are beginning, and everything.

Rene: I get scared a lot of times when I start feeling sick, catching a fever, or my throat starts hurting.

**Time helps to abate fear:**

Rene: And then there are days that I forget I have it.

Chrisy: Then as my attitude started changing and I was educating myself more about it, I just started feeling real energized. (It took) About four or five months to finally accept it.

Clara: Yes, I felt badly and everything at the beginning. But I don't know, within me I already had resigned myself to it because I saw how the illness unfolded (in my husband).

**Does not fear death:**

Clara: Well, I am not afraid of dying. I am not scared. But I don't say I want to die.

Berta: Only God knows, doesn't he? ...And I tell her that I have put them (problems) in His hands for a long time and I am just living my life until He tells me ‘this is it.'
Theme Category # 5: Social Stigma to the AIDS Virus Affects the Lives of Those With the Virus and Their Family

Both the participants and their families experienced the social stigma of AIDS which influenced their patterns of everyday living. Theme clusters which described responses to social stigma included (a) experiencing shame of having the AIDS virus, (b) fearful of social rejection to self and family, and (c) awareness of the widespread lack of knowledge related to the AIDS virus. Tables 4.17 through 4.18 include the theme clusters with supporting significant statements. In the theme cluster Experiencing Shame to Having the AIDS Virus (Table 4.17), various patterns of shame emerged. Although the patterns of shame appear to contradict each other, in reality, a person can experience opposing feelings depending on the circumstances. The women experienced shame that others would discover their infection. Shame kept the women from seeking supportive others or from establishing relationships with members of the opposite sex. Shame was found in family members of those with the AIDS virus. And although upon reflection many of the women saw no reason to be ashamed of having the virus, shame was still experienced.

Fearful of Rejection of Self and Family themes (Table 4.18) related to the fear of being rejected by others in society and having family members also rejected. Care was taken by the participants in deciding who to reveal the secret of having HIV/AIDS, as there was an awareness of potential prying into their lives by others. There was also the
awareness that the media misrepresents and/or miseducates the public on the topic of AIDS.

The theme cluster Awareness of the Widespread Lack of Knowledge Related to the AIDS Virus (Table 4.19) related to limited information the women, and most of society, had on AIDS. Also included in this theme cluster were the painful encounters with others who were ignorant about AIDS as well as concerns that others need to be educated on AIDS.
### Theme Cluster 5A: Experiencing Shame of Having the AIDS Virus

<table>
<thead>
<tr>
<th>Ashamed others will know:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Rene: I denied it, I denied it to her cause she don’t need to know.</td>
</tr>
<tr>
<td>Alicia: But I also think that for them (family) to have...someone with this illness it will be something like...well, it is going to disappoint them.</td>
</tr>
<tr>
<td>Berta: I have never felt ashamed, except that time. I guess that’s why I felt ashamed, because I didn’t know (what they would think).</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Shame impedes seeking supportive others:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Elena: I don’t go to meetings because, you know, I feel embarrassed, you know, going to a meeting and having people know that I have it. Really, I don’t want a bunch of people - the whole world know that I am HIV positive.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Ashamed to Reveal Infection to Member of the Opposite Sex:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Chrisy: It’s changed my way like in meeting guys. Because I can’t meet guys because I’m too embarrassed.</td>
</tr>
<tr>
<td>Clara: What if I find someone again and then when I tell him (she has AIDS), it is going to be the same, and well, it is better I leave it like that.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Others also ashamed:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Berta: But his parents are ashamed of it, that’s why they don’t tell anyone. It is a shame for them because they are the church’s ministers.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>No shame in having HIV/AIDS:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Clara: I said, it is not because I am ashamed, because it was not my fault, I told them.</td>
</tr>
<tr>
<td>Berta: No, I don’t think it is a shame when a person becomes infected with HIV. But I don’t think one has to be ashamed to be like this.</td>
</tr>
</tbody>
</table>
**Table 4.18**

**Theme Cluster 5B: Fearful of Rejection of Self and Family**

<table>
<thead>
<tr>
<th>Fearful of other’s rejection:</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Chrisy: I’d rather not talk to them (guys) because I don’t want to tell them. There are a lot of people who do not understand and they reject you.</td>
<td></td>
</tr>
<tr>
<td>Clara: What if I find someone again and then when I tell him, it is going to be the same.</td>
<td></td>
</tr>
<tr>
<td>Clara: Well, they (people) gossip about everything, things that are beside the point and untruths.</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Family and stigma:</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Clara: Well, there was a lot of talk that he had many women.</td>
<td></td>
</tr>
<tr>
<td>Alicia: I have known that when this illness exists, the children suffer the consequences. Because they (other people) are afraid to come in contact with them, or anything.</td>
<td></td>
</tr>
<tr>
<td>Berta: But then he said no, because by then she’ll be in school and then what...children say things.</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Care in revealing secret:</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Elena: My kids know. We keep it quiet. It’s very hush hush.</td>
<td></td>
</tr>
<tr>
<td>Elena: And I really don’t trust, I don’t trust too many people, you know.</td>
<td></td>
</tr>
<tr>
<td>Berta: No one in his family, we do not want them to know from my husband’s (family).</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Others pry:</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Rene: And, anyway, he kept asking me what was wrong.</td>
<td></td>
</tr>
<tr>
<td>Rene: My sister-in-law in Texas asked her if they knew I had it and she asked my friend, one of my friends that know.</td>
<td></td>
</tr>
<tr>
<td>Clara: But, well, after, there was someone who knew.</td>
<td></td>
</tr>
<tr>
<td>Berta: And you know how people ask us why we don’t give her a little brother.</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Media misrepresents/miseducates:</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Chrisy: I don’t think they inform them the way they should. Usually they (media) always use like adults.</td>
<td></td>
</tr>
<tr>
<td>Berta: I have heard on the TV that a person with HIV has to live away, apart from the community, sort of isolated but that’s not right.</td>
<td></td>
</tr>
</tbody>
</table>
Table 4.19

**Theme Cluster 5C: Awareness of the Widespread Lack of Knowledge Related to the AIDS Virus**

<table>
<thead>
<tr>
<th>Category</th>
<th>Details</th>
</tr>
</thead>
</table>
| Self uneducated on virus: | Elena: And I want to understand it more. I know it's something to do with the blood, you know. My son studies it in school and he tells me and still I don't understand it.  
Rene: I don’t know if I have AIDS, but I know I'm HIV positive. |
| Society uneducated: | Chrisy: Just for the fact that a lot of people aren’t educated about it. All they know is what they hear.  
Clara: Because that is when you see, over there, well in Mexico, the people are ignorant. I don’t know, they take things differently.  
Berta: We don’t want his family to know because they will make deride comments. |
| Hurt by other's ignorance: | Elena: And then my other Hawaiian friend, she knew about it and she didn’t talk to me anymore.  
Clara: And well, as I was telling you, the people take things the wrong way to gossip. And they go around saying things.  
Clara: Perhaps they thought that by being with me they would catch it (she laughs). |
| Concern that others need to be educated: | Chrisy: I really feel that they should educate high schoolers and younger kids about it. They (younger kids) make really stupid comments. Comments I would have made if I would have never caught what I caught.  
Clara: I tell them to be careful, it is hard, very hard to deal with this illness. |
**Theme Category # 6: Compassionate and Adverse Encounters Upon Entering the Health Care System**

Compassionate and Adverse Encounters Upon Entering the Health Care System theme clusters included (a) appreciative for kind and compassionate interactions, (b) learning knowledge to enhance well-being, and (c) adverse encounters with receiving health care. Themes and theme clusters in this theme category may appear to be contradictory. However, individuals may hold opposing views depending on the context of the situation. Tables 4.20 through 4.22 include the theme clusters with supporting significant statements. In Appreciative For Kind and Compassionate Interactions (Table 4.20), the women described various patterns of positive encounters with health care providers (HCP).

**Learning Knowledge to Enhance Well-being** themes (Table 4.21) were related to common measurements and lifestyle patterns that assisted women to determine and maintain their well-being. T-cells counts were used by the women to determine their status against the virus. The women were also aware of eating well, the benefits of decreasing stress, and some held or were aware of the belief that knowing one had HIV decreased one’s life.

**Adverse Encounters With Receiving Health Care** themes (Table 4.22) were related to the negative encounters and events upon entering the health care system. Themes subsumed under this theme cluster included experiencing mistreatment, indifferent care, suffering from treatments or procedures, and many changes in HCPs. Some women were
ignored and others were unable to ask personal questions because HCPs were of the opposite gender.

Table 4.20

**Theme Cluster 6A: Appreciative For Kind and Compassionate Interactions**

<table>
<thead>
<tr>
<th>Appreciative of care:</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Elena: Oh, they (HCP) treat me real nice. Very concerning people. Very caring.</td>
<td></td>
</tr>
<tr>
<td>Clara: Here, no, here all the nurses at the clinics are very good nurses. Everyone, the nurses and the doctors treated me well. They made me feel good.</td>
<td></td>
</tr>
<tr>
<td>Alicia: I feel this is because she has been well treated by the doctors.</td>
<td></td>
</tr>
</tbody>
</table>
Table 4.21

**Theme Cluster 6B: Learning Knowledge to Enhance Well-being**

<table>
<thead>
<tr>
<th>T-cells gauge well-being:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Berta: This time it was 600 and right now I do not need treatment.</td>
</tr>
<tr>
<td>Elena: There were okay, the last time they were 600 and something. They went down to 300.</td>
</tr>
<tr>
<td>Rene: They couldn’t tell me but my cell count is very low.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Changes in nutrition:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Elena: They say, nutritionist says eat proper foods. Eat lots of vegetables. Eat a little portion of everything, you know. And eat lots of salt.</td>
</tr>
<tr>
<td>Chrisy: No. I eat differently now. I take vitamins now everyday. It’s changed in my ways because it’s like now I care about what I eat and how I eat.</td>
</tr>
<tr>
<td>Rene: But I smoke marijuana cause that’s the only thing that makes me want to eat.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Stress and HIV:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Chrisy: It affects my body big time when I’m stressed out. Stress, I’ve noticed like if I’ve been stressed for like a month or two, just stressing about something, and I go and get my blood taken, I’ve noticed a fall in my T-cells.</td>
</tr>
<tr>
<td>Rene: I know I’m not supposed to be smoking (marijuana) and stuff, but you know, it just relaxes me.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Knowledge of early demise:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Elena: I just, I don’t dwell in it, you know, it’s best not to dwell in it because the more you think about it, the sicker you’ll get.</td>
</tr>
<tr>
<td>Chrisy: And I feel if people like worry about it all the time, that’s what makes them sick.</td>
</tr>
<tr>
<td>Berta: He says it is not so much the fear of having the virus but the fear of dying quicker when they tell you are HIV positive.</td>
</tr>
</tbody>
</table>
### Theme Cluster 6C: Adverse Encounters With Receiving Health Care

<table>
<thead>
<tr>
<th>Mistreatment:</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Chrisy:</td>
<td>I ran into some that were really, that criticized me a lot. They made me feel poor about myself.</td>
</tr>
<tr>
<td>Rene:</td>
<td>Yeah he (doctor) goes, ‘Yeah, you are a very sick person’, he goes, ‘Your cell count is so low...you don’t have long to live.’</td>
</tr>
<tr>
<td>Clara:</td>
<td>Then all the nurses were looking at me. Just looking as if I were something rare.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Treated with indifference:</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Rene:</td>
<td>I seen another doctor and he tells me ‘We might have to do surgery again because when we did your surgery, we forgot to find out what kind of TB it was.’</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Suffers from treatments/procedures:</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Rene:</td>
<td>A lot of times it (medication) makes me throw up and especially the big ones. I take a whole lot of medication.</td>
</tr>
<tr>
<td>Rene:</td>
<td>You know, they don’t let you do nothing. I couldn’t drink no water.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Seen by many different HCP:</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Chrisy:</td>
<td>It’s just like just when I start feeling comfortable with a health care professional they move, leave the office or she has to move and see someone else.</td>
</tr>
<tr>
<td>Chrisy:</td>
<td>But I had a doctor and I changed him and I went to another one and, you know, he started seeing me.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Ignored by HCP:</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Rene:</td>
<td>He (doctor) kept putting it off, you know, he didn’t want to discuss it. I asked him if he could test me.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Unable to ask personal questions:</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Rene:</td>
<td>I wanted to ask the doctor why I can’t have sex, but he’s a man and I just...Why I don’t get the feeling (for sexual intercourse).</td>
</tr>
</tbody>
</table>

---

**Theme Category # 7: Struggling to Rebuild One’s Shattered World**

Struggling to Rebuild One’s Shattered World contained theme clusters which described primary issues confronted by the women as they attempted to create a balance.
and restructure their lives. These issues included (a) developing perspectives toward the source of the virus; (b) hope, peace, and conflict with God; and (c) effort made to transcend misfortunate fate. Tables 4.23 through 4.25 include the theme clusters with supporting significant statements. Developing Perspectives Toward the Source of the Virus themes (Table 4.23) were related to views held by the women toward their source of infection. Themes included being unaware the source had the AIDS virus, not being warned by the source, feelings of anger toward the source, and feelings of dejection because of not receiving an apology or acknowledgment from the source.

The women confronted their faith in God as described in the theme cluster Hope, Peace, and Conflict with God (Table 4.24). Various perspectives were described. The women saw God as being merciful and as a means of support during their times of adversity. Experiences also included anger, rejection, re-acceptance of God, and meaning to having the AIDS virus.

Effort Made to Transcend Misfortunate Fate themes (Table 4.25) related to attempts made by the women to endure their present predicament. Many tried not to dwell on having the AIDS virus. There were times when their affliction was transcended and there was more enjoyment and appreciation of life.
<table>
<thead>
<tr>
<th>Theme Cluster 7A: Developing Perspectives Toward the Source of the Virus</th>
</tr>
</thead>
</table>

**Unaware source had the virus:**
- **Elena:** At that time I didn’t know anything, I didn’t know whether he was sick or not.
- **Clara:** He was hemophiliac. He was not to blame.
- **Alicia:** I never thought or imagined that in the past he was an irresponsible person.
- **Clara:** He took my hand and I noticed that some blood from his sores fell on my hand. But it didn’t bother me and that’s when I got it.

**Never warned by source:**
- **Elena:** He should have told me that he had it but he didn’t.
- **Chrisy:** He didn’t believe that he had it.
- **Alicia:** He told me he had (the HIV test) and it was negative, so I believed him and I never imagined that....
- **Berta:** I found out when, when the guy died. I found out that he had died of AIDS.

**Anger toward the source:**
- **Elena:** That’s what I’m so mad about. You know, sometimes I wish, man, I wish I could kill this dude, you know.

**No apology/acknowledgment:**
- **Elena:** He hasn’t told me anything.
- **Chrisy:** I called him and told him and he denied everything.
- **Berta:** I was working and I took some time off to go, but when I was going, he died.
Table 4.24

**Theme Cluster 7B: Hope, Peace, and Conflict With God**

<table>
<thead>
<tr>
<th>Merciful God:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Rene: I just prayed to God that it wouldn’t come back positive, you know, that it would be something else.</td>
</tr>
<tr>
<td>Elena: Right now I do not suffer, thank God!</td>
</tr>
<tr>
<td>Berta: And I tell him that when that moment comes, God will give him strength and the help he might need.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Anger toward God:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Chrisy: It was like God, forget it. I always used to ask “whys”, why did you do this to me?</td>
</tr>
<tr>
<td>Chrisy: A while back I used to say I do not want to know anything about the church, I do not want to know about God. Yes, I got very angry.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Rejects God:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Chrisy: And it was like when I found out what I had, I did not believe in God anymore. There was no such thing as God. Because I felt like if there was a God, this wouldn’t have happened to me.</td>
</tr>
<tr>
<td>Alicia: If God would exist He would not let that our own children would pay for our mistakes.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Re-acceptance of God:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Chrisy: And, when that day and I got that (news child was negative for HIV), that’s when I started believing in Him again.</td>
</tr>
<tr>
<td>Alicia: But then I think it over and I say, no, God knows why He does these things.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Meaning in having the AIDS virus:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Chrisy: It’s like He, it’s like I felt like that’s all He could do to bring me closer to my family. Now I look at it as he did it for a reason, a good reason.</td>
</tr>
</tbody>
</table>
Table 4.25

**Theme Cluster 7C: Effort Made to Transcend Misfortunate Fate**

<table>
<thead>
<tr>
<th>Does not dwell on having HIV/AIDS:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Elena: You know, I take it a day at a time. And I don’t worry about it, I just go on with life.</td>
</tr>
<tr>
<td>Rene: I try not to think about it.</td>
</tr>
<tr>
<td>Clara: Yes, I think about it, yes I do, but not all the time (she laughs).</td>
</tr>
<tr>
<td>Berta: In the meantime I try to live my life and take care of my husband and my daughter and myself. I try to live a normal life.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Transcends illness:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Elena: And then there’s days that I forget that I have it.</td>
</tr>
<tr>
<td>Clara: You know, I don’t even remember that I have the illness. But to be thinking and thinking about that (the illness), no.</td>
</tr>
<tr>
<td>Berta: Well, it isn’t like I try to enjoy it, but I try to live it and understand more.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Appreciates life more:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Chrisy: I better live like my whole life today because God knows if I’m gonna be alive tomorrow, that’s how I thought.</td>
</tr>
<tr>
<td>Clara: So I live my life joyfully.</td>
</tr>
<tr>
<td>Berta: I am happy just knowing I am alive. By being alive I can look at my daughter, who is my greatest happiness until now.</td>
</tr>
</tbody>
</table>

---

**Exhaustive Description of The Lived Experience of Women of Mexican Heritage with HIV/AIDS**

The following section presents an exhaustive description of the lived experience of women of Mexican heritage with HIV/AIDS. An exhaustive description of the topic is formulated from the results of the analysis thus far (Colaizzi, 1978). The exhaustive description is presented using theme categories as sections.
Different life situations or events led to the women discovering they had HIV/AIDS. For some participants, there was suspicion about having the AIDS virus when they learned their significant other had the virus. Suspicion also arose during extended ill health along with having a history of being promiscuous without using protection. Discovery of the virus occurred during a routine physical examination while trying to become pregnant, and in another circumstance, during one’s pregnancy. Having a child diagnosed with the virus led another woman to discover she too harbored the AIDS virus.

The lived experience of women of Mexican heritage with HIV/AIDS was a process which began when the woman was informed of being sero-positive for HIV. A characteristic response to learning one was sero-positive for HIV was being panic stricken because imminent death was linked with the diagnosis.

Doubts related to the diagnosis of having HIV/AIDS virus were experienced by the woman. Furthermore, these doubts were also experienced by certain family members and by some health care providers. The women who could afford it, had their tests for HIV repeated at a different health care facility to verify the result. For those who could not afford to be retested at another facility, doubt lingered off and on for an extended period. In certain family members, doubt continued even after the woman herself believed the diagnosis. Health care providers also expressed doubt when the woman’s cell count continued to remain normal over an extended period.
Facing the reality of the consequences of having HIV/AIDS was a devastating experience. The woman was displaced into an unfamiliar world. In hopelessness, the woman suffered as dreams of living a full life, of fulfilling social roles as an individual, wife, mother; of having more children, of watching one's children grow up were quickly destroyed. Not only was the woman's sense of self destroyed but so were relationships with family and society.

**Unsettledness in Familial Relationships**

Having received the diagnosis of being sero-positive for HIV, a process of unsettledness among familial relationships occurred. Paramount was the fear of being rejected by one's significant other. Precipitating such fear included a combination of factors such as the women's (a) perception of having a transmittable abominable infection with dire consequences, (b) awareness that one's mate was also emotionally affected by the misfortune, and (c) awareness that one's mate was fearful of contracting the virus. This inner fear perpetuated thoughts of possible abandonment or that one's significant other would find another woman. The women without a mate feared rejection by a possible significant other, as some had already been rejected by a member of the opposite sex for having the AIDS virus or had heard of others with the virus being rejected.

Child(ren) were both a source of concern and a source of strength. The women were in turmoil over the future well-being of their child(ren) who would grow up without their mother. Furthermore, there was apprehension over possible transmission of HIV to
their children. Some of the women responded by withdrawing from normal human contact. Berta, for example, described how she held back from comforting her small child during times when the child had cuts or scraps for fear she would transmit the virus to her child. Decisions related to informing child(ren) of their mother's infection were often debated. At the same time, the desire to raise, care for, and be with their child(ren) provided a dominant reason to survive the virus. Older child(ren) not only provided support and comfort but they also helped to guard their mother's secret from others.

As part of a family, the women did not want to be a burden to family members. There was an awareness by the women of the emotional strain and grief suffered by close family members in response to (the women) having HIV/AIDS. Often, attempts were made to try and hide physical ailments such as fatigue and to go on with normal routines in order not to worry family members. Furthermore, present and possible financial debts brought on by having HIV/AIDS were other pressing concerns faced by the women.

The support of close family members was very important to the women. However, the support from family members or a significant other was often times conditional and therefore, partial in character. Generally, only certain family members were informed about the virus as others were not trusted. At other times, supportive family members were hundreds of miles away in another city or country. For some of the women, family members were often too overwhelmed to discuss the consequences of having HIV/AIDS or some merely denied its existence. Consequently, support from family members was present only under certain conditions.
Changes in Patterns of Sexuality

The women developed a social consciousness in relation to their ability to transmit the AIDS virus. The women felt a responsibility not to transmit the AIDS virus to others. This moral obligation extended and affected their normal patterns of sexuality and normal human interactions. For example, some of the women developed strong beliefs that their sexual partners need to be informed. However, they were reluctant to place themselves in a vulnerable position where they could be humiliated or rejected. Consequently, they chose to have limited contact with persons of the opposite sex. One woman would not sleep with her husband during menses even though she had been told by her physician it was safe to do so.

Decreases in sexual desire was mediated by other factors. There was fear of transmitting the AIDS virus to one’s mate who was negative for HIV. Significant concern was experienced when a mate who was negative for HIV refused to wear a condom. At times, physical ailments impaired sexual desire. Other women, simply chose to abstain from sexual activity altogether.

Prevalent Emotional Turmoil Since Contracting the Virus

Distinct emotional turmoil was a process initiated by the diagnosis of having HIV/AIDS and continued throughout the lived experience. Concern for not burdening family members and having conditional support left the women with feelings of aloneness. The women were without an outlet for their innermost thoughts. To further compound
the situation, blame for contracting the virus was an issue to be faced. Some women placed blame for their misfortune on themselves. In other cases, regardless of how the virus was contracted, the women were blamed for contracting the virus.

The process of emotional turmoil was characterized by intermittent pangs of fear and despair. The wretchedness of facing the reality of the consequences of having HIV/AIDS often overwhelmed the women. Certain thoughts, words or events, reminded the women of their mortality.

Social Stigma to The AIDS Virus Affects The Lives of Those With The Virus and Their Family

The lived experience of having HIV/AIDS was a process influenced by social stigma which affected the lives of those with the virus and their family. Society’s dominant view that HIV/AIDS is an abominable infection was to a large degree indoctrinated in the women. Such a view predisposed the women to experience shame for having HIV/AIDS. Shame impeded the women’s ability to attend support groups or reveal their infection to others. Even when the women came to realize there was no reason for feeling ashamed, shame arose and affected the woman during certain unexpected situations.

Social stigma related to HIV/AIDS promoted fear of rejection from others in society. The women feared rejection and discrimination both for themselves and for their family. There was also an awareness of others prying and the vicious social gossip which
develops about those with HIV/AIDS. Consequently, the women took great care to conceal their secret from those not trusted.

The women were cognizant of the widespread lack of knowledge related to HIV/AIDS. Some the women acknowledged that they themselves had limited knowledge about the AIDS virus. Lack of education was seen to be a primary factor for social stigma. Furthermore, there was concern that others were ignorant about HIV/AIDS and therefore, vulnerable to contracting HIV.

**Compassionate and Adverse Encounters Upon Entering the Health Care system.**

Entering the health care system was a process characterized by both compassionate and adverse encounters. Furthermore, it was a system which imparted knowledge and skills useful for the women to enhance their well-being. There was much appreciation and relief for interactions with health care providers (HCP) where one was treated with kindness, respect, and with compassion.

Adverse encounters upon entering the health care system were diverse among the women. Negative encounters included verbal mistreatment by HCPs, indifference by HCPs in the treatment provided, enduring discomfort with treatments or medical procedures, and receiving care from different health care providers. Furthermore, concerns were ignored by HCPs and sexual questions were not asked due to experiencing embarrassment in discussing questions with physicians of the opposite sex.
In attempting to prolong their life, the women began to learn new knowledge and strategies to enhance well-being and to monitor their health. However, some knowledge was also derived from daily interactions with others in their environment. In the learning process, the women struggled to sort and assimilate new and social knowledge related to HIV/AIDS. For example, the women believed or knew others who believed that knowledge of having HIV/AIDS virus speeded up their demise.

**Struggling to Rebuild One’s Shattered World**

Included in the lived experience of women of Mexican heritage with HIV/AIDS was the struggle to rebuild one’s shattered world. This was a process where the women confronted and agonized over issues related to their source of the virus, their faith in God, and struggled to endure their predicament. Confronting their views about the source of the virus encompassed knowing that they were not informed nor protected by their partner or that by misfortune they had contracted the virus. Feelings of despair or anger were compounded, for some women, by feelings of dejection from lack of acknowledgment from a knowing source.

The women confronted their faith in God during their suffering. Various responses were acknowledged. Some of the women experienced outrage and feelings of being abandoned by God. Some women rejected their faith and vacillated in their belief in God. Others, maintained their faith and found considerable solace.
Attempts were made by the women to endure their present state. Strategies included trying to get by one day at a time, trying not to dwell on having HIV/AIDS, trying to live and find meaning to their suffering, and trying to focus on caring for their family. Transcending their misfortune meant having days when the thought of having HIV/AIDS did not enter their minds and were spared for a while from endless suffering.

Having come face to face with their mortality and their misfortune, some of the women came to better appreciate their lives. Though they continued to suffer, their love of close family members influenced their decision to endure the virus and to value the time available.

**The Essential Structure of The Lived Experience of Women of Mexican Heritage**

From the exhaustive description an unequivocal statement of identification of the lived experience's fundamental structure was formulated (Colaizzi, 1978). The following essential structure of the lived experience of women of Mexican heritage with HIV/AIDS has been derived:

The lived experience of women of Mexican heritage with HIV/AIDS is a process of struggling in despair to endure having a fatal, transmittable, and socially stigmatizing illness which threatens crucial aspects of the woman's own self, being, and existence. Diagnosis of being sero-positive for HIV initiates the process of the lived experience and thrusts the woman into an unfamiliar world. Ensuing death is foreseen and initial emotional turmoil continues as intermittent waves of fear and despair throughout the lived
experience. Doubt in the diagnosis emerges and is prolonged in the lived experience. Furthermore, entering the health care system exposes one to positive and negative encounters as well as to educational encounters which assist in promoting well-being.

Social stigma to AIDS, fear of rejection, and fear of transmitting the AIDS virus are dominant factors which adversely affect the continuance of familiar human interactions and relationships. Patterns of human sexuality change, and to various degrees sexual activity is withdrawn. Shame, and blame are experienced for having HIV/AIDS. Furthermore, conditional support predisposes the woman to experience a sense of aloneness and no outlet for innermost thoughts.

There is despair to the reality of the consequences of having HIV/AIDS in relation to family members. The well-being of one's family, especially the child(ren) is foremost in life. Furthermore, there is the desire not to be a burden on the family.

The lived experience includes a slow, arduous, and agonizing struggle to create a sense of balance, gain understanding, and rebuild a new world with new hopes and dreams. Past events are reflected upon, old and new beliefs are negotiated in the context of the present situation in an effort to gain understanding. Love for one's children and family is a significant force which compels the woman to endure her suffering.

**Validation of Essential Structure**

Upon the completion of the data analysis, two participants were contacted by telephone and one was visited and asked to validate that the essential structure of the lived
experience with HIV/AIDS was the same as they had experienced. The essential structure of the lived experience with HIV/AIDS was read to the three participants. Complicated terminology used in the description was clarified. One participant did not agree with one element of the essential structure. The element related to faith assisting to endure the lived experience. This participant objected, saying that although God came to mind, conflict with her faith and in God continued and did not assist in enduring the lived experience. Therefore, the essential structure was restructured to include that faith is confronted during the lived experience. This revision then was accepted by the participant. The revised essential structure was then read to the other two participants. Comments included, “Yes, that’s exactly the way it is” and “yes, that is all true.” When asked if anything should be added or omitted no recommendations were voiced.

Summary of Findings

From analysis of six protocols containing narratives of the lived experience of women of Mexican heritage with HIV/AIDS, 2,464 significant statements were extracted and restated. Meanings were formulated for each significant statement. Seven theme categories and twenty-two theme clusters were identified. An exhaustive description of the lived experience was derived from the theme clusters. Thereafter, the essential structure of living with HIV/AIDS was identified. Inclusive in the essential structure were the following:

1. The process of the lived experience is initiated by the diagnosis of being seropositive for HIV.
2. Initial emotional disruption occurs and continues as intermittent waves of fear and despair throughout the lived experience.

3. Diagnosis of being HIV positive leads to the woman to face in fear and despair her mortality and the consequences of having the AIDS virus.

4. Doubt surrounds the diagnosis of having HIV/AIDS and is prolonged.

5. Positive, negative, and educational encounters are experienced upon entering the health care system.

6. The woman is displaced into an unfamiliar world.

7. Changes in social and familial relationships occur.

8. Social stigma, fear of rejection, and fear of transmitting the AIDS virus are dominant factors which adversely affect human interactions and relationships.


10. Shame and blame for having HIV/AIDS are experienced.

11. Conditional support predisposes the woman to experience a sense of aloneness and no outlet for innermost thoughts.

12. There is significant concern for family and children.

13. The woman does not want to be a burden on one's family.

14. The woman undergoes a slow, arduous, and agonizing struggle to create a sense of balance, understanding, and rebuild a new world.

15. Past events, experiences as well as old and new beliefs are negotiated in efforts to gain understanding.

16. The love of children and family is a driving force to enduring suffering.
Comparisons Between the Two Studies

This section compares the findings between this researcher's initial phenomenological study on a multicultural sample of women with HIV/AIDS and the present phenomenological study on women of Mexican heritage with HIV/AIDS. Similarities and differences between the two studies are presented.

The Samples

The purposive sample in the present study of Women of Mexican Heritage With HIV/AIDS was comprised of 6 participants. A description of the sample was provided in the preceding sections.

In this researcher's initial study of Women with HIV/AIDS, the purposive sample was comprised of 4 women. One woman was Mexican American, two were Caucasians, and one was African American. Outlined in Table 4.26 are the pseudonyms, ages, marital status, years of marriage, number of children, date of diagnosis, approximate years with the AIDS virus, date when medication was begun, initial and last CD4 count, and current symptoms at the time of the interview. Ages of the participants ranged from 24 to 50 years of age; the average age was 34 years. Two of the women were married, one was separated and one was single. The number of children for each woman ranged from 1 to 2. The number of children Diane had was not known to this researcher. Elsa and Carrie indicated they had harbored the AIDS virus for 7 and more than 9 years, respectively. The other two women did not know for how long ago they had the virus. Three of the four
women were on medication for their virus. All the women were symptomatic and one woman (Carrie) had AIDS. Since the interview, Carrie and Chloe have deceased.
Table 4.26

Overview of the Participants

<table>
<thead>
<tr>
<th>Participants</th>
<th>Elsa</th>
<th>Carrie *</th>
<th>Chloe*</th>
<th>Diane</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age in years</td>
<td>24</td>
<td>34</td>
<td>28</td>
<td>50</td>
</tr>
<tr>
<td>Marital status</td>
<td>Married</td>
<td>Married</td>
<td>Separated</td>
<td>Single</td>
</tr>
<tr>
<td>Years Married</td>
<td>7</td>
<td>9</td>
<td>3</td>
<td>0</td>
</tr>
<tr>
<td>Child(ren)</td>
<td>2 DA, (4 &amp; 6 yrs.)</td>
<td>1 son (7 yrs.)</td>
<td>2 sons (4 &amp; 6 yrs.)</td>
<td>unknown</td>
</tr>
<tr>
<td>Years with virus (approx.)</td>
<td>7</td>
<td>&gt; 9</td>
<td>unknown</td>
<td>unknown</td>
</tr>
<tr>
<td>Date Medication began</td>
<td>1/93</td>
<td>1/92</td>
<td>1993</td>
<td>none</td>
</tr>
<tr>
<td>Initial CD4 count</td>
<td>800</td>
<td>39</td>
<td>&lt; 600</td>
<td>~ 800</td>
</tr>
<tr>
<td>Last CD4 count</td>
<td>458</td>
<td>23</td>
<td>464</td>
<td>~ 1300</td>
</tr>
<tr>
<td>Symptoms</td>
<td>Fatigue, dysplasia</td>
<td>fatigue, thrush, lymphadenoopathy, pneumonia, arthritis, retinitis</td>
<td>Fatigue, lymphadenoopathy, vaginal yeast, endocarditis, hepatitis C</td>
<td>Fatigue, lymphadenoopathy, vaginal yeast, insomnia</td>
</tr>
</tbody>
</table>

* deceased

In the study of Women With HIV/AIDS, there was one woman (Elsa) of Mexican descent. A brief orientation to this participant is provided to assist in contrasting the findings between the two studies.

**Elsa**

I first met Elsa, a 24 year old married woman with two young daughters, in the lobby of a hospital. She had felt comfortable selecting the hospital as an interview site as this was where she and her husband often came for their medical treatments. Furthermore, there were study rooms in the adjacent medical library where the interview could take place.
Elsa the Person

Elsa is an attractive-looking woman about 5 feet tall weighing about 105 pounds. She has light complexion, dark brown eyes and hair which she wears in a short and stylish cut. Elsa dresses very fashionably. Elsa projects intelligence and confidence. She comes across as someone who is used to accepting responsibilities and making decisions. Elsa speaks with a Spanish accent, is very articulate, and speaks very rapidly. Elsa was raised by her grandparents (for reasons she did not elaborate) who were very loving and caring. She admits, however, that as she was growing up she still missed her mother’s love. For that reason, she is pained to think her daughters will someday be alone and that they too, will miss their mother’s love. Elsa is immutable in her belief that no one can take care of her children as well as she can. Elsa married a much older man when she was very young (17 years old) and against her family’s wishes. In part, Elsa has distanced herself from her family because she wanted to have her own life and was determined to succeed in her marriage.

Contraction of the virus.

Elsa contracted the AIDS virus from her husband who has AIDS. She harbors no ill feelings against her husband as she feels he too was an innocent victim. Elsa’s husband contracted the virus through heterosexual intercourse from previous relationships before he married Elsa.
State of affairs.

Elsa and her husband are linked with the city's main AIDS resource center. Her husband is on disability for having AIDS, Elsa is a homemaker, and they receive their health care through federal funds for those with HIV/AIDS. Temporary housing is provided for them by the AIDS resource center. Their source of income is through disability compensations which her husband receives. Elsa has been attending a women's support group for several months. She looks forward to attending the group's meetings which are sponsored by the AIDS resource center. Community assistance has been the mainstay for Elsa and her family.

It's been easy for us. I mean I got counseling from the beginning, you know. We have a lot of people out there trying to help us. So it's been good for us. [SS 584a - 587]

Fatigue and poor appetite are Elsa's only symptoms. Several months ago, she underwent surgery for the removal of pre-cancerous cervical cells. Elsa and her family spend a lot of time in the hospital for their frequent examinations and treatments. Elsa, who is bilingual, helps her Spanish-speaking husband fill out questionnaires and hospital forms. Elsa also manages the money for the family. Elsa is aware her husband worries about her health when she is too tired to care for the family. He is very dependent on Elsa. Consequently, Elsa feigns feeling well when she is actually feeling badly. Elsa's main concern is the well-being of her children and husband. Although Elsa is very capable, she fears being left a widow as she has never been alone.
Those who know.

Only Elsa’s husband’s family (who are in Mexico) know they both have the AIDS virus. Elsa does not want to tell her own family as her family thinks she is a success for making her marriage last. She also, has not been close to her family and does not want them to become close just because they feel sorry for her. Elsa and her husband are careful to whom they reveal their secret as they are aware of possible discrimination for themselves and for their young daughters.

Future outlook.

The future for Elsa scares her. However, she presently feels well and is not significantly limited in her activities by the virus. Furthermore, she is relieved by the assistance provided by the AIDS resource center. Elsa values the time she and her family are together.

Two years later.

Contact with Elsa has been lost. Communication with the facilitator of the women’s support indicates Elsa and her family are doing well and that Elsa is currently employed.
Contraction of the Virus Between the Two Studies

Divergent stories inform how the women in both studies contracted the AIDS virus. However, at the time of contraction, none of the women (10) in both studies knew the source of their infection had the AIDS virus. In two cases, one from each study (Chloe and Elena), the sources knew they had the AIDS virus and failed to inform the woman.

Another similarity between the two samples was that the major method of contracting the AIDS virus was through heterosexual intercourse (Table 4.27).
In the present study on women of Mexican heritage, 4 (83%) of the 6 women believed contraction of the AIDS virus was by heterosexual contact and 1 (17%) by accidental contact with another person’s AIDS blood. Of the 4 women in the initial study on women with HIV/AIDS, 3 (75%) believed they had contracted the AIDS virus by heterosexual contact and 1 (25%) through injecting drug use (IDU).

**Education and Socio-economic Status**

There is limited information about the educational and socio-economic status among the women in the two groups to make conclusive statements. None of the women discussed having completed high school or higher education. Only Diane (in the initial study) discussed going to school to obtain her nursing assistant certificate. Furthermore, of all the women interviewed, only Elena was employed earning minimum wage. From this researcher’s perspective, most of the women in both studies were of lower socioeconomic status. Of the actual homes seen, Carrie Chloe, and Diane had nice homes in fairly lower middle class neighborhoods.

**Table 4.27**

**Method of Contraction**

<table>
<thead>
<tr>
<th>Women of Mexican Heritage With HIV/AIDS (present study)</th>
<th>Women With HIV/AIDS (initial study)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Elena - heterosexual intercourse</td>
<td>Elsa - heterosexual intercourse</td>
</tr>
<tr>
<td>Chrissy - heterosexual intercourse</td>
<td>Carrie - heterosexual intercourse</td>
</tr>
<tr>
<td>Rene - heterosexual intercourse</td>
<td>Chloe - injecting drugs</td>
</tr>
<tr>
<td>Clara - heterosexual intercourse</td>
<td>Diane - heterosexual intercourse</td>
</tr>
<tr>
<td>Alicia - heterosexual intercourse</td>
<td></td>
</tr>
<tr>
<td>Berta - accidental exposure to blood</td>
<td></td>
</tr>
</tbody>
</table>
Comparison of Findings

The theme categories from this researcher’s two studies are presented. Thereafter, similarities and differences between the findings of this researcher’s two studies are discussed using the theme categories from the study of women of Mexican heritage as an outline.

Theme Categories

Six theme categories (Table 4.28) emerged from the study of women with HIV/AIDS and included (a) discovering the virus, (b) facing personal and social core issues, (c) sources of sustenance, (d) awareness of an AIDS stigmatized environment, (e) seeking understanding and meaning to having HIV, and (f) evolving life perspectives since contracting the virus.
### Table 4.28

**Theme Categories: Study 1 - Women With HIV/AIDS**

| 1. Discovering the Virus                  |
| 2. Facing Personal and Social Core Issues |
| 3. Sources of Sustenance                 |
| 4. Awareness of An AIDS Stigmatized Environment |
| 5. Seeking Understanding and Meaning to Having HIV |
| 6. Evolving Life Perspectives Since Contracting the Virus |

In the study of women of Mexican heritage with HIV/AIDS, seven theme categories emerged and included (a) personal divergent vignettes describe the encounter with the AIDS virus, (b) unsettledness in familial relationships, (c) changes in patterns of sexuality, (d) prevalent emotional turmoil since contracting the virus, (e) social stigma to the AIDS virus affects the lives of those with the virus and their family, (f) compassionate and adverse encounters upon entering the health care system, and (g) struggling to rebuild one's shattered world. The theme categories for this study are presented in Table 4.29.
Table 4.29

**Theme Categories: Study 2 - Women of Mexican Heritage With HIV/AIDS**

| 1. Personal Divergent Vignettes Describe the Encounter With the AIDS Virus |
|---|---|
| 2. Unsettledness in Familial Relationships |
| 3. Changes in Patterns of Sexuality |
| 4. Prevalent Emotional Turmoil Since Contracting the Virus |
| 5. Social Stigma to the AIDS Virus Affects the Lives of Those With the Virus and Their Family |
| 6. Compassionate and Adverse Encounters Upon Entering the Health Care System |
| 7. Struggling to rebuild One's Shattered World |

**Personal Divergent Vignettes Describe the Encounter With the AIDS Virus**

In their description of the lived experience with HIV/AIDS, the women tell of a beginning, when they discovered they had contracted the virus. Although their stories differ on how they contracted HIV/AIDS, all the women in both studies were panic-stricken and devastated by their diagnosis of being positive for HIV. Even Clara (in the study of women of Mexican heritage) who somewhat expected to have contracted HIV from her husband who had hemophilia was not spared from feelings of devastation.

"It came out positive, you see. Well, yes it hurt me. Yes I felt badly and everything at the beginning. [SS 39-41]"

In both studies, there was one woman (Chloe and Rene) who had suicide ideations following their diagnosis. Chloe was the only one who actually attempted suicide.

Furthermore, the women in both studies acknowledged that at the time of their diagnosis they had limited knowledge related to HIV/AIDS. For some women, there was
not any difference between having HIV and having AIDS. Consequently, imminent death was linked to being HIV positive and their worlds crumbled.

One difference between the two studies related to doubt in the diagnosis. All the study women of Mexican heritage described the existence of doubt in their protocols. Doubt was found not only among the women, but among their family members, and in health care providers. Moreover, doubt persisted for a prolonged time. Factors promoting doubt in the diagnosis of having HIV were described as being due to (a) distrust in the accuracy of laboratory results due to the woman being tested and treated in a county facility, (b) not perceiving themselves at risk for contracting the virus, (c) not having the funds for a repeat test at a private health facility, (d) family members unable to deal with a loved one having a fatal infection, and (e) having continued normal CD4 counts.

Unsettledness In Familial Relationships

The women in both studies greatly valued and were relieved by any support they received from family, friends, and community resources. Furthermore, in relation to family, all the women expressed sadness and concern about the well-being of their children. Children, to the women in both studies, were both a source of concern and a source of strength.

Differences between the two studies, in relation to their family, were many. In the study of women of Mexican heritage, there was fear of rejection by their significant other
or by a potential significant other. There was also an awareness that their mate was overwhelmed by the consequences of their wife having HIV/AIDS and fearful of contracting the virus from them. Furthermore, in the study of women of Mexican heritage, the women described how they did not want to be a burden to their family in relation to their illness or finances.

Support for the women of Mexican heritage was present under certain conditions. Therefore, support was partial in character. For instance, the women were not free to discuss their infection with certain family members who could not tolerate facing the reality of the consequences to the sequelae of HIV/AIDS. Therefore, support from family members was present if the topic of HIV/AIDS did not arise. For the women whose significant partners stayed by their side and who offered support, there were times when the partners were not tolerant of the woman's ailments, feelings, or they were not physically present. In other situations, the woman had total support from her family, but her family was far away in another country. Moreover, the women indicated they would like to meet and converse with other women who were HIV positive. However, circumstances such as too embarrassed to attend support meetings or lack of encouragement from significant other prevented some of the women from attending. In Chrisy's case, she desired to meet someone of the same age who was HIV positive.

Differences were present in the two studies in relation to their children. The women in the initial (multicultural) study with HIV/AIDS had a sense of urgency to assist their children into becoming more capable and independent. The women wanted their
children to do things for themselves, do well in their environment, to be happy in life, and to be able to safely interact with others. By contrast, the women of Mexican heritage, were for the most part immutable in their grief and despair over thoughts of dying and leaving their children without a mother. Furthermore, there was significant fear in some of the women of transmitting the virus to their children.

**Changes in Patterns of Sexuality**

A gradual development of social consciousness developed in the women in both studies regarding the spread of HIV/AIDS. The women felt a responsibility toward not transmitting the virus to others. Their attitudes toward not wanting to spread HIV/AIDS extended and affected their sexuality. In trying not to spread the virus to others, the women undertook different steps to prevent its transmission. These steps included practicing safe sex, having sexual intercourse less often, undergoing surgical measures to prevent procreation, preferring abstinence, and terminating pregnancies.

Differences in the findings between the two studies were that the women of Mexican heritage described a waning of sexual desire for fear of transmitting HIV/AIDS to their partner. For Rene, there was also concern of being blamed if her husband, who refused to use a condom, contracted the virus which affected her sexual desire.

Like, well only God's with you, you know, because we've been, when we make love he doesn't use protection and I guess that's one of the reasons that I really don't want to make love either cause I don't want to get blamed, you know. [SS 140-141]
Furthermore, the decision to withdraw contact with the opposite sex or abstain from sexual intercourse led to experiencing an aloneness and a void in life as captured by Clara’s words:

We say, ‘yeah, I’m comfortable by myself,’ but yes, (in reality) one feels alone. Wishing there were a mate, to talk to, to find out about his day, and say ‘how was your day?’ From this point of view, yes, yes, sometimes I do feel alone. [SS 234-236]

**Prevalent Emotional Turmoil Since Contracting the Virus**

Throughout the lived experience the women in both studies experienced intermittent pangs of fear and despair. Certain words, thoughts, or events reminded the women of the reality of the consequences of having HIV/AIDS and overwhelmed them.

Distinct experiences which were described only by the women of Mexican heritage were of being confronted with blame and experiencing a sense of aloneness. The women experienced self-blame and/or blame by others. Parallel to blame was the notion held by some of the women of being punished by God for misdeeds.

A sense of aloneness was experienced in the lived experience by the women of Mexican heritage. These feelings of aloneness were in relation to their suffering and despair. The women felt they were unable to discuss their innermost thoughts with others and felt alone in their suffering. This finding contrasted with the initial study where the women described their relief of having support from sources such as their significant others, family, and women’s support groups. In the initial study 3 (75%) of the four
women were attending a support group regularly compared to none from the study of women of Mexican heritage.

Social Stigma to the AIDS Virus Affects the Lives of Those With the Virus and Their Family

The women in both studies described their awareness of living in an environment which stigmatized and discriminated against those with HIV/AIDS as well as their family members. Misrepresentation of those with HIV/AIDS by the media further hindered relationships and was acknowledged by some of the women in both studies. Furthermore, the stigma of AIDS influenced changes in relationships with family members and others. Certain families became more close knit upon learning a family member had contracted HIV/AIDS. In other situations, relationships with others including family members were severed because of the virus. As a consequence, the women entered a “relationship minefield”, where they had to discern to whom they could reveal or conceal their secret.

A difference between the two studies was the experience of shame explicit in the study of women of Mexican heritage. Shame was experienced by the women for having HIV/AIDS. Even for the women who saw no reason for being ashamed of having HIV/AIDS, during particular circumstances and situations, shame was experienced.

Compassionate and Adverse Encounters Upon Entering the Health Care System

A diagnosis of having HIV/AIDS established the women in both studies into the health care system. Encounters with health care providers (HCP) were described as being
both positive and negative. Relief and appreciation were expressed by the women for kind, respectful, and compassionate care. Furthermore, the health care system for the women in both studies, became a vital place for learning about the virus and about caring for themselves and their families.

Negative encounters in the health care system were described by the women in both studies. These adverse encounters were both with HCPs as well as with hospital routines or treatments. Mistreatment from HCPs included: concerns of the woman being ignored, verbal abusive, and indifference of HCPs in the treatments provided.

Chloe: “The way I look at it is some people in medical professions figure well you did it to yourself. They tend to pass you off, like you don’t matter.” [SS 89, 175]

Two women, one from each study and both of Mexican heritage, described embarrassment with issues of sexuality. One woman (Rene) described her embarrassment at asking her male physician about her lack of sexual desire. Although it was a pressing concern, Rene refrained from asking the question. Elsa, described embarrassment at asking her husband personal sexual questions as she filled out the hospital’s questionnaire for him. She also described her uneasiness at being present and having her husband’s physician expose her husband’s genital area during a physical examination.

A difference between the two studies related to the knowledge acquired about the AIDS virus. In the women of Mexican heritage with HIV/AIDS, half of the women described their own or other’s belief that knowing one had HIV/AIDS speeded one’s demise.
Struggling To Rebuild One's Shattered World

In an attempt to make sense of their shattered world, the women in both studies, reflected on past events, past behaviors, past beliefs, and past encounters with others. This was a painful process as their past was reviewed in relation to their future. Perspectives toward their source of infection were contemplated, and some of the women in both studies were able to come to terms with their source.

Clear differences were found between the two studies. Attitudinal and behavioral patterns towards enduring their misfortune and transcending their predicament differed between the two groups of women. Progression towards creating a new and stable world was more evident among the women in the initial study. These women in the initial study, described having a close supportive other(s) and to reiterate, three of the four women attended regularly a women's support group for HIV/AIDS. Knowledge about the various ways to impede the progress of the virus was present and consistent among the women in the initial study. Furthermore, all the women in the initial group discussed wanting to or were actively helping others in society.

In comparison, there seemed to be more of a struggle to endure living with HIV/AIDS for the women of Mexican heritage. There were persistent discussions of despair and of feeling alone in their suffering. Furthermore, in the study of women of Mexican heritage, the women described having limited knowledge about HIV/AIDS and ways to impede its progress. Moreover, none of the women of Mexican heritage had ever attended a support group. For most of the women, progression toward coming to terms
with their misfortune and towards rebuilding a new world was an arduous struggle.

Only two of the six women (Clara and Chrisy) appeared to be more appreciative of their life and to savor each day. Clara, however, had been diagnosed five years previously and time may have possibly allowed her to come to terms with her misfortune. Chrisy had normal CD4 counts and did not suffer noticeable ailments.

Summary

The purposive sample was comprised of six women of Mexican heritage with HIV/AIDS. A brief orientation to the participants was provided. Three of the six protocols were in Spanish and were translated into English using the method of back-translation prior data analysis. Although the method of back-translation was highly recommended for translating protocols, it was not infallible in detecting errors. Furthermore, the process of back-translation was very tedious, time consuming, and costly. The extraction of significant statements assisted in finding further discrepancies in the translations. Findings were presented through every step of the data analysis. From the 6 protocols, 2,454 significant statements were extracted and assembled into 162 themes. Themes were then organized into 22 theme clusters from which seven theme categories emerged. The essential structure of the lived experience for women of Mexican heritage was formulated from the exhaustive description of the lived experience. Finally, similarities and differences between this researcher’s two studies on women with HIV/AIDS were presented.
CHAPTER 5

DISCUSSION AND IMPLICATIONS

The findings in Chapter 4 reveal much about the lived experience of women of Mexican heritage with HIV/AIDS, the psycho-social/cultural forces influencing the lived experience and the suffering experienced in the struggle to endure their misfortune of having contracted the virus. This chapter presents a brief overview of the findings in the study of women of Mexican heritage with HIV/AIDS. The following sections then describe the usefulness of the methods used in this research design, the research in light of the literature, the usefulness of the conceptual framework, implications for nursing practice, and nursing theory development. This chapter concludes with implications for further research.

An Overview

Analysis of the protocols revealed seven theme categories which were common in the lived experience of women of Mexican heritage with HIV/AIDS. These theme categories included (a) personal divergent vignettes describe the encounter with the AIDS virus, (b) unsettledness in familial relationships, (c) changes in patterns of sexuality, (d) prevalent emotional turmoil since contracting the virus, (e) social stigma to the AIDS virus affects the lives of those with the virus and their family, (f) compassionate and adverse encounters upon entering the health care system, and (g) struggling to rebuild one’s shattered world.
The essential structure of the lived experience for women of Mexican heritage with HIV/AIDS was found to be a process of struggling to endure both a fatal and a socially unacceptable infection which threatened crucial aspects of the woman's self, being, and existence. Diagnosis of being HIV positive was antecedent to their world crumbling. Imminent death was foreseen and intermittent waves of fear and despair continued throughout the lived experience. Doubt in the diagnosis was prolonged during the lived experience. Multiple psychosocial factors such as the social stigma to AIDS, fear of rejection by others, fear of transmitting the AIDS virus adversely affected continuance of familiar human interactions and relationships. Experienced during the lived experience were shame, blame, and changes in patterns of sexuality. Furthermore, the women experienced frequent encounters with HCPs in the health care system; concerns about the well-being of their family and of not being a burden on the family; and conditional support which left the women without an outlet for their innermost thoughts. The women felt an aloneness and suffered in silence. The lived experience was characterized as a slow, difficult, and agonizing struggle to create a sense of coherence and understanding for their situation as well as to rebuild a new world. Love for their children and family positively influenced the women to endure their suffering and misfortune.

Usefulness of Methods

This section presents issues and insights on the usefulness of the methods used in this research design. Such insights may assist others who endeavor in phenomenology or in cross-cultural research.
Phenomenology In Theory Building

The method of phenomenology has application in the process of theory building. In and of itself, phenomenology does not develop any theories. Phenomenology does, however, generate theory building. From studies in phenomenology, concepts may be substantiated (Smith, 1989), may surface and then possibly need further clarification using the strategy of concept analysis (Walker & Avant, 1988), or may generate hypotheses (Knaack, 1984). For instance, some of the concepts generated from this study which need further clarification or further inquiry (including transcultural clarification) include the concepts of suffering, shame, guilt, social stigma, and connectedness. Findings from phenomenology may assist in the clarification of a concept such as by clarifying critical attributes, antecedents, or consequences. Clarification of concepts is crucial to theory building and in developing instruments. In-depth knowledge and description about a concept enhances the construction of operational definitions.

As an inductive, descriptive science, phenomenology was useful in providing an in-depth description of the lived experience of women of Mexican heritage with HIV/AIDS. Findings from phenomenology may be used to support or generate other research in the process of building transcultural nursing theories.

Bracketing

The approach of phenomenology enhanced the awareness of the particular biases and perceptions held by the researcher enabling a purer look into the lived experience. An
important perspective was omitted that disconcerted this researcher. I subconsciously held the perspective that the women of Mexican heritage with HIV/AIDS would progress in their lived experience to a level where they would transcend their misfortune, lessen their suffering, and live a more content life. In my mind, this would indicate that women of Mexican heritage were therefore, strong individuals. I think women of Mexican heritage endure much in everyday life. Furthermore, as a Mexican American who is proud of my ethnic group, I wanted the progression of the lived experience to at least mirror that of the women in my initial study.

Unfortunately, this was not found as described in the steps of data analysis. A broader understanding of suffering surfaced from the work of Gregory (1994). Gregory’s research on the cancer experience as lived by persons indicated that (a) even when individuals “work through” their suffering they do not stop suffering, and most importantly (b) a person’s inability to find meaning in their suffering should not mean they are less of a human being.

**Feminist Perspectives and Research**

As collaborators in the research enterprise, the participants and the researcher were able come to know one another at a deeper level which assisted the researcher understanding more fully the lived experience in the context of the participant’s world. The betterment of the participants may have occurred in possible feelings of having actively contributed and participated in a worthwhile endeavor and in their enhanced
insight about their lived experience. However, further betterment of women from this research endeavor are yet to come from the distribution of the findings to the various populations in society, not just HCPs or scientists.

Persistent Hierarchical Power in the Research Process

It is this researcher’s perception that the hierarchical power and in-equality in the research process was decreased, however, never absent from the process. The basis for this perception was based on two observations. One was that the women were compensated for their story. They exchanged their lived experience for the compensation offered and to some extent felt obligated to continue in their participation. Second, in the Mexican culture, individuals generally hold health care professionals in high esteem and look up to them in respect. Even after several encounters with some of the participants, this researcher sensed there was a formal, respectful distance between myself and the participants. Actually, informal relationships were better established with Rene’s mother who I met and talked to several times on the telephone. This may have been due to the fact that she was not compensated for her participation and therefore, our relationship was based more on friendship and not on obligation.

Likewise, the issue of reciprocity in the research process may have been hindered by compensating the participants. Anderson (1991) found that the women in her research expected reciprocity in the relationship with them and expected the researcher(s) to respond to their concerns. The women of Mexican heritage may have felt hesitant to ask
for information because of being compensated. The extent of this hesitation is not known to me. During the interview very little questions related to their infection were asked. I even had information which only some wanted. However, as time went on and I kept contact with some of the women (Rene, Elena, Clara), they did ask for further assistance or information.

**Unmasking Oppression**

My research unmasked oppressive behaviors such as concealment of having HIV/AIDS from husband (Alicia), family members or friends (Rene, Berta, Clara, Alicia, and Chrisy), having partial support in dealing emotionally with their infection, fearing rejection, and experiencing shame and blame for having the virus. However, other qualitative research is needed to bring out the elements influencing oppression among this cultural group. Feminist research has an interest in analyzing the conditions of women's lives as well as in understanding them. Other qualitative research may endeavor to delineate the sources and consequences of oppressive forces.

**Maintaining Contact With Participants**

Difficulty was experienced in maintaining contact with all the participants throughout the several months of the research endeavor. Community resources for persons with HIV/AIDS became insolvent in time and contact was lost with some of the participants. The mobility of some of the participants including mobility into another
country further compounded attempts to locate them. Strategies to facilitate maintaining contact may include keeping frequent communication, making sure they still have the researcher’s telephone number, and to remind them by telephone or by mail to contact the researcher if they will be moving.

**Conducting Cross-Cultural Research**

Conducting cross-cultural research entails giving great consideration to possible language barriers and issues of cultural sensitivity during recruitment of participants and during the research process. Further attention needs to focus on the time, expense, and use of proficient translators in the translation process.

**Recruitment of Participants**

The language barrier may be a consideration for others engaging in cross-cultural research. Recruitment of participants, for this researcher, was facilitated by being fluent in the participant’s language. However, it is to be expected that some nuances may be missed using interpreters and translators.

Impediments to accessing participants from a different culture need to be considered in the research endeavor aside from accessing a health care facility. For instance, in the Mexican culture, family problems/secrets are not readily divulged to those outside the family. Usually in the Mexican culture, the woman needs to have the husband’s consent prior to taking part in an endeavor where personal questions will be
asked. This researcher spent four months recruiting participants without success.

Only when compensations were offered did the women come forward.

**Cultural Sensitivity**

Being culturally sensitive assisted this researcher in communicating effectively and in recruiting participants. For instance it was useful to know of the distinct forms of communication (formal and informal) in Spanish, the prominent hierarchical system in the Mexican culture, and of women’s modesty in discussing intimate issues.

**Translation Issues**

In conducting cross-cultural research, translation issues such as the time involved and the cost of translating protocols need to be considered. Moreover, consideration needs to be given to the proficiency and personal characteristics of the translators.

The translation process was not only costly but was time consuming. Each translated protocol cost about $700. Purchase of a transcribing machine was also required. Six months elapsed prior to the completion of the translation enterprise. Prior to its completion, numerous individual meetings with the translators were organized and conducted.

**Proficiency of the Translators**

The proficiency of the translators became evident during the process of back-translation. However, it was of tremendous advantage that this researcher is bilingual and literate in the Spanish language. The method of back-translation is not fool-proof
errors were missed by the translators when translating the huge amounts of narratives in the protocols. As a whole, the translators were proficient in maintaining the contextual meaning, the tone of the narratives, and same level of complexity. Idioms (the style or artistic expression characteristic of the participants) were kept intact.

**Ethical Issues**

Ethical considerations need to be dealt with in any research enterprise. Qualitative researchers are obligated to describe the experiences of the participants in the most faithful way possible even when it is contrary to their aims. A dilemma to consider is how close does the research become to the participant. Frequent interactions and communications with participants draws the researcher into the world of the participant and vice versa. As collaborators in the research enterprise one knows the other as a human being and not just as a sample. Researchers will be faced with issues of privacy and confidentiality related to the participants. Narratives which describe adverse affects on others will be confronted.

**Emotional Reprieve For the Researcher**

Qualitative researchers are vulnerable to suffering emotional turmoil when engaged in research which focuses on a fatal infections such as AIDS. As collaborators with participants, researchers come to know the participants more and come to know their children and other family members. As researchers the reality of their lives is seen, their voices are heard, and are not spared from feeling another’s despair and suffering. Respite
for the researcher is crucial. This researcher engaged in talking with a confidante and in physical activities such as in swimming and walking. Sometimes I met for lunch with colleagues which in part provided a distraction from my own feelings of being distraught. Time alone was also needed to reflect and to try and make sense of the world. It was during these times alone that the frailty of life was acknowledged, the common everyday aspects of life appreciated, and the awareness that others do not have an easy life was inculcated.

**Interface With The Literature**

This section discusses the findings of this study in light of the literature in and outside of nursing research. Research which included Hispanic women (Andrews, Williams & Neil, 1993; Rapkin & Erickson, 1990) was limited. Anecdotal literature (Aranda-Naranjo, 1993; Kleinman, 1988; McGoldrick, Pearce & Giordano, 1982; Nichols, 1985; Rosenberger & Wineburgh, 1992; Sontag, 1990; Sue & Sue, 1990; Worth, 1990) is used only when appropriate. Research articles on women in general and on samples of men are used as well.

**Discovery of The AIDS Virus**

The findings of how the women in both of this researcher’s studies contracted the virus, differed from most of the literature. Exposure to HIV was believed by the women in both studies to be through heterosexual intercourse (80%), sharing needles (10%), and accidental contact with an exposed person’s blood (10%). In the initial study with a
sample of 4, one (25%) woman (Chloe) engaged in injecting drug use (IDU). From a sample of 6 in the present study, two (33%) women (Elena and Rene) had a history of IDU although one of the women (Elena) believed actual contraction of HIV was through heterosexual intercourse.

These figures were lower than those reported by the Arizona Department of Health Services (1995) for the state of Arizona for the exposure of women to the AIDS virus through injecting drug use. The Arizona Department of Health Services (1994) reported percentages of exposure by IDU and heterosexual contact as 39% and 33% respectively in the general female population and 38% and 35% respectively in Hispanic women. Research on Hispanic and non-Hispanic women attending an urban family planning clinic (Rapkin & Erickson, 1990) discovered differences among English and Spanish speaking women in the level of risk behaviors for contracting HIV. These researchers found less risk levels in Spanish speaking Hispanic women than in English speaking Hispanics. These differences were speculated to be the influence of acculturation on risk behaviors in English speaking Hispanics and to the adherence to the Mexican cultural behavior patterning of sexual and substance use by the Spanish speaking women.

Divergent stories informed how the women contracted HIV/AIDS. At the time of contraction, none of the women (10) in both of this researcher's studies knew that the source of their infection had HIV/AIDS. In two cases, the sources knew they had HIV/AIDS but failed to inform the women. One study (Cochran & Mays, 1990) warned against the efficacy of asking sexual partners about their sexual history. This study (N =
665) whose sample consisted of 18 to 25 year old students attending colleges in southern California indicated a sizable percentage of the 196 men and 226 women reported telling lies in order to have sex. Furthermore, men reported lying significantly more frequently than women. In a study (Chu, Peterman, Doll, Buehler & Curran, 1992) using a small sample (N = 52) of female partners of HIV positive bisexual men, awareness of the mate’s bisexual activity differed by race/ethnic group. Eighty percent of the White, 20% of Black, and 22% of Hispanic women were aware of their partners’ bisexuality.

_Panic-Stricken By The Diagnosis_

Upon learning they were sero-positive for HIV the women were panic-stricken in fear of their perceived imminent death. Most of the women in both of the researcher’s studies did not differentiate between being HIV positive and having AIDS. For most of the women, they equated having HIV with having AIDS, which to them meant imminent death. Nichols (1985) described this phase as “initial crisis”, a stage characterized by emotional turmoil. Moreover, two women (Chloe and Rene), one from each group and both with a history of IDU, indicated they had initially contemplated suicide. Of the two, only (Chloe) attempted to end her life by overdosing on injectable drugs and later by slashing her wrists. Suicide attempts and suicide ideation among women were also reported in the literature. In Rose’s (1993) exploratory study on the health concerns of women with HIV/AIDS, she reported suicide attempts and ideation were common in 5 (46%) of a sample of 11 women.
Most of the literature on suicide ideation or suicide among individuals with HIV/AIDS has been limited to samples of men. Suicide rates among men with AIDS were found to be 36% higher than the men without the diagnosis of AIDS and 37% higher than those in the general population (Marzuk, Tierney, Tardiff, Gross, Morgan, Hsu, Mann, 1988).

Reports conflict relative to when in the disease process suicidal activity occurs. A heightened risk of suicidal activity was suggested to occur during the initial crisis phase after diagnosis (Miller; 1990). Nichols (1985), had indicated suicidal thoughts were more prone to occur in the “transitional state”, a state following the crisis stage. Chloe, who attempted suicide in this researcher’s initial study did so within two weeks of her diagnosis. The time of her second attempt was unknown. Since the interview, Chloe has died from complications of endocarditis. Rene reported contemplating suicide immediately after learning about her diagnosis. The literature indicates individuals prone to suicidal ideation or intent were those who had more psychosocial characteristics associated with increased vulnerability to psychiatric distress (Dew, Ragni, & Nimorwicz, 1990). Chloe who attempted suicide in this researcher’s initial study indicated she had a history of being suicidal, which she related to childhood problems.

Chuang, Devins, Hunsley, and Gill (1989) found psychosocial distress to be higher earlier in the disease process than in individuals with full-blown AIDS. These two studies on women with HIV/AIDS did not confirm such findings. Rene and Alicia were found to be struggling in emotional turmoil and in vacillating denial a year after being diagnosed
with AIDS. Clara and Carrie (who did not have AIDS) appeared to come to terms with their illness. This, however, did not mean the women did not at times suffer emotionally as they did suffer. Furthermore, two other women (Diane and Chrisy) who also voiced acceptance of their illness, had normal T-cell counts and were virtually asymptomatic.

**Denial**

Denial was an element of the lived experience which continued on and off for an extended period in the study of women of Mexican heritage. What was being denied was the reality of their situation, which was a threat to their being. One other woman (Elsa) of Mexican descent in the initial study also vacillated in her denial during her lived experience. This was in contrast to the findings in the literature which indicated denial occurred in the initial crisis phase (Miller, 1990; Nichols, 1985) or occurred in the first few months of learning their diagnosis (Aranda-Naranjo, 1993). The narratives of the women of Mexican heritage indicated factors contributing to their on and off denial were (a) distrust of the accuracy in laboratory results due to being tested and treated in a county facility, and (b) not having the funds for a repeat test at a private health facility. Although denial was experienced in the lived experience it was not continuous.

Denial was found to have beneficial as well as detrimental affects on individuals with HIV/AIDS. Denial was seen as a human adaptive response useful in alleviating internal stress (Aranda-Naranjo, 1993; Miller, 1990; Rosenberger & Wineburgh, 1992).
However, some individuals who denied having HIV/AIDS or of being at risk for contracting the virus were found to continue in risky transmission and risk-taking behaviors (Rose, 1993; Rosenberger & Wineburgh, 1992). Findings from the present study with women of Mexican heritage found one woman (Alicia) who vacillated with denial and was not taking her medication because of her perception that she was divinely being punished for past misdeeds.

Denial among family members was found in both of this researcher’s studies. Short-term denial in family members was discussed in the literature (Aranda-Naranjo, 1993). However, in both of this researcher’s studies, denial in family members was prolonged.

**Changes In Familial Relationships**

Changes in familial relationships were evident in both studies and centered on relationships with children, mate, and other family members.

**Children As Sources of Concern and Support**

In both of this researcher’s studies and research on women with HIV/AIDS (Andrews, Williams & Neil, 1993; Frank, Blundo & Brabant, 1995; Rose, 1993), findings indicated that child(ren) were a source of concern as well as sources of strength. Despair centered on not living long enough to watch their children grow up, and concern for who will raise the children, and that the children would grow up without their mother’s love. At the same time, their children provided the women with an incentive to endure and
survive the virus. The formation of strong relational bonds in women with HIV to their children have been found in the literature (Andrews, Williams & Neil, 1993; Dolan & Nokes, 1992; Rose, 1993). Andrews, Williams, and Neil (1993) suggested the role of motherhood assists to enhance self-esteem in women with HIV. Further, feminist writers indicate and describe how women's identities are socially built and perpetuated in the context of relationships of intimacy and care (Chodorow, 1978; Gilligan, 1982). Findings from both of this researcher's studies were not able to confirm or disconfirm such findings.

There were differences between the two studies. The themes in the initial study centered on the women's urgency to assist the child(ren) in their ability to be independent, to care for themselves, to be happy, and to be able to safely interact with others. In contrast, the themes in the present study with women of Mexican heritage were predominately of despair at the thought of leaving their child(ren) without a mother, of fear of transmitting the virus to their child(ren), of issues relating to informing child(ren) of their mother's illness, and of a sense of injustice that children contract the AIDS virus. Differences in cultures may influence these subtle variances in responses among the women of the two groups. Cultural values such as mastery versus harmony with the environment, future versus past and present time orientations, individual versus collateral relationships, and doing versus being and becoming provide the context for human responses (Sue & Sue, 1990). Furthermore, the literature indicates that culturally, Hispanic women tend to be very devoted to their home and children (McGoldrick, Pearce & Giordano, 1982).


**Relationships With Significant Other**

In both of the studies, there was concern by the women regarding their mate, a significant other, or a possible significant other. The women were relieved and appreciated having a supportive significant other. Those without a significant other felt an aloneness. A distinct finding in the present study with women of Mexican heritage was that the women feared being rejected by their significant other. This finding was consistent with that reported by Worth (1990). Further, the single women in both of the studies were hesitant and embarrassed to inform a member of the opposite sex of having the AIDS virus. Consequently, the women withdrew contact with those of the opposite sex. Rose’s (1993) study on women also indicated a decrease in reported sexual relationships and an increased frequency in safe sex and cuddling and caressing.

**Relationships With Family Members**

Three (30%) of the 10 women in both studies indicated they had revealed their infection with all family members. Furthermore, these women indicated, that as a result, their families had become a closer knit family unit. Most of the women in both studies, however, were careful and selective about who within the family to reveal their infection. Rose’s (1993) study on women with HIV/AIDS found that women generally informed only one member of their family, usually their mother. Aranda-Naranjo (1993) reported individuals concealing their infection from family members and neighbors for fear of rejection by the family and fear of being asked to leave the neighborhood by the neighbors.
In the present study with women of Mexican heritage, the existence of partial familial support was more evident than in the initial study. Factors contributing to partial family support included, but were not limited to, their significant other not wanting to discuss the wife's infection, family members denying the woman's infection, being geographically distant from family members, not disclosing to the family they had the AIDS virus, a significant other incarcerated in another state, a significant other being deceased from AIDS-related complications, and the women not wanting to be a burden on the family. Aranda-Naranjo (1993) reported individuals who were unable to inform extended family members experienced a lack of support which was felt by the entire family.

**On Being A Burden**

A theme persistent in the study of women of Mexican heritage related to the women not wanting to be a burden on their family. This was not a consistent finding in the initial study. The women did not want to burden family members with their illness nor with financial burdens due to their treatment. The women went so far as to feign feeling well by continuing in their daily chores, when in reality they were feeling quite badly. Although financial burdens were eventually relieved when public funds became available, some of the women had accumulated a significant debt. The response of the women of Mexican heritage of not being a burden appears to be consistent with their cultural values. Mothers in the Mexican culture have a social role that is inclusive of being nurturant,
supportive, submissive, and self-sacrificing (Gonzalez-Marshall, 1987; McGoldrick, Pearce & Giordano, 1982). Further, Hispanic women tend to be socialized to feel inferior, and suffering and being a martyr are characteristics of a good woman (Sue & Sue, 1990).

**The Stigma of AIDS**

The social stigma of AIDS impacted the lives of the women and their immediate family in both of the studies. Care was taken to conceal their infection from others in society for fear their child(ren), other family members, and themselves would be discriminated against and stigmatized. This finding coincides with the literature which indicated women with HIV/AIDS tended to have fewer friends (Rose, 1993), experience a profound sense of isolation (Andrews, Williams & Neil, 1993), and individuals with the AIDS virus and family members often chose to conceal contraction of the virus from others to avoid stigmatization (Chekryn, 1989; Kleinman, 1988; Sowell, Bramlett, Gueldner, Gritzmacher & Martin, 1991; Weitz, 1991). Andrews and Neil’s (1993) qualitative study on women with HIV further indicated mothers with HIV were bound to their children by secrecy as a means to protect against the social stigma surrounding HIV and AIDS. This was not a consistent finding in both of this researcher’s studies.

**Encounters With Health Care Providers**

Encounters as well as perceptions about health care professionals were described as being both positive and negative by the women in the two groups. Positive encounters were greatly appreciated as was the information provided by health care providers related
to caring for self and family. Perceived mistreatment by HCPs was in the form of indifference to the care provided, lack of attentiveness toward the woman’s concerns, verbal abuse, aversion towards those with HIV/AIDS, and disregard for those who had a history of injecting drugs.

Studies have found variances in attitudes, opinions, and concerns among health care providers regarding the care for individuals with HIV/AIDS. Negative attitudes and mistreatment of individuals with HIV/AIDS by health care providers have been documented in the literature (Foley & Fahs, 1994; Larson-Presswalla, Rose, Cornett, 1995). Studies have cited health care providers’ reasons for avoiding the provision of care to individuals with HIV/AIDS, including but not limited to fear of contagion, blaming the victim, and viewing the illness as a burden and threat to society (Bradley-Springer, Schwanber & Frank, 1994; Meisenhelder & Rice, 1994). Meisenhelder (1994) found fear of contagion to be strongly related to homophobia, fear of the unknown, and lack of emotional involvement with individuals with HIV/AIDS.

The degree to perceived negative encounters among women of Mexican heritage with HIV/AIDS varied. To illustrate, Chrisy perceived health care providers were subjecting her to too many unnecessary laboratory tests for their own curiosity without regard to her and her family’s financial expense. Clara was angered at HCPs who behaved critically and in aversion when they learned she was positive for HIV. Rita experienced verbal abuse from a physician who casually entered her hospital room and scornfully told her she did not have long to live. Dissatisfaction of HCPs among some of these women
was beyond usual dissatisfaction in HCPs as the behaviors of HCPs negated the women’s humanity.

Shame and Blame

Shame and blame were distinct themes which emerged in the study of women of Mexican heritage. Even the women who reasoned that having the AIDS virus was nothing to be ashamed of, in particular social interactions, they experienced shame. Furthermore, some of the women of Mexican heritage concealed their infection from certain family members such as their parents in order not to disappoint them. Kleinman (1988) indicated the impact of being stigmatized by society leads to the individual and family to experience feelings of being less worthy, degraded, deviant, and shamefully different. Moreover, the internalization of stigma may adversely affect an individual’s self-image (Kleinman, 1988). Influential forces contributing to the stigma of AIDS which were recognized and voiced by the women were society’s lack of education about the virus, social sentiment toward individuals with the AIDS virus, the misrepresentation of individuals with HIV/AIDS by the media, and the social fear of contracting the virus.

The theme of blame to having contracted the AIDS virus was another issue which emerged from the study of women of Mexican heritage. Blame for having contracted HIV/AIDS was in the form of self-blame, social blame, or both. Weitz (1991) and Sontag (1990) presented various perspectives on blame. Afflicted individuals may believe their suffering and affliction occurred because of their “mis-deeds”, a view constructed to
make their lives more comprehensible. Blaming persons for their illnesses may also be a way of reinforcing social beliefs that the world is "just" and only the guilty are punished. Parallel to this view are the notions that only the guilty are punished and that those afflicted with disease deserve the illness because they are evil (Sontag, 1990; Weitz, 1991). Further, blaming others may be a way for individuals to avoid acknowledging that they too may be at risk (Weitz, 1991). Sources of others blaming was not uncovered in either of this researcher's two studies.

Religion's Influence

Themes of God and faith emerged only in the study of women of Mexican heritage. This finding was surprising. As this researcher continued contact with the women in the initial study, it was obvious that some had strong religious beliefs which assisted in their enduring or surpassing their fate. Relative to the Hispanic population, Schick and Schick (1991), indicated that 95% of Hispanics claim a religious preference such as Protestant (12%) or Catholic (72%). A small portion (5%) of the Hispanic population indicated other or none for religious preference.

Themes in the study of women of Mexican heritage related to the women confronting their faith and to themes of contracting HIV/AIDS as divine retribution for past acts or sins. Varied paths were taken by the women upon confronting their faith included remaining faithful and using faith in God for strength and hope, becoming angry and rejecting God, or becoming angry and later reaccepting God and their faith. Views
related to having contracted HIV/AIDS as punishment for misdeeds were consistent with western religious views that disease or illness is retribution for sin (Sontag, 1990; Weitz, 1991). The phenomenon of the women suffering in silence did not elicit themes related to religious perspectives. This study suggested suffering in silence was influenced from others in the lives of the women not wanting to discuss or confront issues on the sequelae of HIV/AIDS. Further inquiry into social/cultural and religious influence on suffering is needed.

**Social Consciousness Against Transmitting The Virus**

In both of the studies of women with HIV/AIDS a social consciousness against transmitting HIV/AIDS evolved. Emotional turmoil was involved in the decision not to transmit the virus to others which essentially affected normal human relationships. The issue of transmitting HIV/AIDS to others through sexual intercourse presented much concern to the women. Such concern occurred especially when one’s mate refused to practice safe sex. For the single women, having sexual intercourse meant revealing to another their secret. The women who did have sexual intercourse without informing their partner suffered much guilt. Others (Diane and Elena) chose to abstain from sexual intercourse. Anecdotal literature (Worth, 1992) indicated sexual abstinence as an appropriate response for an initial period while the woman explored her feelings about having HIV/AIDS. However, sexual abstinence was viewed as a poor long-term solution
especially for women who had not worked out their feelings about changing their sexual behavior or engaging their partner in negotiations.

Social consciousness against transmitting the virus affected relationships with family and others. The women in the study of women of Mexican heritage with HIV/AIDS worried and took extra precautions not to transmit the virus to their family members, such as their children. Berta held back from comforting her small child during times when the child had cuts or scraps for fear she would transmit the virus. Berta would not sleep with her husband during menses even though she had been told by her physician it was safe to do so. Women withdrawing from human interactions and relationships for fear of transmitting the virus to child(ren) and partner was found in the literature (Worth, 1990). Furthermore, the study of women of Mexican heritage disclosed fear of transmitting the virus to others. For instance, Berta worried when company came and wondered if she had cleaned the bathroom well enough with Clorox so others would not contract the virus.

**Guilt From The Transmission of HIV/AIDS**

The guilt suffered by the women who had transmitted the AIDS virus to their children was tremendous. Out of the 10 women in both studies, 3 women (Chloe, Chrisy, Alicia) had transmitted the virus to their child(ren). Rene suspected her youngest child might be infected but the thought was so overwhelming that she could not bring herself to have the child tested. The immense burden of guilt experienced by women who transmit
HIV/AIDS may be vented as anger (Aranda-Naranjo, 1993). Both Chrisy and Alicia described their anger at God for allowing their children to contract the AIDS virus.

Rebuilding A New World

Attitudinal and behavior patterns of enduring and transcending the infection differed between the two groups of women. Progression towards creating a new and stable world was more evident among the women in the initial study. In the initial women's study, all the women reported having a close supportive other and three of the four women attended a women's support group regularly. Knowledge in the various ways to impede the progress of their virus was present and consistent among the women. All the women in the initial group discussed wanting to or were actively helping others in society.

In comparison, there seemed to be more of a struggle to endure living with HIV/AIDS for the women of Mexican heritage. The women suffered in despair and usually in silence. Further, having limited knowledge about the virus and ways to impede the progress of the virus was voiced by half of the women of Mexican origin. None of the women of Mexican heritage had ever attended a support group. Their narratives described their support system as being partial in character. In describing states of relatedness, Hagerty, Lynch-Sauer, Patusky & Bouwsema, (1993) indicated connectedness occurred when an individual was actively involved with another person, object, group or environment, and such involvement instilled a sense of comfort, well-
being, and anxiety-reduction. In the study of women of Mexican heritage, involvement with others was present. However, their relatedness was more characteristic of the state of enmeshment with elements of discomfort, anxiety, inability to communicate, coercion by others, the need for self-sacrifice, submission, and the lack of sense of self.

Moreover, fear of rejection by a significant other was a real threat endured. Progression towards rebuilding a new world and establishing a balance in life was characteristically slower, staggering in nature, and in some of the women not readily evident.

Usefulness of Conceptual Framework

In light of this study, the usefulness of Rogers’ conceptual system as well as the underlying philosophy of phenomenology and feminist perspectives are presented. Rogers’ science of unitary human beings was found to be appropriate for the study of women of Mexican heritage with HIV/AIDS. Central to Rogers’ conceptual system are unitary human beings and their environments (Rogers, 1992). Information about individuals cannot be known from studying their parts or the sum of their parts. Furthermore, as irreducible, indivisible, and mutually integrating wholes, unitary humans cannot be studied outside the context of their own environments. The women’s protocols revealed their life-world as being influenced by past psycho-social-cultural events, interactions with others, present situations/social influences, and future perceptions. The lived experience of women of Mexican heritage did not evolve from a vacuum.
Evident from the women’s protocols were the diversity in human field patterning. Rogers’ principles of resonancy, helicy, and integrality assisted in understanding changes that occurred in the lived experience. Upon learning they were HIV positive, changes in the women’s lives began to quickly occur (principle of resonancy). Changes in the lives of the women were continuous, innovative, unpredictable, and increasing in diversity of human and environmental field patterns (principle of helicy). Each woman possessed uniqueness in changing rhythmicities. Furthermore, mutual changes occurred with their environments. The women and their environment evolved and changed together (principle of integrality). For example, the women’s diagnosis affected other family members whose response or effect in turn impacted the woman. Moreover, the lived experience contained changes that occurred out of nonequilibrium and exhibited punctualism not gradualism. For instance, Berta’s life was changing as she and her husband decided to have another child (nonequilibrium). During her physical examination, she was found to be positive for HIV. From that moment on, she saw her life as abruptly falling apart and her life was never like it was before. The direction of her life changed from that moment on (punctualism).

The science of unitary human advocates that the role of nursing is to promote the betterment of human beings wherever they are (Rogers, 1992). Rogers’ conceptual system further acknowledges individual/group differences and encourages the provision of individualized services which coincides with tenet of transcultural nursing (Leininger,
Therefore, the science of unitary human beings was found to be an appropriate conceptual model for studying women of Mexican heritage.

**Philosophy of Phenomenology**

The philosophy of phenomenology was compatible with the goals of this research enterprise which were to understand the lived experience of women of Mexican heritage with HIV/AIDS. Phenomenology acknowledges the significance of individuals and their life-worlds, the world of everyday experiences. Individuals' experience and descriptions about the world which has been experienced and interpreted by others and is handed down to instructs later generations about reality is valued. Therefore, in order to understand the lived experience, knowledge about both the individual and the context of their environment are essential.

The method of phenomenology provided the means to focus on individuals' lived experience in order to better understand the phenomenon of interest. Often in health care settings, nurses assume they know what is best for the client or what nursing intervention is best for all. A changing environment with its changing perspectives, goals, and aggregates of various cultural groups require that changes be made in nursing services based on research. Phenomenology provided the means to inquire into the subjective experiences of participants in order to better understand what it was like to live with HIV/AIDS. As Munhall (1994) indicated:
“phenomenology, as a way of being, takes us from this dazed perspective to a gazed perspective where we give, reflect, and attempt to understand the ‘whatness’ of ordinary life” (p. 4).

**Data Analysis**

Although the steps in data analysis were tedious and time-consuming they served to elicit information by dwelling on the significant statements and themes. From every step of the data analysis findings emerged until the common essential structure of the lived experience was extricated from the protocols.

**Credibility Strategies**

Evaluation of one’s work is essential if others are to acknowledge the finding and use them for the betterment of others. The most useful strategies used by this researcher included peer debriefing, progressive subjectivity and member checks. Prolonged engagement and persistent observation were not feasible with many of the participants due to losing contact with them, spending limited time with some of them, and communicating over the telephone versus being with them. This researcher found these last two strategies not necessary for this research endeavor.

Authenticity in the findings was maintained. This was a struggle as explained under Usefulness of Methods as my findings on women weighted by their suffering and despair conflicted with my own expectations of them to transcend their misfortune of having contracted HIV/AIDS.
Back-Translation

The method of back-translation for translating protocols was useful in maintaining cultural equivalency in the translations, however, it was not error-free. Of surprising interest was that the phenomenological method of extracting significant statements assisted in recognizing errors in the translations. By analyzing the narratives small section by small section errors in the translations were recognized. This was further aided by the researcher being bilingual.

Feminist Framework

Feminist perspectives assisted in enhancing this researcher's awareness of the oppressive state in which these women lived. Various psycho-social-cultural forces promoted the oppression of the women. For example, the stigma of AIDS influenced the shame felt by the women and close family members. The women also lived in a state where they feared rejection by their significant other as well as by other members of society. Culturally, there was the consistent theme of not wanting to be a burden on the family and their dependence on their mate or family members. For instance, Berta, who wanted to attend a women's support group did not attend because her husband was not in favor of her going. Although there was limited information on the women's socio-economic and educational status, it was clear to this researcher the women were heavily dependent on their mates or other family members for their survival.
Implications For Nursing Practice

Women of Mexican heritage with HIV/AIDS would benefit if the nursing care received was culturally appropriate, sensitive, and individualized to their distinct needs and expectations. For nursing interventions to be effective in meeting the physical, psychological, social, economic, and educational needs in women of Mexican heritage, nursing interventions and programs need to take into consideration the characteristics that are distinct to the Mexican and Mexican American population. Knowing these characteristics, however, is not enough as there will be differences among groups and within family members. Therefore, individuals need to be assessed on several important variables.

Factors to be assessed individually in women of Mexican heritage are those related to attitudes, beliefs, education level, socioeconomic status, cultural values, and language (Amaro, 1988). Women's values and attitudes toward sexual behavior and the ability to proceed in risk-reduction activities may be influenced by recent immigration and economic resources (Cochran, 1989).

Women's access to health information and health services will need to be determined. Linking the women with a case manager would assist their accessing health care as well as other needed services. Furthermore, monolingual women of Mexican heritage would benefit from being directed to health care centers or support groups which are staffed with professional interpreters and translators,
Health Care Centers and Support Groups

As managers of community centered health care and support centers, nurses are in a strategic positions to make these centers accessible to women of Mexican heritage with HIV/AIDS. Health care and support centers primarily need to be community-based. Service programs and treatment modalities should be planned and implemented so as to ensure accessible, equitable, and appropriate interventions unique to the Hispanic population. Board members of these centers need to give attention to the identification and elimination of practices which impede the delivery of effective and equitable services. Moreover, the staff of these centers would be given training to increase their awareness and to be sensitive to the distinct life experiences and cultures of minority patients which are related to lifestyles influenced by their experiences with racism (Sepulveda-Hassell, 1980). Attention should be given to the way services are planned and provided so rapport with the patient can be facilitated and the treatment be positively accessed.

Services provided by these centers need to be flexible and accessible. For example, services during the late afternoon or evening should be available for individuals who work during the day or who only have transportation when the husband gets home from work.

Health care and support centers need to be staffed by bilingual, bicultural, and multi-racial individuals. In this manner, culturally appropriate interventions can be facilitated. Findings from this study indicated a need for support groups for adolescents
with HIV/AIDS as well as support groups for the older children of women with HIV/AIDS.

**Health Education**

Health care facilities need to be culturally sensitive and refrain from having too detailed, public AIDS education which may offend community values. Educational programs need to be sensitive to the values of the community’s ethnic groups. For example, traditionally, women of Mexican heritage are not educated explicitly on sexual matters. Sensitivity should be given to the idea of having women ask their partner to use a condom in a double standard society. For a woman to discuss sexual practices can be viewed disapprovingly in certain cultures (Sabo & Carwein, 1994). Moreover, for the woman to generate discussions on sexual practices could be difficult to manage since women are expected to be sexually inexperienced and obedient to male desires. Furthermore, the use of same gender health care providers to discuss matters of sexuality and to instruct the women and their mates should be considered.

Amaro (1988) indicated the need for AIDS educational materials to consider the educational attainment of the particular individual. Furthermore, educational materials need to be developed specifically for the particular Hispanic population. What often occurs is that educational material provided to the Hispanic population has been translated from an English publication.
Health education needs to include information related to the transmission of HIV/AIDS to others in the family. Information needs to be accessible to the older children of women with HIV/AIDS as well. Women in this study, had concerns and withdrew normal human contact because they feared transmitting their infection to their children and mate. Instructional literature on basic and practical concerns which arise from home settings and which are culturally sensitive to individuals of Mexican heritage (versus Hispanics in general) may be useful for this population.

**Counseling Issues**

Findings from this research on women of Mexican heritage with HIV/AIDS described the impact of having the AIDS virus on their mates. Therefore, it is important that the psychosocial needs of both the woman and her partner be addressed. Included in the counseling of couples should be discussions on one’s fears of transmission and contraction as well as changes in patterns of sexuality. Furthermore, discussions should include the fears of the sequelae of the AIDS infection experienced by the individual(s).

Sue and Sue (1990) proposed strategies appropriate for nurses counseling individuals of Mexican heritage. One strategy was to deal with the expectations of the individual(s) by informing them what counseling entailed and the role of each person. Stressing confidentiality was important. Another strategy was to determine the patient’s expectations and to develop appropriate goals with input from the patient. Inquiring about the woman’s views on participating in family counseling are recommended as not all
women want to discuss their concerns in front of other family members. Furthermore, the appropriation of counseling by offspring’s is recommended. In this researcher’s study, Elena’s two adolescent offspring’s conspired with their mother to conceal her infection from others. They too were left alone to deal with their innermost thoughts. Counseling traditional Hispanics are more likely to do well with treatment strategies that are concrete, goal oriented, and structured (Sue & Sue, 1990).

Non-Adherence Issues

Inquires into issues of non-compliance need to be addressed in a respectful, accepting, and non-threatening manner. Nurses need to investigate the reason(s) as to why the women are not following their treatment programs. This study uncovered various psychological influences that impeded the women from taking better care of themselves. Rene at times did not take her medication which consisted of seven pills (some large in size) at one time. Some of these pills she took several times a day. Often Rene was overcome with the daily stresses of daily life, from fatigue, and lack of appetite. Alicia chose not to take her medication because she was going to pay for her mis-deeds. Lastly, Chloe had an addiction to injectable drugs that at times took priority over her life. Aside from providing education, perhaps what is needed is to take the time to listen to their stories and to try understand.
Implications For Nursing Theory Development

The focus on culturally diverse populations with their own specific needs and expectations from health care providers has received limited attention in nursing and in the development of nursing theory. Rogers' (1991) science of unitary human beings is an abstract conceptual model which provided part of the theoretical underpinnings for this study on women of Mexican heritage with HIV/AIDS. The broadness of this conceptual model allows for the study of individuals of a different ethnic group. Furthermore, the science of unitary human beings recognizes the uniqueness of individual field patterning and rhythmicities and advocates individualized nursing care for the promotion of well-being. Health is further acknowledged as a value-laden term which is culturally defined. However, the science of unitary human beings does not focus on or has an emphasis on individuals of different ethnic groups. Only by the creative use of the art of nursing would nurses engage in transcultural research for the purpose of theory development appropriate for individuals of different cultures.

Leininger's (1988) theory of cultural care diversity and universality acknowledges the cultural diversity found among different populations and their need for culturally congruent specific nursing care. Within the cultural care theory, culture and care are inextricably linked together and are inseparable in nursing care decisions and interactions. The cultural care theory has been used to enhance care components which promote culturally specific care. Usage for the theory are to generate grounded and substantive data about care meanings, patterns, experiences, and other processes of care (Leininger,
Furthermore, hypothesis may also be developed from qualitative findings of the theory. Such findings would be useful in providing culturally specific care to women of Mexican heritage with HIV/AIDS.

A major concept which emerged from the study of women of Mexican heritage with HIV/AIDS was suffering. The concept of suffering has been sparsely defined in the literature. Travelbee (1971) defined suffering as “an experience which varies in intensity, duration and depth. Basically, suffering is a feeling of displeasure which ranges from simple transitory mental, physical or spiritual discomfort to extreme anguish, and to those phases beyond anguish, namely, the malignant phase of despairful ‘not caring’, and the terminal phase of apathetic indifference” (p.62). The antecedents, critical attributes, and the consequences to this definition of suffering are not clear. Furthermore, Travelbee’s (1971) definition does not appear to be relevant to the findings of this study. Others associate suffering with a loss or a threat (Cassell, 1982; Charmaz, 1983; Kleinman & Kleinman, 1991). For nursing theory to proceed, concept clarification of the concept of suffering is needed as well as inquiry to differences in concept analysis from different cultural perspectives. The study of women of Mexican heritage with HIV/AIDS substantiates that an antecedent of suffering is a loss to some aspect of the person. Critical attributes substantiated from this study are a sense of helplessness and aloneness. The consequences to suffering may be either positive or negative outcomes.

Previous “scientific” research on different cultures have linked minorities with pathology (Sue & Sue, 1991). Furthermore, social problems encountered by minorities
were assumed to be due to intrinsic factors such as racial inferiority and incompatible value systems instead of the impact of adverse social forces. In developing nursing theory, nurses need to acknowledge that differences among cultural groups exist. This diversity in cultural groups may be viewed as a gift to the species of the human race (Spradley, 1980). Furthermore, nursing theories must begin to be critically examined for their appropriateness among other culture groups.

**Implications For Research**

Findings from this phenomenological study generated further questions for further research.

1. How do women of Mexican heritage with HIV/AIDS fare with attending support groups or counseling sessions? For instance, what are the benefits/barriers in attending support groups for women with HIV/AIDS and what are the affects on family relationships? Are there any cultural differences?

2. How do partners of women of Mexican heritage with HIV/AIDS fare in attending support groups. What are the barriers/benefits in attending support groups. Are there any cultural differences? Are there any gender differences?

3. What is the lived experience of men whose wife/mate is HIV positive? What are their concerns, fears, and needs? Are there any cultural differences or gender differences?
4. How do changes in sexuality affect relationships with mates? What are the women's mate's perspectives and responses to decreases in sexual contact? What factors/perspectives assist mates to deal with changes in patterns of sexuality?

5. What are the concerns and needs of informed children of mother's with HIV/AIDS. Further, how are children affected who have both parents with HIV/AIDS. Are there any cultural differences? Gender differences?

6. Little is known about the incidence of suicide and suicide ideation in women with HIV/AIDS. What deters women from attempting suicide? The psycho-social, socioeconomic, and educational influences also need to be investigated. Are there cultural differences in the incidence of suicide in women?

7. Conditional and partial support was experienced by the women of Mexican heritage with HIV/AIDS. What psychosocial and cultural forces shape this oppressive state? Other qualitative transcultural research may enhance nursing knowledge on the dynamics of supportive family members.

8. The women of Mexican heritage were found to be weighted by despair. What are the processes that assist women of Mexican descent to work through their misfortune and suffering? What factors in their lives compel the women to endure their suffering? Are these processes culturally different? Are there gender differences?

9. In re-building a new world, what factors assist the woman to establish her self-identity and self-esteem? What social/cultural factors exist that already influence the
shaping of women’s self-identity and provide self-esteem? Are these processes culturally different?

10. What educational strategies are most effective with women of Mexican heritage? Is teaching more effective if the woman’s partner is instructed along with the woman? Is the woman’s mate more supportive if he is initially involved in the education process? What effect does educating other family members have on the woman’s sense of having supportive others?

11. How does the diagnosis of being HIV sero-positive affect other family members? What social and spiritual processes enable the family to deal with having a family member with HIV/AIDS? Are there any cultural differences? Further, the course of the AIDS infection on individuals varies from one individual to another. Longitudinal, qualitative family research relative to the impact of the AIDS virus among family members through various phases of the illness is recommended.

12. What other types of modalities do women with HIV/AIDS use to treat their infection? What are their perspectives on holistic modalities, home remedies, or the use of healers from the community to treat their affliction?

13. What effects do holistic modes of treatments such as meditation, prayer, visual imaging, and therapeutic touch have on maintaining or prolonging an individual’s quality of life?
Conclusions

The lived experience of women of Mexican heritage with HIV/AIDS was found to be a complex process involving a struggle to endure the virus, changes in normal human interactions/relationships, and suffering. Numerous psycho-social-cultural processes affected the lives of the women and their families. Having the virus not only affected the woman, but it also made imprints on the lives of those who were close.

Having being diagnosed with HIV/AIDS, the women's world fell apart. The women's personhood crumbled and normal human interactions and contacts were withdrawn. The women found themselves in an unfamiliar world and often times suffered in silence. Some of the women were more adept at enduring their misfortune than others.

The women of Mexican heritage with HIV/AIDS were found to be weighted by grief and despair and seemed to be having a difficult time enduring their misfortune. Different perspectives of the women enhanced knowledge about this phenomena. In promoting the well-being of others, the distinct needs of those of another culture need to be inquired. Further, nurses need to realize and accept that individuals have their idiosyncratic pace for dealing with their illness or misfortune and that some individuals will succumb to despair. Moreover, an individual's inability to endure or a nurse's inability to assist another to endure and overcome misfortune in no way should be viewed as a failure in anyone's part.

Nurses are obligated to use the art of nursing to find meaningful ways to provide needed interventions in a compassionate manner to individuals wherever they are. The
needs of the women in this study were numerous and idiosyncratic. Therefore, generalizations about specific individuals or ethnic groups have little use in caring for others. Nursing care based on knowledge about specific groups is useful, however, not complete. Patients need to be seen and assessed as individuals with their own particular needs and concerns. They need to be treated with understanding, respect, and compassion. These extant views toward caring for others have existed within the philosophy of nursing and continue to be fundamental.
APPENDIX A

RECRUITMENT ADVERTISEMENT
WOMEN OF MEXICAN HERITAGE
NEEDED FOR A RESEARCH STUDY

- MUST BE HIV POSITIVE
- NEED TO BE 18 YEARS OR OLDER
- SPANISH OR ENGLISH SPEAKING
- CONFIDENTIALITY WILL BE MAINTAINED
- STUDY INVOLVES BEING INTERVIEWED BY A REGISTERED NURSE

IF INTERESTED CONTACT: LINDA MOORMAN, R.N.
PATIENT EDUCATION
267-5091
APPENDIX B

CONSENT FORM
SUBJECT'S CONSENT FORM

EXPERIENCES OF WOMEN WHO ARE HIV POSITIVE

I AM BEING ASKED TO READ THE FOLLOWING MATERIAL TO ENSURE THAT I AM INFORMED OF THE NATURE OF THIS RESEARCH STUDY AND OF HOW I WILL PARTICIPATE IN IT, IF I CONSENT TO DO SO. SIGNING THIS FORM WILL INDICATE THAT I HAVE BEEN SO INFORMED AND THAT I GIVE MY CONSENT. FEDERAL REGULATIONS REQUIRE WRITTEN INFORMED CONSENT PRIOR TO PARTICIPATION IN THIS RESEARCH STUDY SO THAT I CAN KNOW THE NATURE AND THE RISKS OF MY PARTICIPATION AND CAN DECIDE TO PARTICIPATE OR NOT PARTICIPATE IN A FREE AND INFORMED MANNER.

PURPOSE

I am being invited to voluntarily participate in the above-titled research project. The purpose of this project is to gain understanding of what it is like for women to be HIV positive.

SELECTION CRITERIA

I am being invited to participate because I am a woman 18 years or older, of Mexican heritage, and who has tested positive for HIV.

SELECTION TREATMENT(S)

My treatment(s) at this facility will not be altered by my participating or by my not participating in this research.

PROCEDURE

If I agree to participate, I will be asked to agree to be tape-recorded while providing a complete description of my experience with being HIV positive.

RISKS

I understand the risks of this study are minimal, however, I may experience temporary anxiety over discussing my experiences.

BENEFITS

I understand there are no direct benefits to be derived from this study for myself other than that of sharing my personal experience with the interviewer.

CONFIDENTIALITY

I understand that my identity and all information I provide will be kept strictly confidential. The interviewer is the only one who will have access to my name.
PARTICIPATION COSTS AND SUBJECT COMPENSATION

I understand the only cost to myself will be three hours of time involved in the interview process to which I am agreeing. I will be paid $50.00 for participating in this research.

LIABILITY

I understand that side effects or harm are possible in any research program despite the use of high standards of care and could occur through no fault of mine or the investigator involved. Known side effects have been described in this consent form. However, unforeseeable harm may also occur and require care. I understand that money for research-related side effects or harm, or for wages or time lost, is not available. I do not give up any legal rights by signing this form. Necessary emergency medical care will be provided without cost. I can obtain further information from Linda Moorman, RN at (602) 992-6418. If I have questions concerning my rights as a research subject, I may call the Human Subjects Committee office at 626-6721.

AUTHORIZATION

BEFORE GIVING MY CONSENT BY SIGNING THIS FORM, THE METHODS, INCONVENIENCES, RISKS, AND BENEFITS HAVE BEEN EXPLAINED TO ME AND MY QUESTIONS HAVE BEEN ANSWERED. I UNDERSTAND THAT I MAY ASK QUESTIONS AT ANY TIME AND THAT I AM FREE TO WITHDRAW FROM THE PROJECT AT ANY TIME WITHOUT CAUSING BAD FEELINGS. MY PARTICIPATION IN THIS PROJECT MAY BE ENDED BY THE INVESTIGATOR OR BY THE SPONSOR FOR REASONS THAT WOULD BE EXPLAINED. NEW INFORMATION DEVELOPED DURING THE COURSE OF THIS STUDY WHICH MAY AFFECT MY WILLINGNESS TO CONTINUE IN THIS RESEARCH PROJECT WILL BE GIVEN TO ME AS IT BECOMES AVAILABLE. I UNDERSTAND THAT THIS CONSENT FORM WILL BE FILED IN AN AREA DESIGNATED BY THE HUMAN SUBJECTS COMMITTEE WITH ACCESS RESTRICTED TO THE PRINCIPAL INVESTIGATOR, LINDA MOORMAN, OR AUTHORIZED REPRESENTATIVE OF THE NURSING DEPARTMENT. I UNDERSTAND THAT I DO NOT GIVE UP ANY OF MY LEGAL RIGHTS BY SIGNING THIS FORM. A COPY OF THIS SIGNED CONSENT FORM WILL BE GIVEN TO ME.

Subject’s Signature Date

INVESTIGATOR

I have carefully explained to the subject the nature of the above project. I hereby certify that to the best of my knowledge the person who is signing this consent form understands clearly the nature, demands, benefits, and risks involved in his/her participation and his/her signature is legally valid. A medical problem or language or educational barrier has not precluded this understanding.

Signature of Investigator Date
APPENDIX C

HUMAN SUBJECTS APPROVAL
29 September 1994

Linda Moorman, M.S.N.
c/o Linda Phillips, Ph.D.
College of Nursing
Arizona Health Sciences Center

RE: EXPERIENCES OF WOMEN WHO ARE HIV POSITIVE

Dear Ms. Moorman:

We received your 18 September 1994 memorandum and accompanying revised consent form for the above-cited exempt project [45 CFR Part 46.101(b) (2)]. As reported, results of this research have led to its expansion, thus it is now requested that only women of Mexican heritage be enrolled to examine cross-cultural findings [subjects to be compensated $50 for the interview]. Approval for this change is granted effective 29 September 1994.

Thank you for informing us of your work. If you have any questions concerning the above, please contact this office.

Sincerely yours,

William F. Denny, M.D.
Chairman
Human Subjects Committee

WFD:rs

cc: Departmental/College Review Committee
APPENDIX D

ETHICAL REVIEW APPROVAL
PROJECT APPROVAL FORM
REQUEST FOR ETHICAL REVIEW OF ACTIVITIES INVOLVING HUMAN SUBJECTS IN QUESTIONNAIRES, INTERVIEWS, OBSERVATIONS, VIDEO/AUDIO TAPES, ETC.

1. Linda Moorman, M.S.N., R.N. Nursing
   Principal Investigator Department
   EXPERIENCES OF WOMEN WHO ARE HIV POSITIVE
   Title of Project

2. SUPERVISING OFFICIAL

   I certify that (1) facilities and personnel are available to the investigator for assuring the safety and well-being of human subjects involved; (2) I will be responsible for continuing surveillance of the proposed program with respect to the rights and welfare of human subjects; (3) no procedural changes relating to the human subjects involved will be allowed without prior review by the Human Subjects Committee; (4) I am satisfied that the procedures to be used for obtaining informed consent comply with the spirit and intent of DHHS regulations; (5) I certify that the investigator is fully competent to accomplish the goals and techniques stated in the attached proposal; (6) the signed consent forms will be filed in the Departmental file and retained for a period of six years.

   [Signature]
   Head of Department, Dean of the College of comparable authority
   [Date]

3. DEPARTMENTAL REVIEW COMMITTEE (Thesis/Dissertation Chairperson)

   We/I have examined the proposal cited above, and find that the information contained therein is complete, that the scientific aspects of the project include appropriate provision for protecting the rights and welfare of the human subjects involved, and that the required forms have been filled out properly in accordance with the Institutional Assurance filed by the University of Arizona with the U.S. Department of Health and Human Services.

   [Box: Exempt from Human Subjects Committee review]
   [Box: Minimal risk to human subjects: Human Subjects Committee expedited review requested]
   [Box: Possible risk to subjects: Human Subjects Committee review recommended]

   [Signature]
   Chairman of Departmental Review Committee
   [Date]

4. HUMAN SUBJECTS COMMITTEE

   The proposal above was approved on this date by the Human Subjects Committee.

   [Signature]
   Chairman
   [Date]
APPENDIX E

THEMES FROM INTERVIEWS
THEMES FROM INTERVIEWS

*The deceptive path to the virus

Symptoms of the virus are unrecognized

Has not experienced any symptoms to the virus

Suspected had the AIDS virus

Feelings of nervousness prior to being tested for HIV

*Panic stricken with fear of imminent death upon learning of ones diagnosis

Devastated to learn offspring was positive for the AIDS virus

*Saddened when faced with own immortality

*Experiences renewed waves of fear with salient body changes perceived to be indicative of the AIDS virus invasion
Time abates feelings of imminent death
a163,b22,b23,b24,b215,b216,b217,d31,d32,d33,d34,d35,d36,d41,d42,d43,d44,d45,d46,

Defends self as a “good” woman
a83,a84,a93,a246,a247,b272,c10,c11,c12,d186,d418,d455,d456,e17,e18,e19,e20,e21,e22,

Had led a low risk for contracting the AIDS virus lifestyle
e18,e19,e22,e4,f8-10,f18-19,f41,f43-45

Reveals a past of risk-taking behaviors
a241,a242,a243,a244,b252,c3,c4,c9,c216,c217,c218,c219,c223,c225,c226,c253,c254,c255,c256,c257,c258,c259,c260,c457,c458,c459,c460,c461

Neglecting to practice safe sex
a48,a49,a50,a51,a52,c3,c4,

Continues drinking alcohol and smoking marijuana
b253,b254,b255,b256,b257,b258,b259,b260,b261,b262,

Smokes marijuana to increase appetite and to help face the world
c128,c129,c135,c168,c169,c170,c182,c183

Aware of others’ danger from risk-taking behaviors
a248,a249,b149,d429,d430,d431,d432,d433,d434,d457,
e271,e272,e281,e282,

Topic of AIDS in women not discussed in community
a112,a113,a114,

Feels alone and doesn’t have contact with other women with the AIDS virus
a112,a113,a114,b131,b132,b133,

Feels alone with no one of same age with the AIDS virus
b132,b133,b134,

Partner does not want to talk about the AIDS virus
c265,c266,f111-f112,f228-236,

Feels alone without a significant other
d151,d152,d153,d154,d155,d230,d231,d232,d233,d234,d235,d236,d237,d238,d239,d240
SUPPORT

*Feels alone with no support or any one to talk to
a91,a92,a93,a95-a97,b18,b19,c57,c67c68,c156,c264,c265,c266,c267c268,c269,c270, c271,c272,d135-d141, d172- 173,e90,e91,e92,e130,e131,e132,e133,e228,f82- 85, f186-198,f201,f228-235,f242-243,f244-249,f555,

* Needing the support of others
a53,a54,a55,a108,b101,b102,b103,c293,c294,c295,d9,d19,d20,d21,d22,d133,d134,d135, d136,d137,d190,d191,d192,d193,d215, d216,e90,f79,f85a,f186,f204-206,f182,f183

Family as a source of support
a151,b25,b26,b27,b37,c47,c48c52,c91,c92,c93,c94,c95,c108, c109,c395,c396,c397,c398,d1,d2,d3,d4,d5,d6,d7,d8,d9,d10,d11,d12,d13,d14,d20,d21,d2 2,d23,d120,d121,f85a,f182-185,f292

Having the virus has brought the family closer
b28,b29,b30,b31,b32,b33,b34,b35,b36,d23,d120,d121,d126,d127,d128,d129,d130,d131,d 132,d133,d134,

Support from community resources
a134,a136,a175,a176,a177,a178,a179,a180,a181,a182,a183,a184,a185,a186,a187,a188,a 1b321,b322,b323,b324,b325,b326,b327,b328,b329,b330,b331,b332,b333,b334,b335,b34 0,e125,e126,e127,e128,e129,e144,e145,e146,e147,e148,e149,e150,e151,

Embarrassment to having HIV impedes seeking support of others
a16,a117,a118,c404,c405,c406,c407,c421,c422,c423,e99,e100,e101,e102,e103,e104,e1 05,e106,

Lives an isolated life
d174,d175,d263,d264,d265,d266,d267,d268,d269,d270,d271,d272,d273,d274,d275,d276 ,d277,d278,d279,d280,f182-185,

Conceals virus from family so family will not be disappointed at her for contracting the AIDS virus
e90,e91,e92,e93,e94,e95,e99,e100

PARTNER

Relieved to having a supportive significant other
a85,a86,a87,a88,a89,a216,a217,A218,A219,A220,a234,a235,a236,a239a240,C69,f94- 97,f104,f105,f210-226,f240-241,f294,f564-575,

Receiving partial support or no suport from those who are close
a56,a57,a58,a90,a91,a218,a219,a220,b18,b19,b20,b21,c68,c69,c70,d135,d136,d137,d138 ,d139,d140,e90,e94-95,f228-236,f293,

At times has no support from partner
b18,b19,c68,c313,c314,
Partner is not physically present to give support
a218,a219,a220,
Partner is not sensitive or understanding of mate not feeling well
b218,b219,c130,c131,c132,c133,c134,c135,c136,c137,c138,c191,c192,c193,c194,c195,c196,c197,c198,c199,c200,c201,c202,c208,c209,c290,c291,c293,c296,c297,c298,c299,c300,c399,c400,c401,c402,c403,
Partner does not want to deal with responsibilities of family and life
c116,c117,c118,c131,c134,c139,c140,c145,
Partner is negative for the virus
c110,c111,c112,c113,c251,f17,f53a,
Tormented by partner’s refusal to use protection
c114,c115,c145,
Partner aware and overwhelmed by the consequences of mate having the virus
c147,c149,c150,c151,c152,c154,f22-34,f297-300,f316-319,f321,f356-362,
Partner is worried will contract the virus from mate
c146,c147,c148,c149,c150,c151,c154,fl23-125,f202,
Partner fearful to discover has the virus
b20,b21,b52,b53,b54,b55,b56,b57,b58,b59,b60,e93,e94,e95,e96,e244,e275,e277,e284,f123-125,f202,
Partner’s illness is more severe
a28,a29,b61,b62,
Partner’s with limited supportive others/family
b194,b195,b196,b218,b219,b220,
Stays with partner for convenience sake only
b84,b86,b151,b152,b153,b154,b155,b156,b157,b158,b159,b160,
Fears rejection by mate
CHILDREN
Has lived with the guilt of transmitting the virus to offspring
b46,b363,b367,b397,b398,b399,b400,b401,b402,b403,b404,b405,b411,b412,b413,b414,e60,e61,e62,e63,e64,e65,e66,e67,e68,e69,e70,e71,e72,e73,e74,e75,e76,e77,e78,e79,e80,e
Greatly relieved when child(ren) was negative for the virus
It is an injustice when innocent children contract the AIDS virus
Denial that offspring is positive for the AIDS virus
Tries to determine future caretakers for children
Unable to face finding out if children(s) has the virus
Children(ren) as a source of support
*Concern for child(ren)’s well-being
Accepts punishment for having transmitted virus to child
Anger toward God

*Acknowledges the power and the mercy of a higher spiritual source (God)
Felt was a sinner and was being punished by God
b379,b380,c159,c165,c166,c167,c168,c169,c170,
Lost faith in God
b384,e220,e221,e222,e223,e224,e229,e230,e231,
Regained faith in God
b386,b387,e227,e232,
Found meaning in illness
b387,b388,b389,b390,b391,b392,b394,b395,b396,

THE SOURCE OF VIRUS
*Unaware the source had the AIDS virus
a24,b14,b15,b16,b17,c216,c217,d35,e24,e25,e26,e27,e28,e29,e30,e31,e32,e33,f255-263,
Anger toward source(s) of virus
   a60,a61,a63,a64,a65,a66,a67,e231,c232,c233,c234,c235,c236,c237,e68,e69,e70,e71,
e72,e73,e74,e75,e76,e77,
   *Never warned or protected from the virus by source
      a59,a62,a73,a74,b13,b14,b15,b16,b17,c218-221,d411,d412,d413,d414,d415,d416,d417,e28,e29,e30,e31,e32,f255-263,
Hurt that did not receive an apology from source
A75,B20,B21,
Wanted to dialogue with and be acknowledged by the source
a76,a77,b20,b21,f287-291,

FINANCIAL CONCERNS
Overwhelmed by medical financial debt
a170,a171,a173,a174,a175,a176,a195,a196,c,350,c351,e143,
Financial burden from not having health care insurance
b309,b310,b311,b312,b313,c352,c353,c354,e143,e147,f409
Perception of unnecessary procedures which were financially and emotionally draining
b314,b315,b316,b317,b318,b319,b320,b321,c355,c356,

Willingness to forego care to keep debt from accumulating
a177,a178,a179,a180,b320,
Does not want family to be financially burdened
a193,a194,b332,b333,
SUFFERING

Is always reminded and thinks about the virus

c90,c263,c332,c433,c434,c435,f74,

*Experiencing feelings of depression

a153,a154,a155,b163,b164,b209,b210,b211,b212,c66,c67,c68,d51,d52,d53,d54,d55,d283,

*Has suffered since learning has the virus

a153,a154,a155,a156,b44,b45,b46,c29c49,c50,c51,c55,c56,c57,c58,c59c88,c89,c315,c42
4,c425,c441,c442,c443,c444,d51,d52,d53,d54,d55,d56,d57,d58,d59,d140,d141,e98,e176
,e177,e178,f92-103,f156,

*Has suffered in life

a119-123,a241-244,b266,b267,b268,b269,b270,b272,b273,b274,b275,b276,b304,c71,c72,c73,c74,c75,c76,c77,c78,d32,d33,d34,d35,d36,d37,d38,d39,d340,d41,d42,d43,d44,d45,d170,d171
,d172,d173,d174,d175,d176,d322,d323,d324,d325,d326,d327,d328,d329,d330,d331,d332,d333,d334,d335,d336,d337,d338,d339,d340,d341,d342,d343,d344,d345,d346,d347,d348,d349,d350,d351,d352,d353,d354,d355,d356,d357,d358,d359,d360,d361,d362,d363,d364,d365,d366,d367,d368,d369,d370,d371,d372,d373,d374,d375,d376,d377,d378,d379,d380,d381,d382,d383,d384,d385,d386,d387,d388,d389,d390,d391,d392,d393,d394,d395,d396,d397,d398,d399,d400,d401,d402,d403,d404,d405,d406,d407,d408,d409,d410,d411,d412,d413,d414,d415,d416,d417,e98,e176,e177,e178,

Prefers not to take medication than to suffer from its affects

c177,c178,c179,c180,c184,c185,c186,c187,c188,c189,c190c277,c278,c279,c280,c445,c446,c447,c448,c449

Suffers from vaginal infections\diseases

a13,b345-351,c2,c15,

Suffers from fatigue

d93,d94,d95,d96,d97,d98,d99,d100,d101,d102,d103,d104,d105,d106,d107,d108,d109,d110,d111,d112,f168,

Suffers from weight loss

c17,c71,c73,c77,

Suffers from hair loss

c,18,c19c426

Suffers from lack of appetite

c126,c127,c128,c129c180,c131,c132,c133,c134,c135

Suffers from lack of sexual drive

c119,c120,c122c123,c124,c125

Suffers from fever
c50,c51,c72,f169,
Suffers from tuberculosis
c104,c105,c106,c107,
Suffers from diarrhea
c171,c172,c173,c174,c175,
Suffers from purple marks/bruising
c82,c83,c84,c85,
Suffers from swollen lymph nodes
c6,c15,
Suffers from herpes
c2,c15,
Suffered from procedures in health care facility
c57,c59,c67,c355,c356,c357,c358,c359,c360,c361,c362,c363,c364,c365,c366,c367,c368,
c369,c370,c371

CHANGES NOTED

*Aware life has changed since contracting the virus
a206,a207,b72,c119-125,c151-153,d23,d93,d94,d95,d108,d109,d110,d113,d114,d116,d117,e141,e42,e43,e139,e140,e179,f61-78,f109-110,f157-181,
Family affected by family member with the AIDS virus
c151-153,f109-110,f138-144,f153,f295-296,f330-373,f534-535,
Changes in eating habits
a134,a135,a136,a137,a138b221,b222,b223,b224,b225,b226,b235,b236,b237,b238,b239,b240,b241,b242,b243,b244,b245,b246,b247,b248,b249,b250,b251,f165,f166,
Concerned about maintaining well-being
a134-139,b244-253,c126-129,c168-170,d116,d117,f74,f165-166,f172-180

Changed perspectives about body weight
b227,b228,b229,b230,b231,b232,b233,b234,c427,c428,c429,c430,c431,c432
Changes is attitude about procreation
b263,b264,b265,f71-73,
Abstinence from sexual activity
a197,a202,a203,a204,a205,a208,a209,a210,f68-70,
Changes in sexual desire and fulfillment
a218,a209,a210,b171,b172,b173,b174,b175,b176,c141,c142,c143,c144,c145,f68-70,f138-144,
Isolates self from men to keep from transmitting the virus
a197,a198,a199,a200,a201
Changes in being more responsible
a197,a198,a199,a200,a201,a202,a203,a204,b77,b88,d113,d114,d117,f62-63,
*Social consciousness related to not spreading the virus
a198,a199,a200,a201,a211,a212,a213,a214,a215,b161,b162,b163,b164,b165,c141,c142,d246-251,e97,e281,e282,e292,f51,f57-60,f126,f146-155,f160-164,f417-420,f422,
Feels individuals must chose whether to have sexual intercourse knowing partner has the AIDS virus
a62,a63,b85,b87,b88,b89,b165,b166,b167,b168,b169,b170,
Is robbed of normal human interactions for fear of transmitting the virus to others f62-74,f330-372,f517-535

EXPERIENCES WITH HEALTH CARE PROFESSIONALS
*Positive interactions with health care professionals
a140,a141,a142,a143,b298,b307,c270-271,d357,d375,d376,d377,d378,d379,d380,d381,d382,d383,e58,f24-25,f35-38,f58-70,f414,
Mistreated by health care providers
b299,b300,b301,b302,b303,b308,b339,c60,c61,d358,d359,d360,d361,d362,d363,d364,d365,d366,d367,d368,d369,d370,d371,d372,d373,d374,
Treated with indifference by health care providers
c23,c60,c61,c62,c63,c64,c65,c66,c67,c371,c372,c373,c374,c375,c376,c377,c378,c379,c380,c381,c382,c383,c384,c385,c386,c387,
Ignored by health care providers
c5,c6,c7,c8,c9,c13,c20,
Unable to ask questions about sexual matters to physicians of the opposite sex
c273,c274
Important questions go unanswered
c53,c273,c274,c275,c276,
Lacks confidence in health care professionals that treats the indigent
a185,a188,a189,b336,b337,b338,c25,c26,c27,
Doubts diagnosis of having HIV
Lack of funds impedes establishing confidence in diagnosis
a191,a192,
Difficulty in having a main health care provider
b296,b297,b305,b306,c5,c54
Physician surprised is doing so well that questions diagnosis
b63,b64,b65,b67,b68,b69,b70,b71,

STIGMA OF AIDS

Does not want others’ pity for having the AIDS virus
c338,d121,d122,d123,d124,d125,f217-218,

*Is blamed for contracting the virus
a83,a84,a92,b302,b303,c218,c219,c220,c221,c222,c223,c225,c226,c227,c228,c229,c158
,d159,d160,d161,d162,d163,d164,d165,d166,d167,d168,d169,e239,e240,f86-88,f106-107,

Blames self for contracting the virus
a50-52,f325,f326,

*Fears rejection from others
a68,a69,a70,a71,a72,a78,a79,a100,a111,a228,a228A,a229,a230,a231,a232,a233,b81,b82
,b83,b84,b92,b93,c344-349,d179,d180,d181,d182,d183,d184,d185,d186,d187,d188,d189,d217,d218,d219,d220,
d221,e93,e94,e95,e140,e142,f86-88

*Fears others’ discrimination in relation to AIDS
a79,a95,a96,a97,a98,a99,a100,a108,a116,a117,b108,c99,c100,c101,c102,c103,c230,c231
,c238,c239,c240,c241,c242,c243,c244,c245,c246,c247,c248,c249,c250,c348,c349,d145-152,d257-258,e140,e141,e142,f86-87

Distrustful of others
a96,a97,a107,b123,b124,c301,c302,c414,c415,c416,c417,c418,c419,c420,c421,c422,c423
,d177,d178,f86-88,f106-107,

Others relentlessly pry trying to learn if has the AIDS virus
a303,c304,c305,c306,c307,c308,c309,c310,c311,c312,c315,c316,c317,c318,c319,c320,c321,c322,c323,c324,c325,c326,c327,c333,c334,c335,c336,c337,c339,c340,c341,c342,c343,c344,c345,c346,c347,c420,d157

Has been inadvertently hurt by other’s ignorant comments or behaviors on AIDS
b114,b118,b119,b120,b121,d145,d146,d147,d148,d149,d150,d151,d152,d153,d154,d155,d156,d190,d191,d192,d193,d194,d195,d196,d197,d198,d199,d200,d201,d202,d203,d204,d205,d206,f106-107,

Relieved has not been directly repulsed by others for having the virus
b115,b116,b117

*Embarrassed (shame) others will know has the virus
Embarrassed (ashamed) to reveal to opposite sex has the virus
b77,b78,b79,b80,b81,b82,b83,b91,b92,b93,b,95,

Is not ashamed of having the AIDS virus
d186,d210,d211,d212,d213,d455,d456,f448-461,f66-492,

Isolates self from men for fear of rejection
b85,b90,b91,b107,b108,b109,b110,b111,b112,b113,b122,b123,
b124,d241,d242,d243,d244,d245,d246,d247,d248,d249,d250,d251,d252,d253,d254,
,d255,d256,d257,d258,d259,d260,d261,d262,

Experienced shattered friendships due to having the virus
a101,a102,a103,a104,a105,a106,d194,d195,d196,d197,d198,d199,d200,d201,d202,d203,
d204,d205,d206,d207,d208,d209

*Hesitancy and care in whom to reveal has the HIV
a80,a81,a82,a95,a108,a224,a225,a226,a227,b78,b79,b90,b91,b92,b93,c344-349,d183,d184,d185,d186,d187,e90,e99-100f75-77,f86-88,f106-107,f203,f299-301,

Family affected by the AIDS stigma
a108,a109,a110,b24,b25,d158,d168,e135,e136,e137,e138,f203-209,f307-309,

Aware of other’s ignorance about AIDS and persons with AIDS
a106,a107,a108,a109,a110,a116,a117,b82,b83,b109,b110,b111,b112,b113,b136,b137,b138,b139,b140,b143,b144,b146,b147,b148,c344-349,d145,d146,d147,d148,d149,d150,d201,d202,d203,d204,d205,d206,d207,d208,d209,
d357,d358,d359,d384,d385,d386,d387,e140-141,f106-107,f448-483

KNOWLEDGE AND BELIEFS ABOUT AIDS

Desire to learn more about the virus
a115,a139,b244,b245,f133-136,

Initially didn’t really know much about the AIDS virus
a25,a35,a36,a37,b11,c98,e11,

Family initially didn’t really know much about the virus
a38,a124,b8,b12,

Aware lacks knowledge about the HIV virus
a25,a36,a37,a38,a39,a124,a125,c328,c329,c330,c331

Lacks knowledge about certain treatments
a130,a131,a134,a135,a136,a137,a138,a139,b345,b354,b356,b357,b358,b359,b360,b361,b362,

*Aware of T-cells as gauges to one’s well-being
Aware stress has a negative impact on well-being.

Belief that knowing one has the AIDS virus speeds up one's demise.

Media irresponsible for educating individuals of all ages about AIDS.

Concerned for other's well-being and that they need to be educated about AIDS.

Does not have all the answers to questions.

Does not want to worry others about her health status.

PERSONAL WAYS TO DEAL WITH HAVING THE VIRUS

Makes effort not to dwell on having the HIV.

Appreciates life more since contracting the virus.

Illness transcended and gets on with life.

FEELINGS, THOUGHTS, AND DREAMS SHATTERED

*Dreams shattered by the virus
Feelings of helplessness over inability to change what is a158,a159,a160,a161,e176,e177,
Feels powerless against the virus a122,a123,e40,e41,e42,e43,e44,e45,e46,
Actively fights the virus as offspring(s) is reason to live b40,b41,b42,b43,b44,d113,d114,d144,
Feels empowered to fight the virus b185,b186,b187,b188,b251,252,d113,d114,d116,d117,f133-136,
Feels hopeful will overcome the virus b417,b418,b419,b420,f133-136,
Wonders why she had to contract the virus a156,a157,c425,c441-442,d391,d392,d393,d394,d395,d396,d419,d420,d421,d422,d423,e17,f39-47,
Regrets past behaviors and events c222,c229,c462,c463,c464,c465,c466,e65,e66,e67,e68,
Blind trust in supportive others a132,a133,a220A,a221,a222,a223,e33,e34,e35,
Fearful of the sequelae of the infection a119,a120,a121,a250,
Fearful of dying a119,a252
Thinks is too young to die a254,b40,b41,b42,b43,
Is not ready to die a253,b40,b41,d49,d89,d90,d91,d296,
Unable to envision own demise a237,a238,b417,b418,b419,b420,
Accepts own demise d41,d42,d43,d44,d45,d46,d47,d48,d91,d293,d294,d298,d299,d300,d301,d302,d303,d304,d305,d306,d307,d308,d309,d331,d311,d312,d354,d355,d356,
Does not fear death d47,d48,d49,d50,
REFERENCES


