LIVING WITH HIV/AIDS: EXPLORING LATINO WOMEN’S NARRATIVES

by

SANDRA YUDILEVICH H. ESPINOZA

(Under the Direction of Patricia Reeves)

ABSTRACT

HIV/AIDS continues to be a major public health problem, and Latinas are overrepresented in the numbers of those infected with HIV. Furthermore, Latinas have yet to benefit from the transformation of HIV/AIDS into a chronic disease. This is due, in part, to the existing knowledge gap in understanding how Latinas themselves define, describe, and assign meaning to their experiences of living with HIV/AIDS.

The central questions guiding this study were: (a) what issues contribute to Latinas becoming infected with HIV? (b) What factors, or confluence of factors, play a role in Latinas living with HIV/AIDS? (c) What does being infected with HIV/AIDS mean to Latinas? and (d) How do Latinas make sense of being infected with HIV/AIDS within the broader context of their lives?

This qualitative study utilized a narrative inquiry approach and included in-depth, semi-structured interviews conducted in Spanish with nine participants who were selected using purposeful sampling. The sample was diverse in age, country of origin, and somewhat variant in current faith identification.

Narrative analysis was used to create a narrative summary for each of the individual participants. The data were also examined using biographic techniques which
directed my attention toward the role and significance of gender and class, family beginnings, starting points, objective life markers, and turning point experiences (i.e., events, often sparked by epiphanies, which cause a change in life course) in relation to HIV/AIDS in participants’ lives. After identifying individual themes, a comparative analysis of themes across narratives was conducted. The data revealed that Latinas experience HIV/AIDS within a context comprised of insufficient formal education, scant HIV/AIDS information, domestic violence, culturally-prescribed gender norms, religious tenets, pervasive poverty, HIV/AIDS-related stigma, and immigration status. In addition, analysis revealed that meaning and sense making of HIV infection is a culturally-mediated response that is congruent with the exigencies in participants’ lives. In exploring the participants’ HIV/AIDS narratives, a richer depiction of their experiences emerged than exists in the literature to date.

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SANDRA YUDILEVICH H. ESPINOZA

B.A., SUNY, Stony Brook, 1971

MSW, New Mexico Highlands University, 1990

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by

SANDRA YUDILEVICH H. ESPINOZA

Major Professor: Patricia Reeves

Committee: Brian Bride
Thomas Hebert
Pamela Voekel

Electronic Version Approved:

Maureen Grasso
Dean of the Graduate School
The University of Georgia
May 2009
DEDICATION

This dissertation is dedicated to the memory of Robert Earl Hiott, Mathew Sanchez, Rusty Wright and the countless other friends and acquaintances lost to the AIDS epidemic. The work is also dedicated to my sister Lynn Miller—whose courage and grit in staring down this disease is truly something to behold.
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CHAPTER I
INTRODUCTION

Background of the Problem

Global statistics regarding Human Immunodeficiency Virus (HIV) and its sequelae, Acquired Immunodeficiency Syndrome (AIDS), are alarming. In 2006, 39.5 million people worldwide had diagnosed cases of HIV/AIDS, 4.3 million people became infected with HIV/AIDS, and 2.9 million people died from HIV/AIDS (UNAIDS, 2006). During that same year, 1.4 million people in the United States (U.S.) already had diagnosed cases of HIV/AIDS; 43,000 people became infected with HIV/AIDS; and 18,000 people died from the disease (UNAIDS).

Clearly HIV/AIDS is a major public health threat, despite numerous advances in prevention and treatment over the past three decades (Hader, Smith, Moore, & Holmberg, 2001; Kauffman Family Foundation, 2006). From its first appearance in the U.S., in 1980 in California, to its official recognition by the Centers for Disease Control and Prevention (CDC) in 1981, the majority of people infected with the as-yet unnamed virus were homosexual men (CDC, 2007b). This preponderance was so large that the illness was initially known as Gay Related Infectious Disease (GRID). By July of 1982, the risk for contracting the disease had shifted to include other populations, and the name GRID was replaced by AIDS. Currently, minority groups are disproportionately affected by HIV/AIDS; in 2004, the incidence rate of diagnosis was seven times higher among
African American men than among Caucasian men (CDC, 2005). However, the most dramatic rise in the incidence rate has been in women.

From 1995 to 2004, the percentage of HIV/AIDS diagnoses in women rose from 15% to 27% of total HIV/AIDS diagnoses. During that same time period, the development of antiviral medications caused a shift in public perceptions of the disease. Previously, HIV/AIDS was seen as having plague-like attributes—people infected with HIV developed AIDS and died in relatively short periods of time. With the advent of antiviral medications, medical outcomes vastly improved. The disease was increasingly viewed, treated, and labeled as a chronic condition (Baumgartner, 2000; Beaudin & Chambre, 1996; Mitchell & Linsk, 2004).

However, evidence suggests a discrepancy between chronic HIV/AIDS in the general population and Latinas’ (females of Hispanic or Latin heritage—subsequently referred to simply as Latinas) experience of the disease. With chronic disease states, when incidence rates (i.e., new cases) rise, prevalence rates (i.e., existing cases) also rise (Friis & Sellers, 2004), especially when death rates are low. This dynamic was seen in HIV/AIDS following the introduction of antiviral medications. However, among Latinas the HIV/AIDS incidence rate rose, yet because mortality remained high, prevalence remained lower than expected (CDC, 2006a)—a dynamic more consistent with acute than chronic disease. This difference requires examination.

The reasons for this discrepancy appear to be rooted in gender-related biological and sociocultural factors. It is a biological verity that women have a higher risk of contracting HIV due to anatomical differences between female and male sexual organs (Padian, Shiboski, & Jewell, 1991). This biological risk factor is compounded by the
greater likelihood of women, rather than men, being infected through heterosexual contact with an infected partner (Padian et al.). Furthermore, for as-yet unknown biological reasons, women develop AIDS at a faster rate than men after becoming infected with HIV (National Institutes of Allergies and Infectious Diseases [NIAID], 2001).

Not all women have been similarly affected by the rise in HIV/AIDS diagnoses. According to the 2005 U.S. Census, African American and Latino women comprised 24% of the entire U.S. female population, yet accounted for 82% of the HIV/AIDS diagnoses in women (CDC, 2006a). HIV/AIDS is the fourth leading cause of death among Latinas who are 35 to 44 years of age. In 2005, the incidence rate of HIV/AIDS for Latinas was more than five times greater than that for Caucasian women: 11.2 per 100,000 versus 2.0 per 100,000 (CDC).

Living with the consequences of HIV/AIDS infection is a complex matter for anyone, regardless of gender, race, or socioeconomic status (N. F. McKenzie, 1991b). However, additional negative impacts are experienced by those who are of color, or poor (Caputo, 2004; CDC, 2002a, CDC, 2006b). For example, women with HIV/AIDS, particularly those of color, are less likely to receive the most aggressive, up-to-date treatment available (CDC, 2006a; Lopez, 2007) and are thus less likely to do well over time. Studies also show that women and minorities are at risk for receiving suboptimum care, including a decreased likelihood of hospitalization (Shapiro et al., 1999). Furthermore, research, prevention initiatives, and health policies related to HIV/AIDS were initially based on the white male experience. To a large extent, the male profile of
an HIV/AIDS patient that emerged in the early years of the epidemic endures today, and continues to impact the female experience of HIV/AIDS (Campbell, 1999).

As the demographic profile of those affected by HIV/AIDS evolved, so did the challenge of meeting their needs. Initially, HIV/AIDS attacked people who were predominantly white, male, middle class, educated, and employed, and who had health insurance (Campbell, 1999; Shilts, 1987). Currently, the population most affected by HIV/AIDS is poor and uneducated, with limited or no access to health care (CDC, 2006b); many Latinas are included in this population.

Aforementioned studies suggest that biological factors likely compromise quality of life for women living with HIV/AIDS. For Latinas, poorer health status and higher infection rates have also been linked to socioeconomic, cultural, and political factors, particularly those related to immigration issues (Amaro, 1995; Amaro & Raj, 2000; CDC, 2006a, 2007b; Engstrom & Piedra, 2006; Gonzalez-Lopez, 2005; Hollander, 2001; Scott, Gilliam, & Braxton, 2005). One socioeconomic factor of prime importance is the role of poverty and its effect on the health status of Latino women.

Within the U.S., more than one in five Latinos lives in poverty (U.S. Census Bureau, 2005) and therefore face a variety of socio-economic problems (Kozol, 1995; Land, 1994). Of most immediate consequence to those infected with HIV/AIDS who are also poor are the disparities in access to, and quality of, health care received compared to more affluent Americans with or without the disease (CDC, 2006b). Latinas are less likely to have health insurance or a consistent source of health care compared with Caucasian or African American women (Agency for Healthcare Research and Quality, 2006). As a result, when Latinas seek care following an HIV/AIDS diagnosis, the disease
process is generally more advanced, and they are likely to experience poorer outcomes than their female counterparts of other ethnicities (Campbell, 1999; CDC, 2006a).

In addition to their indicated influence, sociocultural factors also impact economic factors, access to health care and overall health status (Campbell, 1999; Land, 1994). For example, successful treatment of HIV/AIDS necessitates that patients actively participate in their own care (Apollo, Golub, Wainberg, & Indyk, 2006). For Latinas, this requires overcoming deeply ingrained cultural norms. One such norm requires women to subsume their own ideas and opinions regarding what is best for them and accede to medical care providers’ opinions and dictums without questioning or contradicting them (N. F. McKenzie, 1991b). Moreover, Latinas also have to contend with the confluence of culturally-defined gender roles in the male-female dynamic, the expectations of their roles as mothers and caregivers, and isolation related to their degree of acculturation to the dominant culture. This confluence has a direct effect on a woman’s risk of contracting HIV and then progressing to AIDS (Amaro, 1995; CDC, 2007b; Diaz, Buehler, Castro, & Ward, 1993).

Cultural concepts, including *machismo* which “exaggerates the role of the male in society” (Land, 1994, p. 5), and *marianismo* which “dictates that women must play a submissive role” (p. 5), place Latinas at greater risk for becoming infected with HIV. For example, Latinas are unlikely to discuss, much less insist upon, condom use during sexual activity. This is a serious problem given that, aside from abstinence, condom use is the surest method to prevent HIV transmission. In a truly monogamous relationship the unwillingness to use condoms does not necessarily present a problem. However, a further aspect of machismo complicates matters. Some heterosexual Latino men are known to
have sex with other men while not considering themselves to be homosexual; they do not use condoms, and then go home to their spouses where they also do not use condoms during sexual relations (CDC, 2006a). The women are thus unknowingly put at risk for contracting HIV/AIDS due to ignorance of their partners’ extramarital sexual activities. Though many Latinas do not suspect their spouses of such behavior, even when they are suspicious, marianismo and other sociocultural factors make it unlikely that they will confront their partners.

To prevent HIV/AIDS infection, Latinas must engage with issues of gender, morality, sexuality, religion, and cultural dictums (Amaro & Raj, 2000; CDC, 2006a). For example, the Roman Catholic Church prohibits the use of condoms, endorses female submission to male authority, and promotes virgin-like behavior in women. Therefore, even if they suspect their partner’s infidelity with other women or men, Latinas are unlikely to either confront their partners with their suspicions or raise the issue of condom use.

Understanding Latinas’ risk for contracting HIV/AIDS requires grasping the significance of these factors and that impact on HIV/AIDS prevention and treatment. Such an understanding is also critically important when working with women already infected with the disease. Nevertheless, a review of applicable social science and medical research studies indicates that a comprehensive understanding of how sociological, economic, cultural, and gender issues affect HIV/AIDS transmission, prevention, and care has yet to be achieved relative to Latino women.

There is a growing body of literature addressing the needs of women living with HIV/AIDS, including women of color. However, given the disproportionate incidence
rate of HIV/AIDS infection in Latinas compared to the total U.S. female population (CDC, 2006a, 2007d), there is a surprising paucity of research studies, qualitative or quantitative, that focus solely on Latinas. Furthermore, the studies (e.g., Amaro, 1995; Amaro & Raj, 2000; Barroso & Powell-Cope, 2000; Borrayo & Jenkins, 2003; Cole, Logan & Shannon, 2008) that exist appear to have missed the mark in terms of creating effective prevention and treatment initiatives for Latinas, as evidenced by the high incidence, prevalence, and death rate from HIV/AIDS seen in Latino women.

Existing quantitative research studies focusing on HIV/AIDS that include Latinas as a subpopulation are problematic for several reasons: (a) use of comparison data to draw conclusions (Gutierrez, Oh, & Gillmore, 2000; Land, 1994); (b) use of reductive definitions of acculturation (e.g., acculturation equated only with speaking English) as an independent variable against which dependent variables are measured; and (c) insufficient knowledge of and attention to the contextual nature of disease in Latino culture. Studies in which these problems are evident are further characterized by limitations and findings that are of diminished value for Latino women, as evidenced by the CDC report “Best Practices” in HIV/AIDS research (Lyles et al., 2007). The authors of the “Best Practices” study conducted a review of U.S.-based HIV behavioral intervention research literature from the years 2000 to 2004 to identify the studies most efficacious in reducing HIV risk, both for vulnerable populations and for those already infected and susceptible to contracting secondary infections. Eighteen studies were identified that met the criteria. While study results were described as “directly applicable for populations in greatest need of prevention intervention programs,” none of the studies focused solely on Latinas. Indeed, the only study that claimed to include this population
in fact effectively excluded them by using a study criterion requiring participants to speak English; the study ultimately included only two Latino participants (Lyles et al.).

Qualitative research studies appear to have taken a more effective methodological approach, though they failed to achieve representative results for “subpopulations” (Barroso & Powell-Cope, 2000, p. 232). Barroso and Powell-Cope found only a few studies (Shedlin & Deren, 2002; Shedlin et al., 2006; Shedlin & Shulman, 2004) that addressed some aspect of Latina women living with the disease, and even fewer that took a broad stroke approach to understanding the women’s everyday experience of living with HIV/AIDS—that is, those that focused on the experience of preventing or living with HIV/AIDS within the context of Latinas’ lives as a whole.

Conceptual Framework

There are three main assumptions underlying this study. The first is that science is a non-neutral, politicized form of inquiry (Foucault, 1994; Harding, 1991, 2006). Based on this assumption, analysis of factors such as gender, race, and ethnicity is essential to understand the scientific response to diseases such as HIV/AIDS, as well as to gain insight into varied people's experiences with HIV/AIDS. In other words, disease does not occur in a vacuum. All factors that formulate the context of disease are critical to consider when creating prevention and treatment initiatives intended to meet the needs of those at risk for infection or already infected.

For example, the initial case definition of the syndrome that came to be known as AIDS was based on symptoms exhibited by young, homosexual men. With time, the CDC revised and expanded the definition of what constituted AIDS (CDC, 2002a). However, prevention decisions continued to be based on information gathered from and
about men, even as women were increasingly seen exhibiting immunodeficiency-related symptoms and being diagnosed with immunodeficiency-related illnesses (Campbell, 1999; N. F. McKenzie, 1991b). As a result, female symptoms were masked and many women became ill and died before ever meeting the criteria for AIDS, and prior to qualifying for treatment and assistance programs available to AIDS patients (Campbell, 1999; N. F. McKenzie, 1991b).

The second assumption underlying this study is that diseases occur, are investigated, and are treated within specific societal contexts and require examination within those contexts (Campbell, 1999; Foucault, 1994; Frasca, 2005). Armus (2003) summarized this principle:

Different historical times, social groups, or even individuals produce their own ways of defining the etiology, transmission, appropriate therapy, and meanings for a disease. These definitions reflect not only changing medical technologies and knowledge but also broader influences, including religious beliefs, gender obligations, nationality, ethnicity, class, politics, and state responsibilities. (p. 2)

Using Armus’ conceptualization of contextual aspects of disease will shed light on several facets of treating patients with HIV/AIDS that are currently problematic. One problem is the difficulty many patients have in adhering to the often complicated medication regimens that are required to prevent HIV from becoming AIDS, or to treat HIV/AIDS related illnesses effectively (CDC, 2007b). Literature suggests (e.g., Campbell, 1999; Arthur Kleinman, 1988a; Lopez, 2007) that many compliance problems result from cultural beliefs regarding medical treatment and the meaning of illness, and attitudes regarding what is considered appropriate treatment.
The third assumption underlying this study is Kleinman’s (1988a) theory that doctors and patients operate from different paradigms, and includes the notion that illness has culturally-mediated meanings particular to individuals. In other words, doctors treat diseases whereas patients suffer from illnesses. For the patient, illness signifies the “experience of symptoms and suffering” (p. 5) while for the doctor, disease implies “an alteration in biological structure or functioning” (p. 6). This difference, often misunderstood by doctor and patient, not only leads to mutual dissatisfaction but also to problematic patient-doctor interchanges. According to Kleinman, bridging the divide requires acknowledgement by both parties of the other’s perception of illness and disease—though initiating the effort to do so, ought to be the doctor’s responsibility. Failing to acknowledge that illness and disease outcomes can be impacted by more than biological factors and failing to understand the other’s frame of reference, is to chance poorer outcomes (Arthur Kleinman). Given the multiplicity of factors impacting Latinas living with HIV/AIDS, culturally-mediated paradigms regarding illness and its treatment are a critical matter for consideration if outcomes for Latinas living with HIV/AIDS are to improve.

Statement of the Problem

In 2005, Latinas comprised less than 10% of the more than 143,368,343 females (U.S. Census Bureau, 2000) living in the U.S., yet Latinas represented 15% of the 126,964 U.S. women with HIV/AIDS. In the same year, the disease was the fourth leading cause of death for Latino women aged 35 to 44 (CDC, 2007b). Yet research efforts have not kept pace with the dramatic increase in the number of Latinas infected with HIV/AIDS nor have they adequately reflected an understanding of the non-neutral,
politicized nature of scientific inquiry. Furthermore, studies have been largely concerned
with prevention of infection, and no studies were found providing an emic perspective on
Latinas living with HIV/AIDS in the U.S. This gap evinces a lack of appreciation for the
factors critical to preventing and treating HIV/AIDS in Latinas. In fact, Latinas’ voices
regarding their experiences of grappling with the disease is what is needed.

Epidemiological surveillance data indicate that Latinas experience HIV/AIDS
differently than women from other ethnic groups or Latino males (CDC, 2006a); such
differences place Latinas at a disadvantage in terms of current prevention and treatment
initiatives. The Latina experience of HIV/AIDS is rooted not only in gender, but also in
the socioeconomic, sociocultural, and political contexts of the women’s lives. Some
studies (e.g., Beadnell & Baker, 2000; Cole, Logan, & Shannon, 2008; Jones, Weiss,
Malow, & Ishii, 2001) have examined the relationship between individual factors and
women’s experience of HIV/AIDS. However, they were conducted using a very narrow
context, were based on researchers’ perspectives, and used their definitions and
understandings of cultural factors. Treatment and prevention initiatives based upon these
studies appear to be insufficiently informed by the understanding that illness has
culturally-mediated, individually generated meanings. Instead, the studies reflect a
limited understanding and stereotypical definition of the sociocultural factors pertinent to
Latinas. What remains unexplored is Latinas’ perspective on the experience of
HIV/AIDS. Specifically, what would prove useful is the emic perspective regarding
factors impacting treatment and prevention of HIV/AIDS, remains unexplored and
unknown.
Purpose of the Study

The purpose of this study was to explore Latinas’ narratives of living with HIV/AIDS. The central questions guiding this study were: (a) What issues contribute to Latinas becoming infected with HIV? (b) What factors, or confluence of factors, play a role in Latinas living with HIV/AIDS? (c) What does being infected with HIV/AIDS mean to Latinas? and (d) How do Latinas make sense of being infected with HIV/AIDS within the broader context of their lives?

Significance of the Study

Latino women have yet to benefit from the transformation of HIV/AIDS into a chronic disease (Campbell, 1999). This is due, in part, to the lack of knowledge of how Latinas themselves define, describe, and assign meaning to their experiences of living with HIV/AIDS. This study is significant for its potential to help fill this knowledge gap—a critical need given the importance of understanding this frame of reference in improving outcomes (Arthur Kleinman, 1988a).

Evidence suggests that the basis for Latinas’ alarming HIV/AIDS statistics is found, at least in part, in the relationship between the various contextual factors comprising their lives (Amaro, 1995; Armus, 2003; Campbell, 1999; Land, 1994). Therefore, an exploration and examination of Latinas’ definition of, perspectives on, and experiences with the indicated issues is warranted. There is a dearth of such studies in the literature.

Social workers were at the forefront of the HIV/AIDS epidemic in its nascent phase, providing a wide range of services including case management, brokering of
services, psychosocial support, and advice in matters related to death and dying (Kaplan, Tomaszewski, & Gorin, 2004; Mitchell & Linsk, 2004; Strug, Grube, & Beckerman, 2002). The availability of antiviral medication regimens is the main reason that people with HIV/AIDS are living longer lives. Social workers are now challenged to help people prevent infection and to live with, rather than die from, the disease. As a result, one task that increasingly confronts social workers is to support their clients in complying with very complicated medication regimens (Lopez, 2007). To do this work effectively with Latinas and other minorities, social workers need to have well-developed skills and a comprehensive knowledge of their clients’ lives (Marsh, 2004; Russell, Alexander, & Corbo, 2000; Vinh, Bunch, & Card, 2003). This study’s significance, then, will arise from its representation of the complex factors comprising the context of Latinas’ lives as seen from their own perspectives. The data from this study will provide social workers with the information they need to effectively create prevention efforts and psychosocial and medical treatment initiatives on behalf of Latinas.

Definitions

Definitions central to this study are presented in this section, though some of these will also be comprehensively discussed in Chapter II.

**Acquired Immunodeficiency Syndrome (AIDS)** – A disease acquired through contact with the pathogen HIV. Characterized by a weakening of the immune system, it refers not to one disease, but rather to a group of symptoms that collectively indicate a diagnosis of AIDS. This includes the development of opportunistic infections and certain cancers, as well as a decrease in the number of immune system cells or other medical
events that generally do not occur in a person with a healthy immune system. AIDS is diagnosed by a doctor using particular clinical standards along with laboratory tests.

**Chronic disease** – Any disease denoted by slow progress and long continuance that is rarely cured and is potentially fatal. Chronic diseases can follow a chronic course that is ongoing and without remittance, or a recurrent course, marked by periodic relapses and remissions.

**Culture** – For the purposes of this study, *culture* is given an anthropological meaning. That is, it is a construct referring to a system of symbolic meanings anchored in particular arrangements of social institutions and patterns of interpersonal interactions, and transmitted from one generation to another. It also refers to rules of conduct which delimit the range of accepted behaviors in any given society.

**Disease** – A commonly accepted definition of *disease* is “the impairment of the normal state of functioning of the body as a whole or of any of its parts” (Columbia Electronic Encyclopedia, 2007). Diseases can be acute (sharp and severe symptoms terminating after a relatively short period of time) or chronic (lasting a long time, see definition above). For the purposes of this study, *disease* will at times also refer to a patient’s medical problems from the practitioner’s perspective (see definition of *illness*). According to Kleinman (1988a), whose model of disease and illness was used to frame the study, disease refers to “An alteration in biological structure or functioning” (p. 5).

**Human Immunodeficiency Virus (HIV)** – A virus distinguished from other viruses in that it attacks the immune system, unlike other viruses. Infection with HIV ultimately leads to the destruction of the immune system, leaving the body unable to defend itself against infections which are, in many if not most cases, easily and normally
fended off by the body. HIV is believed to be the virus that causes AIDS. Persons with HIV in their system are referred to as HIV infected or HIV+ (CDC, 2007a).

**HIV/AIDS** - Refers to cases of HIV infection from the 37 areas (33 states and four U.S. dependent areas) that have had confidential, name-based HIV infection reporting long enough to monitor statistical trends, regardless of whether they have progressed to AIDS. These 33 states represent approximately 63% of the epidemic in the U.S. (CDC, 2007a).

**Illness** – A term generally defined as a state of poor health; people are sometimes referred to as being in a state of “ill health.” In some instances, illness is a failure to meet the World Health Organization’s (WHO, 2006) definition of health as “a state of complete mental, physical, and social well-being, rather than merely the absence of disease” (p. 1). For the purposes of this study, unless otherwise noted, the term illness refers to “the experience of symptoms and suffering. Illness refers to how the sick person and the members of the family or wider social network perceive, live with, and respond to symptoms and disability” (Kleinman, 1988a, p. 3).

**Incidence rate** – The number of new cases in a specific area during a specific period among persons at risk. Incidence rate provides a measure of the effect of illness relative to the size of the population. It is calculated by dividing incidence in the specified period by the population in which cases occurred. A multiplier is used to convert the resulting fraction to a number over a common denominator, often 100,000 (CDC, 2007a).

**Latina (or Latino women)** – The term *Latina* refers to women originally from South America, Central America, or Mexico, including indigenous peoples from the areas named, regardless of their current country of residence. It must be noted that this term,
along with its alternative, Hispanic, has taken on racial, political, and ethnic overtones and covers “such a vast number of contradictory traits and elements of group membership that it enrages some as much as it emboldens others” (Caldararo & Quesada, 2006, p. 731). In the current political climate regarding immigration, such terms are particularly charged.

**Prevalence** – The total number of cases of a disease in living persons in a given population at a specific time. Prevalence does not indicate how long a person has had a disease and cannot be used to calculate rates of disease. It can, however, provide an estimate of risk for a disease at a specific time. For HIV/AIDS surveillance, *prevalence* refers to living persons with HIV disease, regardless of time of infection or date of diagnosis (CDC, 2007a).

**Surveillance** – The systematic gathering of information delineating where infections and diseases are occurring, and who is being infected and becoming ill. Surveillance is the primary method used by the CDC to track diseases (CDC, 2007a).

**Surveillance statistics** – Numerical representations of surveillance data.

**Vertical (or Perinatal) transmission of HIV** – The transmission of HIV from mother to child, during pregnancy, labor and delivery, or during breastfeeding.
CHAPTER II
REVIEW OF THE LITERATURE

The purpose of this study was to explore Latino women’s narratives of living with HIV/AIDS. The central questions guiding this study were: (a) What issues contribute to Latino women becoming infected with HIV? (b) What factors, or confluence of factors, play a role in Latino women living with HIV/AIDS? (c) What does being infected with HIV/AIDS mean to Latino women? and (d) How do Latino women make sense of being infected with HIV/AIDS within the broader context of their lives?

A literature review provides the scholarly rationale for research (Creswell, 2007). It highlights the gap in the existing literature with respect to the phenomenon being studied, and provides “a voice for those not heard in the literature” (p. 102). Useful and meaningful research builds on that which already exists, incorporates results from prior scholarship, and suggests the inquiry approach to be employed (Creswell). In essence, a literature review locates a study within the context of previous studies, and at times within the theoretical or paradigmatic frameworks that underlie the study.

This chapter will review five areas of literature. First, I will provide a general overview of HIV/AIDS, including key terms. Second, I will describe the impact of HIV/AIDS on women in general and Latino women in particular, including a delineation of the factors impacting Latinas’ experience of HIV/AIDS. Third, I will present the existing literature on HIV/AIDS and Latinas. Fourth, I will discuss the three assumptions underpinning this study—that science is a non-neutral, politicized form of inquiry; that
diseases occur within the specific context of people’s lives; and, as Kleinman (1988a, p. 41) theorized, that doctors and patients operate from different and often conflicting paradigms as they relate to illness, disease, and their culturally-mediated meanings. Finally, I will demonstrate the value of using narratives in research, particularly in the study of illness.

The literature contributing to current knowledge regarding Latinas’ experience with, conceptualization of, and response to living with HIV/AIDS in the U.S. or emerges from various disciplines, including cultural studies, medicine, public health, psychology, social work, and sociology. Online searches for the literature relevant to this dissertation’s subject matter, as well as related topics, were undertaken via GIL and GALILEO were conducted. The following databases were utilized: Academic Research Complete, Census Data, Current Contents Connect, Dissertation Abstracts, Google Scholar, Medline, Medline Plus, PsychINFO, PubMED, Social Work Abstracts, ProQuest Dissertation Abstracts, ProQuest Nursing and Allied Health Source, Social Services Abstracts, and Social Work Abstracts (Ovid). Various descriptors and combinations of descriptors were used, including HIV, AIDS, Latinas, Latino women, Hispanic women, health belief models, immigration, nature of science, feminism, Latino culture, gender, race, and ethnicity.

Overview of HIV/AIDS

Researchers have offered varying theories regarding the genesis of what is now known as HIV/AIDS. In his book And the Band Played On, Randy Shilts (1987) popularized the notion that Gaetan Dugas, a homosexual flight attendant dubbed “Patient Zero,” was responsible for introducing the disease in the U.S. Subsequent authors and
researchers have countered Shilts’ idea of a Patient Zero by pointing, for example, to the discovery of HIV in blood samples in Africa dating back to 1959 (Zhu, 1998), and to HIV as the cause of death of a sexually active boy in St. Louis in 1969 (Altman, 1982). In addition to questions concerning the provenance of HIV, there is otherwise a wealth of information about the disease, particularly as manifested in the U.S.

The Language of HIV/AIDS

HIV, the virus that causes AIDS, is a blood-borne pathogen transmitted from one human to another. The phrase “blood-borne” signifies that it is transmitted through blood, as well as bodily fluids (such as semen) rich in white blood cells. In their various forms, white blood cells, or leukocytes, comprise the body’s immune system. HIV targets cells known as T helper, or CD4, cells. These cells orchestrate the body’s response to microorganisms, such as viruses. HIV is a retrovirus. Retroviruses use Ribonucleic Acid (RNA) rather than Deoxyribonucleic Acid (DNA) to encode genetic information. HIV invades a T cell, replicates itself within the cell while destroying the affected T cell in the process, then spreads to more T cells. As the number of T cells decreases, there is a concomitant decline in the body’s ability to mount an effective defense against infections and, if the decline continues, a diagnosis of AIDS might be made (amfAR, 2008).

Not everyone who has HIV, or whose HIV disease advances, develops AIDS. However, left untreated, HIV is more likely to progress to AIDS than to remain static. An AIDS diagnosis can result from a variety of clinical causes. One instance signaling an AIDS diagnosis is a decrease in the number of T cells to below 200 cells per milliliter (ml) of blood. A second instance is the presence of an “opportunistic infection” (OI). An OI is an infection that is readily and normally fended off by the body, but which is seen
in an HIV patient as a result of a suppressed immune system. An OI can become life-threatening if not controlled. Common HIV-related OIs include Pneumocystic Jirovecii (formerly Carinii) Pneumonia (PCP), Toxoplasmosis (Toxo), Kaposi’s Sarcoma (KS), Cryptococcal Meningitis (CCM), and wasting (i.e., significant loss of body mass and strength). Typically, OIs occur when people are not on anti-retroviral therapy, or when the therapy has failed (DHHS, 2005).

Transmission and Prevention of HIV Infection in the U.S.

HIV is acquired when a person comes into contact with infected bodily fluids. Primarily this happens through unprotected sex with an infected partner, the sharing of needles, and/or mother-to-child transmission during pregnancy, delivery, or breastfeeding. The fluids involved are blood, semen (including pre-ejaculate), vaginal fluid, and breast milk. These fluids, unlike saliva, sweat, tears, and urine, have a high concentration of white blood cells, which include the T cells targeted by HIV infection and thus are vectors for transmission. For the infected fluids to be efficiently transmitted, they must come into direct contact with the mucous membrane or blood of a non-infected person (CDC, 2007a).

Additional ways of becoming HIV infected do exist, although they are less common. In health care settings, workers can be infected with HIV after being stuck with a needle containing HIV-infected blood, or (even less frequently) after infected blood gets into an open cut or mucous membrane (such as the eyes or inside of the nose). Technically, patients can also be infected in a similar way by a health care worker, although there is only one such incident recorded. Finally, although it is very rare in
countries where blood is screened for HIV antibodies, HIV can be transmitted via infected blood transfusions or blood clotting products (CDC, 1999).

Prevention of HIV transmission from one person to another is generally spoken of as risk reduction rather than risk elimination, particularly in the arena of sexual conduct. This is largely due to the fact that, as far as sex is concerned, the only way to totally eliminate risk is not to engage in it—an undesirable option for most adults. Therefore, critical to HIV prevention is the adoption of behaviors that reduce the risk of contact with infected fluids. For people who are HIV-positive, this means having sex with a partner who is HIV negative and who agrees to a monogamous relationship. For those not infected, it means preferably having sex with HIV negative partners only. Furthermore, regardless of a partner’s HIV status, condoms should be used consistently and correctly. For everyone, risk reduction requires either abstaining from injection drug use or consistently using sterile needles and equipment when using, and ensuring that sterile equipment is used for tattoos or piercings (American Heart Association & American Stroke Association, 2008).

In workplace settings, particularly in health care environments, preventing transmission is largely a matter of infection control. Good infection control, otherwise known as “universal precautions,” requires treating all human blood as if it were infectious, always using a barrier when blood is present, disposing of sharps and bloody waste appropriately, not recapping needles, and seeking treatment immediately in the event of exposure (CDC, 2002).
The Relationship Between HIV and AIDS, and its Impact on Prevention and Treatment

There is a temporal relationship between HIV infection and its discovery, as well as with an AIDS diagnosis. Two to four weeks following the initial exposure to HIV, a person may experience an acute infection with symptoms that mimic influenza (flu). Symptoms such as fever, fatigue, rash, or swollen glands are often either undiagnosed or misdiagnosed as the flu or a viral infection. During this time, the amount of HIV in the blood (called a “viral load”) is very high—sometimes greater than 1 million copies/ml of blood, making the individual highly infectious. It is important to note here that the HIV test does not detect or measure the presence of HIV in the blood. Rather, it indicates whether an individual has been exposed to the virus by detecting antibodies in the blood. As it can take from three weeks to twelve months (referred to as a “window period”) for the body to make enough antibodies for an accurate test, an infected individual can unknowingly transmit the virus to others during that window period (Gilead Sciences, 2007).

About a month after infection with HIV, the viral load begins to naturally decrease and, at six months, the viral load reaches what is called a set-point. That is, the point from which the virus will now replicate. The higher the set-point, the faster the infection is likely to advance. This impacts treatment, as decisions regarding medication regimens are planned according to the viral load. Treatment decisions, such as type and timing of medication, vary and are at least partially dependent on an individual’s ability to evaluate the possibilities presented by the physician (Gilead Sciences, 2007).

Until the mid-1990s, the time frame between HIV infection, the development of AIDS, and eventual death was expected to be approximately two years at the longer end
of the spectrum. With the advent of new therapies, including the use of multiple drug combinations (three or more)—referred to as highly active antiretroviral therapy (HAART)—morbidity and mortality related to HIV/AIDS declined dramatically (Gates Foundation for Global Health, 2007). However, there are two major problems associated with HAART. The first is that the medications must be taken under very specific conditions (such as with or without food) and at particular time intervals. These regimens are neither easy to manage nor easy to tolerate, as each medication has its own, potentially serious side-effects. Additionally, the medications are expensive, often totaling over $1,000 per month. This limits access to medication to those who have insurance coverage or can afford to pay out-of-pocket. New drugs continue to be introduced in the fight against HIV/AIDS. The newest class of drugs is integrase inhibitors—drugs that interrupt the final step of the HIV replication process by preventing HIV’s DNA from being incorporated into the CD4 cell’s DNA. One such drug, GS-1937 (Elvitegravir®), has been approved for use while another, raltegravir, is in advanced clinical trials (Aidsmeds.com, 2007, 2008). The introduction of HAART and integrase inhibitors was expected to decrease the incidence of HIV/AIDS due to their effectiveness in reducing viral loads and consequently the likelihood of HIV transmission (Vernazza, Eron, Fiscus, & Cohen, 1999). However, unintended and potentially negative consequences have been seen. For example, the pool of HIV-infected persons who are actively engaged in sexual activity has swelled as a result of improved quality of life. Combined with the increased longevity of those infected, this has increased the likelihood of HIV transmission (CDC, 2002).
A cure for either HIV or AIDS is missing from the HIV/AIDS treatment landscape. The most promising vaccine candidate failed in advanced clinical trials (Delaney, 2007). Delaney posited that this failure could result in increased pressure and incentives to forward the research on topical gels (microbicides) as a female-controlled barrier to the transmission of HIV during sexual contact. Alternatively, it could also potentially renew efforts to find a cure.

**Women and HIV/AIDS**

Women and men are impacted differently by HIV/AIDS—both physically and psychosocially. While there are many similarities in how HIV and AIDS express themselves in women and men, some differences in surveillance statistics should be mentioned. Since 1985, the proportion of estimated AIDS cases diagnosed among women has more than tripled—from 8% in 1985 to 27% in 2005. Though more men than women become infected with HIV each year, the rising HIV incidence among women is slowly closing the gap between the number of HIV-positive men and women, both globally and in the U.S. In fact, the CDC (2007d) predicted that if new HIV infections continue at their current rate worldwide, women with HIV may soon outnumber men with HIV. Thus, understanding how gender and gender-related factors impact prevention and treatment of HIV/AIDS in women is critically important.

Various studies (Amaro, 1995; Jones et al., 2001; Land & Hudson, 2004; Mrus, Williams, Tsevat, Cohn, & Wu, 2005) have demonstrated that gender and gender-related factors, individually and in concert with other factors, impact women’s risk of infection with HIV/AIDS. The greatest risk factor for women is through heterosexual contact (even if monogamous) with an infected partner (Amaro, 1995; CDC, 2007b). The risk is
compounded by the characteristics of female anatomy—female sexual organs have a larger area of contact for HIV-infected seminal fluid (Padian et al., 1991). Because the only universal preventive measure is consistent and correct use of condoms, risk of infection for women is further magnified by their ability (or inability) to negotiate sexual contact, including the use of condoms (Amaro, 1995; Bowleg, Belgrave, & Riesen, 2000; Diaz et al., 1993; C. A. Gomez, Hernandez, & Faigeles, 1999; Hader, Smith, Moore, & Holmberg, 2001; Kropp, Montgomery, Hill, Ruiz, & Maldonado, 2005). The realization of such negotiating ability is often impeded by socially constructed issues including gender power differentials, poverty and its sequelae, intimate partner violence (IPV), and drug or alcohol abuse.

Gender roles modify sexual decision making and sexual activities. Power differentials are thus a critically important consideration in fashioning prevention education messages and interventions. Saying no to sexual encounters, or insisting on condom use, is largely dependent on women trusting that they will not suffer violence or loss of economic protection at the hands of partners. However, the continuing lesser status of women in many quarters, combined with poor access to financial and other resources, often forces women to yield the control of sexual relations to men (Amaro & Raj, 2000). Women either accede to risky behavior with their partners or, in some cases, engage in activities such as prostitution to financially support themselves and their children. The result is a greater risk of infection (Amaro & Raj).

The poverty experienced by many women, particularly women of color, is another social factor impeding safer sexual behavior. A common consequence of poverty is substandard housing or outright homelessness (Avert.org, 2006; Kozol, 1995). Wenzel et
al. (2006), positing that “housing status is important to understanding HIV risk behaviors among women” (p. 1), sampled women staying in shelters (N=460) and those living in low-income housing (N=438). Specifically, they looked at the risky behavior of having multiple sex partners. While somewhat limited by its single source of participants (Los Angeles County) and the requirements that they be English speaking, the study results were notable for their indication that homeless African-American and Hispanic women were up to five times more likely to have engaged in multiple sexual encounters than those who were in stable, though low-income, housing. The researchers further found that risky behavior was associated with increased interpersonal and physical intimate partner violence (IPV), and with increased drug use. These are all factors that, according to the CDC (2007d), increase the likelihood of women becoming infected with HIV.

Once infected, women biologically experience HIV and AIDS differently than men. First, medical complications such as recurrent vaginal yeast infections, severe pelvic inflammatory disease (PID), and cervical cancer are unique to women and impact HIV risk and HIV/AIDS symptomatology and treatment (CDC, 2007b). These female-only complications can occur in all women and, according to the National Institute of Allergy and Infectious Disease ([NIAID], 2001), when present, the risk for HIV infection is increased. Furthermore, in HIV-infected women these complications happen frequently, potentially complicating their treatment. Second, women develop AIDS at a faster rate than men for as-yet unknown biological reasons (NIAID, 2001), regardless of other factors. Lastly, women experience a different metabolic response to antiretroviral therapy than men (CDC, 2007b), adding another factor that potentially impedes HIV/AIDS treatment.
The impact of gender on AIDS, as in HIV infection, extends beyond biology, particularly as it intersects with cultural and socioeconomic factors. While HIV/AIDS can potentially be managed as a chronic disease, treatment is both difficult and costly, and treatment success is not assured for everyone (CDC, 2007b). Furthermore, infected women may have more difficulty accessing health care—possibly because they are burdened by a lack of financial resources and transportation together with added responsibilities, which could include the care of children and others, some of whom may also be infected with HIV/AIDS (Campbell, 1999).

Clearly not all women infected with HIV/AIDS are similarly affected by all factors, whether biological, sociological, or economic. However, when influential factors are mediated by culture (including language and religion), as is the case for Latinas, the impact is often magnified and made more complex.

Latino Women and HIV/AIDS

Prior to delineating specific aspects of culture and its intersection with biological and socioeconomic aspects of HIV/AIDS, it will be useful to consider briefly the role of culture in people’s lives. This topic will be expanded in a later section of this dissertation. According to Lonner (1994), varying definitions of culture have several characteristics in common, including the view that “culture is a context or a setting within which behavior occurs, is shaped, and transformed, and, that it contains values, beliefs, attitudes, and languages that have emerged as adaptations” (Ortiz-Torres & Serrano-Garcia, 2000, p. 861). Further, the authors suggested that culture not only affects the “construction of gender, power, and sexuality,” it also “defines possibilities and conditions for action, and influences conceptualizations of health and sickness” (p. 861). This conceptualization of
culture is used in studies of varied diseases and illnesses in minority populations. Cultural tenets particularly impacting the HIV/AIDS prevention and treatment experience among Latinas include culturally prescribed gender roles such as marianismo, machismo, fatalismo, familismo, personalismo, and confianza.

As noted previously, HIV/AIDS diagnoses in women are increasing (CDC, 2007b) and treatment is not universally accessible or successful. Therefore, prevention is an important goal. Preventing HIV infection, however, is not a simple matter for Latinas as it necessitates attitudes and behaviors (e.g., self-confidence and assertiveness) that are discordant with Latino cultural tenets and are prescribed behaviors for women. Marianismo and machismo, for example, while they have a “more sophisticated history and different shades of meaning in Mexico and Latin America” (Gonzalez-Lopez, 2005, p. 7) than are normally ascribed to the concepts in research and practice in the U.S., nevertheless are dictums that characterize as taboo premarital sex and conversations about sexuality-related issues (Gonzalez-Lopez).

Marianismo is the Latino cultural value that prescribes Latinas’ display of virgin-like comportment (e.g., Virgin Mary or the Virgin of Guadalupe). An important nuance of marianismo is the expectation that women demonstrate moral superiority by tolerating their spouse’s bad behavior (E. P. Stevens, 1973). Women are expected to be sexually inexperienced at the time of marriage, family caregivers regardless of the personal cost, and remain faithful throughout the marriage (Gonzalez-Lopez, 2005). A Latino woman is expected not to talk to men about sex; doing so implies that the woman is promiscuous. Additionally, talking to men about HIV/AIDS prevention is perceived as implying that the man is promiscuous or that the woman does not trust him (Bowleg,
Belgrave, & Riesen, 2000; McQuiston & Flakerud, 2003; Parrado, McQuiston, & Flippen, 2005). Latinas, therefore, are culturally discouraged from discussing the very issues that must be addressed to protect themselves from contracting HIV/AIDS.

Machismo refers to the exalted position of men in Latino culture – their right to exercise authority over the family, particularly their spouses, and their responsibility to provide for them. In addition, Latino men are expected to embody manliness and virility. According to Peragallo (1996), the concept also includes the idea that men who have sex with men (particularly anal insertive) while continuing to have sex with women are neither homosexual nor bisexual, and that it is not their partner’s right to know of this behavior. Because they do not identify themselves as homosexual or bisexual, Latino men do not perceive themselves to be at risk of HIV/AIDS infection. Therefore, they often do not protect themselves, thus unwittingly spreading HIV/AIDS to unsuspecting Latino women (CDC, 2006a, 2007d).

The intersection of machismo and marianismo adds another level of influence on various HIV/AIDS related prevention behaviors. The most prominent impact has to do with the use of condoms—the only available means, other than abstinence, of preventing the sexual transmission of HIV. Machismo is embodied in one of Latino men’s most important roles: procreation (Peragallo, 1996). This factor, combined with the females’ role of mother, is strengthened by the Catholic Church’s view of sex as an act of procreation and the Church’s outright ban on the use of contraception. The prevalence of condom use among Latinos is a direct correlate of these Catholic attitudes and has been identified as a factor causing increased rates of HIV infection among Latinas (Campbell, 1999; CDC, 2007b; Peragallo, 1996).
Fatalismo, essentially the belief that one has little or no control over one’s life or its outcome, is another cultural concept shown to impact prevention and treatment strategies for Latino women (and men). Because many Latinos strongly believe that the outcome of one’s life is pre determined by God (Larkey, Hecht, Miller, & Alatorre, 2001; West, 2001), they see little point in using condoms. In addition, fatalismo can impact treatment adherence, particularly when a person is challenged by life circumstances. People might question the need or advisability of beginning a complicated and costly medication regimen if life’s outcomes are up to God and are not determined by their own actions. Lastly, fatalismo can explain the limited effectiveness of traditional behavior theories (e.g., Becker’s Health Belief Model, Ajzen & Fishbein’s Theory of Reasoned Action, and Bandura’s learning theory, [as cited in Amaro, 1995]) seen in the Latino community when used as context by researchers or interventionists (West, 2001).

Other cultural issues impacting Latinas’ experience of HIV/AIDS are familismo, personalismo, and confianza. Familismo refers to the importance of, and reliance on, family as support and as the center of a person’s life. Personalismo reflects the Latino value of personalized, caring, and authentic relationships, including those that comprise medical interactions. Finally, confianza indicates trust in personal interactions—trust that rises to the level of treating others as “family” (Larkey et al., 2001; Russell et al., 2000). While these concepts have varying meanings for different subgroups of Latinos, they do have a commonality that is most evident when viewed from the perspective of HIV/AIDS treatment.

Discussing any aspect of HIV/AIDS involves topics that are sensitive and personal in nature. Patients from ethnic minorities are generally less verbally and
affectively expressive, and often less assertive during encounters with care providers than Caucasian patients (Schouten & Meeuwesen, 2006). One of the reasons for the difference is the language barrier. When the provider does not speak the patient’s native language and is left to rely on an interpreter or on whatever level of English the patient speaks, communication is difficult, and the resulting assessment is unlikely to reflect the woman’s whole situation. In addition, the use of an interpreter impedes the building of a trusting relationship with either social work practitioners or medical care providers (Sher, personal communication, October, 2007).

It has been demonstrated that the doctor-patient relationship is critical to good outcomes for those living with HIV/AIDS (Reeves & Arnold, 2006). Poor communication can prove disastrous, given the complexity of HIV/AIDS treatment. Communication difficulties for Latinas are compounded by their view of providers as authority figures—persons to be held in high regard and not questioned. The concept of being a partner with their physician in their own health care, while common to medical practice in the U.S., is foreign to Latinas. When patients have to communicate with their physicians through interpreters, it adds to the difficulties (Burke, 2003; McCoy, 2005; Miller, 2004). Another cultural issue is the continued stigmatization of HIV/AIDS in the Latino community. Whether the characterization is accurate or not, the Latino community associates the disease with homosexuality and sinfulness. Although there is more stigma attached to homosexuality than to the disease (Frasca, 2005; Gonzalez-Lopez, 2005), for many Latinos, HIV/AIDS and homosexuality are one and the same. Stigma, therefore, impacts all aspects of confronting the disease: Who can I tell? From whom can I request support? What will happen to my family and me if the community finds out that I have
HIV/AIDS? How can I get help if no one can know that I am ill? And, if people stay away, who will take care of me when I can’t take care of myself? Not having ready answers, Latinas are presented with an array of social concerns in addition to the health concerns presented by an HIV/AIDS diagnosis. Thus while everyone diagnosed with HIV/AIDS grapples with social challenges, cultural issues within the Latino community magnify socially-related concerns for Latino women.

Socioeconomic factors also compound Latinas’ risk of becoming HIV-infected and subsequently progressing to AIDS. One in five Latinos lives in poverty (U.S. Census Bureau, 2005). Poverty subjects Latinas and their families to substandard education, poor nutrition, substandard housing, homelessness, lack of health insurance, poor medical and dental care, and lower health status than people not in poverty (Campbell, 1999; Ventura, 1976). A number of factors lead Latinas to sacrifice their own health care needs in order to meet their socioeconomic and culturally-prescribed responsibilities. These include difficulty accessing health care, having children, and being either the family’s sole support or an integral part of the family’s support system. For example, with limited money, Latinas are likely to take their children to the doctor rather than to see a doctor themselves, and they will skip their own appointments if they need to do something instead for their children. As a result, the women enter care much further along in their disease process and ultimately do less well than men (Apollo, Golub, Wainberg, & Indyk, 2006; Burke, 2003; CDC, 2006a)—a fact supported by CDC (2007d) surveillance statistics.

To summarize: in many ways women experience HIV/AIDS similarly to men. However, the differences often present great, and for some insurmountable, challenges in
meeting the exigencies of living with the disease. For all women, biology, gender, gender-related factors, and socioeconomic factors individually and in their intersection impact both the prevention of HIV infection and AIDS treatment. Also affected is the trajectory from infection to AIDS diagnosis, and to eventual death from one of the opportunistic infections with which they might be stricken.

Clearly, dealing with HIV/AIDS infection is a complex matter for anyone regardless of race, gender, or socioeconomic status (N. F. McKenzie, 1991a), although people who are of color, female, or poor are more negatively impacted (Bowleg et al. 2000; Caputo, 2004). For Latinas, the issues of culture, culture-related factors, and language add yet another layer of complexity to their experience and to the effort of finding effective interventions to prevent and/or treat HIV/AIDS infection. The following section will review the literature that has illuminated Latinas’ experience and will point to gaps where work remains to be done.

Research on Latino Women and HIV/AIDS

The earliest face of the HIV/AIDS epidemic was male, generally Caucasian, and homosexual, as white, gay men represented the majority of cases at the time. It was also the way the epidemic was represented in the media (N. F. McKenzie, 1991a; Shilts, 1987). However, it is clear that as far back as 1982 (CDC, 2002) Latinos were also affected; 23 of the 154 earliest cases of AIDS-related pneumonia were found in Latinos. The specific number of women among those 23 patients was not identified. However, CDC data in 1983 revealed that Latinos had a several times higher percentage of pediatric AIDS cases several times higher than the rest of the general population—data clearly suggesting that Latinas were among the population affected by the new, emerging
disease. Nevertheless, research that specifically focused on Latinos in general, and on women in particular, was slow to appear. Moreover, the research that was conducted was not always incorporated into effective prevention or treatment interventions.

Across all affected populations, the largest body of research and literature has focused on prevention issues. For women in general and Latinas in particular, it has focused on women’s knowledge, perceptions of risk for HIV infection and prevention of AIDS, sexual practices, and attitudes toward health (Borrell & Crawford, 2006; Bowleg, Belgrave, & Riesen, 2000; Gutierrez et al., 2000; Organista, Organista, & Soloff, 1998; Parrado et al., 2005; Urizar & Winkleby, 2003; Wyatt, Forge, & Guthrie, 1998).

Literature also exists, some since fairly early on in the epidemic, regarding culture and culture-related issues (Land, 1994), as well as their intersection with needs, risk behaviors, and socioeconomic factors such as gender and economic status (Amaro, 1995; Davila & Brackley, 1999; B. V. Marin, Marin, & Juarez, 1988).

Studies have also focused on delineating imperatives for culturally competent strategies aimed at HIV/AIDS risk reduction behavior (Bowleg, Belgrave, & Riesen, 2000; C. A. Gomez et al., 1999; Kropp et al., 2005; Reid, 2000; Russell et al., 2000; Scott et al., 2005). However, Latinos’ specific health status, health-seeking behaviors, and/or family roles have received little study focus with respect to HIV/AIDS (Marshall, Urrutia-Rojas, Mas, & Coggin, 2005). More work has been done in other health areas, such as mental health (Guarnaccia et al., 2007), general health (Sherrill et al., 2005), pregnancy (Fosas et al., 2003), and breast cancer care (Buki, Jamison, Anderson, & Cuadra, 2007).
While the studies that were conducted had varying success, they added to the overall body of knowledge regarding Latinas and HIV/AIDS. They demonstrated the complex nature of culture, particularly across subgroups within cultures, and its relationship to dealing with HIV/AIDS prevention and treatment. One theoretical study is Helen Land’s (1994) excellent analysis of differences among women of color who were infected with HIV and the implications for delivering culturally-relevant services. The author made several critical points regarding Latinas’ high risk for HIV/AIDS. Land identified cultural issues (e.g., acculturation and isolation, culture and gender roles, attitudes toward sexual behavior, lack of Spanish-speaking services), economic issues such as high poverty rates, and legal issues such as documentation status as “common risk factors” (p. 357) for becoming HIV/AIDS infected and as barriers to accessing appropriate medical care.

Land (1994) pointed out the existence of subcultures among Latinos, along with their inherent “racial, religious, linguistic, and socioeconomic differences” (p. 357). However, the analysis and pursuant suggestions for delivering culturally-relevant services fell short. In the attempt to identify differences between women of color (African American and Latina), the discussion lacked sufficient depth, thereby weakening the analysis. In addition, Land fell prey to making the generalizations she warned others not to make. An example was her statement that “many Latinos turn to drug dealing and use out of economic insecurity,” with only one citation (B. Marin, 1990) supporting the authority of the statement, thereby placing it in the realm of stereotype. Lastly, Land’s insightful suggestions for delivering culturally-relevant services lacked specificity as to how her suggestions might be incorporated into programs and interventions, given the
realities within which they operate. This omission detracted from the power that her suggestions might otherwise have possessed.

Other studies have drawn attention to the need for cultural relevance in HIV/AIDS research as well as in prevention and treatment programming, with each study emphasizing a different aspect of the intersecting relationships. A common shortcoming of these studies stemmed from their use of comparison between groups of women of color as the context against which the subject matter is considered, rather than studying a single group. For example, Reid (2000) examined the “usefulness of relationships as the critical factor in preventing AIDS for women of color” (p. 709), underscoring how culture and gender intersect to negatively impact a woman’s health status. She analyzed how poverty compounds the culture-gender-health interplay and discussed the need to factor the dynamic into intervention research and strategies.

In her study, Reid cited her own analysis of psychological abstracts which indicated that in 1997 fewer than 12% of the published articles reported on women, and of those, only 33% focused on women of color. The problem with Reid’s study was that it did not go far enough. Women of color e.g., African American, Latinas, Asian, were grouped together, and conclusions were drawn based on a comparison between the groups, rather than differentiating between each subgroup, and then studying and developing the idea under consideration in greater detail.

Other studies also fall prey to this deficiency. For example, Bowleg et al. (2000) studied the role that risk perception played in HIV/AIDS risk reduction practices as it intersected with the known impact of gender roles, power strategies, and sexual self-efficacy. The authors found that when women perceived themselves to be at no or low
risk of contracting HIV, factors such as gender roles were “inconsequential to their HIV/AIDS risk reduction practices” (p. 613). They also found that their hypothesis that perceived self-efficacy would positively impact condom use was not supported by the results. The authors concluded, in part, that differences in the study population—that is, that is demographics such as ethnicity, and race—explained what they called “mixed results” (p. 617) and suggested that not combining subgroups would have better served their study. Wyatt et al. (1998) studied the interplay between family composition, ethnicity, and lifetime HIV/AIDS risk taking, and had similar problems with their study and its results.

Studies focusing on single groups of people have resulted in more reliable, more readily applicable, and thus more useful results. For example, Organista et al. (1998) studied AIDS-related knowledge, attitudes, and behaviors of female, Mexican migrant workers. Their study demonstrated that while the women possessed knowledge about the major modes of HIV transmission, they were also likely to hold erroneous beliefs about contracting HIV/AIDS from casual contact. In addition, and even more importantly, they found incongruence between positive attitudes towards condom use, the incidence of actual use, and knowledge of proper use. The results of Organista et al. echoed the results of another study conducted by Urizar and Winkleby (2003). Urizar and Winkleby, also using a single population, conducted an assessment survey of a community and agricultural camp and found that higher rates of misconceptions regarding HIV/AIDS transmission occurred among older (i.e., ages 40-64) men, as well as among men and women with less years of education; the result was magnified for those participants who had not recently visited a medical provider medical provider. Both studies’ results are
useful in their specificity for planning interventions specifically designed for the population in question.

Even with its limitations, the literature on HIV/AIDS prevention reviewed thus far strongly suggests that intervention research is moving, however slowly, towards creating a profile of HIV/AIDS that better reflects the changing face of the epidemic. Increased numbers of women of color in general, including Latinas, are being studied. Furthermore, culture, as well as culture-related factors are increasingly included as determinants of HIV/AIDS risk behavior. However, a model that includes gender and culture as predictors of HIV/AIDS risk behaviors is insufficient if it does not also include socioeconomic factors.

As previously noted one in five Latinas lives in poverty (U.S. Census Bureau, 2005) and is regularly challenged by poverty’s sequelae: substandard education, poor nutrition, substandard housing or homelessness, lack of health insurance, and poor or no medical and dental care. Women in this group also suffer from a lower health status than those not living in poverty (Arthur Kleinman, 1980; Kozol, 1995; Lindsey, 2004; Ventura, 1976). The impact on daily life is documented, though sparingly and often indirectly, in HIV/AIDS prevention literature, though it is barely mentioned in treatment studies or initiatives. Articles demonstrating that socioeconomic factors do impact women’s ability to protect themselves from becoming HIV-infected and rapidly proceeding to an AIDS diagnosis, include those of Burke (2003), Diaz et al. (1994), Hader et al. (2001), Bailey (2007), and Campbell (1999).

There is no cure for AIDS, although the use of anti-retroviral medications singly or as a drug cocktail, most often referred to as HAART, can delay the progression of the
disease (CDC, 2005). While AIDS is now often understood as a chronic disease (Baumgartner, 2000; CDC, 2007b; Mitchell & Linsk, 2004), treatment is both difficult to manage and costly. In addition, the lives of Latinas living with HIV/AIDS are often further complicated as they, of necessity and as is customary in their culture, assume a large share of family care responsibilities. They sacrifice their own health care needs in order to meet their socioeconomic and culturally-prescribed responsibilities. As a result, Latinas enter care much further along in the disease process and ultimately do less well than men (Avert.org, 2006; CDC, 2006a; Land, 1994; Marshall et al., 2005). Even when using the most current medication regimens, prescribed according to guidelines, people infected with HIV/AIDS are expected to lose nine-and-a-half years of normal life expectancy. Furthermore, people who do not take the drugs per current standard of care are expected to lose an additional five years. For minority women, this expected loss of years of life is even greater as a result of their late initiation of medication regimens or premature discontinuation of therapy (Losina et al., 2007). Furthermore, minority women are more likely to be prescribed medication regimens sub par to those recommended by guidelines, or to be prescribed regimens contraindicated for their specific medical status (Cocohoba et al., 2007; Wilson et al., 2007). Often poor and without access to health insurance or private physicians, Latinas are without recourse. This means they have to settle for the care that is available; for those women without legal status in the U.S., the possibilities are even more restricted given their inability to access government programs (Marshall et al., 2005).

It is critical to remark here on what might already be apparent to the reader, particularly to social workers who are guided by a strengths-perspective model: While
aspects of Latino culture and culturally-defined gender roles are demonstrated in many, if not most, studies as impediments to HIV/AIDS prevention and treatment, they also provide multiple avenues through which health messages might pass and be accepted. One such concept is familismo. Familismo places the family, rather than individuals, at the center of life. In addition, familismo prizes children, a cultural value also promoted by the Catholic Church and with which Latinos identify strongly (Gonzalez-Lopez, 2005). The high value placed on children is embodied in Latino’s high birth rates (CDC, 2007b), both in their native countries and within the U.S. As with other ethnic groups, Latino mothers are devoted to their children and will do almost anything to protect them, especially from a disease such as HIV/AIDS. The literature, however, indicates that this avenue is often lost as a meaningful pathway for prevention and treatment messages.

The use of the drug zidovudine (also known as azidothymidine [AZT] or by its brand name Retrovir®) during pregnancy followed by treatment of the newborn reduces to negligible the chance of a baby contracting HIV from an infected mother. Thus, prenatal care is a propitious time for delivering HIV/AIDS prevention education, providing HIV testing opportunities, and starting the mother on AZT therapy if she is found to be HIV-positive (Paul, Dimasi, Martin, & Cross, 2005).

Multiple efforts and millions of dollars are expended annually to promote culturally relevant prevention and treatment services. Similar efforts attempt to prevent perinatal (i.e., from mother to fetus or newborn, also referred to as vertical) HIV transmission (CDC, 2006c). Indeed, perinatal transmission has been, relatively speaking, significantly reduced. Nevertheless, 6,000 to 7,000 HIV infected women give birth
annually, resulting in 280 to 370 new perinatal infections (CDC) each year. Many of these infected women are Latina.

Various studies have been undertaken to examine this dynamic, given what is known about vertical transmission. One study (Ruiz, Molitor, Bruckner, & Zukowski, 2002), conducted by public health staff anonymously, tested for the presence of HIV antibodies in blood samples previously collected for metabolic screening from infant heel-sticks. Specimens that tested positive were then tested for the presence of AZT therapy. Results indicated that African-American and Hispanic infants accounted for the majority of positive test results, and Hispanic infants were the least likely to show evidence of AZT therapy. The researchers recommended that innovative approaches be generated to increase the rate of AZT therapy among African-American and Latino women infected with HIV.

While there is some evidence of innovation in this arena, Kropp et al. (2005) indicated in their study (outlined in the following paragraph) that much remains to be done. Using a semi-structured survey and a convenience sample of pregnant/recently delivered Hispanic and non-Hispanic women in four California counties, Kropp et al., compared the two groups of women on rates of timely prenatal care (PNC) initiation, HIV test counseling, being offered the test, and agreeing to be tested. Results demonstrated that Hispanic women, in comparison to non-Hispanic women, had less timely PNC, fewer reported offers of an HIV test, and also fewer actual HIV tests performed. It is important to note that this occurred in a state where the offer of HIV testing to pregnant women is mandatory (Kropp et al.). Clearly opportunities to educate women about HIV/AIDS prevention, as well as opportunities to prevent perinatal
transmission, are being missed, particularly considering other factors demonstrated by the study. Included among them, were first, that when a nurse or a doctor offered an HIV test, Hispanic women were more likely than non-Hispanics to accept being tested. Second, approximately 40% of mothers whose infants were perinatally infected had no documentation of HIV status (CDC, 2006c). Both factors strongly suggested that measures to counter HIV infection in Latinas and their infants are available, and in some cases are mandated by law, yet the measures are not being used effectively if used at all. If they were, HIV incidence in Latino infants would be dramatically reduced – and those women infected would get early treatment and attention, thus improving their chances for good outcomes.

Summary

Throughout this literature review I noted epidemiological statistics regarding Latinas living with HIV/AIDS, including the fact that they comprise a disproportionately large number of new infections. Given such statistics, it is surprising to find a paucity of studies, quantitative or qualitative, that focus solely on Latino women living with HIV/AIDS and their specific needs.

The majority of studies that include Latinas and focus on HIV/AIDS are quantitative in nature. The studies are problematic because of their: (a) use of comparison data to reach conclusions; (b) frequent use of a reductive definition of acculturation (e.g., acculturation = speaks sufficient English to be a study participant) as an independent variable against which dependent variables are measured; , and (c) insufficient acknowledgment of, and attention to, the contextual nature of disease and of the cultural context of Latinas’ lives. The results are studies with methodological
limitations, and findings and conclusions are of limited usefulness to Latino women. Hence, there is a dearth of accurate and useful evidence upon which to base effective prevention and treatment practices. For example, 18 “Best Practices” were listed on the CDC website (Lyles et al., 2007) as having been gleaned from a broad review of intervention research. However, none of the practices were focused solely on Latino women. Even more telling was the fact that the only study that could have captured a significant number of Latino participants effectively excluded them with the criterion that participants be English speaking.

Existing qualitative research studies regarding prevention and living with HIV/AIDS had better methodological approaches, although they are not representative of “subpopulations” (Barroso & Powell-Cope, 2000, p. 352). In their meta-synthesis of the qualitative literature of living with HIV infection, the Barroso and Powell-Cope found many excellent qualitative research studies that focused on prevention of HIV infection and even more focusing on the “broad experience of adults living with HIV in the U.S.” (p. 351). However, Barroso and Powell-Cope found only a few studies that addressed some aspect of Latinas living with the disease, and even fewer that took a broad approach to understanding women’s everyday experience of living with HIV/AIDS (Shedlin & Deren, 2002; Shedlin et al., 2006; Shedlin & Shulman, 2004). In an attempt to expand the body of information regarding Latinas living with HIV/AIDS and to help fill the existing research gap, my study explored Latinas’ narratives of living with HIV/AIDS. Underpinning the study were four assumptions: (a) science is non-neutral and political; (b) diseases occur, are investigated, and are treated within specific societal contexts and require examination within those contexts; (c) doctors and patients operate from different
paradigms; and (d) illness has culturally-mediated meanings particular to individuals and these have a direct impact on, and implications for, clinical care. In the next section I will review literature related to these assumptions.

Theoretical Assumptions

Whether or not it is specified, research of all types is guided by some type of theoretical orientation or perspective (Bogdan & Biklen, 2007). In qualitative research in particular, a theory or perspective, which Denzin and Lincoln (2005) also refer to as a paradigm, serves to orient a researcher’s thinking and provides a filter through which collected data can be analyzed. Such perspectives or paradigms are useful for keeping the data collection process systematic, rather than an “aimless, unsystematic piling up of accounts” (Bogdan & Biklen, 2007, p. 22). That is not to say that being aware of and declaring a priori assumptions that guide one’s research means that collecting data becomes merely a matter of “filling in the blanks” (p. 181). Paradigms do, however, provide a way to “take us deeper into the important parts of our data and expand theory” (p. 181). This research study elicited and analyzed illness narratives from Latinas living with HIV/AIDS and was predicated on the following assumptions.

*Science - Non-Neutral and Political*

Diseases occur and are investigated, and therapies are generated, within specific societal contexts and require examination within those contexts (Campbell, 1999; Foucault, 1994; Frasca, 2005; Marchessault & Sawchuck, 2000). Armus (2003) posited that:

Different historical times, social groups, or even individuals produce their own ways of defining the etiology, transmission, appropriate therapy, and meanings
for a disease. These definitions reflect not only changing medical technologies and knowledge but also broader influences, including religious beliefs, gender obligations, nationality, ethnicity, class, politics, and state responsibilities. (p. 2)

Armus’s conceptualization of the science of diseases frames my thesis that science is non-neutral and political, and will be discussed in more detail in the next section of this dissertation. Diseases such as epilepsy provide evidence for Armus’s conceptualization of science (see Fadiman, 1997). As I will demonstrate, however, nowhere is the evidence more readily apparent than in the case of HIV/AIDS.

**Defining science.** There are myriad views on what constitutes science and the scientific method, though more agreement exists on the latter than the former. Views and positions tend to be determined by who people are, the world views they hold, and the work in which they are engaged (e.g., cellular biologist vs. nuclear scientist vs. feminist philosopher of science). There is a wide gulf between theorists who are concerned with what constitutes truth, reality, and the social construction of reality, and theorists who believe there is a verifiable truth, and a “real world” determinable by facts and evidence. Traversing this divide can be difficult.

There are various dictionary definitions of science, all of which are embodied in a definition posited by Benston (1989), who was at the time a professor of chemistry and computer science as well as a feminist scholar. Of the core assumptions of science and scientific progress, Benston said:

1. There exists an “objective” material reality separate from and independent of an observer. This reality is orderly.
2. The material world is knowable through rational inquiry and this knowledge is independent of the individual characteristics of the observer.

3. Knowledge of the material world is gained through measurements of natural phenomena: measurement in a scientific sense consists of quantification, i.e., reduction to some form of mathematical description.

4. The goal of scientific understanding is the ability to predict and control natural phenomena (this postulate often translates into equating science with power).

As logical and rational as these assumptions may be, and as generally accepted across scientific fields, we are nevertheless left with two main thoughts and questions. First, if an objective reality (a truth) does exist, when (and if) it is found, someone, or a group of individuals via consensus, so declare its existence. That decision is not made in a vacuum—rather, it is grounded in a value-laden context and based within a paradigmatic worldview, and is therefore subjective. We are thus left with a contradiction, given that the goal is to determine an objective reality.

Second, is it in fact objective when certain observations are deemed “facts,” albeit scientific facts, while others are ignored as suppositions (Benston, 1989). These two elements indicate a lack of objectivity and suggest a non-neutral, potentially politicized, and inherently limited scope of scientific inquiry (Armus, 2003; Campbell, 1999; Foucault, 1994; Harding, 1991; Marchessault & Sawchuck, 2000).

Medical science offers an example that extends and adds to this line of reasoning. The driving force in medical science is research. Research is defined as a diligent, systematic inquiry or investigation designed to validate and refine what is known, and to
generate new knowledge (Clinical Research Department, 2005). What is studied, and with what breadth and depth, is decided by researchers—their interests, their world view, and their selected procedural framework all shape the research question. However, decisions made in this way cannot help but be biased. The development of a medication and the risk/benefit assessment of its concomitant side effects (that is, unintended, potentially harmful sequelae) provide an example of the potential for such bias. For example, the suppression of ovulation is the purpose of birth control pills. A secondary effect, stemming from the lack of ovulation, is a change in blood chemistry resulting in potential development of blood clots, and an increased risk of heart attacks or strokes (healthywomen.org, 2008). Even acknowledging that birth control pills have worked well for many women, it is valid to ask whether the benefit of suppressed ovulation is truly greater than the risk of blood clots, heart attack, and stroke for this population of women. Perhaps a more refined, or what Franklin (2000) refers to as a “less distorted” (p. 244), methodology would not have ignored potentially fatal consequences for women in the cost/benefit analysis. What is it about science and scientific research that would give this result? My assertion is that the answer lies, in part, in the non-neutral and political nature of science. This characterization was deduced from the discourses of various scientific philosophers.

*Philosophy of Science.* Chalmers (1999), a physicist and philosopher of science, gave an overview of the “contemporary debate” (p. xvi) over the question, “What is this thing called science?” He noted that in the scientific world, “facts constitute a firm and reliable foundation for scientific knowledge” (p. 4), and that they are derived a priori to theory via objective and careful observation. However, he argued that as facts are fallible
and open to interpretation, they are rendered potentially unsound as a basis on which to build scientific knowledge.

Returning to his assumption that facts can be “considered as the basis from which scientific knowledge might be derived,” Chalmers (1999, p. 41) surveyed how those facts led to the derivation of scientific knowledge. Included in the traditions he surveyed were induction, falsification, and Kuhn’s theory of paradigm shifts. Induction refers to the process of deducing scientific laws or theories from a finite number of facts (Chalmers). The author challenged the laws created in this manner by positing that they “invariably go beyond the finite amount of observable evidence to support them” (p. 41), and therefore cannot be proven based on the evidence. He further characterized the laws as unsound and, at best, “in need of severe qualifications,” or at worst, “thoroughly inadequate” (p. 45).

Falsificationism was advanced by Karl Popper as an alternative to inductivism (Chalmers, 1999). From Popper’s perspective, scientific knowledge was built by generating theories that were as specific as possible, thus allowing for the theories to be “falsifiable” (p. 60). That is, they could be proven wrong by the observed facts. If theories were falsified, other theories, speculative in nature, were put forth to account for what falsified the original theory. Thus, the building of scientific knowledge proceeded by “trial and error” (p. 61) and the most one could hope for was the newly proffered theory being “the best available” (p. 61).

Another view of scientific knowledge was advanced by Thomas Kuhn (Chalmers, 1999). Kuhn posited that researchers’ observations of aspects of what Chalmers called “the real world” were viewed and evaluated through paradigms particular to specific
scientific communities. A “crisis state” ensued when the data did not “fit” the prevailing paradigm. As a result, one or more modifications were made to the original paradigm or an entirely new paradigm emerged—one able to accommodate the new findings. What determined the validity or truth of this new paradigm was a critical mass of scientists’ consensus rather than objective facts.

Other philosophers and sociologists of science included in Chalmers’ (1999) conceptualization of the modern debate regarding what science is, but not discussed here in detail, included: Imre Lakatos, who wrote of theories as structures; P. K. Feyerabend, who advanced the anarchistic theory of science; Bayes, who generated a probability theorem to demonstrate that theories, as advanced by Popper, had more than the zero probability of not being fallible; proponents of the “new experimentalism” (p. 193); and realism and anti-realism views of science. These various traditions reveal that the views on what science is are as varied as those sociologists, philosophers, and scientists who engaged in the debate. In addition, their views, as well as Chalmers’, suggest that the processes of science—that is, observation, experimentation, and facts—are open to interpretation at various points, so are unlikely to be a neutral form of inquiry.

*Politics of science, historically.* Taking an elementary reading of Foucault’s (1994) *The Birth of a Clinic* revealed that the birth of modern medical science had its roots in political life. Indeed, Foucault considered the French Revolution to be the line of demarcation between what constituted medical science in the time leading up to the Revolution and modern medicine as we think of it today. The changes in medicine certainly appeared to echo the political changes. For example, the fall of the aristocracy, characterized as egocentric and self-serving, was replaced by what the people hoped
would be a much more beneficent body politic. They believed that this change would transform medicine, making it much more amenable to being judged and evaluated, and promoting its ability to further the common good. Hence, society would approach an ideal state and be free of disease. For Foucault, “the first task of the doctor (was) therefore political: the struggle against disease must begin with war against bad government. Man will be totally and definitively cured only if he is first liberated” (p. 33).

Developing what he called “An Archaeology of Medical Perception,” Foucault (1994) aimed to dispel the belief that scientific practice was built by a process consisting of similar elements comprising knowledge that were constantly and incrementally gathered into a composite body of knowledge and merely dependent on scientists and doctors to act or build upon it. Instead, he advanced the concept of knowledge development as a non-linear, heterogeneous process, influenced by the people and politics of the day.

The preceding discussion suggests that politics have played a role in modern medical science since its inception at the time of the French revolution. As will be discussed in the following section, politics continue to impact the scientific arena in the present day.

*Politics of Science, Current Issues*

Most relevant to the discussion of the politics of science as it impacts Latinas living with HIV/AIDS is a review of the body of work conducted by feminist scholars. Prior to that discussion, however, a short discussion of feminism is necessary. Feminism comprises various ideological, political, and scholarly viewpoints—it is not a
homogeneous field either in viewpoints or adherents. However, it is rooted in the critical belief that on seeing the world for what it is, one is moved to action (Ehrenreich, 2005; Gonzalez-Lopez, 2005; Nadsen, 2002; Saulnier, 1996; Smith, 2005). A unifying concept in early feminist ideology was, and continues to be, the recognition of gender inequality across all aspects of life. Eventually, the ideology evolved to include concerns not only about power differentials between not only men and women, but also between people of color and Caucasians of both genders.

Feminist scholars have long been involved in a multitude of disciplines including, but not limited to, history, racial studies, psychology, and sociology (Campbell, 1999; Gilligan, 1982). As more women became scientists, women’s studies programs expanded to include the sciences. Feminist scholars began studying the philosophy of science as well as writing articles and books on the topic. Those who have written on socio-politico-sociological aspects of medical science include Ann Fadiman (1997), Sandra Harding (1991), Janine Marchessault and Kim Sawchuck (2000), and Susan Sontag (1978).

In a collection of essays, Harding (2006) demonstrated that science took on a character decidedly not neutral and certainly political. Taking into account the assumption that society had “widespread and powerful forms of structural racism—a race segregated social structure” (p. 18), she suggested an alternative to the oft-asked question, “Is science racist”? Instead, Harding explored the conditions under which a society that is characterized by racism can produce science that does not seek to perpetuate—intentionally or inadvertently—what she called “such white supremacy” (p. 18). Among others, she identified as exemplars of such conditions: (a) the practice of classifying and ranking humans along “natural racial types” and labeling non-Europeans,
Jews, women, and other disadvantaged groups as inferior; (b) research characterized by the misuse and abuse of science and technology as in the Tuskegee experiment and Nazi eugenics; and (c) the disfavoring of all those previously mentioned groups (e.g., “natural racial types” (p. 19), by their “exclusion, marginalization, and restriction to lower level jobs” (Baker as cited in Harding, p. 20).

Harding (2006) argued that issues such as racist practices in science were arguably not of science, but rather of social structures, policies, and political life. She suggested that problems arose from scientists’ support, advertent or not, of “anti-democratic projects” that obscured social and political realities. Therefore, rather than scientific knowledge benefiting everyone, it is largely the dominant classes that enjoy the fruits of scientists’ labors.

McCaughey (1993) disagreed with Harding’s model for critiquing science—a three-part model that used empirical, standpoint, and postmodern perspectives—arguing that Harding’s work was based on a misunderstanding “of the relationship between scientific inquiry, objectivity, and values” (p. 72). While disagreeing with Harding’s epistemological model of critique, McCaughey’s conclusion also suggested that science is not a neutral, non-political form of inquiry. She posited that knowledge claims are dialogues colored by individual perspectives and, further, that “insidiously sexist objectivist claims could appropriately be considered bad science” (p. 82). If this were true, then by extension, one could further conclude that a scientist’s work was rendered non-neutral by the influence of individual interests, opinions, and paradigms.

The material presented thus far demonstrates the breadth of thinking on the philosophical aspects of science. To be sure, it is not a new discourse. Dating back to
Hippocrates and Galen, it is said that, “scientific and medical progress varied depending on the attitude of politics, economics, and levels of superstition … this changed starting in the 1800s” (Clinical Research Department, 2005, p. 1). While much has changed, the practice of medicine continues to be anchored by ancient principles and outdated epistemologies, even in the face of modern society. Understanding medical professionalism lies “not in the Hippocratic Oath, tradition, or ethos in and of themselves” (Jotterand, 2005, p. 7), but rather on a philosophy of medicine that “explores the values internal to medicine” (p. 10).

Fabrice Jotterand (2005), senior managing editor of the *Journal of Medicine and Philosophy*, argued for the need to update the tenets and principles guiding medical practice and the medical profession. He posited that the Hippocratic Oath, the Hippocratic tradition, and Hippocratic ethics were, in and of themselves, insufficient as guides for medicine and the medical profession. He argued that medicine’s guiding principles needed to be expanded to reflect the impact and influence of bioethics, biopolitics, and governmental regulation.

Jotterand (2005) made his arguments in an exposition in which he discussed the “dialectic between past ideals and present reality” (p. 1) in medicine. He highlighted important issues concerning modern medical practice, including the lack of ideological and attitudinal continuity between physicians already in practice and those just entering the field; explored the impact of differing opinions on the definitions of beneficence, wrongdoing and justice; discussed the advent of managed care; and addressed the dearth of medical insurance among the populace. However, most critical to people living with HIV/AIDS, particularly Latinas, was his analytical deduction that:
Contemporary medicine is predominantly dependent on socio-economic criteria external to the traditional set of norms and values internal to medical professionalism. The dependence of physicians on social institutions for the delivery of health care has created a new paradigm in which physicians have a social obligation to respect cost containment policies, which sometimes affect the welfare of the patients. (p. 118)

Jotterand acknowledged that the matter is not a simple one. He concluded, among other things, that there needs to be a critical reading of the “Hippocratic tradition and morality” (p. 122). More importantly for this discussion, he argued that bioethical aspects of medicine needed to be considered within the context of the “political, economic, and social aspects” (p. 123) that have come to be associated with medicine.

This section established and discussed science’s non-neutral and non-political nature. The writings of science philosophers (e.g. Chalmers, 1999; Foucault, 1994; Jotterand, 2005) and sociologists (Campbell, 1999; Harding, 1991, 2006) were offered as support the position. Historical aspects of AIDS provide further evidence for this view.

*The politics of science and HIV/AIDS.* The CDC’s initial case definition of the syndrome that came to be known as AIDS was based strictly on symptoms exhibited by young, homosexual men—men who died in great numbers as a result of those symptoms. As emerging disease patterns were analyzed and new information regarding the symptomatology became available, the CDC revised and expanded the definition of what constituted AIDS (CDC, 2002a). Women were increasingly being seen with immunodeficiency related symptomatology. Research and clinical care, however, continued to be based on and oriented towards men. Furthermore, evidence suggests that
even when it became abundantly clear that women were being affected by the new
disease, the focus was kept on men, thus intimating gender bias (Campbell, 1999; N. F.
McKenzie, 1991a). As a result, female symptoms were masked and many women became
ill and died before ever meeting the criteria for AIDS. Thus, they never qualified for the
programs funded to treat AIDS patients, as eligibility was, and continues to be, dependent

Understanding scientific responses to diseases like AIDS requires analysis
through categorical lenses because without also comprehending how gender, ethnicity,
and race intersect with a disease like AIDS, the result at best is an incomplete and
oversimplified understanding of those responses. Ultimately, this leads to
underemphasizing, if not overlooking, the impact of diseases on women, minorities,
immigrants, and other marginalized groups (Campbell, 1999). This deduction is a logical
and inevitable result of acknowledging the non-neutral and often political nature of
scientific inquiry.

*Scientific responses to diseases.* Scientific research regarding disease etiology and
treatment historically excluded women, except when studying diseases of the female
organs, older people, and ethnic minorities. The reasoning for such exclusion was
ostensibly due to the potential harm of experimentation to a woman’s fertility or, if a
woman became pregnant during the research process, to her fetus. Nevertheless, being on
dependable birth control, having only female partners, or being infertile was, and
continues to be, insufficient to justify a woman’s inclusion in clinical research (Bartlett et
al., 2005). Federal funding sources attempted to rectify the problem of exclusion via a
requirement to include women and minorities in studies they funded. However, 10 years
after researchers were to have begun more inclusionary practices in sample recruitment, they continued failing to meet this requirement, and the requirement became a legal mandate.

When women and minorities were included in scientific studies, the impact of their inclusion was minimized as study results were not broken down by the varying demographics. Failure to study demographic groups was attributed to a lack of statistical power in the research design, meaning that there were too few participants to make meaningful analysis possible (Blauwet, Hayes, McManus, Redberg, & Walsh, 2007). In addition, neither the government nor peer-reviewed journals require reporting of subgroup population data (Bailey, 2007); therefore, subgroup population analysis is not routinely done.

The exclusion of the previously noted demographic groups from scientific research has had relatively serious consequences, including the creation of predominantly male profiles for many diseases and an inaccurate understanding of gender specific drug effectiveness. These consequences are particularly sensitive to underlying poverty-related social factors such as absolute harm, cost-effectiveness, and interaction with other medications (Bailey, 2007; Campbell, 1999; Editorial, 2007). Ultimately, fashioning effective prevention and treatment interventions proved to be major challenges for clinical researchers and social scientists; in the case of many diseases, for example, heart disease and HIV/AIDS, solutions have proven illusive thus far.

*Scientific responses to heart disease.* Though heart disease is not the focus of this study, it is an excellent example of how gender politics and science intersect and impact research outcomes. Heart disease continues to present a challenge for researchers of both
genders. It is currently the number one national health threat for women (American Heart Association & American Stroke Association, 2008). Existing evidence on cardiac disease and care demonstrates that there are critical differences between how cardiac heart disease manifests and functions in women and men. The varying manifestations include differences in symptoms signifying a heart attack, responses to common heart medications used in treating acute coronary syndromes, and the interpretation of diagnostic exams (Blauwet et al., 2007). Notwithstanding, few women are enrolled in cardiac research trials of either new procedures or medications. The results have been poorly understood gender differences in cardiac disease, and sub-optimal cardiac care provided to patients of both genders (Bailey, 2007; Benner, 1994).

**Scientific responses to HIV/AIDS.** Epidemiological statistics regarding Latinas and HIV/AIDS strongly suggest that despite efforts to make treatment and prevention initiatives culturally relevant, such efforts have been largely unsuccessful. The lack of effectiveness results from failing to account for the full influence of socioeconomic and sociocultural factors in Latinas’ lives (Amaro, 1995; Amaro & Raj, 2000). For example, HIV/AIDS continues to be a stigmatized disease (Hollander, 2001), a factor creating an extra burden for Latinas already marginalized by their social and immigrant status (Engstrom & Piedra, 2006). Accessing support, whether from care providers, family members, or friends, is an important factor in successfully managing life with the disease but becomes much more difficult when stigma is present. In a culture where family support and connection is an important value, the impact of stigma is considerable.

There are, however, even more critical issues to consider. There is no cure for HIV/AIDS or vaccine to prevent infection with HIV. Medications exist, however, that
when properly prescribed and used can slow or halt disease progression (CDC, 2007b). However, as noted earlier, such medical treatment is costly and complicated. Prevention rather than treatment, therefore, is the key in dealing with HIV/AIDS, regardless of its characterization as a “chronic disease” (Baumgartner, 2000; Mitchell & Linsk, 2004). In turn, the key to prevention is to refrain from behaviors that put one in contact with HIV-infected fluids.

Power differentials are largely ignored in gender-neutral prevention initiatives. Because many initiatives are gender-neutral, it is not surprising that the initiatives are ineffective (Amaro, 1995; Amaro & Raj, 2000; Campbell, 1999). For Latinas, heterosexual contact represents the largest risk factor for contracting HIV. The safest manner of preventing infection is either sexual abstinence or the use of condoms when sexually active (CDC, 2007b). Yet culturally-bound, gender-related power differentials, coupled with religious prohibitions against the use of condoms, make this a difficult matter, particularly for women who are in violent relationships, who are poor and dependent on their partners for economic support, or for whom cultural strictures impede necessary discussions regarding sexual matters with one’s partner (Amaro, 1995; Amaro & Raj, 2000). The result is that a majority of Latinas do not use condoms, even when they are aware that doing so prevents infection with HIV (Larkey et al. 2001; McQuiston & Flaskerud, 2003; Organista et al. 1998).

When prevention fails, the hope for a healthier future lies in costly treatment regimens. A relatively high rate of poverty—one out of every five Latinos—encumbers Latinas in this regard. Latinas often do not have health insurance; they tend to seek health care only when there is a crisis. As a result, Latinas are late to be diagnosed with
HIV, are often in a poorer state of health compared to other groups at the time of diagnosis, and are at risk for poorer outcomes compared to other groups (Avert.org, 2006; Land, 1994; Ventura, 1976).

Poverty not only impedes women’s ability to pay for care, it also generates life circumstances in which the pull from myriad responsibilities is often inescapable. As a result, taking care of herself, as opposed to taking care of others, is almost always the second choice. Concurrently, stress levels rise, with the latter compounding the negative impact of the disease (Avert.org, 2006; N. F. McKenzie, 1991b; Ventura, 1976).

Prevention and treatment initiatives pay scant attention to this dynamic.

To understand scientific responses to diseases such as AIDS, and to ably translate those responses into appropriate, culturally-relevant health care, researchers must grapple with these issues and understand how they play out in Latinas’ lives. There are “multiple connections between sexuality, gender, and immigration” (Gonzalez-Lopez, 2005, p. 24) and Latinas’ health is dependent on recognizing these connections and their relationship to HIV/AIDS prevention and treatment.

The non-neutrality and politicized nature of science suggests a conceptual framework useful and appropriate for exploring, analyzing, and understanding the narratives of Latinas and HIV/AIDS. Such narratives reflect their individual experiences, indicating who they are in all their complexity and the impact that HIV/AIDS has had on their lives and the lives of those around them.

*The Contextual Nature of Disease*

Having demonstrated the nature of science as non-neutral and political, it is not a great leap to conclude that disease does not exist in a vacuum. Indeed, diseases are in
many ways socio-culturally constructed and cannot be examined outside their societal frame (Armus, 2003). Their etiology, transmission, treatment, and meaning are framed and defined by the past and the present, by social groups, and, at times, by individuals. In turn, the definitions of disease reflect both medical knowledge and technology. Disease definitions are further influenced by broader sociocultural and sociopolitical factors such as religious and cultural beliefs, gender obligations, nationality, ethnicity, socioeconomic status, and the responsibilities of governments (Armus). The literature provides ample evidence for the contextual nature of disease. I begin with the story of cholera in Peru.

The first appearance of cholera in the 20th century in the western hemisphere was in Peru. In 1991 it appeared in three coastal areas almost simultaneously (Cueto, 2003). The disease spread across Latin and Central America fairly quickly, wreaking havoc as it advanced. Peru’s economy suffered as other countries stopped importing agricultural products and seafood of all types (Cueto). This was a critical consequence given the country’s economic hyperinflation and serious political difficulties at the time (President Fujimora was almost entirely focused upon preventing the guerrilla group Shining Path from taking control of the government).

Initially, the response led by Peru’s Health Minister, along with significant support from international health organizations, was excellent. Eventually the national response was abandoned, though doctors, nurses, and public health workers continued to fight against the epidemic (Cueto, 2003). Their efforts kept the epidemic from causing more deaths than it did. However, it was not the lack of a sufficient government response that caused the epidemic to spread, but rather societal circumstances.
The exact source of the introduction of cholera into Peru was never discovered, but it was believed that ballast effluence from ships docking in the harbor was most likely responsible (Cueto, 2003). Water and sewage treatment was poor, especially in the shantytowns where many of the poor lived. Access to safe drinking water was extremely limited and expensive. Hospitals, particularly public hospitals, were crowded and lacked many of the medicinal supplies required to treat patients. People with adequate financial means were able to protect themselves from infection by following the recommendations of public health authorities: to eat only at home, to buy water from a safe source, and so forth. If such people became infected with cholera, they could seek appropriate medical care. On the other hand, being poor generally meant that one was employed as a day laborer, which necessitated being outside the home for many hours each day. This group frequently ate cheap meals offered by street vendors, often consisting of raw fish in the form of ceviche or other uncooked foods (Cueto).

Whether in their shanties or outside the home, people who were poverty-stricken had little or no access to safe, clean water for any purpose. Therefore, they could not keep themselves or their homes as clean as necessary, and were unable to take many of the other precautions that the public health workers advised. As a result, the majority of people who were infected with cholera were the poor and homeless (Cueto, 2003). Furthermore, sociocultural factors such as viewing cholera as “religious punishment, disease as a token of reproach and social inferiority, as well as a metaphor for the social and epidemiological realities” (p. 279) reinforced perceptions that victims brought the disease upon themselves.
The popular perception of cholera thus became one of blaming the victim for falling prey to the disease and considering the victim as deserving of the stigma attached to cholera. The government reinforced this perception and used “the association between filthiness and disease” to “support a campaign that cost little, avoided dealing with the real problems that generated the epidemic, and reinforced the neoliberal trend taken by the Fujimori government” (pp. 281-282). Political expediency was chosen over the overall health of the populace.

The second source of evidence supporting the contextual nature of disease comes from scientists working on diabetes prevention research at the CDC. Diabetes has a “disproportionate prevalence in minority populations” (Taylor, Keim, Fuqua, & Johnson, 2005, p. 1), especially among Native Americans. It leads to a poorer quality of life and increased health care costs. Prevention is therefore of great importance. Nevertheless, effective prevention interventions have been elusive with this population. Taylor et al. recognizing the contextual nature of disease, set out to identify and understand Native Americans’ cultural definitions of health and disease, considering them critical to generating effective prevention interventions.

Using grounded theory methodology, Taylor et al. (2005) carried out a qualitative study which explored and delineated cultural aspects of health and disease among Native Americans. Using specially trained lay interviewers from the participants’ tribe, 79 Native American women from three tribal clinics in northern Oklahoma were interviewed. In three separate sessions, each woman was asked a fixed set of questions regarding perceived causes, treatments, and efficacy of diabetes prevention behaviors. Among other things, results indicated that the women defined health in terms of whether
or not they felt ill, whether they were able to carry out their daily responsibilities, and whether they noted the presence or absence of disease.

Furthermore, the authors found that the women considered overall health to be a personal matter to be addressed individually—many of them had misconceptions regarding disease symptoms and processes, and subscribed to fatalistic views of diabetes (Cueto, 2003). They were more concerned about their children’s or other family members actual or potential diabetes diagnosis. Once diagnosed, the women felt that each person’s responsibility was to follow the doctor’s instructions exactly as given. Given their fatalistic view of diabetes, however, the women also regarded the diagnosis as an event that destroyed health and ultimately resulted in death. They also believed that frequent visits to a doctor’s office equaled or meant preventative behavioral strategies (Taylor et al., 2005).

Lastly, the authors found that despite the limitations of the study (e.g., lay, though trained, interviewers; limited transferability to Native Americans living outside of reservations), results were congruent with previous findings. Furthermore, Taylor et al. (2005) concluded that identifying “disparities in health perceptions and worldviews are essential for developing nutrition education interventions that precipitate behavior change” (p. 7). This conclusion speaks directly to the focus of this study.

A third and final example of the contextual nature of disease comes from various published books that examined medicine, science, and various diseases within the context of their sociocultural and socioeconomic contexts (Armus, 2003; Campbell, 1999; Fadiman, 1997; Foucault, 1994; Sontag, 1989). Anne Fadiman’s (1997) book, The Spirit Catches You and You Fall Down, is essentially a cautionary tale. In the book, she
recounted the circumstances and events comprising a clash between a Hmong (from Laos) child’s parents and a California hospital’s providers, as all of them struggled to provide care to the young child stricken with severe epilepsy. Fadiman found numerous sources of the mutual misunderstanding between the hospital and the family. One source, as she saw it, was the hospital’s perception that the family was difficult and stubborn, and at times completely unwilling to put aside religious beliefs for the medical care the doctors believed the child needed. What the hospital staff failed to see, however, was that the family’s actions reflected not obstinacy, but various intersecting beliefs:

Religion was medicine (italics in the original) … religion was society … society was medicine … even economics were mixed up in there somewhere (you had to have or borrow enough money to buy a pig, or even a cow, in case someone got sick and a sacrifice was required) … and so was music (if you didn’t have a qeej [a spirit] player at your funeral, your soul wouldn’t be reborn, and it might make your relatives sick). (pp. 60-61)

Also feeding the misunderstanding were the differences between Hmong and American views of health care—views which were in almost direct opposition to each other. Where the former saw medicine as totally interlaced with life and death, the latter’s view of medicine was increasingly atomized, with little or no acknowledgement of the relationship between the particles.

Underneath this mutual lack of understanding were various obstacles, chief among them the language barrier. The family spoke no English; the hospital staff spoke no Hmong; and interpreters were not regularly available. Further, while the hospital staff cared deeply about the child, they did not appear to make a significant attempt to cross
the gulf between their own, and the family’s concepts of medicine and medical care. Ultimately, the outcome of the situation was heart-rending. The child was placed in foster care and the parents were charged with medical neglect. The child was returned to the family when no change in her condition was noted while in foster care. Even more tragic was the child’s eventual loss of significant brain function due to the intractable, severe, and repeated epileptic seizures she suffered (Fadiman, 1997).

In *AIDS in Latin America*, Tom Frasca delineated the history of AIDS in parts of the southern hemisphere. Starting and ending his study in Santiago, Chile, Frasca (2005) also journeyed to Peru, Mexico, Guatemala, Trinidad and Tobago, Argentina, and Brazil. He interviewed patients, friends, families, care providers, advocates, and government officials, finding several commonalities in how the epidemic presented itself in Latin America and in how countries and their people responded. One commonality was that all of the countries he surveyed initially ignored the epidemic, believing that it would not affect them (Frasca). Frasca also found, however, that in each country, “the story of HIV/AIDS . . . was unique to its political and cultural contexts, economic conditions, and recent histories” (p. 6).

In summary, this section advanced the concept of diseases as contextual in nature and therefore incapable of being understood outside the societal frames in which they exist. Whether with cholera in Peru, AIDS in Latin America, or epilepsy in the U.S., those affected as patients, care providers, or simply as citizens of a particular country—brought their own systems of meaning and belief to the experience. The evidence I have presented indicates that indeed, sociocultural and sociopolitical factors such as religious
and cultural beliefs, gender roles, nationality, ethnicity, class, and state responsibilities impact the response to a disease and the course of an epidemic (Armus, 2003).

**Culture, Medicine, Illness, and Disease**

“No one can doubt any longer that culture is critical to medicine” (Kleinman & Benson, 2006, p. 834). The role of culture is amply seen in cultural and ethnic health disparities and in its impact on health care practice. In many instances, however, “culture” is perceived as stereotypical notions of cultural characteristics including dress, diet, music, language, and culturally prescribed comportment.

Such characteristics, however, are not the critical, cultural aspects of a people. Culture, according to Kleinman and Benson (2006), while including the abovementioned characteristics, is more importantly and “more profoundly, about what really matters to people” (p. 834). The authors further suggested that culture is about “the changing moral experiences of patients, families, and practitioners” (p. 834) and how those experiences impact both the patients and their experience of illness and disease, as well as doctors, particularly within the patient-doctor relationship.

Kleinman (1980) posited that all societies organize health care activities in a “more or less interrelated” (p. 24) fashion in response to disease, and that the socially constructed group of activities that comprise medicine constitutes its own cultural system—in the same way we consider kinship a cultural system. This system comprises “symbolic meanings, anchored in particular arrangements of social institutions and patterns of interpersonal interactions” (p. 24). Of particular interest to this study are the ideas and understandings that patients and doctors have about illness and disease and what, if anything, their notions might elucidate about preventing and treating HIV/AIDS.
Kleinman’s (Hahn & Kleinman, 1983; Arthur Kleinman, 1988b; A. Kleinman, L. Eisenberg, & B. Good, 1978) delineation of the distinction between illness and disease has its roots in the nascent phase of his research and writings. Working in the margins between medicine, psychiatry, and anthropology, he advanced the concept of the cultural embeddedness of the medicine. Within that context, Kleinman popularized the dichotomy between illness and disease—a key medical anthropological axiom—which he sees as two distinct aspects of sickness. Illness refers to the psychosocial aspects of disease and includes people’s thoughts, feelings, and valuations of disease symptoms, together with communication and interaction between people and their familial and social circles. As conceptualized by Kleinman, illness encompasses people’s responses to diseases as giving their experiences meaning, and allowing them to exert some control over their circumstances.

Disease refers to a malfunction in, or the incorrect functioning of, any organ, part, structure, or system of the body (Arthur Kleinman, 1980). Stated differently, disease is a “disturbance of biochemical processes, anatomical structures, or physiological reactions” (p. 73). Diseases happen to individuals. However, illnesses, as “an intimate part of social systems of meaning and rules for behavior” (A. Kleinman et al., 1978, p. 251), impact both the familial and social systems of which the individual is a part. The question that follows is how these dichotomous models impact the experience of sickness for the individual and the doctor.

The illness experience is culturally constructed and mediated (A. Kleinman et al., 1978). How individuals interpret, engage with, and handle disease is dependent on the understandings and meanings they hold and employ, and are “specific to the social
positions they occupy” (p. 252). Whom the individual turns to with the symptoms they have noted, who they first turn to for care, and how long they stay in care are all impacted by what they have learned about the meaning of being ill in their homes and their communities. Doctors’ activities and explanations have similar roots (A. Kleinman et al., 1978). The dissonance in the patient-doctor relationship stems in part from the fact that individuals present to the doctor, or some other element of the health care system, with an illness. The doctor and/or the medical system on the other hand, respond to and treat disease. For patients, their difficulties lie not only in the disease itself, whatever it might be, but also in the problems that the sickness might be causing. For example, chronic lung problems, which cause difficulty in breathing, could limit someone’s ability to work, which in turn creates economic problems in the home. Consequently, for the patient, the problems with living are the disorder. Conversely, the doctor sees the biologic disturbance as the whole disorder and often ignores the illness problem (Arthur Kleinman et al., 1978). This difference breeds dissatisfaction for both patient and doctor. However, of more importance and potentially greater import is that the treatment prescribed may be ineffective—not due to a lack of efficacy with the medications or the treatment, but because patients do not tend to adhere to a treatment plan if the doctor’s explanations are not congruent with their own beliefs and understandings (Arthur Kleinman et al., 1978).

To summarize: in this section I have outlined the significance of the relationship between culture and disease, and the importance this has for people who are confronted by disease. Also noted was the need for authentic representation of culture—rather than reduction to stereotypes—when it is considered as context for people’s lives and particularly as it provides a contextual understanding of disease. Illness was defined as
the complement of symptoms, problems, and meanings individuals present to doctors or
other medical providers, while disease was defined as the biologic disturbances that
become the focus of medical attention. The difference in patients’ and doctors’
understandings of the two was highlighted, as was the cost of not acknowledging and
addressing this difference.

Illness Narratives

The use of narratives has been promoted as an appropriate, if not ideal, tool for
teaching patient care to doctors and nurses and for use within their practices (Bleakley,
2005; Chan, Cheung, Mok, Cheung, & Tong, 2006; Greenhalgh & Hurwitz, 1999; Wear,
Kokinova, Keck-McNulty, & Aultman, 2005), as well as for social scientists working in
the medical arena (Ville & Khlat, 2007). Specifically, narratives “provide a framework
for approaching a patient’s problems holistically, and may uncover diagnostic and
therapeutic options” (Greenhalgh & Hurwitz, p. 1). Moreover, taking a patient history,
which is a routine part of clinical practice for a doctor, and carrying out an assessment,
which is an integral part of social work practice, is “an interpretive act” (p. 1) and a
central feature of narrative analysis. There is evidence that while not yet common
practice, narratives are nevertheless being increasingly employed (B. Carter, 2004;

Not everyone agrees with the manner in which narratives, or other qualitative
methods, are used in medicine, whether the purpose is to study illness or disease.
Waitzkin (1990) posited that as a research tool, qualitative methods were not
straightforward in their choice of research focus—the analysis of data was difficult to
evaluate, and the presentation of results was unclear. He proposed ways of modifying the
methodology, though his suggestions largely ignore basic tenets of qualitative research. In contrast, Kleinman (1988a) offered illness narratives as an excellent resource for the study of individual experiences of illness and its corresponding relationship to disease.

Narratives allow for the collection of knowledge and information regarding people’s experiences of illness and disease. Patients use narratives to give order and meaning to their own and their families’ experience of illness (Arthur Kleinman, 1988a). To gain an appreciation for the patient’s experience, the researcher or clinician elicits narratives, analyzing them “in light of the different modes of illness meanings—symptom symbols, culturally salient illnesses, (and) personal and social contexts” (p. 49) that the narrator recounts. Examples of illness narratives and their use follow. Their placement here provides evidence of their appropriateness as vehicles for uncovering and exploring the experience of Latinas living with HIV/AIDS.

Illness Narratives in Research

Researchers have historically utilized narratives to study the experience of disease; to illuminate the contextualized nature of the meanings of sickness and health; and to explore the relationship between ideas of sexuality, disease, culture, and gender (Emami, Benner, & Ekman, 2001; Keese, Ahmad, Nelson, Barney, & Duran, 2004; Moreno, 2007). Emami, Benner, and Ekman studied ways that Iranian women who had immigrated to Sweden late in life perceived, experienced, and conceptualized their health situations. Employing a phenomenological framework, they found that the women’s narratives evinced interpretations and conceptualizations of health that were mediated by a culturally-defined understanding of health. Based on the meanings that the women ascribed to health, their ideas regarding health prevention and maintenance, and the
specific knowledge they held regarding how to prevent illness and maintain health, the researchers developed a sociocultural health and illness model that could be employed to better understand the women’s experiences.

Keese et al. (2004) elicited the narratives of Hispanics living on the U.S./Mexican border and studied factors leading to the respondents being tested for HIV. Their analysis revealed that various cultural factors impeded HIV prevention efforts and put Hispanics at risk, including culturally-mediated beliefs regarding the causes of, nature of, and responsibility for illness, and the notion of predestination (that is, whatever happens is God’s will). More specifically, Keese et al. found that cultural beliefs impacted respondents’ perceptions of personal risk regarding HIV infection—beliefs that led respondents to agree to be tested but not to use condoms or reduce risky behaviors. The researchers found not only that the majority of participants did not consider themselves to be at risk, but that none of the women did. Furthermore, women connected their risk only to their own behavior, but not to the behavior of others. Finally, study findings indicated that the participants equated an absence of symptoms with not being ill. This led to their questioning the need to take any medication as they did not see that they were ill. More importantly, they questioned why they should have any treatment at all if HIV/AIDS cannot be cured and is fatal.

Moreno’s (2007) study had a fairly wide focus. It explored the relationship between culture, gender, structural factors, abuse, trauma, and HIV/AIDS in Latinas. Analyzing narrative as well as focus group data, she found four emergent themes: (a) histories of trauma, (b) living with HIV, (c) vulnerability, and (d) la suerte (luck). Analysis further revealed that the women considered issues such as machismo,
marianismo, and fatalismo as risk factors for HIV infection and IPV. The women in Moreno’s study reconsidered their existing notions of IPV and felt that it was exacerbated by threats of deportation and by their HIV status. This study, in addition to the others previously described, exemplifies the narrative approach and attests to the aptness of its use with populations confronting HIV/AIDS.

To summarize, narrative inquiry and analysis lends itself to the study of illness experiences across various settings. Illness narratives have the potential of making known a patient’s particular, concrete, and culturally mediated experience of illness. They also give voice to the psychosocial and existential qualities of illness, and sometimes disease—qualities such as “inner hurt, despair, hope, grief, and moral pain which frequently accompany, and may even constitute, people’s illnesses” (Greenhalgh & Hurwitz, 1999, p. 48).
CHAPTER III
METHODOLOGY

Introduction

The purpose of this study was to explore Latino women’s narratives of living with HIV/AIDS. The central questions that guided the study were: (a) What does being infected with HIV/AIDS mean to Latino women? (b) What issues contribute to becoming infected with HIV? (c) What factors, or confluence of factors, impact the lives of Latino women living with HIV/AIDS? and (d) How do Latino women make sense of being infected with HIV/AIDS within the broader context of their lives?

This chapter presents the methodology used to explore and analyze, from sociocultural and political perspectives, the narratives collected from Latino women living with HIV/AIDS. It comprises the following sections: Study Design, Narrative Inquiry, Sample Selection, Data Collection, Data Analysis, Validity and Reliability, Limitations, Researcher Orientation/Bias, and Summary.

Design of the Study

Latino women are disproportionately diagnosed with HIV/AIDS infection in relationship to their representation in the U.S. population (CDC, 2006a). Nevertheless, no quantitative, and very few qualitative studies have focused solely on Latino women living with HIV/AIDS or have specifically addressed their needs. Furthermore, there is little evidence that existing study results have been translated into effective prevention and
treatment initiatives. Attesting to this failure is the continuing rise in the HIV incidence and death rates for Latino women due to AIDS (CDC).

The paucity of studies on and lack of efficacious prevention and treatment interventions for Latino women are due largely to three factors. One is the frequent use of reductive definitions of cultural variables. A second factor is insufficient acknowledgement of the contextual nature of disease. The third and most important factor is a lack of recognition and understanding of the critical role played by the intersection of gender, culture, and socio-political-economic factors in the lives of Latino women, particularly as they grapple with preventing or living with HIV/AIDS (Amaro, 1995; Campbell, 1999).

Qualitative research studies focusing on HIV/AIDS do exist, though not across all populations. In a metasynthesis of qualitative studies, Barroso and Powell-Cope (2000) found that while the research appeared to be adequate in terms of studying the broad experience of adults living with HIV, the studies were not sufficiently representative of subpopulations, which includes Latino women (Barroso & Powell-Cope). Later studies (Ailinger, Gonzalez, & Zamora, 2007; Shedlin & Deren, 2002) confirmed Barroso and Powell-Cope’s findings, concluding that few of the studies attempted to go beyond understanding specific, narrowly-focused aspects of people’s experiences of living with HIV/AIDS in subpopulations.

The choice of a qualitative research methodology for this dissertation was driven primarily by my recognition that qualitative inquiry best serves the research questions being asked, the subject matter at hand, and the Latino women who are the focus of the study. The few previous qualitative studies in this area raised intriguing questions that
have yet to be explored, and only hint at the richness of experience that may be uncovered through this approach. Specifically, qualitative methodology was ideal for studying and giving voice to Latino women’s unique expressions, perceptions, and experiences of living with HIV/AIDS.

Qualitative research can take many forms, and is often referred to as an “umbrella term” (Creswell, 2007; N. K. Denzin & Lincoln, 2005; Ezzy, 2002; Merriam & Associates, 2002). While varying in some ways, qualitative designs all share certain characteristics, though they may not be represented equally across designs. Researchers employing qualitative methodologies are interested in the emic perspective. That is, they seek to discover the meanings people give to their world in general, and to the phenomenon of interest in particular. These meanings are socially constructed as individuals interact with their world, and are therefore fluid and permeable rather than fixed (Creswell; Ezzy; Merriam & Associates). For example, I was interested in exploring Latino women’s experiences of living with HIV/AIDS; more specifically, I wished to elicit their own descriptions of their lives as they confronted the numerous challenges of daily living further complicated by HIV/AIDS.

While qualitative researchers do not create a priori hypotheses for a study, they often use theoretical lenses through which to view the phenomenon under study (Creswell, 2007). In this study, sociocultural, economic, and political lenses were used to examine the lives of women living with HIV/AIDS. Employing these perspectives allowed for meaningful organization of the information gleaned from the narratives; it also created a context within which HIV/AIDS could be studied within this subpopulation of women.
As a researcher, I was interested in understanding Latino women’s experiences of living with HIV/AIDS within the culturally-laden contexts of their lives. In many ways, then, this was also a study of culture, reflecting Geertz’s (1973) description of culture as a “web of significance [the individual] himself has spun” (p. 5), and in which the individual is “suspended” (p. 5). This focus on culture, combined with Geertz’s argument that the analysis of culture is “not an experimental science in search of law but an interpretive one in search of meaning” (p. 5) reinforces the value of narrative inquiry for highlighting the meanings Latino women ascribe to their experiences of living with HIV/AIDS.

Various aspects of qualitative methodology lend themselves to the study of culture—a major contextual aspect of Latino women’s lives and experiences of living with HIV/AIDS. Two of the methodological characteristics most critical to this study were that the researcher is the primary instrument for data collection and analysis, and that the aim of the research is on the emic perspective (Merriam & Associates, 2002). This meant that while collecting and analyzing raw data, I could identify and record non-verbal communication, clarify and probe verbal responses, and confirm the accuracy of my impressions through member checks with the respondents as the interviews proceeded. Performing the study in this fashion allowed me not to only better describe the role that HIV/AIDS played in Latino women’s lives, but also to illuminate the meanings my respondents gave to HIV/AIDS.

Qualitative researchers are oriented to real-world circumstances. They collect data in the environment or context in which the respondents live or experience the phenomenon under study, as opposed to working with respondents in a laboratory or
other artificial environment (Bogdan & Biklen, 2007; Creswell, 2007). Data for this study were collected in each respondent’s home, a place which, as was expected, suited the Latino women interviewed. Being in their own homes helped the respondents feel more at ease and self-assured, and strengthened the relationship between them and me.

Relatedness, or being connected to another person, is an important cultural value, particularly in interactions such as contact with a medical provider or with an interviewer asking personal and intimate questions. Latinos prefer, for example, intimate, face-to-face, eye-to-eye interaction in familiar settings, rather than formal meetings in offices. In addition, it is important that there be a feeling of confianza (trust) and personalismo (personalized caring) when engaging in conversations with other people (Larkey et al., 2001; Russell et al., 2000).

The characterization of “being related” was engendered by several factors in addition to my presence in the women’s homes: bringing a gift of foodstuffs bought in their neighborhoods, (my) being Latina, and my ability to conduct the interviews in Spanish without an intermediary. Being able to speak to me directly in their own language, Spanish, allowed the women to fully express themselves using the language and, by extension, the culture in which their experiences occurred. At the same time, promoting relatedness with the participants also generated a potential problem for my dissertation committee; I discuss how I approached this later in this section.

Much of qualitative research uses inductive logic rather than the deductive logic prevalent in quantitative research. This study was driven by data rather than by pre-existing hypotheses or “postulates” (Merriam & Associates, 2002, p. 5). That is, the concepts, ideas, and abstractions regarding the experiences of Latino women living with
HIV/AIDS that are detailed herein arose from data produced by the narratives, and were informed by the theoretical assumptions that underpin the study.

Additional examples of the use of inductive logic in this study are related to the “research process for qualitative research [being] emergent” (Creswell, 2007, p. 39) and the fact that when interpreting someone’s life experience, “nothing is trivial . . . everything has the potential to be a clue” (Bogdan & Biklen, 2007, p. 5). Therefore, interviewing participants face-to-face, in situ, allowed for the discovery of additional clues that “unlocked a more comprehensive understanding” (p. 5) of the women and their experiences of living with HIV/AIDS. This approach made it possible for me to pursue lines of inquiry, or modify other aspects of the study, as suggested by participant responses (Merriam & Associates, 2002).

For this study, such flexibility also allowed a deeper exploration of responses through the use of probing questions. It gave participants the freedom to reply to my questions with the rich detail of stories, rather than being limited by the restrictive instruction to answer questions with “yes,” “no,” or other pre-selected choices. Additionally, the emergent quality described by both Creswell (2007) and Merriam and Associates (2002) afforded me the opportunity to change some aspects of the analysis as the project progressed. Such changes were approved by the chair of my dissertation committee and are described in a later section of this chapter.

To summarize, a qualitative paradigm best served my study, which aimed to uncover the emic perspectives on being a Latino woman living with HIV/AIDS. The study explored the sociocultural, political, and economic contexts of the lives of Latino women grappling with HIV/AIDS. The qualitative research methodology used in the
study required me to be the key data collection instrument as well as the data analyst. Thus, my experience with the subject matter, which includes extensive knowledge of Latino culture as well as HIV/AIDS, enhanced my ability both to complete a thorough literature review and to carry out the study itself.

At the same time, both my background in HIV/AIDS and my experience with Latino culture also introduced a potential disadvantage, particularly regarding the outcome of the study. As the primary researcher, my subjectivities were potentially “virtuous” (Peshkin, 1988, p. 18) and useful for “making a distinct contribution” (p. 18). However, I had to be vigilant in setting aside my personal point of view and perspective (Merriam & Associates, 2002) to present a description born of its “own intrinsic system of meaning” (p. 94) rather than imposed by sources external to the phenomenon. This was particularly pertinent regarding the use of Spanish to conduct the interviews. Because the members of my dissertation committee do not speak Spanish, they had to trust the English translations I provided. I addressed this potential concern by having several of the Spanish-language transcripts and their translations reviewed by Spanish-speaking peers. This process also helped ensure that my conclusions originated from the data rather than from the particular Spanish-to-English translation.

Choosing a tradition or type of qualitative research for a study is dependent on the questions a researcher wants to explore. Researchers in various disciplines ask questions relative to their own field of study, and the methodology chosen must be consonant with the questions asked. According to Merriam and Associates (2002), there are six “more commonly used approaches to doing qualitative research” (p. 6). While all fall under the qualitative rubric, each has a distinct focus and its own methods of sample selection, data
collection and analysis, and reporting. The six approaches are: basic interpretive, phenomenology, grounded theory, case study, ethnography, and narrative. In the following section I discuss the aspects of narrative inquiry that made it the most appropriate methodological choice for this study.

**Narrative Inquiry**

People come to know the world largely, but not solely, through the stories they are told, and they explain their view of the world through the stories they tell. Oral and written narratives often reveal what people think is generally important in life, and display the factors that individuals consider particularly significant when grappling with the question of life’s meaning (Chase, 2005; N. K. Denzin & Lincoln, 2005; Lee, Rosenfeld, Mendenhall, & Tynes, 2004). Because narratives offer a window into people’s subjective lives and experiences of the world, narrative inquiry is ideally suited for the purposes of this study.

The telling of stories and their subsequent analysis are subjective processes that do “not assume objectivity” (Riessman, 2002, p. 696). In fact, part of the purpose of narrative inquiry is to “privilege [the] positionality and subjectivity” (p. 696) of participants. As my goal was to obtain Latino women’s perspectives on living with HIV/AIDS, the purpose of narrative inquiry is consonant with the focus of the study.

People lead storied lives shaped by cultural, political, and historical contexts (Connelly & Clandinin, 1990; Moen, 2006; Riessman, 2002). As a result, personal narratives provide insight into how people see themselves in the world and reflect the “intersection of biography, history, and society” (Riessman, p. 697). Moreover, in light of Armus’s (2003) view that, “diseases cannot be examined outside their societal frame” (p.
2), narrative inquiry is a particularly apt approach for exploring Latino women’s experiences of living with HIV/AIDS.

In addition to the role narratives play in people’s lives, a second reason for choosing narrative inquiry was that “storytelling is a relational activity” and a “collaborative practice” that encourages others to “listen, to share, and to empathize” (Riessman, 2002, p. 697). As an experienced social worker, I recognized that these familiar characteristics of professional interactions would support and facilitate the interview process, and were appropriate to Latino women given the cultural importance of interactions governed by personal rather than institutional or formal contacts (Burke, 2003).

A third reason for choosing narrative inquiry was that it allowed the “systematic study of experience” and of the “changing meanings of conditions that affect women disproportionately” (Riessman, 2002, p. 707). Such conditions include poverty, intimate partner violence, and diseases such as HIV/AIDS. Given my belief, based on my experience as a social worker, that these conditions negatively impact Latino women’s health, this methodology provided a more formal framework in which to explore the effects of these conditions on Latino women living with HIV/AIDS. In addition, personal narratives provide “windows into lives that confront constraints of circumstances” (p. 707), a characterization that certainly applies to many Latino women in general, and to the participants in this study in particular.

The narrative approach allowed me to collaborate with participants as I strove to validate the interpretations drawn from the participants’ stories (Connelly & Clandinin, 1990). The act of eliciting the stories underscored both the differences and the similarities
between clinical and research interviews, and between narrative interviewing and other qualitative interview approaches. Seeing the women’s lives through their own eyes, I was uplifted both professionally and personally by the astounding strength, will, and “heart” they exhibited. The experience of interviewing the participants was transformative for me as the researcher—an occurrence that Moen (2006) attributes to the use of this particular methodology. From practical learning—such as appreciating the difference between interviewing as a social worker aiming to assist “in the field” vs. interviewing as a social science researcher—to refining intellectual understandings—such as what truly constitutes cultural difference, how it affects everyday life and what this means for practice and research--undertaking this study changed how I will approach research and teaching in the future.

In addition, the participants reported that after being interviewed about becoming HIV positive and living with AIDS, they felt they had truly “been heard,” a dynamic which, for some, is a rare occurrence. Thus, being listened to in this manner was a positive affirmation of themselves and their experiences. Lastly, creating and narrating their own life stories gave the women an opportunity to organize and make sense of their lived experiences in a manner not previously afforded them. They were able to talk freely, knowing that my interest was only in gathering their stories, understanding their experiences, and turning that knowledge into effective prevention and treatment initiatives, and not in taking advantage of them in any way.

In sum, I chose a narrative inquiry approach for this study as it best served two of the main paradigms framing the study. First, this approach supported the belief that “there is a widely recognized disconnect between HIV/AIDS and sexual health policy
and intervention, and the experienced realities and lives of the people and communities most affected by the epidemic” (Fulbright New Century Scholars Program, 2004-2005, p. 1), including Latino women. Second, it recognized that HIV/AIDS is embedded in socioeconomic, sociocultural, and political contexts and is a gendered experience. Thus, the narrative approach to qualitative research is an apposite lens through which to interpret the narratives of Latino women living with HIV/AIDS.

Illness Narratives and Culture

Researchers have historically analyzed narratives to study the experience of disease, to illuminate the contextualized nature of the meanings of sickness and health, and to explore the relationship between ideas of sexuality, disease, culture, and gender (Emami et al., 2001; Keese et al., 2004; Moreno, 2007). Emami et al. studied ways that Iranian women who had immigrated to Sweden late in life perceived, experienced, and conceptualized their health situations. Employing a phenomenological interpretation of the narratives, they found that women’s interpretations and conceptualizations of health were mediated by culturally-defined understandings.

Keese et al. (2004) elicited narratives from Hispanics living on the border between the U.S. and Mexico to study the factors leading them to be tested for HIV. Their analysis revealed that there are various cultural factors impeding HIV prevention efforts. These factors included culturally-mediated beliefs regarding the causes, nature, and responsibility for illness, and the notion of predestination. Cultural beliefs impacted participants’ perceptions of personal risk regarding HIV infection, which led to being tested, but did not increase condom use or reduce risky behaviors. For example, only a fraction of participants considered themselves to be at risk, and none of them were
women. Latino women believed only their own behavior put them at risk for contracting HIV and knew they were not engaging in risky behavior (i.e., having multiple sex partners, using drugs, etc.). The women did not take into account that their partner’s behavior contributed to their vulnerability as much as, if not more than, their own actions. Therefore, they did not see the need to protect themselves during sexual relations. Participants equated an absence of symptoms with not being ill, leading them to question the rationale for taking medication if they did not feel ill, and ultimately to ask, “Why seek treatment if HIV/AIDS is fatal?”

Moreno (2007) looked at the relationships between culture, gender, structural factors, abuse, trauma, and HIV/AIDS in Latino women. Analyzing narrative and focus group data, she found that four themes emerged: histories of trauma, living with HIV, vulnerability, and *la suerte* (luck). Data analysis also revealed that participants considered issues such as machismo, marianismo, and fatalismo as risk factors for both HIV infection and intimate partner violence (IPV). Study participants expanded and reconfigured their notion of IPV to include a form of situational abuse, such as threats of deportation, which were in turn exacerbated by their HIV status.

These studies exemplify the value of the narrative approach in examining the relationship between illness, culture, and the structural components of people’s lives. They also illuminate key issues that must be addressed if prevention and treatment initiatives are to be effective for culturally diverse populations, and attest to the value and suitability of using narratives with populations confronting HIV/AIDS.
Sample Selection

Qualitative research uses various sampling techniques depending on the type and purpose of the study, and a single study might employ more than one sampling strategy (Creswell, 2007). Participants are purposefully chosen for the richness of the information they provide (Patton, 1990). Driving the choice is the question: Who will provide the most comprehensive information to answer the questions of the study? Criteria are set for selecting participants, thus invoking criterion or purposeful sampling (Creswell, 2007).

The first step in purposeful sampling is determining the selection criteria by which study participants will be chosen (Creswell, 2007). The participants in this study met the following criteria: each was (a) a Latino female from South America, Central America, or Mexico; (b) either a first- or second-generation immigrant, though first was preferred; (c) at least 18 years of age, (d) diagnosed with either HIV or AIDS, and (e) willing to discuss her experiences as an HIV/AIDS infected woman. I used a screening guide (Appendices A1 and A2 [Spanish/English]) to determine whether potential participants were eligible for inclusion. Within this scope, I sought a sample reflecting the heterogeneity of Latino women who are living with HIV/AIDS. Creswell termed this approach *maximum variation sampling* and stated its purpose as documenting diverse variations and identifying important common patterns.

The study criteria were selected based on several considerations. First, the descriptors “Latino” and “Hispanic” are used to refer to widely diverse groups of women from the Caribbean, South America, Central America, Mexico, or North America. Each group has its own characteristics and its own view of the experience of being HIV positive or having AIDS, with known, marked differences found between American-born
Latinos, Latinos who are long-term residents of the U.S., and other Latino groups. To minimize the outcome of such diversity, and to account for the fact that the Hispanic population in the Southeast is largely from South America, Central America, and Mexico (U.S. Census Bureau, 2005), I limited participation to women with a heritage from those parts of the world.

As I was interested in identifying native cultural influences on the illness experience (Armus, 2003; Arthur Kleinman, 1988a), the preference was that participants be first-generation immigrants, though the study permitted the inclusion of second-generation immigrants as well. These subgroups are unlikely to have fully adopted the cultural norms of the host country (Armus; Engstrom, 2006). In fact, this was true for all participants, even though one of them had been in the U.S. more than 20 years. The age criterion, 18 years or older, permitted the women to give consent; furthermore, in Latin American countries as well as in Mexico, once people reach 18 years of age they are treated as adults. Lastly, since this was a study analyzing the experiences of Latino women living with HIV/AIDS, having an HIV or AIDS diagnosis and being willing to talk about it was a necessary, though perhaps self-evident, criterion for inclusion.

The stigma associated with being HIV/AIDS infected in the Latino community had implications for the manner in which participants were invited to participate (Armus, 2003; Frasca, 2005). Latinos are more likely to participate in a study if they are personally approached by someone they know (Cameron, 2000; McQuiston & Flaskerud, 2003) or introduced by a mutual acquaintance. Additionally, Latinos are more likely to participate in a study that is conducted in Spanish, by a Spanish-speaking researcher (A. Korte, personal communication, December 17, 2007). Ultimately, the flyers I created for
this study (see Appendices B1 & B2 [Spanish/English]) were not used. I thought it unlikely that Latino women would even approach the flyers in a public place, much less take one. This suspicion was confirmed by care providers, several of whom were from the Latino community.

I recruited participants by first making contact with medical care providers whose patient population was likely to include Latino women. Either by email or telephone, I contacted the person at each agency or clinic who was the most likely conduit to potential participants; in two cases, I went to the agencies in person to make appointments to meet with them. Ultimately, my meetings were with the directors of programs or clinics and with the person serving as interpreter for the Spanish-speaking clients. I introduced myself by providing personal information that was authentic and likely to give me credibility, and that let them know who they would be entrusting their clients/patients to. The governing body of each agency then had to grant permission for participants to be contacted about participating in the study; only then could agency personnel begin the process of contacting potential participants.

The Spanish-speaking staff member at each locale contacted prospective participants while keeping in mind my instructions that this was to be truly an invitation to the women, which they were free to decline without fear of repercussions. The women were given my contact information and were asked to call me to discuss participating, or they could give permission for me to call them directly. Whether they called me or vice versa, the conversations started with an introduction, followed immediately by my asking if they understood why I was calling and if they were interested in participating in the study. Everyone I contacted, or who contacted me, agreed to participate.
I also attempted to use snowball sampling. After each of the first five interviews, I invited the participants to ask other Latino women who were also living with either HIV or AIDS to call me if they would like to discuss participating in the study, and I left index cards with my contact information. No one was recruited in this fashion. By that time, it was also clear that a sufficient number of participants approached through the agencies would agree to participate.

Sample size in qualitative research is governed by “general suggestions” (Creswell, 2007, p. 126), and the actual number of participants is determined by the needs of the study. According to Creswell, sample size in narrative inquiry varies and can be as few as two or three participants. More important to this study was that participants represented a range of Latino women living with HIV/AIDS. Ultimately, 10 Latino women agreed to participate in the study and all 10 were interviewed. However, due to equipment malfunction, the data of only nine of the participants were used. The interview with the tenth participant did not properly record, and the field notes I took did not generate sufficient data to include in the study.

The interviews with the nine participants in this study took place between April and August of 2008. Initial interviews lasted between 50 and 75 minutes; in-person follow-up interviews with six women lasted 20 and 45 minutes, respectively; telephone follow-up interviews with two other women lasted, on average, 25 minutes each; and one participant requested the follow-up interview be via email at her request. The typed transcripts in English totaled 316 pages, approximately the same number of pages as the corresponding Spanish transcripts. In addition, there were one to two pages of typed, single-spaced field notes per transcript.
The women ranged in age from 23 to 48 years old; four were in their 20s, three in their 30s, and two in their 40s. All came from South America, Central America, or Mexico. All the women were born and raised as Catholics. Four of the women now describe themselves as “evangelical Christian,” one has adopted her husband’s Baptist religion, and the remaining four continue to be Catholic. Whatever their denomination, religion in one way or another plays an important part in each of their lives.

In terms of education, two of the women have college degrees, two went to school through the ninth grade (the most common ending point in the countries represented in this study), two completed the eighth grade, and the remaining three had three or fewer years of education. Seven of the women are married and have children; two are single and have never had children, though both currently have boyfriends. None of the women had any education regarding HIV or AIDS prior to becoming infected. All described themselves currently as being of a low socioeconomic status; only two were of a higher socioeconomic status either prior to coming to the U.S. or prior to becoming either HIV infected or diagnosed as having AIDS.

Data Collection

Bogdan and Biklen (2007) and Merriam and Associates (2002) described three major sources of data: interviews, observations, and documents. This study used interviews and informal observations as the sources of data.

Interviews

Modeling the work of Bogdan and Biklen (2007), Creswell (2007), and Merriam and Associates (2002), I conducted semi-structured interviews. While the questions were prepared in advance, as required by good research practice as well as by the Institutional
Review Board at the University of Georgia, there was no fixed plan, order of questions, or exact wording for the questions. The initial questions were broad in order to elicit the participants’ experiences without predefining the content of our interactions. Several interviews required additional probing questions to encourage more in-depth responses and to explore, when possible, topics within specific contexts in a more substantive way (Bogdan & Biklen; Creswell; Merriam & Associates). Participants in two interviews simply did not give extended responses, no matter how many probing questions I asked or in what manner I asked them. A third interview started out similarly, but ended with the participant opening up and providing more in-depth responses.

Interview questions were designed to explore the participants’ HIV/AIDS experiences. The aim was to privilege the emic perspectives, particularly with respect to the definition of critical concepts relative to the experience of being HIV positive or living with AIDS. Previous studies seeking effective interventions for this population were prescriptive in nature; they relied on etic definitions of critical concepts, based on behaviors or beliefs as described by an observer. In contrast, this study sought to “give voice” to Latino women themselves. Interview questions (see Appendices C1 & C2 [English/Spanish]), therefore, covered the following general topics: (a) Latino women’s lives in their native countries and their subsequent immigration to the U.S.; (b) the experience and meaning of being HIV/AIDS infected; (c) how the participants made sense of the experience of living with HIV/AIDS; and (d) socio-demographic, as well as other, factors that influenced their experience of being HIV/AIDS infected.

I conducted two interviews with each participant: an initial interview and a follow-up interview. Initial interviews ranged from one to one and one-half hours, and
the location and language choices were made by the women. In every case the participants chose to have the interviews conducted in their homes, and in Spanish. Even Marisol, who has been in the U.S. for almost 20 years—the longest of all the participants—asked to have the interview conducted in Spanish. She speaks minimal English and said, proudly, “[Spanish] is the language of my birth, where I’m from and it is part of who I am; I’m also just more comfortable speaking in Spanish.” Follow-up interviews, conducted in a similar manner as the initial interviews, lasted from 30 to 45 minutes except for two that were done by telephone, which lasted 15 to 20 minutes. The time between initial and follow-up interviews varied from three weeks to two months.

All information provided to the participants, including consent forms (Appendices D1 & D2), opening statements (Appendices C1 & C2), and information about resources were available in both Spanish and English; participants elected to use only the materials written in Spanish. Prior to beginning the interviews, they signed a consent form, after which I made the opening statement and gave them an opportunity to ask questions. At the close of the interview I provided time for debriefing, without recording this part of the conversation. I again gave them an opportunity to ask questions about the study, me, or anything else they wanted to know more about. I provided them a list (Appendices F1 & F2) of counseling resources should they need support as a result of their participation. In the interest of full disclosure, I should add that while the resources I gave them are legitimate and available, realistically the participants had ready access to only one person: a Spanish-speaking counselor working for a local HIV/AIDS counseling and advocacy agency. The other resources were either too costly or required transportation that the women did not have. Lastly, I gave each participant a $40 honorarium in the form
of a Wal-Mart gift certificate, as Wal-Mart was the store most favored by the participants and most convenient to their homes.

Interviews were digitally recorded and transcribed verbatim by a professional transcriptionist/translator who produced transcripts in both Spanish and English. I first read the Spanish transcript while listening to the digital recordings, corrected any transcription errors, and filled in the blanks. Next, I read each English language transcription while listening to the digital recording, again correcting any transcription errors and filling in the blanks. I then repeated the process, this time correcting any translation errors; this was particularly important as a poor translation can change the meaning of words, leading to compromised data and thus to mistaken interpretations.

In addition, within 24 hours after each interview I listened to the recordings of the interviews, familiarized myself with the data, and made timely adjustments in my interview style. One such adjustment, suggested by my major professor, involved making sure my questions were more open-ended and asked in such a way so as not to “lead” the participant to a particular answer. Lastly, the English language transcripts were used as the source of supportive data for findings. While providing data in both Spanish and English might have better supported its authenticity, particularly for readers with Spanish-language proficiency, doing so would have made this document excessively long.

Informal Observations

Observation is one of the major methods of data collection. The researcher’s role in this method ranges from being a complete observer, and thus unseen by those being observed, to being a part of the group being observed, and as such participating in the
phenomenon under study (Merriam & Associates, 2002). Another level of observation is more informal and conducted in tandem with an interview, which is the method I chose for this study. Keeping in mind the dictum that “everything is data” (Baumgartner, 2000, p. 98), immediately after leaving a participant’s home and before driving home, I stopped to create field notes that recorded my observations and impressions during the interview. I also noted the names of all who were present during the interview, as well as the respondent’s presentation, affect, tone of voice, and facial expressions. After listening to the recording, I expanded the field notes by adding analytic impressions.

The field notes also included three consultations I had regarding two of the interviews. In one case, I placed a call to a professor at the University of Texas at Austin (E. Pomeroy, Personal Communication, June 5, 2008), whom I knew had engaged in research similar to mine. We discussed how best to manage information that, while critical to the analysis, had the potential to reveal information about a respondent’s immigrant status. I also called a Mexican-American doctoral student with whom Dr. Pomeroy works, who is also addressing issues of potentially revealing participants’ immigrant status (Y. Aguilar, personal communication, June 8, 2008). The consultations resulted in a decision to include all data pertinent to participants’ narratives and critical to the analysis, while avoiding, to the extent possible, directly referring to their immigration status. We determined that this approach would not result in harm to the participants, all of whom participated anonymously; documentation indicating their identities was destroyed.

I consulted with a third individual, former professor and Mexican-American scholar Dr. Alvin Korte, who lives and works in New Mexico, via email (A. Korte,
Personal Communication, May 28, 2008). This consultation focused on participants’
allusions to certain concepts, for example, machismo and gender roles, without referring
to them by name. Dr. Korte offered insights and suggestions regarding how to address
this dynamic; I refer to this material in the data analysis section that follows. This
consultation also became part of my field notes.

Data Analysis

It is important to keep in mind two major points when undertaking narrative
inquiry. First, the participants’ perspectives are of primary interest. Second, the
participants’ narratives are impacted not only by the context in which they are told, but
also by the context in which the related experiences are lived (Merriam & Associates,
2002). Awareness of context is, therefore, not just important but critical to data analysis,
given that the aim is to understand participants’ experiences.

Furthermore, narrative inquiry may also be informed by the researcher’s discipline
and theoretical perspective. Depending on the perspective taken or the context within
which the narrative was elicited, the same narrative can reveal various stories.
Nevertheless, whatever analytic lens is applied, discipline-specific perspective employed,
or collection method used, “all revolve around an interest in biographic particulars as
narrated by the one who lives them” (Chase, 2005, p. 651).

The HIV/AIDS narratives provided by the participants were powerful, evocative,
and capable of standing on their own. Nonetheless, interpretation was necessary because
while “verbal . . . expressions of meaning given by the individuals being studied . . . are
windows into the inner life of a person,” the openings are “filtered through the glaze of
language, signs, and the process of signification” (Denzin, 1989, p. 14). I did not assume
that the narratives would be presented in a uniform or linear fashion; I believed that each woman would have her own reasons for choosing which details she considered important enough to include (Denzin; Johnson Bailey, 1994). My interest was in understanding how each woman understood her life as a whole, particularly with respect to becoming infected with HIV or living with AIDS. Therefore, though I imposed some order and interpretation upon the data presented in the narrative summaries, I found little in the data that was not pertinent to the study.

The overarching analytic methodology employed in this study was Polkinghorne’s (1995) narrative configuration approach, complemented by Denzin’s (1989) interpretive biography method of analysis. In addition, Chase’s (2005) analytic schema provided the rationale for analyzing individual narratives first and conducting comparative analysis second (see Figure 1).

![Figure 1. Analytic schema. Individual analysis→1 Comparative Analysis→2 (Chase, 2005)](image-url)
Basing his analytical methodology on Jerome Bruner’s (as cited in Polkinghorne, 1995) work on cognition, Polkinghorne referred to narrative studies as being either narrative-type narrative inquiry or paradigmatic-type narrative inquiry. In the former type, “events and happenings are gathered as its data and [it] uses narrative analytic procedures to produce explanatory stories” (Polkinghorne, p. 5). In paradigmatic-type narrative inquiry, stories are gathered as the data and methods are used to “produce taxonomies and categories out of the common elements across the database” (p. 5). In other words, the researcher either begins with the narrative data provided by participants and creates a story, or begins with the participants’ stories and delineates themes or other taxonomies found within them. I employed both of the analytic types described by Polkinghorne, imposing each one distinctly, as will be described later in this section.

Denzin’s (1989) interpretive biography method is based on his view of personal narratives. That, he largely views people’s lives as a product of the challenges they face in their daily experiences of living, experiences that are grounded in “family beginnings” (p. 17). In the case of the participants in this study, HIV/AIDS presents one of their central challenges. Denzin’s approach provided a framework for examining the participants’ narratives, directing my attention toward the “influence and importance of gender and class, family beginnings, starting points, objective life markers, real persons with real lives, and turning point experiences (meaning those events, often sparked by epiphanies, that cause someone’s life to change course)” (p. 17). With this information at hand, I was almost ready to begin the analysis.

Chase’s (2005) analytic schema, sometimes referred to as an analytic strategy, also influenced the form used in this study, as I adapted Chase’s suggestion that
narratives be analyzed individually before comparative analysis is undertaken. In analyzing the data, I first located major themes within individual narratives, and then compared those themes across narratives. Chase’s approach calls for beginning with the narrator’s voice, as heard during the interview, when analyzing elicited narratives. Thus, I extended the narrator-listener relationship into the analysis, which in turn provided support for the assertion that the narrative summaries are a co-creation between the researcher and each respondent.

Data analysis began with the verbatim transcription of interview recordings as described earlier in this section. I then reviewed each transcript, utilizing Denzin’s (1989) biographical lens, and making notations in the wide, numbered margins as I worked through each narrative. Specifically, I kept in mind Denzin’s postulate that narratives are expressions of people’s life experiences, and as such they demonstrate the influence of constructs such as gender, class, and culture. I looked for themes that reflected these constructs in each narrative and catalogued my findings. I repeated this process until I had created a three-part profile for each respondent: a demographic description, a narrative summary, and an analytic commentary. These profiles are presented in Chapter IV.

The first part of each participant’s profile, demographic descriptions, are comprised generally of the more objective markers, though where appropriate or where they add coherence to the material, some subjective data were also included. The material in this section represents “unique and general features of the life” (N. K. Denzin, 1989, p. 56) of each woman and elucidates the context of each woman’s life, and thus of her HIV/AIDS narrative.
The second part of each woman’s profile, the narrative summaries, represent the first major level of data analysis and were constructed using Polkinghorne’s (1995) narrative cognition model of analysis, i.e., narrative-type analysis. Having viewed the data through Denzin’s (1989) biographical lens, I identified “key, critical points about the life in question” (N. K. Denzin, p. 19). In addition, I identified biographical particulars the participants considered to be important and “configured [the factors] into a unified whole in which each element was connected to the central purpose of the action” (Polkinghorne, p. 11), or the story’s denouement. These configurations are presented as “stories” that are explanatory in nature, wherein a “plot” (p. 8) serves as the organizing principle. The plot also functions as a selection mechanism for the critical events and actions, or what Denzin (1989) referred to as structural elements (i.e., gender-, culturally-, or socioeconomically-related factors) in the women’s lives that are pertinent to the story’s denouement, which in this case is their becoming HIV positive or being diagnosed with AIDS. Further, it is this “emplotment” that imposes the time element of the stories, namely, the beginning, middle, and end (Polkinghorne, 1995, p. 5). Lastly, with respect to the summaries, I organized the data so that it suggested the relationship between the elements and their impact, either individually or as a confluence of factors, on the participants’ lives, and particularly on their HIV infection or AIDS diagnosis narrative.

I verified the English-to-Spanish translation of the summaries with all but one of the participants. I read three of the summaries to the women by telephone, presented four in person, and sent one via email at the participant’s request. The participant to whom I did not present a final narrative had moved back to Mexico by the time I completed the process. I nevertheless included her narrative, as she was one of the women whom I saw
in person for a follow-up interview. During this particular second interview I clarified information already provided, as well as posed questions again to fill in data that I had missed as a result of an equipment malfunction. Furthermore, discovering at that time her intention to return to Mexico, I verified my understanding of what she had originally narrated.

The third and last part of each profile, an analytic commentary on each woman’s narrative, represents the second level of analysis of the data. As Polkinghorne (1995) recommended, I returned to the original transcripts, that is, the participant’s own words, to carry out the analytic procedures used to generate the commentaries. I re-read each transcription, including all the notations in the margins, isolating the major themes, major events, and other happenings pertinent to each woman becoming HIV positive or being diagnosed with AIDS. What was written was “an analytic abstraction of the case”—something I repeated for each woman interviewed.

The data analysis described up to this point focused on individual narratives, for the purpose of making the whole of each respondent’s HIV/AIDS story known to the reader. The third, and final, level of the analytic schema extended individual analyses by identifying themes found within narratives and comparing them across transcripts. To do so, I used Polkinghorne’s (1995) paradigmatic analytic procedures, i.e., the analysis of narratives method, to “produce taxonomies and categories out of the common elements across the database” (p. 5). The research questions guiding the study were then used to compile and organize the findings. This analysis highlights the inter-related factors comprising the contexts within which the nine participants live their lives. Finally, the analysis explicates the ways in which the participants’ day-to-day lives, and the existence
of HIV/AIDS within them, are constrained by the reality in which they live. This third level of analysis is presented in Chapter V.

Validity and Reliability

Rigor in research is ensured through the principles of validity and reliability (Merriam & Associates, 2002). Rigor is necessary for findings to be believed, trusted, and relied upon. The approaches I used to ensure rigor are described below.

Internal Validity

Internal validity is the principle of congruence between what the researcher claims to have found and the reality of the situation (Merriam & Associates, 2002). How validity is addressed depends at least partially on the assumptions made and questions asked by the researcher (Merriam, 1993). In this study, ensuring internal validity necessitated keeping in mind the assumption in qualitative inquiry that there are “multiple, changing realities” and that “individuals have their own unique constructions of reality” (Merriam & Associates, p. 25). Qualitative researchers do not seek to measure a single, distinct reality. Hence, because I was the data collection instrument, my biases, my choice of questions and manner of posing them, and my ability to listen all potentially influenced the data I collected, how I interpreted it, and what sense I made of it—which, of course, raised the question of how to ensure internal validity.

Of the various strategies available to address the issues of internal validity, I used the four that are often referred to as principal approaches: Triangulation, peer review, member checks, and exposition of researcher subjectivity. Triangulation is the best known of the techniques (Creswell, 2007; Merriam & Associates, 2002) and its use in this study was modeled on Mathison’s (1988) conceptualization of the strategy. As
defined by Mathison, triangulation is typified by one or more of the following techniques: employing more than one method to both collect and analyze data, using multiple data sources, multiple levels of data, or multiple researchers. I used three of the four techniques.

I collected data through interviews and enhanced it with data gleaned from the informal observations accompanying the interviews. The illness narratives produced were analyzed using Polkinghorne’s (1995) narrative- and paradigmatic-type analysis, first individually and then in the aggregate, as suggested by Chase (2005). Further, I applied Denzin’s (1989) biographical lens during data exploration and analysis, identifying participants’ biographical particulars and what they considered to be the relevant contextual aspects of their lives. I was especially interested in identifying those particulars that played critical and/or enduring roles in the respondent’s HIV/AIDS narratives.

Using multiple data sources obtained from nine Latinas living with HIV/AIDS, I “made sense of the social phenomena” (Mathison, 1988, p. 15) that comprise their experience, as viewed from the emic perspective. Further, employing existing empirical data, my store of data regarding HIV/AIDS prevention and treatment, and the elicited illness narratives themselves—that is to say multiple levels of data—I expanded triangulation, thus ensuring greater internal validity.

To further strengthen internal validity I employed peer review. I enlisted the help of four peer reviewers including a Mexican-American scholar (a former professor and now colleague), a researcher at the CDC, a professor at Portland State, and a medical clinic staff member who works with people with HIV/AIDS, including Latinos. The
reviewers examined various portions of the data and were asked to determine whether the findings and interpretations were credible, that is, whether they were congruent with the data.

I also conducted member checks to safeguard internal validity. They consisted of presenting my findings to the participants and eliciting their opinions as to whether the results seemed reasonable, thus amplifying the likelihood that my results accurately represented the participants’ views of their experiences (Reinharz, 1992). Furthermore, as I conducted the interviews I checked with the participants to see if my understanding of what they were conveying rang true. I also shared preliminary findings with three of the participants and asked if the results seemed credible, in addition to verifying their individual narrative summaries.

Finally, I made known to the reader my theoretical framework and assumptions, and presented a subjectivity statement setting forth my personal biases, all in furtherance of internal validity. Thus, as Merriam and Associates (2002) suggested, I made my relationship to the study transparent, allowing readers to see how conclusions regarding the data may have been influenced by my perspectives.

External Validity

External validity is the degree to which research results can be applied, generalized, or transferred to other situations (Merriam & Associates, 2002; Trochim, 2006). My interest, however, was “not to find out what is generally true of the many” (Merriam & Associates, p. 28), but rather to understand “the particular in depth” (p. 28). In this sense, external validity addresses whether the specifics learned in one situation can be used in subsequently encountered situations that are similar, particularly with respect
to their context. Making this determination is left up to the reader, an approach referred to as “user generalizability” (p. 29).

There are two strategies most commonly employed by qualitative researchers in deciding whether study results are applicable to the situations with which they are working. The first is employing multiple sites, cases, or situations and making a special effort, whenever possible, to include those who represent variation. The second is providing sufficiently detailed information regarding the population and situation being studied, and thoroughly describing both the research context and assumptions central to the research. Meeting these two conditions increases the likelihood that readers will detect similarities with their own situations, and that they will identify a greater range of situations for which the study findings might be applicable (Merriam & Associates, 2002).

I employed both strategies—multiple cases and rich, thick description of the study and its particulars. While the number of cases considered, nine, was relatively speaking small, in narrative inquiry an acceptable number of participants can be as low as one. Therefore, it can appropriately be said that there were multiple cases. Demographic variation was achieved in current residence, country of origin, and the respondent’s age. The study sample was representative of both urban and rural areas in the state in which participants currently live; participants emigrated from Central America, South America, and Mexico; and participants ranged from 25 to 48 years of age.

As generalizability is left up to the user, and statistical generalizability is not the goal of qualitative research, the second strategy took on greater import. Therefore, to assist readers in making connections with this study and its results, I presented each
respondent’s HIV/AIDS narrative in full, rich detail. In addition, the circumstances and contexts in which those stories are grounded were similarly described. The fullness and richness of the descriptions will help readers identify congruence between the present study’s situation and their own, thus fostering generalizability. Lastly, external validity was enhanced by locating study results within the context of previous research and determining to what degree my results were corroborated by previous research (Baumgartner, 2000).

Reliability

Qualitative research is concerned with human beings and their behavior, which is almost never static (Merriam, 1993). More to the point, qualitative researchers want to know and understand how individuals perceive the world. Since no two individuals see the world in exactly the same way, getting different results over time does not discredit the results; instead, it indicates the variability of individual perception (Merriam). Therefore, unlike quantitative researchers, who are concerned with whether or not two researchers independently studying the same topic or population will get the same results, qualitative researchers focus on “whether results are consistent with the data collected” (Merriam & Associates, 2002, p. 27, italics in original).

Qualitative researchers also ask whether their conclusions make sense to others, and whether the readers or consumers of the research concur that the results are consistent and dependable (Merriam & Associates, 2002). Strategies available to ensure reliability in qualitative research include triangulation, peer review, disclosure of researcher position or bias, and an audit trail (Merriam & Associates). I used all four strategies; the first three techniques were discussed under internal validity.
The fourth strategy, an audit trail, consisted of recording in detail all aspects of the study, particularly how data collection was undertaken, how data were analyzed (including categories derived), and how decisions were reached throughout the study (Merriam & Associates, 2002). I began the audit trail by recording the process of applying for study approval from the university’s institutional review board. I included my thoughts, hunches, and ideas about the data collected during interviews, data collection issues, and comments and assessments of the study processes overall. Lastly, I recorded all the contacts I made during the study. Essentially, I created a “trail of crumbs” that led from the beginning of the study to the results.

Limitations of the Study

In detailing this study’s limitations, it must be stated that sampling was driven by the desire to learn in depth and detail about the experience of particular participants, in this case Latina women and their experiences of living with HIV/AIDS. Furthermore, an overriding interest was the impact of culture on that experience. In this case, therefore, purposeful sampling required that the participants be first- or second-generation immigrants, preferably the former. Nevertheless, the impact of the study findings is limited as they reflect the experiences of nine Latino women living with HIV/AIDS—a relatively small study sample.

Further limitations were engendered by other sample characteristics. One is that the sub-group of Latino women who comprise the sample, by virtue of being first-generation immigrants, is not representative of all women or even of all Latino women living with HIV/AIDS. Another limitation is that all the participants are from one Southeastern state, further restricting representativeness. Lastly, with respect to sample
characteristics, there was little variation in participants’ socioeconomic status or educational backgrounds.

Finally, study findings are potentially limited by the lack of time and money available to do more than one initial and one follow-up interview with each respondent. Latino women are relationship-oriented in general, but especially so when it comes to sharing intimate information (Gonzalez-Lopez, 2005). Therefore, while the women were open with me and treated me as someone they could confide in, additional interviews over time might have produced more complex data than that which I elicited.

Researcher Orientation/Bias

A critical aspect of conducting qualitative research is ensuring a study’s internal and external validity, both discussed in the previous section. Achieving this task is largely dependent on establishing the credibility or verifiability (Creswell, 2007) of the study and its results. One source of credibility is the transparency of the researcher’s biases and assumptions, or subjectivity, given the researcher’s potential to impact a study (Peshkin, 1988). Subjectivity, according to Peshkin, is akin to wearing an article of clothing that cannot be removed.

In retrospect, much of my life appears to have been preparation for taking on this exploration of the HIV/AIDS narratives of Latino women, starting with my Latino heritage. Born of Chilean parents and raised in Santiago until the age of 10½, my parents’ divorce brought me to the U.S. My mother came to this country on a tourist visa which she overstayed, thus becoming for a time an undocumented immigrant. Eventually marrying an American citizen, her status in this country was legalized. Having this
potentially strong identification with the women I interviewed afforded some degree of insider status for me with these participants.

Strong and abiding commitments to justice, fairness, service, and the maintenance of culture were gifts from my mother and two Jewish fathers. Although my mother was Catholic, I was raised as a Jew, and Jewish values of “doing good” for others, performing mitzvot (worthy deeds), and promoting justice and fairness were inculcated into my upbringing. My mother’s influence continued with our arrival in the U.S. at a time when it was not terribly hip to be ethnic. Because my mother wanted me to fit in, she downplayed my Latino heritage and culture. In fact, for a long time she forbade my brother and me to speak Spanish at home. In addition, we dropped the commonly used second last name (Hope Espinoza in my case). It was not until 13 years later, when I returned to Chile to visit my biological father, that I realized why I had felt that something was missing for so many years. Culture is a powerful influence that does not easily disappear. Being Latino is something I treasure, and it very much informs who I am.

I was raised in the Bronx, New York, from the age of 10½, went to a state university on Long Island with the benefit of scholarships and loans, and lived and worked in Manhattan for many years. An awareness of and familiarity with the experience of loss began at this point with my mother’s untimely death in 1973. It also engendered the characteristic of “pushing on” in spite of circumstances. I went on to work as a school teacher, a waitress, and a social worker. I lived in New York for 25 years, subsequently moving to Georgia, New Mexico, Washington, and then back again
to Georgia. I have been exposed to diversity all my life, and my experiences have fueled my commitment to liberal, feminist, non-racist politics.

Late 1979 found me living in New York when cases of Kaposi’s Sarcoma (KS), initially called “gay cancer”; cases of Pneumocystic Carinii Pneumonia (PCP); and other immune deficiency illnesses surfaced. When mainstream news reports of the illnesses began in 1981, and the CDC published its first Morbidity and Mortality Report, GRID (Gay-Related Immune Deficiency) was the initial acronym given to the compendium of illnesses with which gay men were being diagnosed, followed by ARC (AIDS-Related Complex), and finally AIDS (Acquired Immune Deficiency Syndrome).

No matter what it was called, AIDS decimated the gay male community. Following the lead of others in the gay community, Robert, my roommate and longtime, intimate friend, and I staffed education tables in the street, attempting to raise awareness of the deadly virus. I also trained as a buddy, a person who provided all types of support to those infected. At the same time, I began developing a program for babies with AIDS (known as boarder babies); these babies were living in hospitals due to the lack of homes to which they could be discharged.

In October of 1986, Robert was diagnosed with AIDS and 10 months later died, at home, in my arms. My response was to become increasingly involved in the AIDS community, first as a way of dealing with the overwhelming loss of this young man who had become central to my life, and then to address that “something has got to be done” force that ultimately energized me. Two years later, and two weeks prior to starting a Master’s in Social Work (MSW) program, my youngest sister was diagnosed as HIV positive. I left New York, eventually becoming a social worker.
While my social work career has not been as an “AIDS social worker,” it has always revolved around physical and mental health and, almost serendipitously, often with Latino women, children, and sometimes men, where my Latino heritage and native Spanish speaking ability were strengths. When I began thinking about potential dissertation topics, a confluence of work and life experience appeared to frame an ideal issue on which to focus my energy and commitment. A literature review helped narrow my focus to HIV/AIDS and Latino women.

When HIV initially surfaced, gay men and their willingness to speak up and demand action, sometimes at great personal sacrifice, were a critical, motivating force in health care, social services, and political spheres. Often with no apparent success, they demanded to be heard and did not stop until they succeeded. In contrast, whether for personal or culturally-defined reasons, or due to their perceived need to hide because of their immigrant status, Latino women do not publicly speak out. They are one of the fastest growing populations currently impacted by HIV/AIDS, and they are not heard. When Latino women do speak up, neither their voices nor their stories are privileged. Instead, what little research has been done is based on what others, usually non-Latinos, identify as their needs, and is often based on stereotypical notions of Latino culture. It is from this frame and worldview that I approach this study, ever mindful that it may not be the view of the women whose narratives have been elicited.
CHAPTER IV
FINDINGS: PARTICIPANT PROFILES

Polkinghorne’s (1995) narrative-type analytic model was adapted to create the narrative summaries presented in this chapter; his paradigmatic-type model was used for the analytic commentaries. A third, comparative form of analysis will be presented in Chapter V.

Presenting the participant profiles in this structured manner provides the reader with an overview of each woman’s demographics, a description of her life from the emic perspective, and an analysis (from the researcher’s perspective) of the intersecting factors that resulted in the participant’s HIV infection. I seek to present each HIV/AIDS story as an aggregate construction, before analyzing the similarities and differences between the stories (Chase, 2005) in the next chapter. It is important to note that each participant’s experience was unique to her; each has an individual story to tell. The reader may notice more similarities and differences between the women which could occur as repetitive. However, such repetition is occasionally necessary to clarify the connections between objective (biographical information provided by the participants) and subjective (researcher comments/analysis) data.

The demographic profiles include the following descriptive information: pseudonym, age, marital status, socioeconomic status (SOS), number of children, country of origin, and language spoken. Other data, objective or subjective, is provided as appropriate. The profiles, starting with participants’ demographic information, set the
stage for the participant’s story, providing contextual information, and other clues that will allow for a more in-depth, more comprehensive understanding of the participants and their experiences of living with HIV/AIDS.

The narrative summaries, representing the first level of data analysis, highlight influential and pertinent aspects of the participants’ lives with respect to their experiences of living with HIV/AIDS. The narratives are explanatory in nature. They integrate critical events and actions into an organized whole—a story whose denouement is the woman’s HIV/AIDS status. The organizing principle in each narrative is “emplotment” (Polkinghorne, 1995, p. 7), giving contextual meaning to individual events by using a conceptual scheme. Included in the stories are elements that provide a general sense of who the participants are, identify critical events in their lives, and reveal what Denzin (1989) refers to as biographic particulars. These elements contribute to the stories’ denouement by completing the context and enriching the content of the participants’ narratives (N. K. Denzin, 1989; Polkinghorne, 1995).

The analytic commentaries complete the participant profiles and represent the second level of data analysis. Each explores the biographical particulars thought to have contributed to the participant’s infection with HIV and comprises the first part of Chase’s (2005) two-part narrative strategy, as outlined in Chapter III. Adapting the biographical lens posited by Denzin (1989), I identified emergent themes as well as gender, cultural, and socioeconomic influences affecting the participants’ lives. In addition, I highlighted events or experiences that were influential in shaping participants’ life, what Denzin refers to as turning point moment (p. 22). Such paradigmatic analysis used the original
transcripts, i.e., the participants’ words, rather than summarized or emplotted narratives that include the researcher’s voice.

A summary of participant demographic information is presented in Table 1. I assigned the pseudonyms by looking for Spanish names whose meaning most fit my overall impression of each woman; participant data, including the participant profiles, are organized in the order in which the participants were interviewed.

Pilar

Demographic Information

Pilar is a married, 41-year-old woman from Peru. She has lived in the U.S. for six years but does not speak enough English to carry on a significant conversation. She is a college graduate who worked as an accountant in her country of origin. She does not currently work so she can stay home to care for her disabled child. Pilar describes their SES as low-income; the family’s main source of income is her husband, and they receive some disability assistance for the daughter. The family’s income is reduced by child support that her husband pays for two children from former marriages. Pilar and her husband have access to HIV medications and HIV-related health care, but the only family member with health insurance is their daughter, who has Medicaid coverage.

Pilar is a petite woman with high cheekbones, cafe-con-leche colored skin, and almond-shaped eyes. She lives in a cozy, clean apartment containing many signs of a toddler’s presence. When I arrived at her apartment, her daughter greeted me at the door alongside her mother. The child was playful and independent, rarely making demands for Pilar’s attention during the interview. Pilar’s husband was at his usual Friday evening ball game and did not return while I was there.
Table 1

Participant Demographic Summary

<table>
<thead>
<tr>
<th>Name</th>
<th>Age</th>
<th># of Children</th>
<th>Marital Status</th>
<th>Country of Origin</th>
<th>Religion</th>
<th>Status*</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pilar</td>
<td>41</td>
<td>1</td>
<td>M</td>
<td>Peru</td>
<td>Evangelical Christian</td>
<td>HIV-positive</td>
</tr>
<tr>
<td>Carmen</td>
<td>27</td>
<td>1</td>
<td>M</td>
<td>Mexico</td>
<td>Baptist</td>
<td>HIV-positive</td>
</tr>
<tr>
<td>Paz</td>
<td>23</td>
<td>3</td>
<td>M</td>
<td>Mexico</td>
<td>Catholic</td>
<td>HIV-positive</td>
</tr>
<tr>
<td>Gloria</td>
<td>38</td>
<td>5</td>
<td>M</td>
<td>Mexico</td>
<td>Catholic</td>
<td>HIV-positive</td>
</tr>
<tr>
<td>Valencia</td>
<td>27</td>
<td>4</td>
<td>M</td>
<td>Guatemala</td>
<td>Catholic</td>
<td>HIV-positive</td>
</tr>
<tr>
<td>Isabel</td>
<td>27</td>
<td>2</td>
<td>M</td>
<td>El Salvador</td>
<td>Evangelical Christian</td>
<td>HIV-positive</td>
</tr>
<tr>
<td>Susana</td>
<td>36</td>
<td>0</td>
<td>S</td>
<td>Peru</td>
<td>Evangelical Christian</td>
<td>AIDS</td>
</tr>
<tr>
<td>Marisol</td>
<td>48</td>
<td>7</td>
<td>W</td>
<td>El Salvador</td>
<td>Evangelical Christian</td>
<td>HIV-positive</td>
</tr>
<tr>
<td>Mercedes</td>
<td>25</td>
<td>0</td>
<td>S</td>
<td>Belize</td>
<td>Catholic</td>
<td>AIDS</td>
</tr>
</tbody>
</table>

Note: No participant speaks significant English; all began life as Catholics though some have become Baptists or Evangelical Christians. *The source of all participants’ HIV infection was heterosexual contact.

Neither Pilar nor Antonio has documented legal status in the U.S., though their daughter is a citizen. As a result of her legal status, Pilar does not have a driver’s license, thus she generally only drives to attend her own or her daughter’s medical appointments.

Pilar appeared slightly nervous at the start of the interview, though after a few minutes she warmed up. For an extended period of time, and without prompting other than an initial question, she talked easily and steadily. Pilar’s narration was often accompanied by either an intense or sad affect, though she also smiled at many points throughout the interview.
Narrative Summary

Pilar was born the second of four children to a middle-class family in Peru. She was raised “in a good home” and was taught to value education, abide by Catholic religious tenets, and respect her cultural heritage. Pilar reported that she was raised “very strictly,” and that her mother did not discuss matters of sexual intimacy with either her or her siblings. When she went out on dates, “about once a month,” she was expected to let her parents know who would pick her up, where she was going, and who would bring her home. This pattern continued until she met her novio (fiancé). Pilar learned what she knew about relationships with men, including sexual intimacy, from her sister and friends. Her mother, she stated, “got red just at seeing two people kiss” on television shows or movies. She knew from her Catholic upbringing that she was expected to be a virgin when she got married.

At the age of 28 Pilar became betrothed, which to her meant that she could be sexually intimate. She did not discuss this with anyone, including her novio, nor did she discuss using protection (i.e., birth control or STD prevention). Eventually Pilar married, and she and her husband moved into their own home.

Pilar continued to work; her husband co-owned a business. His business failed, and he was left with debts he could not repay. Furthermore, already in debt to everyone he knew, Pilar’s husband was unable to borrow money to repay his business debts. The only solution he could see was to go to the U.S. to work, which he did. Expecting her husband to return fairly soon, and so that she “would be there if he called and not have to worry,” Pilar stayed in their home, rarely leaving except to work. When he did not return to Peru as quickly as expected, and with her husband’s permission and encouragement,
Pilar moved back in with her parents. For a year her husband called at least once a week. One evening their call ended as usual, with him saying he would talk to her the following week, but she never heard from him again. Repeated calls to his telephone number in the U.S. and to his parents yielded no information.

A college friend of Pilar’s who was living in the U.S. at the time invited her to come for a visit. She traveled to the U.S. for a three-month visit, which went well, though on her return to Peru, Pilar nevertheless felt depressed, lonely, and at a loss for what to do. With encouragement from her friend and her brother, Pilar once again traveled to the U.S. for a visit, with no plans to stay permanently. Nevertheless, she delayed her return to Peru as she met new people and greatly enjoyed her time with them. The result was that Pilar lost her job in Peru and subsequently decided to make a new life for herself in the U.S. She found a job in a factory, where Pilar met Antonio, the man who she wed after divorcing her first husband.

Antonio wooed Pilar with his charm. They became intimate without having any conversations about using condoms or any other type of protection. Eventually she accepted his marriage proposal. However, before they were married, Antonio was hospitalized with what initially appeared to be appendicitis. Instead, he was diagnosed with lymphoma that was sequelae of HIV and qualified him for an AIDS diagnosis. Pilar was tested and found to be HIV positive. Before she could deal with her own health situation, however, she felt that she first had to help Antonio, who was very close to death, get through chemotherapy and start on anti-retroviral treatment. She waited almost two months for her own treatment to commence.
Once Antonio was out of the hospital, Pilar began to feel the stress of their eroding relationship. He began to be verbally, and occasionally physically or sexually, abusive. With the help of a therapist and caregivers at the infectious disease clinic in her community, Pilar learned to cope with her own HIV infection and began developing skills to address Antonio’s behavior. Unfortunately, after a few individual sessions, Pilar’s therapist insisted on joint therapy for the couple. Those sessions gave Pilar the impression that the therapist “was siding with [my husband].” She discontinued therapy. In spite of these issues, Pilar married Antonio, and when medical circumstances allowed, they had a child.

When asked why she would not only marry, but have a child with a man who abused her, Pilar’s response was that she had always wanted to have a family and children. After learning that she was HIV positive, she felt that marriage to Antonio would be her only opportunity to do so. Their daughter is not HIV infected, though she was born with Down syndrome. Pilar is unlikely to leave her husband, even though he is abusive. She has figured out how to “take him down a peg or two” and has “fought back” by denying her husband sexual relations, having decided that sex is what got her into her current medical situation. She takes “solace in God,” believing that “everything has a purpose.” She expends her energies on her daughter, who will always need her because of Down syndrome. Pilar sees her job as making sure her daughter is able to “have some kind of life.”

Analytic Commentary

Pilar’s beginnings, and thus her prospects for a future that would hold all she wanted, including health and economic prosperity, were promising. She was part of a
close, intact family with parents who loved and respected each other and their children. Pilar’s mother, with her father’s support, made sure her children received an education; Pilar earned a college degree and obtained a professional job with health insurance. At the same time, motivated by a combination of cultural and religious imperatives about what it means to be a woman in her country, she looked for and found a man she could marry and have children with. Cultural and religious tenets, however, combined with a change in economic fortune, interfered with Pilar’s plans for herself.

The religious (Catholic) and cultural expectations of Pilar’s upbringing meant that when she married, she was naïve about men and sexual activity, and uneducated regarding the potential health implications of unprotected sexual intercourse, e.g., HIV or other STDs. Her own father was faithful and loving towards her mother, thus Pilar naively expected the same treatment from her spouse. However, getting married led to a series of events which Denzin (1989) identified as the objective/subjective markers of a life, or turning point moments. For Pilar, they are the frame within which her HIV infection occurred.

Pilar’s husband’s failed business venture in Peru led to his travelling to the U.S. to work in order to salvage his economic situation—an event that turned into one of Pilar’s turning point moments. Within a year, her husband disappeared, literally, in the time between two of his weekly phone calls, presumably he started a new life in the U.S. Pilar was left to wonder what happened to him and was confronted with choices about the course her life would now take.

Adrift, depressed (by her own admission), and encouraged by a friend living in the U.S., Pilar chose to leave her life in Peru behind and travel to the U.S. Unbeknownst
to her, however, Pilar’s upbringing had ill-prepared her for the life that awaited her. She
did not speak English, had insufficient funds, was emotionally drained as a result of her
husband’s abandonment, had no significant knowledge of the social and medical crisis
created by HIV/AIDS, and did not consider herself to be someone for whom sexual
activity represented risk-taking behavior. When she met Antonio, Pilar’s background and
recent abandonment left her vulnerable to his charm, and he eventually became her
novio.

Pilar’s life in the U.S. has been a series of choices fed by her loneliness,
depression, and vulnerability. Meeting her husband set in motion events that led to
shame, depression, and a sense of defilement. He was, and occasionally continues to be,
physically, emotionally, and sexually abusive, and he infected her with HIV. It is not
clear whether he knew his status, though Pilar suspects he did. Once Pilar knew of her
own HIV infection, she felt the only way to fulfill her destiny as a woman, to marry and
have a child, was to stay with her husband. In fact, they married, and when Pilar’s doctor
advised her that being pregnant would not stress her own immune system and that she
was unlikely to pass HIV on to an infant, the couple had a child.

Presently, Pilar is constrained by the politics of immigration in the U.S. and by
the political and sociocultural aspects of HIV/AIDS in her own country and, to some
extent, in the U.S. as well. She cannot travel to Peru even to visit, as she would not be
able to re-enter the U.S. Pilar cannot legally drive due to her immigration status, and she
cannot work due to the responsibilities associated with her daughter’s medical needs.
Furthermore, if she were to go to Peru, her parents and other family members would
certainly find out about her HIV status. While she knows they love her and would most
likely support her, in Peru there is a real stigma associated with being HIV positive, regardless of how one became infected. In addition, it is unlikely that she would be able to afford or obtain her HIV medication in Peru, or provide for her daughter’s ongoing, lifelong medical and educational needs.

How does Pilar survive in her situation? First, cultural imperatives, rather than restricting Pilar, are in this situation the driving force to forward movement, with all that it implies. Her role and responsibilities as a mother supersede all else; of paramount importance are her daughter’s needs, rather than her own or Antonio’s, and her daughter’s well-being. Second, Pilar had an epiphany and a resultant transformation. She realized that she had a “voice,” one with which she could, and does, defend herself against the defilement perpetrated in various ways against her by her husband—as when she was forced to have anal sex, or when they were evicted from their apartment for non-payment of rent while her mother was visiting from Peru. Pilar somehow went from being “mild-mannered,” to being someone capable of being “violent, not physically, but in words.” She is bold in her determination not to be mistreated by Antonio, denies her husband sexual relations altogether, and calls the police if she feels threatened physically. Pilar has had her husband jailed on more than one occasion, and is prepared to do so again. These actions, however, come with a price. She is always on guard against potential violence and, in denying him sexual intimacy, is also denying herself the benefits of adult physical contact.
Carmen

Demographic Information

Carmen is a slim, attractive, 27-year-old married woman from Mexico. She is shy but smiles easily, particularly when she talks about her son and husband. Carmen went to school through the eighth grade. She has been in the U.S. for 11 years and has learned to speak enough English to converse with her husband and seven-year-old son, who are American and speak little Spanish. Both Carmen and her spouse work, though she does so only part time.

The family lives in a double-wide mobile home on a pretty, quiet, and private piece of rural property. As I drove up, a man and young boy in a pickup truck drove away. As Carmen opened the door to let me in, she explained that her husband and son did not want to leave for their fishing trip until I arrived, so they could determine if I was someone she could safely be left alone with; how they made that decision, however, was not clear and I did not ask her to elaborate on the matter.

Carmen’s home was well-kept and tastefully decorated, though the family is clearly one of modest means; Carmen identified the family’s SES as “low-income.” Family pictures adorned the walls, and a hutch contained trophies from various athletic activities. She recounted proudly how her husband or son won each trophy. Although soft-spoken, Carmen quickly warmed to the interview and willingly answered questions. At times her answers were short unless asked for father detail. She did not rush through the interview, but it was clear that she had strong feelings about several aspects of her circumstances and situation, exhibiting a sad affect or crying at times as she narrated her story.
Narrative Summary

Carmen is the oldest of nine brothers and sisters. Until the age of 14 she lived in a small, rural town on a rancho, a rural plot of land that supports income-generating activities such as farming and raising livestock. In Latin America and Mexico ranchos exist on a much smaller scale than is called to mind by the English word “ranch.” Carmen worked in the fields alongside her father, who taught her how to plant corn and beans. The family’s impoverished circumstances, however, necessitated her father’s periodic travel to work the agricultural fields in the U.S., leaving Carmen’s mother to tend their land.

While her mother worked in the fields, Carmen’s job as the oldest female child was to help with the household chores and take care of the younger children. After school she also helped her mother in the fields. Carmen could see that her mother not only worked hard outside the house, but also, “with so many little kids, feeding everyone and cooking for everyone,” worked hard inside the house—even with Carmen’s help. Although her parents encouraged her to stay in school, saying that it “would be good for her,” at the end of eighth grade Carmen dropped out to stay home full time and work alongside her mother.

Carmen had a traditional rancho upbringing; her parents were strict, Catholic, and did not allow her to date until the age of 16, and then it had to be in “front of . . . [my] parents.” While Carmen’s mother was “warm and loving and talked to us all the time,” she never had conversations with her children about sexuality or relationships with men. However, through inexplicit church teachings and parental expectations, Carmen understood that she was to remain a virgin until she married.
Carmen had several brothers, sisters, and maternal aunts and uncles already living in the U.S. She asked, and eventually received permission from, her father to join them in the southeastern U.S. Once there, she promptly began to work. It was in the workplace that she met the man who was to become her first sexual partner, her husband, and the man who would infect her with HIV.

Carmen did not know him for very long before they became novios, a status which in much of Latin America is less prohibitive of sexual involvement. Carmen and her partner were, in fact, sexually intimate before marriage. They married after a short courtship, never having had a conversation about birth control or STDs, including HIV. Carmen was quite naïve, having lived a sheltered existence. She expected to be with her husband “for the rest of my life, have children,” and assumed her husband would be sexually intimate only with her. In addition, she had no familiarity with drugs or their accompanying lifestyle.

Before moving in with him, Carmen did not know that her husband was a drug (primarily heroin) user. She attributed his red eyes and listlessness to fatigue from the hours they were both required to work in the pollera (chicken processing factory). After eight months of marriage, Carmen, her husband, and two of his siblings were in a car accident in which the two siblings died. Carmen’s husband was critically injured, and she was hospitalized for a week with several broken bones.

On the second day of Carmen’s hospitalization she was informed that her husband had AIDS and that she was HIV positive. She could not understand how or why she had become infected since her husband was her first and only sexual contact. Hospital staff educated Carmen about HIV and AIDS, about which she knew almost nothing, and
helped her understand how her infection had occurred. As difficult as the information was for her to comprehend, it was even harder for her to accept that her husband knew he had AIDS, and had neither told her nor made an effort to protect her from becoming HIV infected by using a condom during sexual intercourse. When she asked him why, he answered that he had wanted a family and children and believed that Carmen would not marry him if she knew the truth.

Carmen stayed until her husband was discharged from the hospital and she was certain someone would take care of him at home. She then moved in with relatives and never saw him again. Her husband was eventually taken back to Mexico by his mother, where he died within a year of his return.

Carmen’s initial response to her medical condition was suicidal—indeed, she made two suicide attempts. She believed that when others found out about her HIV status she would be ostracized or rejected. Part of this belief extended from her husband’s behavior when she left him. He called her names and told her that she would “wind up living under a bridge.” Expecting to suffer a terrible end, Carmen felt it was unfair to ask anyone, especially her parents, to go through that experience with her. Nevertheless, she informed her parents in Mexico of all that had happened, sharing with them her newly discovered HIV positive status. Other than one uncle, her family was kind and supportive. She went back to work and tried to move on with her life.

Carmen’s reserve and wariness about becoming involved with another man meant her current husband had to very actively pursue and woo her before she eventually agreed to date him. Initially she rejected his advances, knowing that dating him would necessitate divulging her HIV status. When she finally did agree to date him, his response
to her disclosure was, “So what? We are all going to die of something.” Following treatment with highly active anti-retroviral therapy (HAART) that put her HIV into the undetectable range, Carmen and her husband decided to have a child.

Carmen said that as a result of her faith, meeting her second husband, her family’s positive response, and having her son, she no longer thinks about committing suicide and instead thinks about a future with her husband, raising their son. In addition, she gains strength from educating her family and friends about HIV infection and AIDS. Although people in her family rarely discussed sexual matters at all, Carmen now talks to her siblings and friends straightforwardly, describing exactly what it takes to remain free of STDs in general and HIV in particular.

At present, Carmen’s major concern is that, after deciding to have a child, her husband has refused to resume using condoms and also refuses to be re-tested for HIV. Six years have passed since his initial HIV test, and his only response to Carmen’s requests for him to use condoms or get tested is “I love you . . . we all have to die of something.” Carmen is very worried about his unwillingness to take better care of himself and wonders what would happen to their son if both she and her husband were to develop AIDS.

*Analytic Commentary*

Carmen’s beginnings, while modest, are also grounded in her intact, respectful, and loving family. Being very close to her mother, Carmen modeled her own behavior on her mothers, and, given her somewhat overdeveloped sense of responsibility, she left school at a young age so she could help her mother take care of the younger children. Closing the door on her formal education was a turning point moment in Carmen’s life,
as she turned towards fulfilling her culturally-prescribed role as a Latino woman—that of caretaker and mother.

Carmen’s lack of education extended to relationships with men, and she had no sex education from anyone. Sex was for married people and was a private matter that took place behind closed doors. HIV/AIDS or other STDs, therefore, were not discussed even between siblings or friends—a factor that directly contributed to her becoming HIV positive.

Carmen’s socioeconomic status, as well as her desire for what she thought would be excitement, led her to emigrate to the U.S. Although bright, the 19-year-old woman who arrived in the U.S. was also shy, soft-spoken, and quite naïve in social matters, including drug use and indicators of drug-using behavior. When she met the 20-year-old man who became her novio and first sexual partner, Carmen believed that this would be his first sexual encounter as well. It never entered her mind to discuss using a condom as birth control, much less that there might be any other need to do so. HIV/AIDS was not part of her reality; it was something that happened to other people. Even when she discovered her novio was an intravenous drug user, she did not make the connection between his drug use and a potential HIV/AIDS diagnosis, and thus had no sense that she was in any way at risk if she had unprotected sex with him. In addition, it was unthinkable to her to even bring the matter up with her novio.

Carmen’s response to discovering her HIV status was shock and disbelief. Driven by shame and grief, she twice attempted suicide by taking what she thought would be overdoses of prescription medication. Religious belief, her realization that “God must not want me to go; he must want me to be here,” and the love of a new man convinced
Carmen that she had much to live for; beginning conversations with her novio about children cemented her decision.

In addition, rather than fear the stigma she was sure she would face, she confronted it directly. Carmen informed her parents and many other family members of all that had happened. While her parents did not reject her, there were others in the family who did. Nevertheless, she continues to maintain contact with the family members who accepted her in spite of her HIV status. Indeed, it has become her mission to make sure none of her siblings or friends become HIV infected, even though doing so requires going against strong cultural tenets. For example, she encourages the women she knows to refrain from having sex without condoms, demonstrating her willingness to go against the Catholic position against condom use.

Carmen also drew strength from experiencing acceptance at work. When her colleagues became aware of her HIV status they demonstrated knowledge of HIV infection transmission mechanisms through their willingness to share meals with her and to include her in social outings. These actions boosted her self-esteem, gave her the confidence to move forward in her life, and encouraged her to think about how she could use her experience to make a difference in the lives of others.

One co-worker continued to pursue her romantically even after she told him why she was reticent to become his girlfriend. Carmen’s HIV status did not stop them from marrying, and they had a child. Because Carmen followed the doctor’s instructions exactly, the child was born HIV negative. Carmen considers her son the ultimate reason to stay healthy and happy. She found purpose in life through her dedication to raising her son and making sure she is around to see him grow up.
Carmen has also demonstrated that deeply ingrained cultural beliefs and culturally mediated gender roles remain a part of who she is, even when they represent a potential threat to her family’s well-being. For example, the couple stopped using condoms when they elected to have a child (with her doctor’s approval), and, at her husband’s insistence, have never gone back to doing so. Carmen’s entreaties have not only failed to change her husband’s mind about condom use, he has also refused to be re-tested for HIV. Believing that a wife must abide by her husband’s decisions, she does not make using a condom a condition of having sex. Having become quite educated about HIV and knowing that should her husband develop a different viral strain she could become re-infected, Carmen nevertheless believes that she must abide by her husband’s decision regarding both condom use and HIV testing, regardless of what it could mean for her, for her husband, or potentially for their son

Paz

Demographic Information

Paz is a married, 23-year-old Catholic woman from Mexico. She has a ninth grade education and appears older than her stated age. Her family recently moved to the East Coast from the Southwest, their original entry point into the U.S. Paz is shy and quiet; during the interview she often looked down and averted her eyes, though she also smiled from time to time. At one point I thought that she did not want to continue and offered to end the interview. She indicated that she wanted to finish by looking up and waiting for the next question.

Paz’s family lives in a trailer situated away from the street. It is small, well-kept, and clean, though I did notice an occasional cockroach. The home was hot, even though it
was not terribly warm outside. The only cooling sources were an air conditioner in the children’s bedroom and a fan in the living room.

There are four children in the family: two school-aged, a toddler, and an infant. Prior to the birth of the last baby Paz worked at night while her husband did casual labor during the day. Neither of them has ever earned more than minimum wage, if indeed they have ever been paid that much. As a casual laborer, her husband’s employment is never assured, which makes meeting their financial obligations difficult. For example, during our first visit, a Tuesday, Paz said that she was not sure whether they would have the rent when the landlord came to collect it on Friday.

With a primary need such as rent uncertain, secondary needs such as health insurance are out of the question. Both Paz and her husband get their HIV-related care, including medications, at an infectious disease clinic providing free services to people with HIV or AIDS. They have no other health or dental coverage. The two youngest children have Medicaid, which is fortunate as the toddler was born with HIV. Because babies are born with their mother’s immune system and shed it by 18 months of age the family hoped he would shed his HIV positivity. Indeed, the test results were HIV negative at the 18-month time point and the medications were discontinued. The older children (five and six years of age) are without health insurance of any kind.

Paz does not drive and there is no public transportation in the rural area where she lives. Furthermore, she does not speak any English. The family does not have a telephone. Having only recently moved to the area, she does not have any friends nearby. A Spanish-speaking counselor makes weekly home visits to the couple.
Narrative Summary

Paz, her three sisters, and one brother were born in Mexico. They lived on a rancho with “cows and things like that,” where everyone had a hand in keeping things running. When not in school, the children were expected to do all the household chores except cooking; it was always their mother’s responsibility to prepare meals for the family. In addition, they helped when needed in the fields. Paz was the middle child and exhibited several of the characteristics often ascribed to children in the middle of the birth order; she felt left out, believed she was unloved by her parents, and thought life was unfair (Myers, 2008). Paz shared, “well, it was kind of hard being in the middle . . . sometimes [laughing a little] I thought they loved the others more than me . . . like I was being ignored or something like that. And always . . . someone was giving [me] orders.”

The children’s routine involved work and school during the week and work on Saturdays; on Sundays they went to a nearby river to “sometimes wash clothes and sometimes just to swim.”

Paz was raised Catholic with traditional Mexican cultural values and customs. Her education about boys and sex consisted of her mother warning her to “be careful . . . Not to be running around . . . Not to be going with men just like that . . . and to be careful to not get pregnant.” Her mother never explained what “being careful” meant. Paz reported that in school “they taught us about condoms,” but only in the context of not getting pregnant and without any instruction on how to use condoms. She went on to say, “But really, I didn’t really know about condoms or any of those things.” The role of women, Paz learned, was to “stay at home and take care of the children,” while the male role was to “go to work.” She was taught that in marriage women “shouldn’t go with other men
and supposedly that is true for men as well,” she added, snickering.

When the children were young, their medical treatment consisted largely of home remedies, or if the illness “was very serious” they might be taken to the doctor. Paz added, “but we almost never [went to the doctor] . . . because we were never sick . . . and it is the same with our children here.” The family was naïve about medical issues. Asked about her knowledge of HIV/AIDS before coming to the U.S., Paz said that “they taught us that it’s [HIV] transmitted with needles, with a blood transfusion, and having relations.” It took several prompts for her to explain what she thought it meant to have protection from becoming infected with HIV. When Paz did comment, she said, “Not inject [yourself] with needles . . . and use protection.” It took yet another prompt, asking what “using protection” meant to her, for Paz to say, “Yes, condoms . . . but they did not say anything else.” When commenting to Paz that some children talk to older siblings about matters such as sexual activity, she responded that “I would have . . . never . . . it never entered my mind [to talk to my sisters].”

Due to the family’s poor economic circumstances Paz’s father would often travel to bigger towns to find additional work. During those times the family stayed on the rancho. It was less expensive to stay there, and Paz’s elderly maternal grandparents who lived there required periodic assistance due to failing health. Eventually, however, the family, minus the grandparents, was forced to move to the city in an attempt to improve their economic situation. To that end, when Paz finished middle school she found a job as a live-in nanny. She did not hold this job for very long, however, as her grandparents fell ill and she returned to the rancho to help care for them. She never again worked in Mexico.
Paz met her future husband at a basketball game while she was still in school. They dated for a year before marrying when Paz was 16 years old. “Dating” consisted of going to public activities such as soccer or basketball games, participating in family activities, or going for walks and talking; the couple was never out of someone’s sight for very long. They neither talked about nor engaged in sexual relations. After marrying, the couple moved into his parents’ home and within a year Paz had her first child. When she wanted a “break,” Paz visited her grandparents, as her own parents had moved to the U.S. to seek better economic opportunities. Eventually, her husband, following his own siblings, traveled to the U.S. for the same reason, though his first stay lasted less than a year. During a visit from her husband, Paz again became pregnant. The birth of her second child brought greater responsibilities and economic pressures from which they found no relief in their country.

By the time Paz’s husband left for the U.S. a second time, again looking for a way to improve his family’s economic situation, her parents had returned to Mexico. It was two years before Paz and her children could join her husband. It took that long for them to save enough money to make the trip and for the children to be old enough to travel safely. The young family settled in the Southwest, where they remained for approximately four years. Life was quite difficult in their first home. As Paz related, “There we were alone . . . my husband had to work all the time to be able to pay the bills . . . sometimes we would come out alright, but a lot of times we wouldn’t . . .” The birth of a third child made things even more difficult. Paz’s husband decided to move the family to a city in the Southeast where his brother lived, hoping that being near relatives would provide the support they needed. Initially they lived with her brother-in-law and
his family in very tight quarters. When I interviewed Paz, it had been only a couple of weeks since they had moved into their own rented trailer.

Paz became pregnant with her fourth child shortly after moving to the Southwest. Her HIV status was discovered during her prenatal care, and the couple found out that they were both HIV positive. They were shocked at this devastating news. Paz recalled, “I couldn’t believe it . . . . I didn’t believe it [at first] . . . . I didn’t understand how I could be positive, how I could have gotten it.” She said, “Well, now, what else can I do, but believe it and get used to it.” What motivates her and her husband to move forward is “thinking about the children. They are little. They need me. They need us. I think all the time about what would happen to the children and that pushes me to keep going.”

Paz has given some thought to how she became infected. When she tried to speak to her husband, his response was either “I don’t know how I could have gotten infected” or “I don’t want to talk about it.” Paz does not feel there is any point in pressing him. The most conjecture she engaged in was to say, “Well, he was here for two years by himself before I came . . . .” and trailed off without saying anything else. Her husband is the only man with whom she was ever sexually intimate, and she has never had a blood transfusion or used drugs of any kind. Paz intimated that she understood her husband is the likely risk factor for her HIV infection, though more disturbing to her is that they have never discussed their HIV positivity with each other. Even in counseling sessions, Paz noted, her husband said “almost nothing.”

Paz and her husband are on the same medication, at the same dosage. Paz said she takes hers daily and assumes her husband does the same, though she has not questioned him about it. She said, “I know he does [take his medicine] because I see the empty water
“...and I know it is not mine.” Paz has told no one of their HIV status. Outside of their care providers and a support group she attended once, no one else knows about their condition. Out of fear of what others might say or do, Paz has no plans to tell anyone, including her family, believing “there is no reason to tell them.”

Analytic Commentary

Paz was the only woman in this study who I thought would not remain in the study. She was shy, unaccustomed to talking about herself, and even less accustomed to having others express interest in what she thought or said. She may also have been concerned about what I thought of her and her family. When given the opportunity to end the interview without losing the promised honorarium, however, she chose to continue.

Paz’s biographical particulars, especially as a young child, were very similar to those of many other participants. She was born into an intact family, to parents who were poor, hardworking, loving, and Catholic, but who could do little beyond keeping the children housed, fed, and clothed. Paz managed to go to school through the ninth grade, what is called secundaria in Mexico, but no further. She is not “worldly;” other than moving to the U.S. in search of a better income she has not traveled, even within her own country. She has not read many books, did not have many friends in Mexico outside of her siblings, and has not made many friends in the U.S.

Paz’s lack of education extended to relationships with boys and what they might entail—sex and HIV/AIDS. The only sex education Paz received was how to prevent pregnancy using the only method allowed by the Catholic Church, that is, the rhythm method—a method of birth control in which the couple abstains from sexual intercourse during the period when ovulation is most likely to occur (thus preventing pregnancy). Paz
learned only that being infected came from “having a blood transfusion or going to bed with someone” and could not or would not say where she learned this. She did note that it “may have been on television” or “maybe in school.” Paz was a virgin when she married, and even then there were no discussions about sex, condoms, or any other means of protection against sexually transmitted diseases (STDs). In reality, such diseases were not anything she ever thought about, or considered as something she might be affected by. Even now that both she and her husband are HIV infected, they do not have any discussions regarding sexual activity—a reality about which Paz expressed some frustration/disappointment through her affect and body language.

An important turning point moment for Paz was her husband’s first trip to the U.S., which he undertook in an effort to find work. The decision to make the trip, and the timing of it, was unilateral. He did not ask for her input, and Paz did not feel it was her place to question her husband’s decisions. When he sent for his wife and children, Paz was thrust into an unfamiliar world where she did not speak the language and had no family other than her husband to rely on. It was a remarkable leap of faith, especially because she did not know her husband that well given that for most of their married life he had been travelling to find work either in Mexico or in the U.S.

Paz’s experience after finding out about her HIV status was indicative of the shape and nature of her relationship with her husband. As mentioned previously, Paz discovered that she and her husband were both HIV positive during her fourth pregnancy. When all her husband would say was, “I don’t know how I could have gotten infected,” Paz did not press him to say more. She was prevented from demanding a more satisfactory response by a combination of her personal communication style and the
culturally imposed directive to not question her husband, especially on sexual matters. The only option she saw was to “concentrate on the children—and move forward with our lives. They [the children] force us to look to the future.”

Concentrating on the children is her response to being infected with HIV. The belief that her children need her drives her to comply with her medical regimen, which includes attending medical appointments despite her transportation issues, taking her medications, and following the advice of her counselor. Her counselor urges her to recognize, for example, that “the disease has no cure, that all I can do is control it,” and that what happened “is not my fault . . . and I am not a bad person.”

Paz’s own needs, and even those of her husband, are secondary to the needs of their children and the family as a whole. If her husband refuses to discuss what has happened to them, then so be it. Paz hopes she will one day return home, though she knows this will only happen if she and her husband can make enough money to start a new life in Mexico, having “something [we] can do.” Her first priority is to maintain their family by keeping a roof over their heads and food in their stomachs.

Gloria

Demographic Information

Gloria is a 5’ 6”, attractive, 38-year-old Mexican woman of medium build with light coffee-colored skin. She has five children, though only two live with her in the U.S. On the day I interviewed her she was wearing shorts, a light colored t-shirt, and no shoes. Her hair was mussed, evidence of having just gotten up from a nap. Both of Gloria’s daughters were at school. I brought Mexican snacks from a neighborhood store, which she gratefully accepted. Gloria is soft-spoken, and smiled or cried at times throughout the
interview, though appropriately given the nature of the conversation. She appeared happy
to participate in the study and was gracious when the need arose to do a second interview
to clarify and amplify some of the recorded material.

I arrived at Gloria’s home late for the appointment, having taken a couple of
wrong turns on my way. Gloria lives in a community that at first glance looks like many
other middle-class communities in the Southeast. On closer inspection, however, one
notices that the houses are in very close proximity to one another, some look to be in
disrepair, and others exhibit butcher-paper window shades or no shades at all. Gloria did
not immediately come to the door either in response to the knock or my telephone call.
As I walked back to my car, however, she opened the door. As I entered the house my
attention was immediately drawn to a very large television set in the living room as well
as the computer sitting in the corner, neither of which belonged to Gloria. Gloria and her
boyfriend rent part of the house and live there with the man who owns the house and all
its furnishings.

Gloria’s regular income comes from working one or two days a week at a local
open air market. She supplements this income by making and selling tamales in the
surrounding neighborhood. She described her economic status as “very low… we are
poor.” Without her boyfriend’s financial help, Gloria could not have paid the rent on
several occasions. In addition, other than her access to HIV-related health care and
medications, neither she nor her daughters have health or dental insurance, and there is no
money for out-of-pocket medical expenses. This was a particular burden for Gloria as she
was having “terrible gum problems,” which she demonstrated by moving several of her
teeth back and forth. The family has minimal access to transportation, given that such
transportation depends on a family friend who was neither able to register the car nor get a driver’s license. Because being stopped for any traffic infraction would put the friend in jeopardy for driving without a license, they only request his help with transportation for absolutely critical activities.

_Narrative Summary_

Gloria is one of ten children born to a father who had difficulty finding work and a mother who tolerated his physical and occasionally sexual abuse for the entirety of their relationship. The children were not safe from his abuse either. Gloria related that her father’s behavior was largely motivated by jealousy of any attention paid to her mother, including by her children. The problem was that “she was very pretty . . . she is still very pretty,” Gloria said, and she naturally drew attention. Gloria’s father, however, felt that his much younger wife “courted” attention.

He was louder and more violent at home when unemployed. At some point during Gloria’s childhood her parents separated, though not for long. When her father became ill with cancer, her mother and one of her older sisters took care of him until his death. Gloria’s mother never remarried or lived with another man.

Gloria and her siblings’ daily lives consisted of going to school and then going home to do chores, finish their homework, and play with each other. They were rarely allowed outside and then only to play in their own yard; their mother did not want her children to be out of her sight for long. The children were not permitted, as many other children were, to go to the “plaza,” a small, park-like area in the middle of town containing a pergola-type structure where music was often played. Furthermore, although they were Catholic, Gloria did not remember going to church. The children were
punished physically for any infraction, which most often meant being hit with a belt. The girls were not allowed to date, though eventually they were permitted to bring a boy home. The rule, however, was that they were to be either in the house or in the yard with him, and always in the presence of others. This rule remained in force until the girls married.

Neither Gloria nor her siblings received any education about the opposite sex from their parents or in school. Gloria did learn that she was expected to be a virgin when she married, but could not say how she knew; “I just knew.” Later she was told by her mother “not to get pregnant,” though no one ever told her how to prevent pregnancy. Gloria did say she “knew about condoms,” but did not or could not elaborate other than to say, “I heard about them in school.” To explain just how private her mother was and how unwilling to recognize any aspect of sexuality in public, Gloria shared that her mother “would hide the evidence of her own pregnancies by covering her belly with a towel or scarf, even at home.” She went on to observe, “My mother was strict, closed off, cold, about everything . . . in everything she did.”

Gloria was 15 years old when her father became ill and her mother ended their separation. Gloria moved in with her sister’s family to help care for her nieces and nephews. For Gloria this did not bring relief from her parents’ rules. Instead, she was subjected to her sister’s “meanness” and punishments, including “hitting.” Gloria stated, “My life went to ruin.”

After her father died Gloria moved back into her mother’s house. Instead of returning to school, however, she started working so that she could help support the family. Along with her mother and sisters, Gloria made and sold tortillas while other
family members earned money running errands or doing other odd jobs—whatever they could do to make “a few cents.” Her father’s death had not caused much of a change at home. Gloria’s mother continued to be strict, often mean, and continued to withhold her affection. When asked to elaborate, Gloria became somewhat defensive, saying she did not “want to judge my mother,” as if my questions were critical of her mother. As my assurances that this was not my intention did not seem to fully disabuse her of the idea, I respected her feelings and asked no further questions about her mother.

Gloria has been married three times, each marriage taking place “at the courthouse, not in the church.” The first marriage, lasting five years, was to a man whose family never warmed to their new daughter-in-law. The couple had two children. Gloria’s husband was an alcoholic, abusive, and “always out with either his friends or other women.” When the marriage ended, Gloria moved to Tijuana. There she met her second husband who, while not abusive, left her for another woman right after their first daughter was born one year into the marriage.

Between marriages, Gloria returned to her mother’s home. She found work mainly cleaning houses and taking in other people’s ironing, though at times she had to resort to finding things to sell to support her children. When Gloria met the man who would become her third husband, she dated him for a year before accepting his offer of marriage, in the hope that getting to know him better would result in a marriage that lasted and was free of abuse. Once married, she again moved out of her mother’s home.

Gloria’s third husband was not much different from the first two. He drank, ran around with his friends, went out with other women, and was abusive. However, he did attempt to support the family, which now included a child born to him and Gloria. He
provided for them by periodically traveling to the U.S. where he harvested crops in various parts of the country.

Upon returning from one such trip, Gloria’s husband became ill. He was hospitalized once, and it was during this time that she learned he had AIDS. Gloria also found out that her husband had known for a long time he was infected with HIV and that his cousin, an M.D., had begged him to tell her. Her husband’s disease progressed, and he developed extreme night sweats, fevers, and other symptoms. Even more alarming to Gloria was his extreme weight loss. Nevertheless, he refused to go back to the doctor and denied he had AIDS. Gloria’s in-laws declined to take part in caring for him in any way. When she could not manage by herself any longer, and her husband had weakened to the point that he could not stop her, she took him to the emergency room where he was admitted to the hospital. When he died about a week later, Gloria was on a bus on her way to the U.S.

By this time Gloria knew she was HIV positive and had begun taking medication. The daughter born during her third marriage was not HIV infected. Medically, Gloria did well after arriving in the U.S. She was fortunate enough to move to an area where an HIV/AIDS clinic was located. The clinic was able to provide HIV care and medication, but not other medical or dental care. Periodontal disease threatened the loss of her teeth due to the infection in her gums. The poor condition of her gums also presented a real medical threat, as a gum infection can lead to a systemic infection which, in turn, can attack the heart (Johns Hopkins Point-of-Care-Center, 2008). To be able to take care of her teeth, get support and help from her family, and respond to the needs of all her daughters, Gloria had decided to return to her home country, but had not yet done so.
Analytic Commentary

The connection between Gloria’s biographical particulars and her HIV infection is generally a straight line. She came from humble and violent origins. The family was always poor even with both parents working. Her mother generally worked at home taking in laundry, making tortillas, and doing ironing or errands for others. Sometimes her mother would find things she could buy and sell, like clothing or make-up. Gloria’s father was a laborer. For a long time he worked fairly steadily; however, as he got older and his alcoholism grew worse, it became harder for him to find work.

The lack of a steady income put pressure on everyone, including the children. In addition to attending school, all the children had to participate in taking care of the household, even the youngest ones like Gloria. These economic pressures, as well as the personal difficulties between the parents, resulted in a lack of nurturing beyond providing for the children’s most basic survival needs.

Gloria learned about domestic violence at an early age. Her father’s violent behavior was most often directed at his wife, whom he abused physically, sexually, and verbally, often in front of the children. In addition, Gloria’s father would punish the children severely if they misbehaved while he was drunk, often hitting them “hard,” as Gloria recalled, with a belt. At times, her mother also resorted to physical punishment when they did not do as they were told. This created an ever-present tension at home—one that they were eager to escape as soon as they could. Rather than adopting the attitude that “no one will ever do that to me,” however, Gloria instead saw her mother as a heroine of sorts, in that she tolerated all of her husband’s behavior towards her, often suffering his abuse in silence.
Gloria experienced abusive behavior not only from her father and occasionally her mother, but also, as one of the youngest children, from her oldest sister and occasionally from the others. When she was told she would need to leave school for a while to care for her sister’s children, Gloria saw it as a reprieve from her life at home—a break from being hit, a break from “meanness.” However, she felt “fooled,” as her sister treated her very much as her mother had done.

Gloria learned from her mother’s and sister’s behavior what it meant to be a wife and mother. Her mother never said anything to Gloria about her father’s treatment of her or conveyed that this was not acceptable behavior. Moreover, she never taught Gloria about sex, or what was considered “normal” in an intimate relationship. She did learn that she was expected to be a virgin when she married, and that the only acceptable means of birth control was the rhythm method.

Gloria moved back home after her father died. Eager to experience life herself and understanding that she needed to be a virgin when she married, Gloria married the first man who wanted to be her novio. He turned out to be much like her father in terms of abusiveness, though unlike her father, he left Gloria and their two children for another woman. Gloria’s second husband was also an alcoholic and left her within a year of their marriage, right after their daughter was born. Gloria then met another man but waited until she knew him “much better” before agreeing to marry him. Nevertheless, he turned out to be very much like her first two husbands. Gloria described this third man as a “libertine” and said she suspected “he was running around with other women” when he said he was out with friends. However, though she suspected him of having sex with
other women, she did not insist on his using condoms when they had sexual relations and in fact never even requested that he use them.

Gloria never suspected that she or her husband might become HIV infected. What she knew about how HIV was spread was minimal, heard through a filter of, “This happens to other people, not me, I don’t sleep around. . .” What she did not know was that her husband was HIV infected when he met her and elected not to tell her. When he became ill and developed AIDS, he still did not tell her, choosing to believe, Gloria said, that “he did not have it, that it was just not true.” By the time she learned of his HIV status, when he got so ill that she took him to the emergency room, it was too late; she was already infected. Gloria felt it was “by God’s providence” that the daughter they had together was not infected.

Gloria’s behavior after discovering her HIV status exemplifies the cultural mandate that Latino women take care of their husbands and families regardless of the husband’s behavior towards them. Gloria remained with her husband, taking care of him, finding ways to take him to medical appointments, obtaining his medications, and making sure he took the medications even when he did not want to. She continued to do this even when his own family refused to help him. When Gloria realized that his family blamed her for his illness, believing she had infected him, she did not correct their mistake. In the end, Gloria was sadder about his death than her own infection. She reflected, “I don’t hold a grudge towards him; I would not say that.” She attributes his not telling her that he was HIV infected to “ignorance . . . He was from a rancho and there are many ignorant people there.”
Life since her husband’s death and the discovery of her own infection has not been easy for Gloria. In many ways, her life post-HIV infection is fueled by the same issues that caused her to become infected in the first place. She continues to be poor and lack medical and dental care for anything beyond HIV-related issues. It is difficult for her to find work as many of the jobs available to immigrants, such as working in a chicken factory, are off-limits to her given her need to avoid contact with anything infectious, such as salmonella or other bacteria. She takes her five medications based on faith that they are what she should be taking, and that there is not something better. She does not understand what the medications do, or what it would take for her to go from being HIV positive to having AIDS. Gloria does not know that her immune system could fail if the medicines she takes stop working.

What peace Gloria has found comes from concentrating on her daughters. She sees them as her reason for living—not only to take care of them, but also to prevent them from suffering a fate similar to her own. Gloria is also driven to take care of herself by the thought that her mother and her sisters would be terribly “sad” if something happened to her. Lastly, she trusts in God to take care of her and has a strong belief in fatalismo, the belief that, “what happens, is going to happen [and there is nothing I can do about it].”

Valencia

Demographic Information

Valencia is a 28-year-old woman who looks much younger than her stated age. She is petite in stature, round-faced, and somewhat round-bodied, though not overweight. Valencia, her husband, and their toddler live in a large, attractive, well-kept apartment
complex that sits very high up above the street. Their apartment is nice, clean, simply furnished, and cozy. Valencia greeted me warmly and accepted the chicken I brought from a local restaurant as it was lunchtime, though she saved it to share with her husband later. For the duration of the interview, her husband and their child remained in a bedroom and happy play could be heard over the television, neither of which was terribly loud. Valencia has three other children who are being cared for by her mother in Guatemala, her country of origin.

Valencia has been in this country for three years. She has a second grade education, speaks no English, and although she and her husband both work, she nevertheless described the family as low-income. The couple makes ends meet by renting one of the bedrooms to a woman Valencia met at work; the young lady works nights and was asleep in the bedroom as I interviewed Valencia at the dining room table. When the renter began to move around, Valencia started to look and act uncomfortable. This prompted us to move outside to finish the interview on the third-floor landing. Given the time of day and the location of the landing on the top floor of the building, being overheard by passers-by was not an issue. Beyond the standard concerns about confidentiality, no one other than her husband knows about her HIV status, including the renter, and Valencia wanted to keep it that way.

Valencia exhibited a reaction to being interviewed that was typical of many of the participants: Her responses, affect, and facial expressions indicated that she could not quite believe someone was interested enough in her to ask the types of the questions I was asking. She was, at first, utterly surprised at being asked to talk about herself and her life—almost to the point of being reticent to do so.
At first I did not realize what, other than being raised a strict Catholic, was behind some of the body language, facial expressions, and affect I was seeing. On the one hand, she was more than willing to participate in the research, particularly if it might help another woman, as evidenced by her answering all the questions posed no matter how embarrassed she might have felt or how odd she might have thought them to be. Yet on the other hand, Valencia was clearly not accustomed to being asked about herself, much less in the habit of actually talking about personal matters, particularly those of a sexual nature. She often looked down as she spoke and tittered as she answered questions, and her responses tended to be short. As with other participants, Valencia often had to be asked follow-up questions for further clarification.

_Narrative Summary_

Valencia is the fifth of eight children. She grew up in what can best be described as abject poverty in a rural area of Guatemala. For a long time her family lived without electricity or running water and it took everyone participating in some way to keep the family fed. This often involved her father and some of her older siblings traveling to find work. Valencia herself left school after the second grade to help out at home with the youngest children, eventually finding whatever paid work she could to provide financial assistance to the family.

Valencia described her parents as “very good to us” and as strict but rarely “hitting us.” In any case, there was not much opportunity for the children to get into trouble. The family led a simple life that revolved around keeping everyone housed and fed, educating the children for as long as possible, and going to church. For the children, recreation meant playing with each other in and around the house. For a long time they
were not allowed to date, and, when they could, it was not dating as recognized in American culture. If they knew someone of the opposite sex, particularly the girls, that person would come to the house and be with the whole family, rather than alone with the person they had come to see. Valencia did not remember ever having a conversation about boys—much less about sexual matters—with either parent, nor does she recollect having any such conversations with her sisters. What she learned about sex she learned from her first husband, with whom she had her first intimate relationship.

Valencia met her husband in the town in which they both lived, and they did not “date” for long before they decided to marry. They were not sexually active until their wedding night, and two children followed in short order. As in her family of origin, life was challenging for the young couple and revolved around maintaining their home and caring for their children. Both Valencia and her husband worked long hours to feed, clothe, and house the family.

The marriage itself did not blossom or develop well. Valencia’s husband was unfaithful, and his infidelity apparently became known to other members of her family before it was known to Valencia. Unsure whether to tell her or not, Valencia’s sisters told their mother what they knew, and her mother informed Valencia of their suspicions. Her mother further advised Valencia that if she chose to stay with him, she would have to learn to live with her husband’s philandering ways. When Valencia confronted her husband he denied being unfaithful, and chose to believe him. However, when she saw pictures of him with other women, she decided to leave him.

Valencia and her two children moved back in with her parents and stayed there for about two years. When she felt the children were old enough not to be too much
trouble for her mother, Valencia moved to the city to find work and left her children with
their grandmother. The children’s father did not pay any child support; he essentially
abandoned them, leaving others to help support Valencia and the children. Nevertheless,
it was largely up to her to take care of herself and her family. To meet her responsibilities
Valencia found work cleaning houses. She saw her children only occasionally, though
she did so whenever she could and whenever she needed to deliver the money necessary
for their care.

Valencia met her second husband while living in the city. Shortly after getting
together they married and within a year had a child. While this second husband, like her
first, was not faithful, she recognized the signs of his infidelity much sooner. This time,
she did not wait for overwhelming evidence; instead Valencia left him immediately and
moved back in with her parents. Approximately three years later, she was talked into
coming to the U.S. by others while her children remained with their maternal
grandmother in their native country. Several of her siblings were already here, though in
a different state than the one in which Valencia now lives.

Valencia found work quickly and there she eventually met the man who became
her third husband. She finally found someone who cared about her, loved her in fact. The
peace and contentment she felt did not last, however, for during the prenatal care for their
first child Valencia learned she was HIV positive. She was stunned; she could not
understand how this had happened to her. Valencia did not know much about HIV in
general, and did not understand how it was transmitted. All she knew about AIDS was
that it was “bad, very bad” and that “people died from it,” though she could not be sure
where she heard this bit of information.
Prior to giving birth to her fourth child, Valencia took medication not only for herself, but also to ensure that her baby would be born HIV negative, which he was. Adding to that good news was that her current husband also proved to be HIV negative. How, then, had she become infected? Her first husband and all his progeny tested HIV negative. However, Valencia learned that her second husband had been ill with an HIV-related illness. Given that she had no sexual partners other than the men she had married, the source of her infection appeared to be her second husband.

The behavior of Valencia’s third husband stands in stark contrast to that of her previous spouses, including his reaction to finding out about her HIV positivity. At first quite troubled and fearful about telling him of her HIV status, she nevertheless quickly decided she had no choice, determined not to do to him what had been done to her. Valencia felt he had a right to know and to make his own decision regarding being half of a sero-discordant couple (one HIV positive and one HIV negative).

To Valencia’s relief, after taking some time to go off by himself and “be quiet, real quiet,” her husband came back and said, “As long as you take your medicine you’ll be ok”—something she does with the necessary regularity. Valencia also considers herself fortunate that after telling her parents and most of her siblings about her HIV status, they were as supportive as they could be from a distance. She and her husband continue to work, and she continues to send money to her mother to care for her three children in Guatemala. Valencia shared that she misses them very much and they miss her. Nevertheless, knowing that Guatemala does not offer much in the way of work and that her children’s fathers will not provide any support, Valencia feels she has no choice
but to stay and work for as long as possible, despite the inherent difficulties of living in the U.S.

*Analytic Commentary*

After re-reading Valencia’s interview transcript, the field notes, and the constructed narrative preceding this section, the best word to describe the nature of all three is straightforward. Knowing the typical demographic profile of the Latino woman who is at risk of becoming HIV infected, Valencia’s story and its denouement, as well as her HIV/AIDS narrative and its construction, are very concordant.

Valencia suffered in a variety of ways from her disadvantaged childhood. Neither she nor her siblings finished school, even to the normal completion point in Guatemala, which is secundaria, or ninth grade. Valencia as a result barely reads, works for less than minimum wage, has no health insurance (other than strictly HIV-related care), and lives far from her native home and her three oldest children. Furthermore, Valencia and her siblings grew up with the typical values of Catholic, rural Guatemalan families. They had no significant education about the opposite sex, and no education at all regarding sexuality or HIV/AIDS took place in the home. Nevertheless, they understood that the girls were expected to be virgins when they married, and that until that time they were to “stay away from boys . . . not run around with them . . . not get pregnant.” Pregnancy was prevented using the only method approved by the Catholic Church, commonly known as the rhythm method. Valencia could not say how she knew what was expected of her; she “just knew,” though she did imply that she learned it at home.

Cultural and religious values are also clearly evinced throughout Valencia’s reports of her marriages/relationships. She learned about sexual relations from her first
husband, the first man with whom she was intimate; that education began on her wedding
night, albeit wordlessly. Valencia could not fathom asking questions about or
commenting on the experience either then or now.

While she reported that her husband “treated me good and everything,”
Valencia’s lack of sophistication regarding Latino men and their habits makes her
assessment questionable. It also illuminates Valencia’s blindness regarding her husband’s
philandering in the face of the evidence inadvertently gathered by her sisters. Valencia
chose to believe her husband’s denial and give him a chance to “change his ways”—
meaning she hoped he “would not go out with his friends so much.” Only when she saw
pictures of him with other women did she finally force him to leave. Valencia did learn
from this experience, however. When her second husband began demonstrating similar
behavior, she not only recognized the signs of philandering, she also trusted what she was
seeing and left him, determined not to tolerate infidelity again.

Valencia’s current marital situation is unlike her previous marriages. Her husband
is very supportive, encourages her to take her medication as she should, and otherwise
makes sure she takes care of herself. His consideration has even extended to not balking
at their need to use condoms during sexual intercourse. His behavior has greatly helped
Valencia, as it was not easy for her to arrive at the fairly calm, steady state she was in
when I interviewed her. She had to fight depression and fear of the unknown, for herself
and her newborn as well as for her husband. Her faith and inner strength, along with the
love and support of her family, have seen her through very difficult times.

There are still tough times ahead for Valencia, particularly emotionally. Three of
her children are growing up without her. Her plan had always been to return to her
children and her life in Guatemala after saving enough money to start a business there or, alternatively, to bring her children to the U.S. if she could do so safely. Now it is unclear whether either scenario will happen. Returning to Guatemala would present an uncertain future for her, and saving enough money to bring the children here is unrealistic without a drastic change in her current economic circumstances.

Isabel

Demographic Information

Isabel is an attractive, full-bodied, 27-year-old woman from El Salvador. She is married and has three children. Isabel has a third grade education and, by her own admission, “barely reads.” She and her three siblings were raised Catholic, though over time she has become an evangelical Christian, and since coming to the U.S. even more fervently so. Financially, the family continues to struggle, though their current situation is an improvement over the circumstances that brought them to the U.S. Currently, only Isabel’s husband is working, but it is not steady employment. To help make ends meet, the couple rents the second bedroom in their apartment to a fellow countryman, a common practice among Latino immigrants in the U.S.

Isabel’s apartment is in a quiet complex full of greenery. It is in the back of the building and is particularly quiet, with a lovely view facing a stand of trees. Isabel recounts that the quiet has not always been an advantage, as on one occasion someone attempting to rob them was able to climb through their renter’s window without being seen or heard. The would-be robber fled when he heard Isabel and her baby moving about in the living room.
It took a while for Isabel to come to the door in response to my knock, prompting me to think I was mistaken about either the time or date of the interview. Opening the door, she explained that she had been napping while waiting for me to arrive. Isabel happily accepted the bag of sweet breads I brought from the Salvadorian bakery around the corner. Her son, who had been playing in the living room, came to greet me. As we settled at the dining room table to talk, Isabel sent her son into her bedroom where her husband, who was at home that day, played and watched television with their son during the entire interview. While at first she appeared somewhat nervous, after a few minutes of conversation Isabel warmed up to me and was fully engaged in telling me her story.

**Narrative Summary**

Isabel is the oldest of four children. Her mother, a single parent, worked long hours as a hospital cook to support her family. Always tired by the end of the day, she had little energy or attention to give her children, especially the oldest. By the end of the third grade, Isabel left school to stay home and take care of the younger children. To make things easier, one of her two brothers was sent to live with his grandmother.

Isabel learned to cook by the age of seven. Her days consisted of cleaning, washing, and cooking for her siblings and her mother. She spent long days on her own supervising the children, making sure they completed their daily homework assignments and trying to get them to help with the chores. Isabel described her early life as that “not of a girl . . . it was [that] of a woman. Since I was little I learned to be a woman and mother to my siblings.”

The one respite for Isabel was the year she spent living with a friend of her mother’s. With her mother’s blessing, Isabel went to keep her company and help with the
household chores. While in many ways things were similar to being at home, Isabel observed, “At least there I didn’t work alone . . . the lady worked with me.” Also, the woman “loved me a lot . . . she would buy me all my clothes and everything.” Isabel also shared that the woman “was very kind to me . . . . She was gentle and kind.” The bond between them grew so strong that Isabel came to call the woman “Mom.”

When her mother became ill approximately a year later, Isabel returned home to again care for her siblings and her mother. She also began looking outside the home for companionship. At the age of 15 she had her first sexual experience with a boy who, Isabel said, “only stayed with me for one week.” Because they did not use protection, Isabel felt fortunate that she did not get pregnant. Her second sexual encounter mimicked the first. Both experiences happened against a background of ignorance regarding relationships with men, as well as sexuality more generally. Isabel knew little about her own body and the changes it would go through as she matured; she knew little about preventing pregnancy and even less about protecting herself from STDs.

As for HIV/AIDS specifically, Isabel knew only that it is a disease that leads to death. She explained, “my mother worked in a hospital where she heard about all of those things . . . and said nothing . . .” Implying that her mother was not the only one who was remiss in educating her children about such matters, Isabel characterized the people in El Salvador as “knowing nothing and saying nothing” and as “very private” about personal matters such as sexual relations and their potential consequences.

Isabel met the man to whom she is now married in her hometown in El Salvador. They married not long after meeting and had a child shortly thereafter. Life in their country was difficult, and work was extremely hard to find. To be successful, people
often had to travel to other towns, sometimes far from home. Making matters even more difficult, Isabel noted, there were “thieves everywhere trying to steal your money . . . especially on some roads.” As a result, people would at times come home with little to show for their labors.

When he saw that things were not improving—were desperate, in fact—Isabel’s husband made arrangements to come to the U.S. Isabel stayed behind with their daughter until he could send for her. While she waited, Isabel had a one-time sexual encounter with a man she met in town. She explained that she did this “to fill the void in my soul . . . I was lonely.” They used no protection of any kind. It took almost two years for Isabel’s husband to make the arrangements to bring her to the U.S. Her sister-in-law helped her husband with the initial $8,000 that it cost to make the trip, and they only recently finished paying her back. For many reasons, not the least of which was the prohibitive cost of travel to the U.S., Isabel left their daughter in El Salvador with her mother.

The couple was extremely happy to be together again and within a year or so, Isabel became pregnant again. During the fifth month of her pregnancy Isabel learned that she was HIV positive. She was, to say the least, “shocked.” Isabel described her feelings about having the virus in her body as being “hard for me. It is hard to find out that your body is dirty and that your blood is dirty.” The clinic visit during which she learned of her HIV status was one of the few to which her husband was unable to accompany her, as his job that day was nowhere near the clinic. So Isabel went alone and convinced the doctors, against their better judgment, to give her the results anyway. Her immediate response to the news was, “How? I don’t know how this happened!”
It was not difficult for Isabel to figure out who had infected her, given the timing of the discovery. Her husband and the daughter still living in El Salvador with Isabel’s grandmother were HIV negative, so her husband could not have been the source of her infection. Isabel suspected that her one-time extramarital affair had to be the source. Her husband, whom she had told of her indiscretion, agreed. News from El Salvador that the man in question was sick and was HIV positive confirmed their suspicions.

Isabel felt fortunate that her husband, knowing what happened, was nevertheless supportive from the moment they learned of her diagnosis. Others in his family, without even knowing how she became infected, have been neither accepting nor kind. What mattered and continues to matter to Isabel’s husband is that his wife takes the prescribed medications to give her the best chance to do well. The couple’s next hurdle was making sure their child would be born without the virus.

Given Isabel’s HIV positivity, her pregnancy was considered high-risk and was therefore followed very closely. She was educated about the vertical transmission of HIV and was given the medications appropriate for a pregnant woman. Furthermore, arrangements were made at the local hospital for Isabel to deliver her baby via C-section.

Unfortunately things did not work out as planned. When she experienced stomach pains, Isabel was taken to the hospital and found to be in early labor. She repeatedly told the medical staff that she was HIV infected and that she “was supposed to have an operation to have the baby.” It is unclear what went wrong, as an interpreter was present, according to Isabel. This person ought to have translated Isabel’s words to the medical staff. Nevertheless, Isabel was allowed to stay in labor for more than eight hours, at the end of which she gave birth vaginally.
Isabel never clearly learned what was or was not done for the baby after he was born. The outcome was that the baby was born HIV positive and now takes four medications, twice per day. He is due to be tested for HIV once more at 18 months, and if he is still positive at that time, the baby will be deemed to be HIV positive permanently. Isabel said she was told by clinic staff that “the hospital made mistakes.” She was also told that “it is futile to try and do anything about whatever happened,” i.e., sue the hospital, given her immigration status and the concern that it would become widely known. Isabel feared being deported and therefore unable to continue to access care either for her baby or herself. Thus the only action to be taken, as she says, is to “pray…and believe in God and in His will for my baby’s and my life.”

Isabel continues to fight depression. It is hard for her not to feel guilty about her son’s infection with HIV. She is reminded of this at least twice per day when she gives him his medication, and she aches for her son. The support group Isabel attends is a source of comfort but at the same time a reminder of what could happen to her. In the group, there are people who have been infected for a long time and have already been diagnosed with AIDS, or who are HIV positive and have done less well than others, even on HAART medication. One of those people, a woman with whom Isabel had become close, recently died. These circumstances have made it even more difficult for Isabel to set aside concerns about her son’s or her own HIV infection and about the potential short- and long-term consequences for both of them.

Analytic Commentary

Isabel’s biographical particulars, along with the sociocultural context of her life, are clearly suggestive of the trajectory of her and her toddler son’s HIV infection. She
was the oldest child in a single-parent family headed by her mother. With no father and a mother who worked long hours, it eventually became impossible for Isabel to stay in school, and she stopped going, thus setting in motion a major turning point in her life. Among other consequences, Isabel barely reads, and thus is limited in the type of work she is able to do.

Rather than receiving an education that might expand her opportunities, Isabel instead was schooled in what it was to be a mother and a dueña de casa (lady of the house). Her mother saw this as a fit education for a young woman who, it was expected, would eventually marry and have her own family. What Isabel lacked was her mother’s guidance and assurance that she was a smart and capable person. Her mother did not provide a foundation of security for Isabel, nor did she provide the love and reassurance children need to develop into self-assured adults.

Inadequate parenting, abandoning her education, and taking on adult roles too soon led to Isabel’s searching for companionship outside her home. She plunged into dating without any education about relationships with men or sex education, both fed by a cultural precept in her country mandating “being private about personal things, especially about things having to do with sex.” Even more dangerous, and with greater consequences, Isabel did not see herself at risk of being infected with HIV.

Once married, a common scenario emerged—economic hardship and an inability to find work, leading to Isabel’s husband traveling to the U.S. and a two-year wait before she could join her husband. With the separation extremely difficult for her, Isabel made a fateful decision that changed the course of her life. She had a one-time, unprotected
sexual encounter with a young man who infected her with HIV. Whether he knew his HIV status is not known. What is certain is that he was the source of Isabel’s infection.

All the factors that surrounded Isabel’s life in El Salvador continued to shape her life in the U.S.: poverty, lack of education, culture, and religion. Most impactful was a second pregnancy and the discovery of her HIV positivity. Though she received the requisite high-risk pregnancy care from a local clinic, including appropriate medications, and made plans to deliver via a C-section—the method indicated for HIV infected pregnant women to reduce the risk of vertical transmission—her baby nonetheless was born HIV positive. A hospital error led the baby to be born via vaginal delivery, and he most likely became HIV positive as a result. Whether the error occurred because Isabel and her husband speak little English, because of incompetent translation, because of their lack of knowledge of the health care system, or because of callous hospital staff remains an open question. Most likely, it was a combination of some, or all of those factors. The weight of knowing she brought the virus into their family, and more importantly, to her baby, was almost more than Isabel could take—and led to a suicide attempt, albeit not a serious one in that the amount of medication she took was far too small to kill her.

Isabel has come far both in her acceptance of her HIV infection and in her ability to manage her own and her child’s infection. Her husband’s love and support, her deep and abiding faith in God, and her belief in God “not giving you more than you can handle” has helped her move forward and not be overwhelmed by guilt and shame. However, the most important factor in adapting to life both as an HIV-positive woman and as the mother of an HIV-positive child has been her love for her youngest child and for her daughter who remains in El Salvador—“they need me,” she says.
This young family continues to be impacted by poverty, their immigration status, and an uncertain future. Isabel’s husband is able to find only occasional work as a laborer, which pays very poorly. His opportunities for employment are further limited by his inability to get a driver’s license because of his immigration status. Isabel has not been able to work at all since her child was born because of his need for HIV-related care. She hopes when her son has a blood test at 18 months, after he has shed the immune system with which he was born, he will no longer be HIV positive. However, Isabel has been warned that every indication suggests this will not happen for her son. Her faith and belief in God’s ability to “create miracles” keep her believing otherwise.

Isabel’s mental health is continually challenged by the thought that she might never see her daughter in El Salvador again. In her country she would have to pay for the medications that both she and her son need, which renders returning to El Salvador an economic impossibility. Bringing her daughter to the U.S., Isabel said, does not appear to be an option, as the couple’s “economic situation is very bad.” The choice for the foreseeable future will continue to be whether to “pay the rent,” send money to her mother “so that she has her food,” or meet some of their other financial needs—not the life she hoped to have and certainly not a life full of possibility.

Susana

Demographic Information

Susana is a 36-year-old university graduate from Peru. She is single, has never been married, and has no children. Susana is the youngest of four siblings, was raised Catholic, and was a fairly regular churchgoer earlier in life. She attended private schools growing up and did well enough in school to earn scholarships for her early studies and
assistance to attend college later on in her life. Susana had a middle-income lifestyle with
her family of origin, even when their means did not quite rise to the middle-income level.
The family was traditional in its cultural and religious values, expecting, for example,
that she and her sister would “get married in white” (i.e., both be virgins when they
married).

I arrived at Susana’s home after making several phone calls letting her know I had been stuck in traffic and gotten lost. She greeted me warmly and gladly accepted the treats I brought, which, like those for other interviewees, were purchased in her neighborhood. Susana lives in a rented room in a small, privately-owned house that is well kept both inside and out; the front yard is surrounded by a white picket fence. A woman was sleeping on the living room sofa so Susana led me to her room, where it is evident that she spends much of her time when she is at home. The room is small and neat. It contains a full-sized bed; a desk with a laptop computer; an accompanying stool; books; a chair; and various other items, such as bottles of water, against all four walls of the room. Susana keeps things neat and everything has a place; I got the distinct impression that a lot of thought had been given to arranging the room and considerable effort expended to keep it as arranged.

As nice, relatively speaking, as Susana’s living quarters might be, they belie her economic circumstances, which are those of a very low income person. She works part-time hours (more when additional work is available), generally for not quite minimum wage. She has no private transportation, no health insurance other than access to HIV-related health care and medications, and no savings. However, Susana’s educational and
employment background and history in Peru help her make a small income go as far as it needs to, covering rent, food, transportation, and other personal needs.

Susana is a slim, attractive woman who is, at times, animated, intense, or sad, but always forthright when she speaks. She is clearly intelligent and gutsy, able set goals for herself and do what is needed to accomplish them. Susana is friendly, speaks easily, and readily shares information about herself, her history, and her current situation. It is obvious that she enjoys telling me her story and feels she has something important to say.

**Narrative Summary**

Until the age of six, Susana was part of an intact, middle-income family. She and her siblings attended private school, which is common for middle-class families in many Latin American countries. Two of her siblings attended college. She was very close to her father growing up and remembers that “he loved me very, very much,” which made her parents’ divorce when she was six very difficult for Susana. This event required her mother’s return to work, but no matter what, “we never lacked bread, milk, meat, or fish . . . we always had food and a good education.” Continuing in private school was made possible by her mother’s industriousness, but also by Susana’s hard work and intellect, given that “we did well . . . we got good grades . . . . That helped out my mom a lot . . . then she did not have to pay much for us at school.”

Susana’s mother was strict with the children, especially after the divorce and particularly with the girls. There were rules, but “she also trusted [them].” Nonetheless, when Susana was 14 and still playing with dolls, her 16-year-old sister became pregnant—an occurrence that created a “war” in her family. The sister ran away to escape everyone’s wrath, but her mother found her, brought her home, and helped her finish
school and go on to college. For Susana, her sister’s actions meant that she now lived under her mother’s extremely close supervision. Not only was she not allowed to participate in many social activities, particularly those that were co-ed, her mother also delivered her to school (which was two blocks away) each morning, picked her up at the end of the day, then dropped her off at home to do her homework. When boys or “other friends” would approach her, Susana’s mother would “scold them . . . chase them away.”

After a couple of years Susana talked her mother into easing the restrictions on her social life. They reached an agreement that allowed her to go out but also required her to call home to let her mother know where she was, whom she was with, and what time she would be home. Her mother also had conversations with her regarding boys and relationships: what to expect, how to behave, and most importantly—given what had transpired with her sister—how to protect herself. Protection, however, was a matter of saying “no” to sexual relations or using the rhythm method of birth control. This information, while not sufficient, was still more than any given prior to her sister’s pregnancy.

By her second year of college Susana had not yet had her first sexual experience, though she learned from her friends that they had already engaged in sexual relations, and that they had “[done] it in this place or that . . . . They [said] they spent time at a hotel . . . and talked about [their experience].” She, on the other hand, had been dating a man for a couple of years, and they had not yet been intimate, which led her to ask herself, “What is wrong with me, why am I not having those experiences?” Susana soon decided that it was an experience she wanted, and at 24 years of age, during one of her “safe times of the month,” she was intimate with her boyfriend, a man she “knew . . . [she] would marry.”
By the time she was 25, Susana had almost finished college and her boyfriend was pressing her to marry. Her mother, however, did not like this man, telling her daughter, “he’s not for you . . . there’s something about him . . . don’t marry him.” Susana thought these were simply the words of a mother not wanting to lose her daughter, but nevertheless felt like she was caught in a vise. Between her boyfriend, her mother, working, and going to school, she felt great pressure. To relieve that pressure and to think about what she wanted to do, she went on a sojourn to Chile.

Chile was a splendid experience for Susana. She joined a choir and her singing was of such high quality that she was offered a scholarship to attend the music program at the top university in Santiago, the capital of Chile. Her mother and boyfriend, however, had other plans for her. Their combined entreaties eventually had the desired effect, and Susana returned to Peru. Things with her boyfriend, however, “were not right.” First, he was generally not feeling well, but more disturbingly, he was having terrible headaches. Susana finally convinced him to see a doctor, and when x-rays did not indicate anything wrong, he felt vindicated and for a while “felt better.”

The second issue with her boyfriend led Susana to break off their engagement and end their relationship. She discovered that while she was in Chile, he began dating a girl from his church who became pregnant. Then, via a series of events, she discovered that her boyfriend had in fact been seeing other women during the entirety of their relationship. While he denied everything, her mother’s warnings about this man now made sense; Susana’s decision to leave him was permanent. Two years later they ran into each other, and she was shocked by how sick he looked. He denied that his extreme weight loss was anything serious, and said “no” when Susana asked if he had AIDS.
Subsequently, she found out that he indeed had AIDS and, when she was tested, Susana found out that she herself was HIV positive.

Like several of the other women interviewed for this study, Susana’s response was to question how she could go on living with this disease, and to wonder what point there was in living if she was going to die from AIDS anyway. However, unlike many of the other women, but in concordance with her background, she consciously and purposefully decided to educate herself: “And off I went. I found a clinic where I could get care.” Her effort to be proactive at first was stymied. Susana discovered just how much she did not know about HIV/AIDS, how complicated the treatment could be, and even more to the point, how much it would cost to access the care she found—“I wasn’t working [then] and so I didn’t know how I was going to pay for [care].” Thus, Susana became so depressed she wanted to end her own life. The only person she could turn to, the only person who knew of her condition, was her sister, and indeed she came to Susana’s aid and “bought [her] medicine at first.”

Between the interactions with the people she met at the clinic and her sister’s help, Susana moved on, even finding a job that offered benefits. However, in Peru “medicine is not free”; it has to be paid for and “it’s expensive.” Even with health insurance and what she and her sister could pay, it was getting impossible to manage; depression set in again. As a solution, Susana’s sister, who is also a professional, moved to Mexico in the hope of finding better paying work so she could continue helping Susana. When things did not go well in Mexico, she immigrated to the U.S., where she had friends. Susana’s sister was able to continue helping her buy the medications she required.
Susana “did ok for a while.” However, her medications stopped having the desired effect, her “counts got real low,” and she began getting ill. When the medication regimens available in Peru were exhausted, she approached her doctor and asked, “What are we going to do now? What else am I going to take?” The doctor’s response was, “Now we keep giving you the medicine until you get so sick that we bring you into the hospital,” to which Susana replied, “What, to die?” And he didn’t say much to that, but his face said it all . . . and eventually [he] said, ‘Well . . .’”

Susana was not going to sit around waiting to die, however. As soon as she could, she made arrangements to travel to the U.S. to live with her sister. Once here, Susana “found a place to get treatment, got a job and started learning English.” Things were beginning to look up. However, the first and then the second medication regimens made her even sicker than she had been in Peru, leading her to become increasingly depressed and to question her decision to come to the U.S. Susana started planning how to get back to Peru because “if I am going to be that sick, maybe die, I might as well go back to my country since that is the only reason I came here.”

By now Susana’s CD4 (T-cell) counts had gotten low enough for her to be diagnosed with AIDS. Fortunately, an experimental treatment was found for which she qualified. This treatment had the desired effect and lacked the side effects Susana had suffered with her previous drug regimens. Her T-cells have improved and her viral load is undetectable. In addition, Susana’s doctors referred her for treatment for her depression, and to her great relief, it is also working well.

Susana has moved on and has even made some changes. When living with her sister made it impossible for Susana to continue the activities she had come to appreciate
and love (i.e., studying English, having a more professional job, living as she liked in her own room), she moved out of her sister’s home. Now she lives on her own in an area where she can access public transportation, dress as she likes, listen to music of her choosing, and worship as she wishes, whether it is in a Catholic church or in her sister’s very conservative Evangelical church. In spite of her successes, much of Susana’s future remains in question. Her medical treatment is experimental, and thus could stop working without something to replace it being available. In addition, her life in general is limited by her immigration status. For example, Susana would like to see her mother, yet going to Peru would put her at risk of not being able to return to the U.S.; she would love to go home to live, but the ongoing medical treatment that she needs is not available in Peru.

Analytic Commentary

Susana’s narrative summary recounts her life story, particularly as it speaks to her becoming HIV infected and now living with HIV as an immutable fact of life. Her biographical particulars, along with the sociocultural context of her life, display a clear path to her HIV infection and to being diagnosed with AIDS. Furthermore, many of the circumstances that contributed to Susana’s HIV infection continue to have an impact on her life as someone living with AIDS.

Early on, it appeared that Susana’s life trajectory would have taken her to a very different place than where she finds herself now. In spite of her parents’ divorce when she was six years old, Susana and her siblings had the benefit of a private school education. Indeed, all but one completed a college education. In addition, while not wealthy, they never lacked shelter, food, or clothing, and though as children they did not have health insurance, fortunately they were a healthy family.
While Susana was well educated academically and professionally, she lacked education regarding relationships with men and sexuality in general. Her mother, as a Latino single parent, kept the children and especially the girls close to home. Susana was not allowed to go out and play unless she was with her mother or older sister, and as she and her siblings got older they were not permitted to go to coed parties or to date. When Susana’s older sister got pregnant, her mother’s restrictions increased.

Susana’s school curriculum did not include sex education or education about STDs, including HIV/AIDS. What Susana did hear about HIV/AIDS she interpreted as not pertaining to her; she understood HIV to be a virus that infected people who were drug abusers, had multiple sexual partners, were prostitutes, or had received a blood transfusion—none of which applied to her. “Protection,” to Susana, amounted to not getting pregnant, and that was to be accomplished through the rhythm method, as espoused by the Catholic Church and by “what [she] heard from female friends.”

With all her education and independence, Susana nevertheless was a traditional Latino woman. She wanted to marry, have a home, and start a family. However, she was also naïve about men’s behavior when away from their steady partners, and was not accustomed to talking to men about sexual activity. For example, while she was busy with her university studies and with work, her longtime boyfriend, with whom she had not been sexually intimate, engaged in sexual intercourse with other women. When Susana became suspicious and questioned him, she chose to believe his denials. When she and her boyfriend finally became sexually intimate, it set her on a course very different from anything she had ever intended; instead of a future that included a
professional career and a family, she would instead have a life that focused on staying alive, in a country that is not her own, far from her mother, extended family, and friends.

Susana made an effort to take stock of her life and re-evaluate what she wanted for herself and for her future. She went to Chile to rest and get away from her life in Peru. Susana’s interests and engaging personality, as well as her talent and intellect, brought her to the attention of academics in Chile who offered Susana a music scholarship to the university there, as well as the opportunity to perform. She was quite excited about the offer and initially decided to accept it. However, Susana was dissuaded by her mother and her boyfriend, who convinced her to return to Peru “to be with them.”

Upon her return, Susana immediately began to see signs that her boyfriend was involved with other women, and that he was not well. He steadfastly denied that she had cause for concern on either front. It took Susana’s discovery that he had gotten another woman pregnant for her to finally break off her relationship with him. Unbeknownst to her, she was by that time already infected with HIV. When Susana discovered she was HIV positive, her education and independence helped her cope. She found a clinic that provided treatment and began receiving care, and became educated about HIV/AIDS. Susana was extremely fortunate that her sister was able and willing to help her pay for the medications, given that Susana’s health insurance was inadequate to meet her needs. Then, when they could no longer afford to continue buying Susana’s medications, her sister moved to Mexico in an effort to earn more money. When that proved insufficient as well, the sister immigrated to the U.S.

Unfortunately, Susana’s medications did not work as well as hoped, and she became more ill, eventually receiving an AIDS diagnosis. Her doctor advised her that
there was nothing else they could do until she became so ill that hospitalization was required. Susana called upon her considerable strength, faith, willpower, and independence and traveled to the U.S. to join her sister.

Once in the U.S. Susana, “by the grace of God” (and through her own hard work), found a clinic that provided services at no charge. Even so, her health declined to the point where it looked like she might succumb to an AIDS-related opportunistic infection. Susana implored her doctors to find another treatment. Through her own great effort and with help from her sister, with whom she was now living, she made it to all the doctors’ appointments and was enrolled in an experimental trial. As a result, her health began to improve. Susana even managed to find work, though at a level far lower than she is capable of, and began to learn English. She is grateful to all the elements that came together—her sister, her doctors, and most importantly her faith—for rescuing her from almost certain death.

Susana now faces the future with some degree of optimism. Nevertheless, it is a rather circumscribed future given that she is living with AIDS, has very limited access to work opportunities that pay a living wage, and is caught between her illegal immigrant status in the U.S. and her inability to get adequate medical care should she return to Peru. As a woman with loving parents and siblings, a college education, and considerable talents and abilities, she clearly hoped for more.

Marisol

Demographic Information

Marisol, at 48 years old, is the oldest woman interviewed for this study. She is petite, pretty, and soft-spoken. Originally from El Salvador, Marisol lives in a rural town
in the southeastern U.S. She, three of her children, a daughter-in-law, and a grandchild all share a home owned by one of the children. Marisol has been in this country for 17 years and proudly reported that she recently became a permanent resident of the U.S. She intends to become a citizen and knows that to do so will require being able not only to understand English (which she does already to an extent), but also to speak it, which she does infrequently. It is something she is seriously considering because, as she puts it, she wants to “have the honor” that being a citizen confers. Marisol wishes only that her current job as a nanny left her more time during the week to take an English class.

When Marisol first arrived in this country, she lived and worked in New York. She reports “it was much easier then, as an immigrant, to get a job.” At that time, she was supporting herself financially, as well as sending money to El Salvador to support her husband and children and saving money to bring them to the U.S. To this end, she worked two jobs, as a housekeeper and a seamstress. Once she began bringing her children to the U.S., her brother invited her to move from New York to where she lives today. This move, given the area and the current political climate, has placed greater limits on her opportunities for work. As a result, Marisol has never been able to consider herself above low income. She manages to live nicely, however, given the family’s unity and cooperation with each other, particularly in matters of living accommodations. Moreover, Marisol has been able to keep herself nicely dressed thanks to her talent for sewing—something in which she takes great pride.

Marisol’s room is one of two rooms in the daylight basement of the home she lives in. It is, in effect, a mother-in-law apartment. She has access to a full kitchen, a bathroom, and a utility room. Besides what looks to be a comfortable bed, Marisol has
given the room a cozy feel with many personal touches. She has a small television, two comfortable chairs, and a small refrigerator (though there is a full-sized refrigerator in the kitchen) for her use in the room. The area is well kept and neat, though not luxurious. Outside her apartment door, Marisol has planted and nurtured a small garden. The fairly rural neighborhood in which she lives is quiet and peaceful, thus adding charm to her living conditions.

Marisol and I bonded almost instantly, in part because of the relative closeness of our ages; I am only 10 years older than she. Furthermore, she has many of the mannerisms and speech patterns that my own mother had, as well as sharing some of the circumstances my mother found in the U.S., though their arrivals were separated by 20 years. Both women landed in New York at a time when things were very different for immigrants than they are today, particularly for those seeking economic opportunities and a different type of life as women. Also, both women went to Long Island, New York, to live and work as housecleaners; Marisol supplemented the income from her job as a nanny by sewing for others, and my mother added to her income by working as a live-in nanny. Finally, both Marisol and my mother shared a love of talking; they each spoke well, though Marisol was much more willing than my mother to talk about her life, particularly her childhood.

**Narrative Summary**

Marisol has lived most of her life in poverty, including in her family of origin. She said, however, that even though they were poor they still had “a lot of love growing up in . . . [their] family.” Her parents set a positive example as a couple, being kind to each other and staying together until her father died a year ago from cancer. Her parents
were strict and very traditional, particularly in terms of cultural tenets and dictums, as well as in their Catholic beliefs. God came first for her parents (as for Marisol), followed by their children, then each other. Marisol echoed her mother’s feeling that she “would give my life for the children . . . . I do whatever I have to . . . I am very protective of them.” As for beliefs about relationships between men and women, Marisol shared that she and her female siblings were taught that “you had to be a virgin when you married . . . . That having a partner means not being with someone else . . . . Everyone can have [sexual relations], but only if you are married and respect each other.”

Marisol was indeed a virgin when she married, and she married intending it to be for life. Things were “good at first,” she said, and she and her husband even went to church together “until we had our first baby.” Her husband then began mimicking his own father’s behavior and having extramarital affairs on a regular basis, which included having children with other women. Also, by the time their three other children were born, he was demonstrating a propensity for domestic violence towards his wife while lacking a proclivity for work. As a result, Marisol said with great emotion, “If you only knew how in my country I and my babies suffered hunger. We did not have clothes. I made our . . . clothes because I know how to sew pieces of rags together.” When Marisol finally saw that her husband, as she put it, “did not want to get ahead in life,” she decided to immigrate to the U.S. to find a better life for her family. Leaving the children with her parents and siblings, she traveled to New York on her own.

At first, life in the U.S. was very difficult for Marisol. She missed her children terribly, and her husband would neither contribute financially nor help with their day-to-day care. Within two years of arriving in the U.S., Marisol had saved enough money to
bring her husband to join her, thinking that now, together, they would be able to make a better life for themselves and their children. Much to her chagrin and heartache, when he arrived she discovered that he had a woman and child whom he had left in El Salvador. His intentions in coming were unclear given those circumstances. In addition, once in the U.S., her husband either refused to find work or, when he was working, refused to share in the household expenses. Marisol could not tolerate his behavior any longer and insisted on a separation. Her husband’s response was that if she “did not want anything to do with me, then he did not want anything to do with his children.” Marisol helped him buy a plane ticket to go back to El Salvador, though since that time, neither Marisol nor her children have had any contact with him. They know nothing of his life or whereabouts, though they presume he is back somewhere in El Salvador, where he was headed when he left the U.S.

Until she was able to bring all her children to the U.S., Marisol periodically traveled to El Salvador for visits. She would spend a month making sure they were well situated and then would return to the U.S., all with legal permission. After bringing the first of her four children to the U.S., her oldest, she began to “feel more consoled” and a little more at peace about her decision to move to the U.S. As Marisol saw it, coming here was “the right thing to do.” It also helped that she began to go to church again. She felt that the thoughts that “tormented me began to leave my head . . . in the church . . . I felt a lot of peace.”

The arrival of her first child in the U.S. coincided with the move from New York to the Southeast, where her brother was living. Marisol now took even greater refuge in the church and made it her second home. Feeling that what mattered to her “was . . . [her]
heart . . . becoming free of what was oppressing” her, Marisol cut ties to many of the things in her life she saw as representative of the oppression she felt, including what she wore. For example, she stopped wearing all the gold she had become accustomed to wearing because, as she said, it was what “people in New York did.”

Music was one of the mainstays of the church Marisol attended. The drummer in the church band courted Marisol until she agreed to go out with him. She was not looking to get involved with anyone again and felt distrustful of men—and to some degree, of people in general—so the courtship took time. Marisol took the time to get to know him well before she agreed to marry him.

This marriage was very different from her first. According to Marisol, her second husband “worked and was a true partner in many ways.” However, from the beginning of their marriage Marisol felt that he was keeping something from her. This feeling was so strong that she told him she knew he “was not telling . . . [her] something . . . . We are not a warehouse for keeping things inside.”

What he was keeping from her was the fact that he knew he was at least HIV positive, if not already progressed to AIDS. Marisol described herself as someone who “is not easily deceived, because there was something in here (pointing to her heart) that tells me that the person is not telling me the truth.” What helped deceive her, however, was that she knew nothing about HIV and its transmission, or what it meant to have AIDS. All she knew was that AIDS was something that made people very sick and then they died. Certainly her new husband did not fit the bill in Marisol’s eyes. In fact, she said, “it happened . . . and it was strange because he looked good, he looked fine . . .”
Eventually Marisol’s husband began to suffer from headaches, stomach ailments, fevers, and other maladies. The first major medical occurrence involved high fevers and trouble breathing. Marisol took him to the emergency room, where he was quickly admitted. That day she went to work and later received a call from her daughter saying that her husband had “escaped from the hospital . . . took the tubes out and everything . . . . [He] got a neighbor to bring him home . . . . He came home wearing his hospital gown.” Still Marisol did not know what was making him ill and no one who knew could (or did) tell her. His condition improved, though he continued to have the assorted illnesses from which he had previously suffered. He kept his medications in a locked box under the bed and did not allow Marisol to go near it. The only medication she ever saw him take was a small white pill.

He stopped working and stopped sleeping very much, particularly at night. During the day he watched television and took sleeping pills so that he would sleep during the day. He became increasingly depressed and progressively thinner. She described him as “wasting away.” It was a nightmare for Marisol, particularly as she did not know what was causing his illness. Everyone had ideas, including the notion that he was using heroin, which would explain why he was not eating and was getting so thin. The only person who suspected HIV/AIDS was a brother-in-law whose wife prevented him from telling Marisol of his suspicions. During his last illness, Marisol’s husband was literally carried to the hospital in someone’s arms against his wishes.

At the hospital Marisol’s husband underwent a battery of tests, and Marisol was informed of the reason her husband was so terribly ill. Her response was total disbelief;
the idea that AIDS could be killing her husband was completely outside her reality. She said:

I almost fainted and I did not know what to do. I was scared and thought, how could you have done this? Why didn’t you tell me the truth, and what would it have cost you? . . . . I did not need you for my papers, I already had my permissions. I would have married you anyway . . . . I would have always taken care of you but I needed for you to tell me the truth.

Marisol’s husband never responded to her questions, and literally hid his head under the sheets and blankets. He was placed in a hospice facility where he died soon after his admission. “Why Lord, why the lies, and that is what I can’t come to understand,” Marisol exclaimed.

Marisol herself was tested and found to be HIV positive. She has not yet begun a medication regimen; Marisol said she’s been told that she is not sick enough to do so yet. She now spends a lot of time alone. Her children have their own lives. Even living in the same house she does not see them as often or spend as much time with them as she would like. She attends church regularly, though she is not very close to anyone. Marisol spends a lot of time, she says, “talking to God and reading my Bible.” On several occasions, the daughter who lives in the set of rooms next to her has come in to see who she is talking to. Marisol says to me, “Thank God there is God to talk to, because if not, I would have no one.”

**Analytic Commentary**

Marisol’s narrative summary recounts her life story, particularly as it speaks to her becoming HIV infected and now living with HIV as an immutable fact of her life.
Her biographical particulars, along with the sociocultural context of her life, display a clear path to HIV infection.

Economically, Marisol came from humble beginnings. While she may have lacked material possessions and access to a quality education, however, neither she nor her siblings lacked parental love or cultural or religious education. They learned from their mother that a woman’s place was in the home and that children would always come first, that they were to be virgins when they married, and that the only thing that superseded any of those aspects of life was God. God came before anything else, even children.

Marisol grew up wanting a family, a “home with pretty things,” and a husband who would want those things as well. She had dated infrequently before meeting the man she married, and so had little experience with men. However, she did have her father as a role model. She picked someone who appeared to possess the qualities her father had—to be hard working, loyal, and trustworthy. Marisol’s choice of a spouse became a major turning point moment in her life.

Until the couple had their first child things were good between them. Marisol and her husband both worked, and they enjoyed each other’s company. She did note that he liked to go out a lot and drank more than she liked, but he took her with him so she did not think his behavior would become a problem. However, things changed after their first child was born. Her husband became boorish and abusive and went out all the time with his friends, though now he left his wife at home with their child.

Marisol shared that, “I married for life.” Being Catholic, divorce did not enter her mind, and culturally, she understood that she simply had to accept her husband’s
behavior. The couple had more children and her husband’s behavior deteriorated. He stopped working regularly. Although she could not prove it for a long time, Marisol suspected that when her husband went out he saw other women. Indeed, she found out much later that he not only had sex with other women, but also fathered several children out of wedlock.

To feed her children, Marisol did odd jobs and found items such as clothing that she could sell. To clothe herself and her children, she gathered up “rags that [I] sewed together so that I and my children would have something to wear.” Despite her efforts, Marisol and her children often went hungry.

Fortunately, Marisol was a strong woman. She arranged for her children to live with family members and immigrated to the U.S. to try to make a better living. Being an industrious woman and arriving at a time when it was easier for immigrants to enter this country and become employed, she quickly found work. However, she missed her children terribly and suffered from depression.

Eventually, Marisol saved enough money to bring her husband to join her in the U.S., naively thinking they would have a new start. However, this was not to be. When Marisol refused to tolerate his unwillingness to work and demanded a separation (though she did not want a divorce), he left, punishing Marisol and the children by refusing to have anything to do with any of them. Finally, she realized that this relationship would not work. Surprisingly, considering all that he had made Marisol suffer, she nevertheless helped her husband return to El Salvador. They presume he is still there, though neither Marisol nor her children have had any further contact with him.
Marisol’s depression grew worse after her husband returned to El Salvador, not because she missed him but because she felt he had made her “look like a fool.” As a result, she reports that on more than one occasion she “wanted to drink poison.” Marisol did not give in to the temptation, instead allowing her faith in God and her love for her children to override the suicidal thoughts. In addition, she was helped by her belief, as a Catholic, that in committing suicide she would be guilty of a mortal sin.

Despite all she had experienced, Marisol managed to work and save enough money to send for her children. She also sought and received support from two family members living in the Southeastern U.S. After relocating to that part of the country, she looked for support at church, changing allegiances and becoming Pentecostal. Marisol was happy with her new church. She made friends easily, got involved in church activities, and started dating again. Marisol was not hoping or expecting to remarry, so when one of the church members began wooing her, she resisted his advances. He was persistent, however, and her continuing desire for a “pretty home and family” eventually led to their marriage.

Although Marisol had lived in New York during the height of the AIDS epidemic, she was not aware of how much the disease had spread or that its cause was HIV, and she knew little about how one became infected. When Marisol and her novio first became intimate, she did not think to ask him to use a condom. Even though she sensed that “there was something that he wasn’t telling me, something that he was hiding,” she nevertheless chose not to trust her instincts, opting instead to trust this man. Because they had met in church, she believed he therefore must be trustworthy. Marisol admitted, however, that while she had this “hunch,” she never dreamed that the secret he was
keeping from her was his HIV status. He chose not to tell her that he was HIV positive and chose not to use a condom to protect her from becoming HIV infected as well. Although he had been advised by his medical care providers to tell her of his condition, he did not tell her, and Marisol became infected with HIV as a result.

Her ignorance about HIV and AIDS extended to a lack of knowledge regarding the signs and symptoms of AIDS. As her husband grew increasingly ill, Marisol failed to grasp either the gravity of his condition or its potential to affect her as well. His care providers failed to convince him to inform her of his condition, so she did not find out until his final hospitalization. In addition, the local health department failed to perform a contact tracing, namely, contacting anyone with whom an HIV-infected person had sexual contact, as required by state law. Performing such due diligence would have warned Marisol of her contact with a person who had developed AIDS. To date, Marisol is not aware that the health department had a legal responsibility to warn her.

Marisol has finally gone back to church and, as she shared, “much as I liked having sex, I am now celibate and intend to stay that way.” She is happy to have God to talk to and a grandchild to dote on. Marisol still has trouble accepting that someone who claimed to love her would have hurt her in this way, and could have been so selfish as to conceal his HIV status. It is ironic that her husband’s fear of her leaving him was baseless. She believed in “marrying forever, no matter what . . . I never would have left him. I loved him.” Thus Marisol “forgave him,” blaming herself for failing to trust her instincts and for allowing herself to be deceived yet again.
Demographic Information

Mercedes is a 25-year-old woman from Belize who attended school through the ninth grade. She is single, has never been married, and does not have children. Mercedes has been in the U.S. for four years and speaks very little English, though she has made efforts to learn it. She left home at the age of 15 and has been on her own ever since. Mercedes reported always having had a low socioeconomic status, even when she was employed. She worked only briefly before she was hospitalized and diagnosed with AIDS. Mercedes spent almost two months in the hospital in the course of three separate hospital admissions. Since being released from the hospital she has not been able to find work, and financially, things have gotten worse rather than better.

I was on time for the interview with this bright, attractive, and very pleasant young woman. She was casually but nicely dressed and had a generally healthy appearance. Nevertheless, her outward appearance belied the sadness and loneliness she appeared to feel and which was evident at various points in the interview. Since this was a morning interview, I brought orange juice, coffee, and breakfast food from a shop in her neighborhood; she was happy to have the food and especially the coffee. We sat on a comfortable sofa in her living room; her boyfriend and their renter were both at work. The apartment was large, well kept, and not too warm, though it was hot outside.

Mercedes was somewhat nervous at the start of the interview, though drinking coffee together, chatting about nothing in particular, and telling her about the research and why I was conducting it put her more at ease. At that point she began speaking
candidly and easily and continued to do so throughout the interview, even when she was talking about difficult matters.

**Narrative Summary**

Mercedes remembered her life as a very young child as “real nice.” Her family was of a low socioeconomic status, but they were happy and had enough to eat and a roof over their heads. Although they were Catholic, religion did not play a big role in their lives. Things changed, however, after her parents divorced. She and her sister stayed with their mother, and two months later their mother remarried. Mercedes said of this time, “it was real difficult to adapt to another person that one doesn’t know.” Her mother began giving priority to “other things instead of [her] children,” as Mercedes saw the situation. From the beginning neither sister got along with their stepfather; as time went on, things got progressively worse.

The sisters, and especially Mercedes, were popular at school and had many friends. Whether the stepfather did not like her friends, was jealous, or whether something else was going on was not clear. Whatever his motivation, he lied to Mercedes’ mother about what Mercedes was doing with her friends. Her mother believed him rather than Mercedes and became physically abusive with Mercedes, mimicking her stepfather’s treatment of her.

Mercedes’ stepfather was mean and authoritarian and when he drank, which he did often, he became louder and more abusive. He began molesting her, though she denied that there was ever an incident involving penetration. Whenever she refused to do what he asked (and when he drank, Mercedes reported that he “wanted everything done for him”), the stepfather would tell Mercedes’ mother about some infraction Mercedes
had allegedly committed. Rather than ask Mercedes what had happened, her mother simply believed her husband and punished Mercedes. Her stepfather’s behavior also provoked jealousy in her mother, as her mother did not like all the attention he paid Mercedes. Mercedes surmised that her mother suspected he was either molesting Mercedes or otherwise behaving inappropriately with her, and she blamed Mercedes for his behavior.

Mercedes left home, afraid it was only a matter of time before her stepfather’s constant touching and inappropriate kissing would become an attempt to force her to have intercourse with him. She had no place to go, so she spent many days on the street, sleeping and eating where she could. Having no money and no one to turn to for help, Mercedes got a job at a bar where she could also rent a room.

The job at the bar entailed more than serving drinks. Mercedes would have sex in her room with men she met, though she firmly denies being forced to do this as part of her job. Rather, she said that she either liked the man and wanted to “have a good time,” or wanted to make money “to buy the things I needed, like tampons and things like that . . . I had no one to take care of me so I had to do what I had to do.”

Mercedes had no prior education about sexual matters, her own body, or how to protect herself from pregnancy or disease. She knew nothing about HIV/AIDS: what it was, how it was transmitted, or how it affected people. On-the-job training, as it were, taught her that she needed to use condoms if she did not want to become pregnant. She took this lesson very seriously, saying that:

Yes, there were many times that I had relations and the man would say that he did not like to use condoms and since they were not my boyfriend and nothing to me,
I was not interested in having relations without a condom. So I would tell him that he would have to use a condom or we would not have relations.

The whole time she lived and worked at the bar she never once had sex without a condom.

Eventually Mercedes came to feel that “the life that I was living was fun but it was a very lonely life . . . . You would laugh with everyone while you were with them but when you were alone it was very difficult.” When she met a man who “treated me well and everything . . . then [he] told me he loved me and wanted to take me from this place,” Mercedes decided it was time to leave the bar. She moved in with him and they were together for approximately five years. Mercedes said, “Yes, he was good at first. Well, later life was harder because he was a libertine.” Further, she imagined that he was also having sex with other women while he was out having fun.

Things between Mercedes and her boyfriend became increasingly difficult, and they began to fight regularly. He “pushed me, said bad and nasty words, and things like that, but he never hit me.” However, the fight that ensued after Mercedes came home to find him in bed with another woman became very intense, and this time he did hit her. Mercedes left. When she told her mother what had happened, her mother allowed her to come home, offering to support her so she could separate from this man. Mercedes took her up on the offer but the arrangement did not last long, as Mercedes’ mother blamed her for her situation. She told Mercedes, “if you knew that he liked to go out and everything and accepted him like that . . . then everything that happened to . . . [you] was because . . . [you] accepted it.”
Mercedes quickly realized that living at her mother’s house was not going to work. First, there was her mother’s verbally abusive behavior towards her. Second, although her novio was having affairs with other women, he did not want Mercedes to leave him. She discovered that he was a local gang member, had lots of friends, and was not going to let her get away with making him look bad by leaving him. So, to escape from him permanently and to protect herself, Mercedes found a way to travel to the U.S.

A year or two after arriving in the U.S., Mercedes began having terrible headaches that did not respond to any of the medications she took. She would not go to the hospital, however. Initially she thought the headaches would go away. Further, she had no health insurance and was barely making ends meet with the work she was able to find. Eventually she had no choice but to let a friend take her to the emergency room. She was admitted to the hospital and given a battery of tests. After three days a doctor came to her and told her she was HIV positive. All Mercedes could think was that now she would surely die.

Mercedes was discharged from the hospital after 15 days, and was instructed to go to the clinic in three days for medication and follow-up care. Mercedes did not follow the instructions. Like at least two other women interviewed for this study, she planned instead to kill herself (in Mercedes’ case, by throwing herself in front of a train).

Mercedes was admitted to the hospital again a week later and was diagnosed with toxoplasmosis, a parasitic infection (in her case in the brain) that now qualified her for an AIDS diagnosis. Her CD4 cell count was extremely low, indicating that her condition was serious and potentially fatal. She started taking the prescribed medications, but was
not able to take them without vomiting. She was hospitalized once more before her condition stabilized enough to enable her to take the medicine without vomiting.

Mercedes shared that during this last hospitalization she had a “vision.” She described it as “having seen, but not really seen, Jesus floating right above me.” Mercedes came to understand during this vision that “it was not [her] time” to die. Thereafter, she felt a sheer determination to survive and hung on to a will to live, both of which led her to take the prescribed medication regimen exactly as directed. Mercedes considers herself lucky to have done so well. People she knew who started out in much better condition have already died. Mercedes remembers one in particular, a woman she met at the clinic, who died because she “could not tolerate the medicine and just didn’t take it.”

A man who was first her friend, someone with whom she occasionally had sex, became her boyfriend. This man has supported Mercedes more than she ever expected anyone would. He was fortunate because in the beginning of their relationship they did not use condoms when having sex; he has since been tested several times and continues to be HIV negative. Now they use condoms religiously.

Mercedes feels lucky that she has people who support her. She attends a support group sponsored by the clinic where she receives medical care, and has a therapist who works with her at home. Even more valuable, she feels, is the support she gets from her boyfriend. Wistfully, Mercedes talked about how wonderful it would be if she could also have her family by her side as she walks down this path. She knows that more than likely, however, she will never have the freedom to go home again.
Analytic Commentary

Mercedes’ biographical particulars, along with the sociocultural context of her life, display a clear path to her HIV infection and to being diagnosed with AIDS. Furthermore, many of the circumstances that contributed to Mercedes’ HIV infection continue to have an impact on her life as a person living with AIDS.

Mercedes’ life began as so many other lives begin in Belize, the country of her birth. She was born into a poor, though intact family. As a young girl she felt loved, particularly by her father, with whom she was very close. Her parents’ divorce, therefore, was a difficult moment in Mercedes’ life. It was also one of several turning points in her life. She is still not clear why her parents divorced; all that Mercedes is sure of is that from that moment on, her life was never the same.

Within six months of the divorce, Mercedes’ mother had a boyfriend. She not only allowed him to move in with her and her children, but also welcomed his taking over the role of “father,” much to the consternation of the children. Mercedes was particularly worried and upset that his interest seemed to focus on her. It is hard to know what his motives were initially, but his actions clearly created a rift between Mercedes and her mother. He made accusations about Mercedes’ behavior at school, claiming that she was misbehaving in various ways. He made a special point of telling her mother that he had seen Mercedes involved with boys in the schoolyard. In addition, he began making sexual advances towards Mercedes. For example, he would fondle her, force her to kiss him, or force his kisses on her. When Mercedes tried to tell her mother about his behavior, her mother chose to believe her husband instead of her daughter. Feeling threatened, Mercedes left home to live on the streets at the age of 15. Her mother did
nothing to stop her from leaving, and Mercedes believes that her mother did not try to find her once she left.

After spending several nights sleeping on the streets and begging for money to buy food, Mercedes found a job and place to sleep in a local bar. Although her room was part of the establishment, Mercedes denied that she was required to have sex with customers, though if she wanted to, she could. She eventually decided to have sex with selected men, rationalizing that she had to be able to “buy the things I needed,” and that she had a right to “have fun and not be lonely.”

Mercedes had no sex education, nor had she been taught anything about her own body. What she learned, she learned from other women at the bar, either from observation or direct questions. She had no knowledge regarding STDs, though she had learned (from an unspecified source) that for women in her circumstances the best way to prevent pregnancy was to use a condom.

It is not hard to imagine that a girl her age would be frightened and lonely living and working in a bar. Yet she managed to survive, and in fairly good shape. She had the wherewithal to keep herself “safe” from the dangers she recognized, including pregnancy and being taken advantage of by older men. Still, she was lonely and wanted a different life. So when she met a good-looking young man who seemed different from the other bar patrons and he invited her to live with him, she happily accepted his invitation.

At first things went well between Mercedes and her boyfriend. He treated her kindly and provided the security she had not had for a long time. They spent time together and when he went out, Mercedes always went along. Her trust in him was such that when they had intercourse, she did not even consider asking him to use a condom.
This became another turning point moment in her life, though she did not know it for at least another year.

As time went on, however, the relationship deteriorated. Her boyfriend went out without her, stayed out late, and at times did not come home. He was unwilling to tolerate being questioned, though Mercedes increasingly tried. He denied sleeping with other women and responded to her challenges by becoming nasty, calling her names, and frequently shouting at her when they spoke. He never hit Mercedes, she said, until she came home one day and found him in their bed with another woman. When she reacted by getting angry and raising her voice, he responded by hitting her. Mercedes left her boyfriend and went back to her mother’s home. However, her mother felt Mercedes had no reason to complain; somehow, in her view, what happened was Mercedes’ own fault. As a result, Mercedes was not able to stay with her mother for long.

Another factor that complicated Mercedes’ life was her discovery that her boyfriend was a member of a well-known, well-organized gang. If she were to stay in Belize she would never be able to fully get away from him; indeed, she feared that her life would be in danger. The only way out she could see was to leave the country and go where he could not find her.

Mercedes managed to accomplish a task that was far from easy: She traveled to the U.S., found a place to live, and secured a job. For a while it seemed that she had finally found peace and happiness. When Mercedes began having headaches, she treated them with over-the-counter analgesics. However, instead of going away, the headaches worsened both in frequency and intensity. The medication she was taking stopped being effective. The headaches worsened until the pain became so unbearable that she allowed
a friend to take her to the emergency room at the local hospital. After hours of radiologic exams and laboratory work, Mercedes was admitted to the hospital for further tests. At the end of the testing, she was informed that she had AIDS. Mercedes spent approximately one month in the hospital that first time, during which time she was literally pulled back from the brink of death.

Mercedes had a difficult time adjusting to her diagnosis. Initially she resisted taking her prescribed medications and was hospitalized a second time as a result. When her body could not tolerate the medications she was hospitalized a third time. Between the first and third hospitalizations she planned how she would kill herself, eventually deciding to throw herself in front of a train. However, she had a “vision . . . [she] saw God . . . who told [her] it was not [her] time [to die].” The vision was another turning point moment in her life; it brought her back to her faith.

Being back in touch with her belief in God has allowed Mercedes to appreciate the few people she does now have in her life. She has been especially buoyed by a male friend who has become her greatest source of support as well as her intimate partner. In addition, Mercedes has made use of the support system available through the medical clinic that provides her care and medications. With all that she has, however, it is clear that she is also lonely. Mercedes has not been able to find work since her diagnosis and spends her days at home alone. She doesn’t drive, and getting around on public transportation, while possible, is difficult. Not having a personal source of income discourages her from spending any money that is available. Furthermore, the only people who know of her medical status are her boyfriend and people she knows at the clinic. People with whom she socializes, such as her female roommate and her roommate’s
friends, do not know that she has AIDS. Mercedes does not want them to know, as she fears being stigmatized by them. She has good cause for concern, given the comments she has heard them make in reference to those who are HIV infected.

Mercedes, in spite of—or perhaps because of—her current and past challenges, has managed to find meaning in her predicament. She has done so by helping others who, like herself, are facing difficult circumstances. Understanding how difficult it is to work through the initial discovery of an HIV/AIDS infection towards accepting the condition and tolerating the medications required for treatment, Mercedes encourages others to push through the difficulties and give themselves a chance to do well. She does all of this despite an uncertain future—one in which she is unlikely ever to return to Belize, where her family still lives.

Summary

Even with all the reading, studying, and researching I engaged in prior to collecting the narratives, I began the interview process not knowing what I would find. Would the women be open with me? Would their stories be anything like what I had read previously? How would it be to listen as a social work researcher rather than a social worker assigned to assist them? How would it feel to identify with them in so many ways, yet be so different at the same time?

I was stunned by some of the things I heard and not at all surprised by others. In many instances, the data contained in the women’s narratives reflect the findings of studies previously conducted. Often, however, the data were not merely substantiated by the literature. Rather, the women’s stories and words gave substance, context, and depth to previous research findings.
The two findings that are most evident from even a cursory reading of the narrative summaries, and that I found most surprising, were the high levels of violence in the women’s lives and the low level of education most of them received. By education I do not refer solely to years of formal schooling; I refer also to the lack of education about sexuality and HIV/AIDS. These findings will be discussed in more detail in later chapters.

The women were all hospitable, warm, open, and kind. Those who were initially apprehensive quickly warmed up, and all were cooperative. Even when they could not comprehend why I would be interested in some of the topics I brought up—as, for example, when I asked them to tell me about their childhoods—they nevertheless answered the questions. When I asked for intimate details of their lives, as when I asked if they had ever had conversations with their novio, boyfriend, or spouse about protecting themselves during sexual relations, they still cooperated. This last type of question, however, raised another dilemma that merits further discussion here.

For most if not all of the women, asking questions in their more formal phrasing clearly did not produce the same results as asking the questions in their more common, vernacular parlance. When I asked, “Did you discuss using condoms with your novio before having sex?” or when I used specific words for anatomical parts, for example, penis or vagina, the terms and phrasing made some of the women blush or titter as they responded. Using vernacular terms led to more direct responses and to questions that did not require explanation. The women were thus able to feel that I would understand them, as they understood me, without requiring explanations.
The conversations as a result were more intimate, which in turn deepened the level of the information the women were willing to share. It is important to note that this was not a “technique” I used to get the women to talk. Rather, it was a naturally occurring way of speaking that arose out of the women and me not just feeling, but being related—as two people with something profound in common. It was also made possible by speaking to each other directly in our shared native language, thereby accessing the feelings and emotions that contextualized their experiences.

This leads to another important characteristic of this study. Aside from my intellect, personality, and training, the most valuable assets I brought to this research were my native Spanish-speaking ability and my identity as a Latino woman. The value of being able to speak to the women in their own tongue, or at least in the language in which they are most comfortable speaking about the intimate details of their lives, cannot be overestimated. From the very first conversation in which we set up meeting times and other details of our interactions, the women spoke to me directly and could weigh for themselves whether I was someone they could talk to, someone who would understand them, and most importantly, someone they could trust. Not having to use an interpreter allowed us to have a direct relationship, which was an invaluable asset in establishing rapport.

Further evidence of the importance of speaking the women’s primary language is evinced in their day-to-day medical care. For all the women, the people on their care teams whom they most connect with, the ones they most trust, confide in, and turn to in times of trouble or need, are the interpreters or the Spanish-speaking provider (in the case
of the women in this study, the provider was a therapist from an HIV/AIDS service organization).

To recruit women for this research project, I first approached the people in the organization who had the authority to grant access to potential participants. Prospective participants were then invited to consider being a part of the study by someone on their care team. Subsequently, either the women were given my number to call, or they requested that I call them to set up interview appointments. All interview dates, times, and places were set by the women, and all chose to conduct the interviews in their homes at various hours of the day. I met one spouse and several sets of children.

While in many ways the interviews followed a conventional style, they also diverged from conventional techniques in some ways. All of the homes could be described as casual settings and all the participants wore casual, though respectful, dress. While for some the “formal” part of the interview took on a question-and-answer type format, all also included segments of time before and after the recorded portions of the interview that were more personal in nature. During those times, the women asked personal questions of me, such as whether I was married or had children. In those interviews in which I shared that I had personally taken care of people with AIDS and had a family member who was HIV positive, the women demonstrated great interest by asking many questions. Some interviews involved drinking coffee or tea and eating various specialty foods that the women had prepared especially for me. I brought snacks or other foodstuffs to all but the first two interviews. Everything I brought was purchased in the woman’s neighborhood, and in many cases the items were country specific, such as
pan dulce (sweet bread) from the Salvadorian bakery. The participants clearly appreciated this gesture.

Finally, the women’s recounting of their narratives was very engaging and authentic. For some, this was an opportunity to unburden themselves of feelings they had about of their experiences. Some women spoke haltingly, at times having to be prodded to expand on things they said. Other women spoke much more forcefully, with one leaving me feeling as if she had been holding on to all she had told me for a very long time. All of the women spoke with the knowledge, or at least the hope, that their stories would help other women avoid their own fate.
CHAPTER V
FINDINGS: COMPARATIVE ANALYSIS

In Chapter IV, I introduced readers to the nine study participants through a three-part presentation of their narratives: a demographic profile, a narrative summary (the first level of analysis), and an analytic commentary (the second level of analysis). Adapting the analytic schema suggested by Chase (2005), I presented the participants first as individuals before asking readers to understand and appreciate their similarities and differences. Presenting the data in this manner was critical to underscoring individual contributions to the gestalt of the participants’ master narrative of living with HIV/AIDS.

Chapter V comprises a comparative analysis of the participants’ HIV/AIDS narratives—the third and final level of analysis. Adapting Polkinghorne’s (1995) paradigmatic-type analysis model, I returned to the original transcripts of participants’ individual narratives, reexamining them through the biographic lens suggested by Denzin (1989) and described in detail in previous chapters. I determined what, if anything, I might have missed in my first pass through the data when I identified the themes contained therein.

After completing this process, I compared and contrasted all themes across narratives, looking for similarities and differences among these themes. I paid particular attention to those factors unique to the experience of being Latina and living with HIV/AIDS (D. Stevens & Doerr, 1997) and those that are hallmarks of the contexts within which the participants grapple with HIV/AIDS—socioeconomic, gender-related,
and cultural factors. Such factors are defined by Denzin (1989) as biographical elements having particular impact on people’s lives regardless of what they might be confronting in their daily living. Lastly, I assessed how the participants’ lives were impacted by these biographical elements individually and/or in concert.

This research was motivated in part by the paucity of studies focusing solely on Latinas’ emic perspectives on living life as HIV/AIDS-positive women. The research questions, what issues contribute to Latinas becoming infected with HIV, what factors, or confluence of factors, play a role in Latinas living with HIV/AIDS, what does being infected with HIV/AIDS mean to Latinas, and how do Latinas make sense of being infected with HIV/AIDS within the broader context of their lives, were thus designed to illuminate the critical elements of that experience, and they can provide the framework for presenting the findings (see Table 2).

Contributing Issues to HIV Infection

Analysis of the nine HIV/AIDS narratives comprising the study revealed that the following issues contributed to the participants becoming HIV infected: lack of education, domestic violence, culturally prescribed norms, and religious tenets. The first two issues were commonly experienced among the participants, and exerted a strong and direct influence both on their lives and in becoming HIV infected. The other issues were no less consequential, though their effect was greater as they intersected with, and potentiated, a lack of education and the pervasiveness of domestic violence.

**Lack of Education**

Lack of education in the participants’ lives consisted of both inadequate formal schooling and a dearth of education specifically about HIV/AIDS. Pilar’s and Susana’s
HIV infections were directly linked to the latter, while those of Carmen, Paz, Gloria, Valencia, Isabel, Marisol, and Mercedes were associated with both. A lack of education

Table 2

*Conceptual Themes and Respective Properties*

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<tr>
<th>Research Questions</th>
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<td>Contributing issues to HIV infection</td>
<td>Lack of education</td>
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<td>Insufficient formal education</td>
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<td>Scant HIV/AIDS information</td>
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<td>Culturally-prescribed gender norms</td>
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<td>Being a good caregiver</td>
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<td>Summoning courage in adversity</td>
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<td>Making sense of an HIV/AIDS diagnosis</td>
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<td>Deepened relationship with God</td>
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<td>Resolve to prevent infection in others</td>
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is a critical risk factor for becoming HIV infected and for progressing to AIDS at a rate faster than it is for more educated individuals (CDC, 2006a).
Insufficient formal education. When money was scarce, one of the first things to be eliminated from families’ daily lives was education for females. For eight of the participants, termination of their education was a turning point moment, that is, a moment that in some way changed the course of their lives (N. K. Denzin, 1989). For Isabel, the moment came when her mother began working longer and longer hours, and she could not afford to pay someone else to take care of the children. Speaking matter-of-factly, Isabel, who grew up in a single-parent household, shared the following:

My mother worked at the hospital all day and I stayed home alone with my brother and sister . . . my other brother lived with someone else . . . I cooked for them and washed clothes . . . I did all those things from a very young age and that’s why I didn’t finish school. Instead of having a childhood, I learned how to be a mother at a young age.

Valencia, in contrast, grew up with two “very loving parents.” However, she said of their circumstances:

We were very poor . . . [and had] no electricity in our house . . . . That is why I only studied to the second grade . . . . I stayed home to help take care of the younger kids and took care of the house while my mother was at work.

In the participants’ countries of origin, it is not unusual for families to stop sending their children to school after a certain point, and this is done without legal penalty. While public education is available in these countries, it is costly, as parents must pay for uniforms, shoes, school supplies, books, and the myriad other materials students need, and that in the U.S. are supplied by the schools themselves. Keeping children at home thus cuts down considerably on household expenses. For a family such
as Valencia’s, living in what can best be described as abject poverty, it often becomes necessary to choose between feeding and minimally clothing children or sending them to school.

For participants like Mercedes, family circumstances other than poverty impacted their ability to get an education. Her parents divorced and, as Mercedes recounted, “They went their own way . . . My sister and I stayed with our mother . . . We moved from one place to another.” The instability disrupted their education, and the subsequent abuse Mercedes suffered at the hands of her new stepfather only made matters worse. In response, she left home and school, and never finished her education.

In contrast to the seven participants who either did not make it to the ninth grade or did not go beyond it, Susana and Pilar both attended college and became professionals in their native country. The difference was two-fold: Susana and Pilar came from lower middle-income as opposed to poor families, and they had mothers who were determined to see their children go to college no matter what it took. When asked about how she managed to attend college, Pilar responded:

In the first place, my mother is a woman who came from a professional family. She, regretfully, was not able to study as her younger brothers did. She and her older brother [who also did not attend college] were the ones who helped my grandmother move ahead in life, as [my grandmother] was a single mother and raised the children on her own. And so my mother always dreamed that her children would become professionals. My mother’s words always stayed in my head: “We are poor and we don’t have money to leave you as an inheritance, so
the best inheritance that I can leave you is a profession.” My mother always
wanted us to be professionals so that we could get ahead in life.

While privileged by their level of formal education, however, Susana and Pilar were
nevertheless not spared the effects of not having an HIV/AIDS education. The schooling
that they and other participants in this study did receive did not teach them how to protect
themselves from becoming HIV infected.

Scant HIV/AIDS information. The nine HIV/AIDS-infected study participants
embody the results of failing to educate people in a forthright and open manner about
HIV/AIDS. In fact, only Pilar reported ever having heard a presentation or discussion
about HIV and its transmission. When asked specifically what she knew about
HIV/AIDS before coming to the U.S., or before discovering she was HIV positive, Pilar
responded, “In school they taught that it’s transmitted with needles, with a blood
transfusion, and having relations . . . . They said, to ‘take care of yourself . . . [do] not
inject with the same needles.’” Like so many other participants, Pilar stopped talking
without explaining what to “take care of yourself” meant. When asked, she responded
that it meant, “When having sex, use protection.” I asked her to clarify what she
understood the phrase, “use protection” to mean, to which she replied simply, “use
condoms.” When Pilar first met her second husband, however, she did not use condoms.
When asked why, she commented:

We didn’t talk about using condoms and we didn’t use condoms. No, I say now
that it was ignorance on my part because . . . you see the news . . . it is a disease
that has been going around the world for years. They say, “be safe, wear
protection,” they talked about prevention, prevention, but when you are in your real life . . . . I did not do it.

Susana, the other college graduate, had beliefs similar to those of Pilar and others in the study. She noted:

No, I did not know how to protect myself but what happened was that . . .

[searching for words] . . . . That I did not . . . that was so distant for me because I was not a prostitute, I would not sleep with many guys, I would not inject myself [with vitamins, a not uncommon practice in Latin American countries], and I was not a drug addict. Because that is how it is presented in Peru, when it is presented.

The other participants who had heard “something about AIDS,” for example, Carmen, had “only [seen it] on television” and “only in passing.” They also either did not believe what they heard or thought “it could not happen to me.” Carmen, looking sheepish, voiced her response to the minimal information about HIV/AIDS she had received:

I did not believe it. I thought that it only happens to people, well, like I saw on television, to people that would sleep around without protection. I said, well, that is not going to happen to me [laughs]. But it happened.

Mercedes, who at 15 began living on the streets to escape her mother’s and stepfather’s abuse, shared the following:

When I began having sex I had never heard of AIDS. Then several years later, I heard that there was a lot of AIDS and that people were dying of AIDS . . . . That is how I began hearing about AIDS – I would hear that a certain person died.
What did they die of? They died of AIDS but I really did not know—how? How could I get AIDS? I never thought it could happen to me.

Valencia, unaccustomed to talking about herself, summed up succinctly the participants’ feelings about their relationship to HIV/AIDS: “No, never in my life did I think that was something that I would have . . . never . . . it never entered my mind.”

Marisol, whose manner of speaking and use of language belied her lack of formal education, demonstrated that simply living in the U.S. for most of one’s adult life does not ensure acquiring knowledge about HIV and its transmission, its progression to AIDS, or what an AIDS diagnosis signifies. Marisol arrived in the U.S. in November of 1989, at a time when the AIDS epidemic was widespread and frequently covered in both television and print media; it also appeared as a theme in various network television programs. Marisol lived and worked on Long Island, New York, a place close to Manhattan, one of the epicenters of the epidemic. One, therefore, might expect that Marisol would be educated about HIV and its basic transmission mechanisms, if not about AIDS. But, when asked what she knew about HIV/AIDS prior to learning that she was HIV positive, Marisol said:

Nothing . . . I had never seen anything . . . . I would go to my checkups in New York but they never told me anything. I never had seen anything on television . . . . [But] I hardly watched television because I was working . . . . It was [in Georgia] that I saw on television how people would feel, how they got, and everything that would happen [when they got HIV/AIDS]. Only one time [I saw something] but everything had already happened to me.
Marisol shared that before she and her husband married she had “a feeling there was something he was hiding.” Attempting to draw him out, she said to him on more than one occasion, “I know that you are not telling me something.” And although he refused to talk, she married him nonetheless. Marisol’s questions turned into more serious attempts to uncover what he was “hiding,” she said, only after several months of marriage.

Marisol’s narrative demonstrates the consequences of not being familiar with how HIV/AIDS might express itself in one’s physical appearance and health in general. In recounting this part of her story, Marisol’s affect, facial expression, and manner of speaking all suggested that she cared greatly about what others would think regarding her “being deceived in this way.” In particular, she seemed eager to make me aware of why she did not know her husband was living with AIDS, probably from the time they met, and certainly for the last two years of his life. Looking at me with an expression that communicated that she was desperate for me to believe her, Marisol shared,

It was strange because he looked good, he looked fine . . . . Like I told you, as a result of being ignorant, things happen to a person. I did not know anything specific, but I did know he was keeping something from me . . . . It was an ordeal but he got better that time.

Marisol’s husband did not tell her why he had come home without being discharged from the hospital, or what he had been treated for. She did find out subsequently that he was receiving follow-up care, including medication from a clinic, which he kept in a locked box under their bed. However, until he died, Marisol remained unaware of what medications were in the box or what they were intended to treat; the key to the box stayed hidden until well after her husband died. She remarked:
All I ever saw him take was a little white one [pill], but he said it was for a fungus. He had a nail he was losing and he had something like what I have here on my hand that looked like little rashes. And that the pill was for that and I believed him . . . . He was fine for only one year but that year he did not want to go to church. He only stayed in the house. He was always in the house and no one could take him out of the house. He hardly worked and then he did not go to work at all. He was not sleeping at night. I had to sleep separately from him because I had to sleep because I did work. He would not sleep and spent all his time watching television and took sleeping pills . . . . He was getting more and more depressed and was wasting away. I was very concerned when he stopped eating . . . . His eyes starting sinking in more and more every day . . . . I would ask him to tell me what he had, please tell me what you have and please eat . . . . He would urinate in the bed. I went through a lot with him. His feet and knees were getting stiff and when I would take him to the bathroom he would fall. You could see he was real bad but he did not want me to help him . . . . I think he made in the bed [urinated] because he had taken too many pills at night . . . trying to overdose I think.

Marisol continued in this vein for a while longer until I eventually was moved to ask, “Did you even suspect his illness might be AIDS?” She responded:

“No, I had never seen anything. I was so ignorant, I couldn’t even imagine. The only one that was suspicious was my brother-in-law, an American . . . He told my sister . . . [who said] “Oh no, leave that alone. . . I don’t think so, not Junior” . . . . When he was real bad I could not handle him anymore . . . . I took him to the
hospital, well, my son [took him] in his arms . . . . And we took him to the hospital . . . They did all kinds of tests, of everything, and when they started telling us what was going on, what he had, I almost died. I almost fainted and I did not know what to do . . . . He died in a hospice.

*Domestic Violence*

The phrase *domestic violence* (DV), as opposed to *intimate partner violence* (IPV), is consciously employed here as it is broader in scope and encompasses all types of violence occurring in the home, including violence between parents and children. The participants experienced various forms of DV in their families of origin, stepfamilies, and/or intimate partner relationships. Some were abused by a parent while others were physically and/or sexually assaulted by intimate partners, which made them fearful of suggesting condom use, much less insisting on it. Partner assault included being forced to have sex, or not being allowed to use condoms, or both. Four of the participants were infected by having sexual relations with an HIV-infected or AIDS-diagnosed partner. They did so not knowing their partners’ HIV/AIDS status.

Gloria and Mercedes experienced violence in their childhoods. Gloria initially did not mention DV as an element in her life growing up. However, when she talked about what she learned from her mother about social and sexual relations with men, Gloria indicated that her father had been violent towards her mother, her siblings, and her. When prompted, Gloria shared that this was something “[I] don’t like to talk about, like to remember.” She added that she learned to tolerate things as her mother had done, “for the children.” Gloria’s description of her parents’ life together was telling, full of violence and need:
My father hit my mother a lot. She endured a lot . . . . He would go out with other women . . . . When my dad would beat her, he would leave her bleeding. And she would take it. My mother has a deep scar here [points to her face] . . . . My mom was real pretty when she was younger and still is to this day. The thing was that my dad was much bigger than my mom and since my mom was real pretty, he was jealous of her . . . . He did not like for her to go out . . . . My mother tells us that she never knew what a kiss was. That when my dad had sex with her . . . he would hit her real bad . . . . Sometimes he would also hit us [the children] if he didn’t like something we had done . . . . And he would get mad because even though he worked, we were a lot of kids to feed and clothe . . . so he resented us.

Mercedes’ experience with violence began as many other events did in her life, with the introduction of her stepfather into their family. From the beginning, she said:

He would tell my mom he saw me with guys and my mom would believe him and fight with me. She would hit me . . . . He would drink. He wanted to control us . . . . He was always very violent and when he was drunk he . . . would touch me . . . . He would grab me and kiss me . . . . He kissed me by force, he would touch me . . . . But penetration he never did.

Eventually, as a result of her stepfather’s actions and feeling that what mattered to her mother was “keeping her husband rather than looking out for her children,” Mercedes left home, with “nowhere to go but the streets.”

Pilar’s experience with violence began while living with her soon-to-be second husband. They not only had sex without using condoms, he “was kind of forcing me to have anal sex. I didn’t like it but he would insist. A lot of times he was forcing me to
have sex when I didn’t want to, too.” Pilar’s novio subsequently became gravely ill, and it was discovered that his illness was due to the failure of his immune system; he had AIDS. Pilar not only nursed him through his illness, but decided to stay and marry him.

Once married and recovering from his brush with death, Pilar’s husband “began abusing [her] physically, verbally, and even psychologically.” Pilar tolerated his behavior because, now HIV-infected herself, she believed, “I will not have this opportunity [to marry] again.” She felt that returning to her country was not an option, as she would have no job there and few options once she reached the point where she needed medication that was unavailable in that country. So Pilar stays, though now she defends herself against her husband’s abuse both verbally and by calling the police when she has to.

It is important to note that violence in the participants’ lives was not solely physical, sexual, or emotional. The men also perpetrated violence by withholding information that had potentially grave consequences; they neither told their partners they were HIV positive or had AIDS, nor did they practice safe sex so as to prevent the transmission of HIV.

Pilar suspected that her husband knew he was HIV positive before they became a couple, though she cannot prove it and he has denied it. However, Carmen and Marisol have every indication that they were knowingly infected by their long-term partners; that is, the men knew they were HIV positive or had AIDS and were well aware of the potential consequences of engaging in unprotected sexual intercourse. Given that HIV destroys the immune system and can lead to death, the act of knowingly infecting someone fits the criteria for a violent act. Furthermore, in some states (e.g., Georgia,
Washington, and Missouri) knowingly engaging in such an act is a felony (Lambda Legal, 2009) and individuals found to have done so are prosecuted and often imprisoned.

Carmen met the man who would become her first sexual partner and novio in the city where she lived upon arriving in the U.S. At the time, she was naïve about HIV/AIDS and had no experience, either personal or familial, with any type of drug use, including alcohol. Even had she known her husband was using drugs, however, she may not have recognized the risk of becoming HIV/AIDS infected, as she was unaware of HIV transmission mechanisms or the relationship between intravenous (IV) drug use and HIV infection. Carmen eventually discovered this information, and learned that she herself was infected with HIV, through her involvement in an accident in which she nearly died. Clearly still troubled by what happened to her, Carmen recounted the following:

Well, after eight months of being together, we had a car accident and we were taken to the hospital. There they told me that I was HIV positive. They explained to me how someone could get infected, like with drugs or something like that, or with a lot of sexual partners, but he was the only one I was ever with [sexually]. The second day was when they told me and I said, “Why?” “How?” It had to be with the person with whom I was living since he was my first and my only . . . . I demanded an explanation. I went to the hospital to see him and I asked him. He told me that he loved me . . . . He did not tell me anything because even if he told me something I was not going to believe him, or accept it . . . . I asked him all that and he said that he wanted to have a family . . . . He knew he had the disease but he never told me . . . . When I talk about it, it still makes me angry.
Marisol did not discover her husband had AIDS until he lay in the hospital gravely ill. Even then he was loath to tell her. Still horrified by what had been done to her by a man “who said he loved me,” Marisol recalled the questions she asked that were never answered: “‘How could you have done this to me? Why didn’t you tell me the truth? What would it have cost you?’ No, he stayed quiet and covered his face with the sheets and he did not say anything.” Marisol was told by the clinic where she had now begun her own medical odyssey that they had educated her husband about the risk he posed to others if he engaged in unprotected intercourse. In addition, when her husband informed the clinic of his impending marriage, they “begged” him to inform Marisol, and continued to do so throughout the time he was their patient.

Culturally-Prescribed Gender Norms

Research has demonstrated that some cultural beliefs can be positive mediators of behavior, while others encourage behaviors that increase the risk of contracting HIV (CDC, 2008; Gonzalez-Lopez, 2005). Furthermore, Latino cultural beliefs regarding the expected behavior of females and males have impacted social norms regarding sexuality, creating double standards and inequalities that influence HIV risk behaviors (Amaro, 1995; Amaro & Raj, 2000; CDC, 2008). The participants’ narratives revealed that the cultural norms with the greatest consequences for their HIV/AIDS narratives were related to gender roles, gender-specific characteristics, sometimes referred to as attitudes, such as machismo and marianismo, as well as the value Latino’s placed on family, a concept known as familismo; all were discussed in detail in Chapter II.

Gender roles are culturally mediated. The driving force behind who the participants, with the exception of Susana and Mercedes, had become and how they
viewed themselves was most directly expressed by Pilar, who said, “To be a woman in my country is to have children and a family.” In addition, what was considered the most important part in their education was what Valencia expressed as the need to “learn to cook, clean, and take care of [my] younger brothers and sisters,” rather than academics. This lack of formal education left the participants unable to financially care for themselves and their children and dependent on their partners or spouses for financial support. Being in that position led them to tolerate abusive behavior or behavior that put them at risk for HIV infection, and generally left them feeling they could not safely negotiate sexual activity.

Machismo can represent strength and motivation to protect the family, both considered protective HIV behaviors (B. V. Marin, 2003). For example, Mercedes reported that her boyfriend, “Knows I’m sick and still [he] takes care of me and stays with me . . . . He uses condoms.” And Marisol shared that when her current husband “found out I was positive, he was upset and worried at first, but said he loved me and I was his wife, and he would stay and take care of me.”

On the other hand, machismo also represents the cultural belief that males are the dominant, more powerful gender. A common way that they exert their dominance and power is by engaging in unprotected sexual intercourse outside of committed relationships. Extramarital sexual liaisons may be with women or men, although when it is the latter, it does not mean the participants in these interludes consider themselves to be homosexual or bisexual. The men, sometimes HIV infected—aware or unaware of their HIV status—return home and have unprotected sex with their partners, putting them at risk for contracting HIV. Carmen relayed that her husband “knew he was sick and still he
didn’t tell me. When I asked him why, he said it was because he wanted to have a family with me and thought I would leave him if I knew.” When I asked Carmen and other participants why they did not use condoms, their responses echoed that of Isabel, who stated, “We just don’t talk about [sex or sexually-related matters] . . . . We don’t talk about condoms.” Sometimes machismo leads men to force women to have sex, often unprotected, as in the case of Pilar, who relayed that her novio forced her to have anal, unprotected sex.

Marianismo, the cultural imperative for women to be “good,” be respectful of their spouses, be chaste before marriage, and accede to their husbands’/novios’ wishes and not question them, especially about sex (Amaro & Raj, 2000; Gonzalez-Lopez, 2005), puts women at risk either directly or indirectly. None of the study participants, even those with a college education, felt they could challenge their partners when they suspected or knew something was amiss, or even when they knew some behavior was putting them (or their partner) at risk. Carmen described her husband as being “wonderful” about her HIV status and initially using condoms as recommended to keep himself safe from infection. However, since the couple stopped using condoms six years ago so Carmen could become pregnant, he has not been willing to resume condom use. Although he has been informed by doctors that not only could he contract HIV, but he could also re-infect Carmen with a different strain of the virus, he remains unwilling to change his mind. Carmen feels she “cannot say anything more . . . . It is up to him . . . . There is nothing else I can do.” Withholding sex is “unthinkable,” she says, insisting, “I could not do that.”
Marianismo also expresses itself in a woman’s desire to be a good wife and not press her husband for information he does not wish to provide. Paz, infected by her husband, has never learned how he became infected. When asked if she had raised the issue, Paz responded that she had tried, but her husband consistently responded that he “didn’t want to talk about it.” She reported they do use condoms, due to their counselor’s recommendation since discovering they were both HIV positive but “we don’t talk about it.” In fact, not pressing partners or spouses about sexual matters is a common thread running through all participant narratives. Not one respondent reported bringing up any sexual matter or starting a conversation about sex, including the use of condoms, prior to having sex for the first time—or ever, for that matter. And only one participant, Pilar, has ever refused her partner sex, and she was able to do so only after being “slapped around one too many times.”

Lastly, familismo, the concept of placing family at the center of one’s life, was evident in the HIV/AIDS narrative of every participant, though more pronounced in the narratives of those who were married and/or had children. Regardless of her own needs, each respondent put her family, including her spouse, first, even if it meant putting herself at risk. One such example came from Carmen, who found out as a result of being in an automobile accident that her husband was dying from AIDS and had infected her with HIV. Rather than leave him to fend for himself or force his family to take responsibility for him, after he was released from the hospital, she felt she “had to stay with him [to] make sure that he was going to be okay.” Even as he verbally abused her, called her names, and told her if she left him she “would wind up living under a bridge,” she stayed, making sure he was cared for. Gloria provided a similar example when she
stayed with the man who had knowingly infected her when no one else would care for him, and continued to do so until he could no longer be cared for at home. She said, “I was his wife, he was my family.”

Religious Tenets

Data analysis revealed that religious tenets figured prominently in the HIV/AIDS narratives of the study participants, either directly or in concert with other biographical particulars. In every case participants’ adherence to these tenets had largely negative consequences as it discouraged or prevented the conversations necessary to prevent HIV infection (CDC, 2008) and discouraged or prevented the use of condoms, which offer the only way other than abstinence to prevent HIV infection via sexual contact (CDC). The role that the Catholic Church and the Catholic religion played in the participants’ lives, and for several continues to do so, is so pervasive that religious teachings are simply part of who the participants are, and are often undistinguished as such. As a result, unless asked directly, most participants did not bring up the church in relation to sexuality or expected sexual behavior. How and when I asked questions about the church or about church teachings corresponded with the rhythm of the ongoing conversation and with the style in which participants were responding to other questions or prompts.

I asked Pilar if the church prohibited the use of condoms, or if it took no position. Speaking in narrative form, she answered:

In the Catholic religion . . . the idea is that you should not have sex until you marry . . . . Contraceptives are abortion pills . . . why are they going to talk to you about this [condom use] if they disagree with [you] having sex in the first place.

When I asked Carmen what in her upbringing had affected her decision not to talk
about condom use or about protecting herself during sexual intercourse, her response did refer, albeit indirectly, to the Catholic Church:

Well, I think that since my parents are very Catholic, from a rural area . . . they were very closed minded . . . they did not talk about that with us and when I came here [the U.S.] my uncles did not talk to me about that [either] . . . . [here], they are more open and they talk about things without shame.

Gloria was asked what she learned, if anything, about sex and condom use, and from whom she learned it, and said, rather tellingly, that she learned “to not have children we are only supposed to have sex during certain times of the month . . . . It is a sin to use condoms.”

Overall, data analysis revealed that participants’ reticence about talking openly to anyone about sexual matters during their younger years was attributed to religious tenets as espoused by the Catholic Church. Susana’s comment, “in my country most people are Catholic and so I think that’s why they don’t talk about sex,” reflected the position of most participants. Marisol, the oldest participant and the one who has resided in the U.S. the longest, summed up best what people see as the Catholic Church’s influence on sexuality and sexual conduct in many Latin American countries, including Mexico:

Well they taught us primarily the family traditions of our country . . . that you had to be a virgin to marry . . . . They [the Church] teach you to have one partner.

That having a partner is not to be with someone else. That is what we were taught in those times.
However, Marisol clearly sees these teachings as a positive influence and lays current problems, including the spread of HIV/AIDS and other sexually-transmitted diseases (STDs), on not heeding the Church’s doctrines:

Now everyone is liberated and it doesn’t matter to them to be with “Peter” and “John” and to be unfaithful to their husband every time . . . they see a pretty face. In the time that I was raised it was not like that.

Only one participant, Mercedes, did not attribute the teachings of the Church when asked why she thought that as a young woman she learned “nothing” about having relationships with men, including what being intimate with them might entail. She shared:

I really do not know. I do not think that it is because of religion, because my mom is not religious. I really do not know because the way that they never spoke to me about sex, never told me that I had to use protection, or what she expected from me, nothing.

It is important to note that poverty buttressed and often exacerbated each of the factors contributing to participants’ HIV infection. The insidious nature of poverty will be discussed in greater detail in the next section.

For seven of the participants, poverty has been a presence in their lives since birth. Denzin (1989) would say that poverty and its impact on the participants’ lives is an “objective marker,” reflecting “key, critical points about the life in question” (p. 17). Such markers can be one-time events, like the death of one’s father, or ongoing aspects of one’s life, like poverty. Ultimately, objective markers frame and/or shape lives, giving
them “coherence” (p. 17). They can also be antecedents to turning points moments, which I will detail in later paragraphs.

The most significant consequences of poverty on the participants’ HIV-infection trajectories were their inability to get a good education and their or their partners’ need to travel far from home to provide for their families or themselves. Not having an education meant: (a) the participants were economically dependent on their spouses, some of whom, like Marisol’s, were violent alcoholics who did not provide for their families; (b) when the participants were forced to be on their own for various reasons, as in the cases of Valencia and Mercedes, their work opportunities were limited to very low-paying service jobs; and (c) their worlds were very circumscribed, leading to a lack of access to information about various subjects, including communicable diseases. When their husbands left home alone to seek work elsewhere, they experienced greater opportunities and perhaps more temptation to have extramarital affairs, which they did without using condoms. When they returned home, often infected, they in turn infected the participants.

Factors in Living With HIV/AIDS

Three factors impact the lives of the participants in living with HIV/AIDS: poverty, HIV/AIDS-related stigma, and immigrant status. Factors impacting the lives of the study participants had three themes: poverty, HIV/AIDS-related stigma, and immigrant status. Many of these factors are either extensions or modifications of the biographical particulars that led to their becoming HIV positive or developing AIDS.

Pervasive Poverty
Poverty has been and continues to be an influential factor in the life of every participant. Only Pilar and Susana were not born into poverty though, by their own account, their economic status, while stable, was certainly not above lower middle income. For the other seven participants, poverty and its effects—substandard or low level of education, mediocre or poor housing, lack of health insurance, and limited access to medical and dental care—have been and continue to be characteristics of their lives. In addition, Pilar, since being abandoned by her husband, and Susana, as a direct result of her rapid progression to AIDS, have both joined the economic ranks of their fellow study participants.

Confronting and grappling with poverty-related circumstances has been a precursor to what Denzin (1989) defined as life shaping, “key turning point moments [that] leave permanent marks” (p. 22). For all participants, except Pilar, emigration was, in one way or another, a result of wanting to “have a better life that I could have in my own country,” as Carmen states and other participants similarly noted. So it was that participants’ arrival in the U.S. became a key turning point moment that left an indelible mark. For Pilar, being in the U.S. plunged her into poverty, given that she has not been able to practice her trade as an accountant and must manage financially by working as a grocery store clerk, when she can find work.

Poverty has continued to shape the participants’ lives, particularly now that they are living with HIV or AIDS. Of most consequence has been coming to grips with the fact that in order to receive the medical care they need, they cannot return to their countries of origin. The care and/or the medications required are either unavailable there
or prohibitively expensive. For all participants this has meant leaving behind children and/or other family members.

While being in the U.S. has in many ways been a boon to participants’ health, as it relates to their HIV/AIDS status, being poor in the U.S. nevertheless has its own set of health consequences. The relationship between poverty and poor health is well established. Lower socioeconomic status (SES) individuals tend to have poorer overall health, and do more poorly when they do contract certain illnesses than do people with a higher SES. People who live at or below the poverty line do the least well (Kleinman, Eisenberg, & Good, 1978; Levin & Browner, 2005; WHO, 1954) across all aspects of health, but particularly when it comes to the prevention of illness.

Social determinants of disease, including SES, play as large a role in HIV/AIDS outcomes as its biological determinants. One example is the poorer, global HIV survival rates in geographical areas with lower SES (McDavid, Hall, Ling, & Song, 2007). For the nine study participants, the connection between poverty and HIV/AIDS does not bode well, and some impact can already be seen within this group, particularly in the HIV/AIDS treatment arena.

While all participants have access to the necessary HIV medications and to HIV/AIDS-related health care through the Ryan White Care Act and the AIDS Drug Assistance Program, none has health or dental care insurance. Gloria, for example, related that she is in “desperate” need of periodontal care. On the day I interviewed her, she demonstrated the poor condition of her gums by touching her teeth and showing me how loose they were. Gloria shared that, “I have been waiting for two years to get my teeth fixed . . . the clinic has been trying to get someone to do it for free because I don’t
have insurance or money and it’s expensive.” I then asked if her ability to eat had been affected, and Gloria responded that she can “hardly eat anything . . . I eat a lot of soup and sometimes chicken, very “blandito” [soft] . . . like I used to make for the kids when they were babies.” When asked about nutritional supplements like Ensure, she responded that “it’s too expensive . . . they gave me a few cans but then they said I couldn’t have any more.” When I checked with the clinic nurse, she said that Ensure was too expensive to keep, and what they had was generally donated. As a result, the clinic staff had to “ration” what was available among all the patients. The nurse further shared that services like dental care “were donated” and that “we can’t find enough dentists that are willing to work on Medicaid patients, or even less for free.” Even though Gloria has been told, she said, that her dental infection “could get into the rest of my body and make me really sick,” she has no recourse other than to live with it here in the U.S.

Isabel has also been impacted by the intersection of HIV and poverty. While pregnant with her last child, Isabel discovered she was HIV positive and was assigned to a high-risk pregnancy clinic. She reported that “they told me that by taking the medicine it could save my child from getting infected too . . . so I took the medicine.” Isabel further commented that “they told me that they were going to do a C-section before he was born (sic) (It should be noted that a vaginal or C-section delivery of an infant is the only medical service that Medicaid covers for immigrant women). In the hospital they did not do the C-section.” In response to my question as to why she thought this had occurred, Isabel divulged:

I do not know what happen. I spoke with the clinic and told them my situation. I told them why didn’t they do the C-section and they told me in the clinic that it
had been a mistake from the hospital. Since I am illegal, I cannot do anything because they can throw me out of the country . . . if I was to complain about the hospital because they [the clinic] say it was a mistake. That surgery was scheduled three weeks before my child was born and I had my son at eight months. I arrived with pain to the hospital but I told them that I was infected [with HIV] and that I was scheduled for the surgery so that my child would be born well. They left me all night with pain . . . . They did not save my child.

It is important to make note here of two pieces of information which answer questions the reader is sure to have after reading Isabel’s recounting of the events surrounding her son’s birth. First, a language barrier ought not to have existed as Isabel reported that an interpreter was present throughout the eight hours that “they made [her] stay in labor.” Isabel’s questions, statements, and protestations, were posed to the medical staff in English through this person. Second, the events of that day would not have been allowed at a private hospital, or even in the same hospital where Isabel delivered, if she had been covered by private medical insurance. Insurance coverage for C-sections is much higher than what Medicaid pays for the same procedure (S. Mannen, personal communication, February 6, 2009). That is why doctors and hospitals are often reluctant to accept Medicaid patients for any reason, but particularly so for obstetrics care.

Poverty creates many sources of stress for these participants, which is particularly troublesome because stress is contraindicated for the health of HIV-positive individuals and even more so for those living with AIDS (Science Blog, 2001). Poverty indeed impacts almost every aspect of the participants’ lives. For example, it limits the jobs they can accept to those that can be reached by public transportation or by walking, or to those
nearby so that transportation (e.g., taxi or local livery service) is not prohibitively expensive. For Latinas this has traditionally meant working in chicken or fish processing plants or in carpet factories. However, these jobs involve a variety of dangers for people whose immune systems are compromised: contact with animal byproducts, extremely cold working conditions, repetitive motion, and long hours on one’s feet, and, in the carpet factories, airborne dust and fiberglass particles.

As a result of inherent environmental dangers, participants have not been able to take jobs traditionally open to them, even when available. Instead, they are limited to taking even lower-paying jobs, like dish washing or house cleaning. Gloria resorted to making money by cooking tamales and then selling them door-to-door in her neighborhood. The low wages earned, regardless the type of employment found, results in, as in Gloria stated, “Not having the money to buy what we need in the house.” For Marisol, as well as others, poverty has necessitated her to “live with roommates so that we can pay the rent—and they don’t know about me [AIDS diagnosis] . . . if they knew, maybe they wouldn’t live here.” For others, circumstances have deteriorated such that they often find themselves in situations such Paz and her family did. The day I interviewed her, Paz reported that “today is Wednesday, and we still don’t know how, or if we are going to be able to pay the rent on Friday.” This type of stress takes its toll, especially when there are children involved, which is the case for all but two of the participants.

Finally, while poverty is a social contra-indicator for people with HIV/AIDS in general, it is even more so for women (Campbell, 1999) and especially for Latinas, who are already isolated by language, cultural barriers, and immigrant status (Engstrom,
2006). Not surprisingly, then, poverty promotes isolation for these participants. Isabel spoke for many when she said, “I wish I could get together with people [HIV-positive individuals] more often but I don’t have a way to get there, and I can’t afford a taxi.” The participants either do not own cars or cannot afford the insurance for them, and there is little to no public transportation in the areas where they live. In addition to furthering their social isolation, this adds to their stress levels because they either have to find rides with friends or family members, or to find money for taxi fares to get to their own or their children’s medical appointments. The result of such social isolation and stress is poor mental health. Carmen, Paz, and Isabel, for example, each said that they often lacked someone to talk to, which led to feelings of loneliness and depression.

HIV/AIDS-Related Stigma

Stigma related to being HIV positive or having AIDS has not abated in spite of increased understanding of and education about the disease, its means of transmission, and the fact that it affects all types of people world wide. UNAIDS (2008) has reported ongoing prejudice and discrimination against people living with HIV/AIDS, in spite of laws created in various countries specifically to protect the rights of those individuals. Stigma can occur at many levels and in many types of organizations—in governments and health care systems, in employment and housing, and in communities, schools, and families (Zaccagnini, 2009).

Regardless of where it occurs, the effects and consequences of HIV/AIDS-related stigma are grave. However, stigma is not a singular phenomenon; it varies widely not only between countries, but also between different groups of people within these countries (Zaccagnini, 2009). As Frasca (2005) reported in his book, AIDS in Latin
America, HIV/AIDS-related stigma is quite prevalent in Latin American, though how it manifests and the impact it has varies from country to country—including those countries from where the participants emigrated.

The participants were first affected by HIV/AIDS-related stigma prior to becoming infected. Stigma is partly to blame for the absence of open communication and education about the disease (Frasca, 2005), and the resulting lack of information was a key factor in their becoming infected in the first place. In addition, every participant has experienced stigma-related repercussions of living with HIV/AIDS. It is the source of much of their isolation from friends and families and of poor self-esteem, depression, and stress. In addition, at least one respondent, Isabel, believed that the “poor care” she received when she delivered her child was due to stigma, as well as economic self-interest on the part of the hospital. Isabel felt that they “didn’t care, because maybe they thought I shouldn’t be having a baby if I am HIV positive.” Isabel herself believed that being HIV positive, especially after passing it on to her infant, made “my blood dirty; if someone gets it [my blood], I could kill them . . . . Look at what I did—I passed it to my baby.” She is reminded of what she “has done” every time she gives her son medicine, which she dispenses three times per day.

Participants have encountered HIV/AIDS-related stigma in all aspects of their lives, including church, family, friends, and neighbors. Pilar’s experience with stigma in her church was unexpected and particularly painful, given that she had found such refuge from troublesome aspects of her life there:

I told the church pastor about my problems [including HIV status] and he told his wife, who then gossiped to other church members . . . . People rejected me, not
wanting to come near me, and gossiped about me . . . . I had to leave the church
where I had found so much comfort.

For others, stigma at church exacerbated their sense of isolation, as Marisol
demonstrated: “I have no one . . . . I can’t tell anyone at church . . . . And I hear people
say bad things about people they think have the virus . . . . And they don’t even know for
sure.”

Families, as has been detailed in Chapter II, are so important in participants’ lives
that anticipating how a family member, especially a parent, might react upon hearing that
another family member is afflicted with HIV/AIDS causes great stress and anxiety.
Moreover, this concern has isolated people from important sources of support as Susana
demonstrated when she said, “I need my mother and I wish I could tell her about what I
have, but telling her what has happened to me may give her a heart attack.” It can also
cause great anguish for a mother who worries about an infected child, Isabel stated with
grave concern in her voice:

My son is positive . . . what will happen to him as he gets older? . . . And what if I
am not here to help him? . . . And then other people will know what happened!—
that I infected my son!

When families are not available to provide support and succor in times of need,
friends and neighbors often play that role, providing a last line of defense against
loneliness and isolation. This potential protection, however, was nullified for many
participants given the worry that their HIV/AIDS diagnosis would be discovered. Many
comments about this were similar to the one made by Carmen who declared, “Thank God
for Mary at the clinic who is the only one that I can really talk to because she knows and
she always helps me.” Even when living with roommates, an economic necessity that also has the potential for being a source of friendship and support, concern about their HIV/AIDS status being discovered and “what people will do,” robs people of the opportunity for real friendship, as Mercedes voiced:

We live with a roommate . . . a girl I knew from work. She doesn’t know about me. One night she and some other girls convinced me to go out with them . . . and as we sat there having some drinks and snacks, we sipped from each other’s glasses to taste the drinks. Now I have heard them talk bad about people who have AIDS . . . about what it means. And all I could think about was, what if they found out I had the virus? What would they do to me? . . . Thank God my roommate has her own bathroom and we don’t have to share. That would be terrible because then if she found out.

Valencia’s comments echoed those of Mercedes. According to Valencia,

We live with a girl I met at work, but I don’t know how much longer we can keep doing it . . . I’m worried that she will find out I am HIV positive and tell other people, maybe someone from where I work . . . and then I might lose my job.”

In fact, the day I was in Valencia’s home was one where the roommate was also at home and getting ready for work. As the young woman moved around the apartment, Valencia got increasingly nervous, and was only too pleased to move the interview outside where she would not be overheard.

HIV/AIDS-related stigma has appeared alongside other forms of stigma and discrimination from the beginning of the epidemic, as Randy Shilts (1987) so eloquently chronicled in his tome, And the Band Played On. Homophobia and racism played key
roles in how the epidemic of the then-unknown disease was addressed. Its effects can be seen in how children like Ryan White, from Indiana, or the Ray boys, from Florida, were treated, as well as how Haitians were ostracized and spoken of when it was believed they were a source of the disease. To some extent this type of thinking has continued, though the targets of stigma and discrimination may have changed. More recently HIV/AIDS-related stigma has appeared alongside misogyny and anti-immigration sentiments—two dynamics that have particular impact on the Latinas who comprise the sample in this study.

*Immigrant Status*

Immigrant status is an issue that has added great stress to the lives of the study participants, whether or not they have legal status in this country. Those with legal status are afraid they will suffer as a result of “being lumped in with everyone else.” Those without it grapple with everyday life from a place that is difficult for the rest of us to imagine—even those of us who sympathize, empathize, and understand their predicament and their struggle. Many of the participants are not able to work at jobs that pay a reasonable wage, even when they are available, since they do not have a social security number. Pilar shared that “I am a bookkeeper/comptroller in my country. I have a college degree . . . yet, I can’t get a job doing what I know how to do.” Similarly, Susana, also a college graduate with an accounting degree, works in an office, “answering his phones.” They are thus relegated to jobs that are low paying, have no benefits, and provide no protection or recourse in the case of an on-the-job injury. Many of these jobs, referred to as “day labor,” are not secure beyond the one day, literally, that people are asked to work. Paz shared that “my husband works doing yards, but some weeks he only works a day or
two . . . and he has to stand out there waiting for someone to pick him to work . . . some days he makes so little it hardly pays for his transportation to and from work.”

Furthermore, the participants worry daily that they, or their partners, may be arrested for not having proper documentation, put in jail and deported.

Transportation is another critical issue the participants confront almost daily. Due to their immigrant status, they cannot legally obtain a driver’s license. For those who do have access to personal transportation, driving means knowing that if they are stopped, “all hell breaks loose” as Gloria graphically noted. They can be taken to jail, fined, and then deported if they are found not to have proper documentation. As Pilar explained:

I try not to go out so much to not run the risk of getting stopped and them [police] finding out I have no driver’s license . . . Even if I have to take [my daughter] to doctor’s or therapist’s appointments, I only go and come back and don’t spend so much time out.

When I asked Paz how she got herself or her son to their doctors’ appointments, she said “Well, if my husband can’t get a ride, then we have to pay to take a taxi . . . . We have to go to our appointments.”

The far-reaching consequences of immigrant status on participants’ lives were evident throughout the interviews. It exacerbates isolation, given that they cannot tell anyone about their legal status; it also impacts their ability to work and carry out necessary daily activities. Of even greater import, however, is that the only access to services that Paz’s family, other than the two children born in the U.S, has, is the crucial access to HIV/AIDS-related health-care and medications. Paz shared, “I cannot get the help I need . . . . Even if it is something one of my children needs.”
Lastly, for participants like Gloria and Valencia, who have children in the U.S. as well as at least one who remains in their home country, or whose parents and most, if not all, family members remain as well, life is an ongoing, constant dilemma. Valencia shared that she,

[Gets] sad because they are so far and I cannot go see them . . . . I couldn’t get back here . . . What do I do? Do I go back to Guatemala so that I can be with my other children, or do I stay here where I can provide a better life for the child now living with me . . . and send money home so that my children there can be educated?”

Her immigrant status makes it impossible for her family to be together and, at the same time, receive necessary medical care, and maintain the necessities of life, such as a roof over their heads and food in their stomachs.

Isabel is another participant caught in the quandary of whether she can safely go home to be with her daughter, now living with her mother, and to gain, as a secondary benefit, her mother’s love and care. She made the following poignant remark as she talked about her husband:

He is the only thing that I have here and my child. In this country, I do not have anyone else. At this moment is when someone really needs their mom. She tells me to come back but it frightens me . . . . Well, I would have to think first about how to get medicine for my child . . . yes, more for my child [who is HIV positive].

Lastly, Gloria’s circumstances and remarks sum up how many of the participants feel about the “push-pull” dilemma of being an immigrant in the U.S. She was told by
one of her daughters, “Mom I miss you a lot.” Gloria responded by getting emotional “because I am not with them.” Furthermore, she becomes conflicted by being in the U.S. given familial circumstances and events, sharing that,

I have a grandson who is 8 months old . . . . One of my daughters is getting married in church on June 7 . . . she wants me to come and be with her on her wedding day.

Gloria’s dilemma is further complicated by the suspicion that her daughter is being abused by her novio having been asked, “What would happen if I left him?” Therefore, Gloria shared, “I want to leave and do not want to leave because I have my daughters over there but I do not know how I am going to do over there,” referring to her HIV status and her ability to support her children.

It is important to note that while each factor contributing to HIV infection, and then living with HIV or AIDS, individually impacts participants’ lives, they also intersect at various times, places, and circumstances in ways that exacerbate the individual effects. The results often create untenable situations for the participants. For example, poverty in the family of origin resulted in a lack of education, and lack of education, in turn, yielded few professional opportunities and low socioeconomic status. Even for the well-educated participants, local economic conditions provided few opportunities to put their education to practical use.

Moreover, culturally-mediated gender roles often led to power inequities between participants and their partners. The question that remains, then, is, what motivated participants’ behaviors regarding sexual decisions and conversations—was such behavior motivated by culturally-mediated gender roles, power inequities, religious beliefs, or was
it a function of a lack of education about potential illness? Or does the answer lie in a combination of these factors? The participant narratives demonstrate that these objective factors influenced each other, and that both independently and in their intersection they all shape the participants’ experience of HIV/AIDS, and further, they comprise the context of their lives.

Meaning of HIV Infection

When asked about what it meant to them to be HIV positive or infected with AIDS, the participants generally responded in concrete rather than abstract terms. They talked about how HIV/AIDS impacted their day-to-day lives and their responsibility to meet daily challenges, rather than waxing philosophical or reflecting on their internal thought processes about the disease. For example, when asked what it meant to her to be infected with HIV, Paz responded, “What do you mean?” When I explained, she answered, “It means I have this virus and it could make me sick . . . and to not get sick I have to just take my medicine.”

Valencia initially answered, briefly and simply, that it meant “nothing” to be HIV positive. It took several carefully crafted, probing questions to encourage her and the other participants to think more about the question. For example, first, not wanting to ask leading questions, I asked Valencia what she thought of being HIV infected, and again she looked perplexed as to what I was asking. I then asked if she thought being infected said something about her and she shrugged her shoulders. I followed up by asking a couple of other questions, to which Valencia eventually responded by speaking about what she needed to do to stay well, which was to “take my medications” and “go to my doctors’ appointments.”
In spite of this tendency to respond in very concrete terms about the meaning of HIV/AIDS in their lives, two main themes emerged: being a good caregiver and summoning courage in the face of adversity. The nature of the participants’ responses around meaning making in general, and of the data encompassed by the themes, is best summed up by Nietzsche’s (as cited in Frankl, 2006, p. 109) quote: “He who has a why to live for can bear almost any how.”

**Being a Good Caregiver**

Upon being informed of their HIV positive status, all but one of the participants responded with incredulity and an initial wish to die. One participant, Carmen, attempted to take her own life on two different occasions. Participants to be drawn out of that state by the promise of children, their sense of responsibility for their children they already had, or their concerns about how their death would affect other people in their lives, such as their mothers, siblings, or boyfriends. Marisol was the only participant for whom God was initially as strong an influence as her children in dissuading her from acting on her wish to die upon learning of her HIV diagnosis. For the rest of the participants, drawing on their belief in God for strength did not come until later.

*Children.* The participants, especially though not solely those with children, viewed their most significant role as being a mother. So strong is the value placed by Latinas on motherhood (Gonzalez-Lopez, 2005) that Pilar’s first response to her HIV status was, “Now I’m stuck . . . who will have me, now that I have HIV? How can I have a family, [and] children?” And, rather than leave her abusive novio, she married him so that she *could* have children. Now, “everything is for my daughter… whatever the doctors tell me to do, I do it… I am the only one she has.” And given her daughter’s
disabilities, Pilar understood that her daughter “will always need somebody to take care of her . . . and if not me, then who?”

Carmen’s response echoed Pilar’s words. Initially, Carmen believed being HIV positive meant that, “I was going to die.” What followed directly from that ascribed meaning was that, “I wanted to die,” and indeed, as previously mentioned, she made two attempts to end her life. What ultimately brought new meaning to her life was meeting her future husband. “We started talking about having a child,” she said. Now she believes that having a child is “what pulls me out of [depressed] moods.”

Given the significance of motherhood in the participants’ lives, it is not surprising that they consider caring for their children to be the most important job in life. It is, thus, not unexpected that Paz considered being HIV positive meant she “had to take medication and take it just like the doctor says so [she] can stay well and be able to take care of [her] children.” When asked what she thought about her HIV status when she was alone and feeling what she described as “depressed,” Paz said she just looked at her children and they “pulled me forward” and got her out of her “moods.” Paz’s response was fairly typical to that of all participants, although each expressed it somewhat differently.

Gloria, having had the experience of nursing her husband through a painful and “terrible” death from AIDS, had a somewhat different vantage point from which to ponder the question of what it meant to live with HIV. She had been the only person willing to care for her husband. For Gloria, therefore, HIV raised such questions as, “Who will take care of me? Who will take care of my children?” Gloria also said:
I have to live my life normal... But I can’t work in the chicken plant because it’s too cold... and because [handling] the dead chickens could harm me... I have to take care of myself so my youngest daughter doesn’t find out [about Gloria’s HIV status] and so worries about me... My other daughters, the one’s in Mexico, they need me too... Who will be there to teach them?

For Isabel, who discovered she was HIV positive while pregnant with her son, HIV meant forever living with the knowledge that “my son is infected” and that “he got it from my dirty blood.” She went on to say that, “I still cry sometimes about being infected... thinking of what might happen to me... especially when I see other people get sick and die.” However, looking at her son and thinking about “who would take care of him if something happened to me” was enough, as other participants said, to “pull me out of those kinds of moods.”

*Significant others.* When the meaning of HIV was not expressed in terms of children and their care, it was framed in relation to the responsibility the participants felt to providing physical and especially emotional protection for their mothers or significant others. For Pilar and Isabel, after thinking of their children, they pictured HIV as having a grave impact on their mothers. Pilar said, “It would kill her,” while Isabel worried, “she would have a heart attack.” For Pilar, her HIV status meant that, “I can’t go back [to my country] because if I did... and I got sick... my mother would then find out.” Isabel said that for her, HIV meant she “can’t get my mother’s support... When I’m feeling bad or depressed, I don’t call her because she will ask me, ‘what’s wrong?’”

Even Mercedes, who felt her mother “abandoned [her] to be with her second husband,” expressed the meaning of her AIDS diagnosis in a manner somewhat similar to
that expressed by Pilar and Isabel. Considering the question of meaning, her thoughts turned to both her mother and her boyfriend, and what her death “would do to them.” These considerations motivated Mercedes to give her best effort to pulling herself back from the brink of death, both physically, as “when they told me in the hospital I was going to die if I didn’t take my medication,” and emotionally, as when she thought of “killing myself by jumping in front of a train.”

An additional finding was that with or without children, not all participants thought solely in what I earlier defined as “concrete terms,” that is, in terms of children or mothers and significant others. Pilar, Susana, and Mercedes, for example, were more reflective than the other participants in responding to the question of meaning. Pilar’s response was particularly thoughtful, even eloquent:

I have two concepts . . . from the point of religion and health. I have HIV because I was irresponsible. The people that are HIV positive can be infected [she now knows] from transfusion or different ways. If we are talking sexually, we’ve got to be responsible because we do not protect ourselves. The women, we are stupid, even having an education. In that moment [of having sex], we don’t think about it. I see it from the point of view of a Christian and I accept the responsibility . . . according to my Christian faith, he and I should not be together [sexually], we had to get married first. But I had to first get divorced. In that lapse . . . in the eyes of God, we were not allowed to have sex. From a Christian’s standpoint, I see my disease as maybe a result of my disobedience to God because I am sure that if I had obeyed the word of God, [He] would have taken care of me. So, from two viewpoints, something different and something in common . . . I have my
responsibilities, no, not all because two people lie in the bed. But the moral is, women, take care of yourselves . . . two have to think, but the man never thinks. We have to think for two.

Susana, a single woman and college graduate, also made very thoughtful comments, revealing a fair amount of self-analysis:

Sometimes, I think about what it means for me to have AIDS and I think I have AIDS for some reason. Sometimes, I also think that maybe it’s because I should have not had relations without first getting married because during my youth I told my mom that I wanted to be a nun. I felt close to religion and for many years I said first I am going to have children . . . then I entered the university . . . and things changed. I looked at having sex as being normal . . . that I did not have to be a virgin at the altar, they were going to love you the same. I think that I left religion and HIV infection happened . . . so maybe it means I should not have left my religious ideas behind like that. I should have listened to my mother when she tried to tell me that he [man who infected her] wasn’t good for me.

Mercedes was a young woman who possessed street smarts, worldliness, and sabiduria (wisdom) gained from living on the streets of Belize. However, her circumstances and, thus, her motivation to reflect were somewhat different from those of the other participants. Mercedes’ trajectory from being diagnosed with HIV, which she was made aware of while hospitalized due to “crushing” headaches, to being diagnosed with AIDS and confronting her own death, occurred within the space of two or three days. She did not have time to adjust to the idea of being HIV positive before she was
forced to confront the reality that she could, imminently, die. When she first heard the
diagnosis, Mercedes said, “I went into shock . . . I could not accept that I had [AIDS].”
She felt her life was over. To Mercedes, having AIDS meant learning and making choices
about how to proceed with her life, despite the diagnosis she confronted daily:

I do not have to get up every day with the idea that I am going to die tomorrow. I
have to get up every day and decide to live . . . [to] take my medicine . . . even if it
makes me sick . . . [to] figure out how to keep the medicine down . . . [remember
to] think that I don’t necessarily have to get sick.

These last three participants were able to take a step back from their lives and all
three were able to reflect on what it meant to have HIV/AIDS. Their comments pointed to
similar subjects and reflected the same cultural and religious values that were evident in
Mercedes’ remarks at the beginning of this section. In devoting themselves to the role of
caregivers, these women committed themselves to finding the internal and external
resources necessary to confront the daily challenges of their lives. In this way, all of these
participants displayed their own brand of courage in the face of their life circumstances.

** Summoning Courage in Adversity**

The second theme in the responses of the participants to an HIV/AIDS diagnosis
is contextualized by considering the following. “Courage,” as defined in Merriam-
Webster’s (2004) dictionary, is a “mental or moral strength to venture, persevere, and
withstand danger, fear, or difficulty” (p. 299). The root of the word, “cuer,” is “heart.”

Victor Frankl (2006) in *Man’s Search for Meaning*, states: “One should not search for an
abstract meaning of life. Everyone has his own specific vocation or mission in life to
carry out a concrete assignment . . . In a word, each man is questioned by life; and he can
only answer to life by answering for his own life; to life he can only respond by being responsible. Thus, responsibleness [is] the very essence of human existence” (p. 109).

Frankl’s words direct us not only to the meaning of life in the larger, general sense, but also to the particular element that “questions” each man (or woman), such as living with HIV/AIDS in the context of this analysis. All of the participants responded to their test by “being responsible” — and it is that which sources the meaning given to their diagnosis.

Whether or not the participants viewed themselves as courageous (they generally did not), a close reading of the narratives reveals characteristics that could be assessed as such. Against overwhelming odds (including government bureaucracy, lack of money, and the inability to speak English), they chose to travel far from home to make better lives for themselves, their children, and often their extended family at home. In addition, seven of the nine participants discovered their HIV status after arriving in the U.S. Nevertheless, the participants did not spend their time bemoaning their fate, blaming God, or blaming the men who infected them; rather, they moved on with their lives, as demonstrated by the following narrative excerpts.

On meeting the 23-year-old Paz, one would get the distinct impression that she would never describe herself as “brave” or “courageous.” Indeed, it was difficult for this shy person to talk about herself at all. For instance, it took a series of questions to uncover that she had studied through to the ninth grade and subsequently “came to the U.S.” It then took the remainder of the interview and a follow-up interview to discover the events that transpired between completing school and immigrating to the U.S. She was clearly unaccustomed to being asked for her opinion about anything. Yet, this unassuming person travelled by bus, car, and at times on foot, to a country with a foreign
language and where she did not know a single person — to join her husband in making a better life for their family. When asked why she had done this, she answered, “Because at home we couldn’t find work and we have two kids . . . We want them to go to school.”

Then, after confronting all these obstacles (and more, including a fourth pregnancy), she was again “questioned by life” (Frankl, 2006, p. 209) in the form of her HIV diagnosis. Her response was not to give up; she followed the instructions of her doctor and counselor to remain healthy, and thereby to be able to “take care of [her] children . . . and . . . work so [she] can help [her] husband.” Courage in the face of adversity seems a fitting way to describe Paz’s response to challenging life’s circumstances.

Isabel’s story is similar to Paz’s story, and not unlike those heard from the rest of the participants. This 27-year-old woman had a third-grade education, could barely read, and spoke little to no English. Both she and her husband “escaped” to this country, leaving their child in the care of remaining family members:

“The very critical situation . . . there, life is real sad . . . people cannot buy even tortillas, or if they can, they, as we say, can’t buy the egg . . . at times I ask . . . to give me the opportunity to win the lottery so that . . . I can help others . . . and send money so that my little girl has food.

As if travelling to the U.S. without their daughter was not enough of a challenge, Isabel was diagnosed with HIV at the same time she found out that she was pregnant with her second child. Isabel said she was “glad that God brought [her] to this country so that I and my child can live longer.” Also, rather than voicing resentment and anger about all that had happened, including not being able to find work, Isabel remained glad that they undertook the hazardous journey to the U.S. She viewed her health and that of her child,
as her responsibility, in addition to sending money to El Salvador to support the daughter living there — and that is what she and her husband worked to do.

Abused, frightened, often hungry, and unable to find work in her native country, Marisol left her children with their maternal grandmother and traveled to the U.S. almost 20 years ago. She was approximately 28-years-old at the time, spoke no English, and knew only a few people in the U.S.; however, she was driven to come here “because of necessity. She said, “The father of my children did not work in my country and did not help me with my children.” In the intervening years, driven by her sense of responsibility for “my children . . . their well-being . . . and their education,” Marisol managed not only to support herself and her children, but also succeed in earning enough money to bring them all to live with her, and gained legal permanent-resident status. During this time, Marisol remarried, only to discover at her new husband’s deathbed, that he was dying of AIDS-related complications and that he had infected her with HIV. Rather than shy away from this new challenge that “God had given [her] . . . maybe a test,” Marisol decided she “had to face this . . . I am going to face this.” And she did so, deciding that she would live her life “speaking the truth,” saying that this would “make [her] feel free and in peace.”

Making Sense of an HIV/AIDS Diagnosis

Asking participants what sense they made of being infected with HIV or having AIDS elicited responses not unlike those about the meaning of HIV infection; namely, participants responded in concrete, rather than in abstract terms. Their narratives pointed to taking action in response to family or personal needs, because of, or in spite of, their diagnoses. Their responses can be categorized by three themes: treating it as “just one
more thing” in their lives, a deepened relationship to God, and a resolve to prevent infection in others.

“Just One More Thing”

One of the assumptions on which this study is based is that diseases occur, are investigated, and are treated within specific societal contexts and that they require examination within those contexts (Campbell, 1999; Foucault, 1994; Frasca, 2005). This is especially true in the case of HIV/AIDS, as this study’s findings, as well as those of other authors (Amaro, 1995; Campbell, 1999), suggest. For study participants, this meant that their experience with HIV/AIDS was set against a context comprised of, as indicated in the previous two sections of this chapter, a lack of education, domestic violence, culturally prescribed norms, religious tenets, pervasive poverty, HIV/AIDS-related stigma, and, for almost all participants, a problematic immigrant status. Unfortunately, the participants’ lives continue to be mired in most of these circumstances. It is not surprising, therefore, that one way they made sense of their diagnoses was by grappling with it as “just one more thing” as they continued to take on, in spite of how they felt, whatever life demanded of them.

Participants’ reaction to their HIV/AIDS diagnosis as if it was one more demand on their already-burdened lives was not immediate, however. Initially, they demonstrated very different attitudes. Pilar, for example, shared that “when they told me [that she was HIV positive] . . . I cried . . . I never thought that would happen to me . . . . I did all the right things [to not get infected].” At the time, her novio, Antonio, was gravely ill, having just been diagnosed with AIDS and it was not known “if he would make it.” So Pilar “went to the hospital every day, to stay with him and to accompany him [and] I would go
after work.” It was when he was well enough to be discharged from the hospital that Pilar “felt the burden of the disease.” However, the period of “depression” that she experienced did not last long. Marriage and a child ensued—events that Pilar shared while choking back tears: “I wanted all my life . . . to have a family.” Talking about how she goes about her daily life today, Pilar stated, “I take my medicine . . . . And everything I do is for the good of my daughter.”

Paz’s initial response to her diagnosis, which she received during her last pregnancy, was “I couldn’t believe it . . . I didn’t believe it . . . I was in shock . . .” When I asked how she feels now, she responded, “Well now, what else can I do, but believe it and get used to it?” She added,

Now, practically, we’ve gotten accustomed to being infected. We don’t think or talk about illness or anything like that—we concentrate on the children—and move forward with our lives. They force us to look to the future; that’s how we manage. We know that the disease has no cure, that you can just control it.

She goes about her life, taking care of her children, and working whenever she can. According to Pilar, “I do this so I can help my husband, since that is why I came [to the U.S.].” Given how difficult it is for them to pay rent, buy food, and pay for transportation, it is not surprising to see the ways they make sense of HIV infection.

Similar to Pilar and other participants, Valencia’s response to learning about her HIV diagnosis was, “Well, I got real scared because from what I have heard of the disease, it is real bad and people die from that . . . . I spent all my afternoons crying.” She, like the others, also had thoughts of wanting to die. When she finally told her husband of her diagnosis, he, “at first got real serious and I did not know what he was
going to say. Then later [same day] he said for me to take my medicine and don’t worry.”

Now, Valencia said, having HIV is “not such a big deal . . . . I only take my medicine and
that’s it.” When asked what effect HIV has on her life now, Valencia shared, “Well, now,
nothing . . . . I work . . . . I take care of my son . . . . I have to send my mother money for
my kids.” HIV is “just one more thing” among many others she must contend with.

Although the particulars may differ, each narrative revealed a similar experience:
The participants discovered their diagnosis and went through a period of shock and
disbelief, which was followed by a period of adjustment generally lasting no more than
six months. Even for Susana and Mercedes, both diagnosed with AIDS, getting past the
shock and the initial period of wanting to die lasted less than six months. For these two
young women, making sense of their diagnosis meant taking action and being responsible
for what life was demanding of them. Each of them had to take life saving action. Susana
needed to find treatment not available in her native country, and, as it turned out, only
available experimentally in the U.S. And, Mercedes needed to be able to tolerate her
medication to improve her chances of not succumb to the ravages of AIDS.

*Deepened Relationship With God*

All the participants are fairly religious by their own account, though some attend
church more regularly than others. For several, not only has their faith in God not
wavered in the face of HIV/AIDS, it has deepened. It is this more profound relationship
that is evident as they make sense of their diagnoses.

Pilar, Catholic until she came to the U.S., where she became “Christian,” was not
always a regular churchgoer. Once married, HIV positive, and a victim of domestic
violence, she and her husband “began attending church to work on our behaviors,”
because, as she described, “I have my character.” Her husband continued being violent toward her and Pilar defended herself by “learning to be violent . . . . Not physically, but with words.” Increasingly, she “sought refuge in God.” She went on to say, “I do not know what would have happened if I would have not done that. I try to take solace in God and to say that in God everything has a purpose, right?” However, the path to God had its trials. First, the pastor of her church, with whom she shared her HIV status, started “preaching that AIDS is a disease from the time of the lepers and that we were sinners.” Then, he divulged her HIV status to his wife, who told other women in the church. Pilar and her daughter were ostracized and eventually the family left the church. Pilar’s response, however, was not to abandon God or blame God; rather, she simply found another church she and her family could attend. She prays nightly, thanking “God for this day and thanking him for what my daughter has learned . . . . What I most ask of God is health and many years of life.”

Carmen was raised Catholic but had not been a regular churchgoer since coming to the U.S. When she did not die after her second suicide attempt, she said to herself, “God must not want me to go; He must want me here.” Since then, Carmen has come to “pray a lot more and lean on Him a lot.” After marrying her current husband, she became a Baptist so that she could attend church with him; now the family attends regularly, along with their son. “Praying,” said Carmen has “helped me deal with this virus . . . now I don’t spend so much time thinking about being HIV positive.” She also has come to think that the virus she has “is just a sickness, like anything else. It’s not a punishment from God.”
Isabel, from a religious family, has been encouraged by her mother to “have trust in God.” She shared that since discovering she was HIV positive, she has “sought refuge in God.” She went on to note: “I have been going to church so that I could feel good, forget that I have this disease, but there are moments that it’s impossible to forget.” As Isabel continues to grapple with circumstances brought on by being HIV positive, she goes back to God regularly, “asking Him to erase all the bad in me.” God represents the possibility of forgiveness for her, sharing that she asks,

God for forgiveness for blaming Him [for HIV] but God knows what He does.
The only thing that I ask is that I am able to resign myself to this and to help me every day, to give me life, to bring forward my son with his disease and medicine . . . . God has given me those burdens. And, [since] He has put them there, He has also helped me learn to carry them.

Each woman has a story to tell regarding her deeper relationship with God as a result of having to make sense of HIV or AIDS in her life. Marisol “prays every day.” She speaks to God “like I’m talking to a person.” With a note of serenity in her voice she said, “it gives me joy and beauty in my heart.” Susana reported that she “goes to church but sometimes I just read the Bible at home.” Mercedes made sense of having AIDS with the help of God as well. She reported, in fact, that during one of her hospitalizations she had a “vision.” She quietly related that:

I was lying down and I saw Jesus and He opened His heart. He told me that it was not my time. I was almost dead and when I woke up I asked myself, “What happened here?” I really don’t know if I lived it or dreamt it . . . I thought I had [really seen Him], and I clung to that.
The experience in the hospital led Marisol to this conclusion: “If I am here then God is giving me the opportunity to change . . . I want to be in peace . . . . I learned that one has to do things while alive.” Mercedes also said that God saved her because “maybe I have something to accomplish in my life . . . for others . . . or for me.”

*Resolve to Prevent Infection in Others*

To some extent each participant has reached out to prevent infection in others as a way making sense of one’s own diagnosis. Some, like Valencia, have done it indirectly, by “telling [my] mother so that maybe she would talk to my brothers and sisters,” and others, like Carmen, by being open about their diagnoses with their immediate and extended families, and then by “sending cards and letters to my sisters and my cousins . . . telling them to be careful, to take care of themselves . . . so that what happened to me does not happen to them.” Carmen has been very forthright with one of her sisters, a single mother who “is out there going out with lots of guys and not using protection . . . and she has kids . . . . I tell her, who will take care of your kids if something happens to you. She tells me to mind my own business.”

Reaching out, Carmen shared, has not been without cost, but as her remarks indicate, she does not turn away. “An uncle who I was very close to . . . like my father . . . won’t talk to me . . . he sees me, sees my face, and he turns his back on me . . . that hurts me a lot . . . I loved him and I still do even if he is like that. Because he also has children and I say that he needs to get informed how things are because I feel that the way he thinks is not right.”

Two of the participants, Isabel and Mercedes, have attended a support group on a regular basis. Through this, they have learned about HIV prevention, as well as how to
halt HIV from progressing to AIDS. Armed with that knowledge, they have resolved to “tell others about what being careful means,” and as Isabel said, to “tell them (women) to be careful about [whom] they go with.”

Isabel’s prevention efforts have been geared toward her own relationship. She said that, “Before, he never used condoms. Now I force him to do it because things would be worse if all three of us [she, child, and husband] were infected . . . . Now I always bring that stuff . . . condoms from the clinic which they give me. I tell him that he has to take care of himself. I do not want to infect him because that would be another guilt that I would have to carry.”

In a similar vein, and armed with what she has learned both from her own experience and from the group, Mercedes has also resolved to prevent infection in others, starting with her own partner. She said that they used condoms “because if he is good with me, I also have to be with him. I do not have to expose him so that he gets infected. So I have to find ways of . . . preventing infection because if it happens to one, you have to do everything possible so that it does not happen to someone else.

Mercedes would like to do more to prevent infection, and she certainly would be a good person to talk to her peers about how to protect themselves. However, she feels that, “there are many people I dare not tell . . . some of my friends . . . because I hear how they talk about people who do have AIDS.” She knows that it is a “lack of education . . . they do not know how it really is . . . some of my friends think you can get it from drinking from a glass that someone with AIDS used.”

Marisol, a woman with grown children, has resolved to do what she can so that her children do not “go through what I have gone through.” She is preventing infection
by making sure her sons do not engage in high-risk behaviors. For example, Marisol said she has told them they “do not have to be like their father—irresponsible and a womanizer . . . or a Don Juan [macho].” She also relayed that she talks to her daughters “very honestly and directly,” reminding them that “having relationships outside of marriage is not good, because that is known as fornication to us . . . having relations without protection, no.”

It was interesting to see that several of the participants—Pilar, Paz, and Susana in particular—participated in this study as a way of helping others to prevent “what happened to me from happening to them.” Mercedes was the most eloquent in this regard. When I asked her toward the end of the interview, as I did all the participants, if there was anything else that she thought I should know about either her experience with HIV/AIDS and/or helping other Latinos, she asserted:

Yes, yes. It is important that when one speaks to the teenagers—it needs to be done forcefully, they need to be told that they need to protect themselves—because they do not listen. They do not think it’s important to talk about. Saying that it is far away from me and that is never going to happen to me. Teenagers are like that—they live in a fantasy world. They spend so much time on the Internet and so many things like that. So I believe that we must direct ourselves more to the parents . . . . You have to start teaching kids about things when they are young.

Chapter Summary

Analysis of the nine narratives comprising this study found that lack of education, domestic violence, poverty, culturally-prescribed gender norms, and religious tenets—
both individually and in intersection—indeed have a significant, contributory effect on participants’ HIV/AIDS diagnosis.

The trajectory to becoming HIV positive or developing AIDS is fairly clear, though its delineation here is not meant to insinuate that the process is linear: Poverty leads to poor or little education which, in turn, diminishes the chance of being exposed to either sex education or to HIV/AIDS education. Regardless of the level of education, certain cultural factors (e.g., machismo, marianismo, and gender-related values that discourage conversations about sex) make it nearly impossible to provide effective education about HIV/AIDS given the necessity to talk about sex and condom use, in any effort to prevent HIV/AIDS infection.

Domestic violence leads to passive behavior, such as women tolerating abuse or not feeling like they can safely negotiate sexual contact, much less condom use. Further, violence can lead directly to HIV infection if an HIV-infected partner knows he is infected, and neither informs the female nor uses a condom. Moreover, domestic violence is perpetuated by cultural values that promote the dominance of males over females, and women’s acceding to the wishes of men. Condom use, an HIV-risk protective behavior, is inhibited by the cultural belief that, “To be a woman is to have children,” which is not a problem in itself, although, it can intersect with another cultural value, machismo, which men often interpret as a prerogative to have extramarital affairs. Men’s affairs can involve sexual relations with women or men, increasing men’s risk of acquiring HIV, which he then brings home to his unsuspecting wife, who is not using condoms because she is motivated to have children. If the wife questions her spouse prior to having sex, the
occurrence of the affair is denied, especially if they involve other men, they then engage in intercourse and now both the woman and man are HIV infected.

Religious tenets often overlay everything else in the participants’ lives. For example, women are to remain virgins until they are married, condom use is always a sin, and talk about sex outside the marital relationship is seriously frowned upon. The suppression of “sex talk” intersects with machismo and marianismo, inadvertently giving men even greater license to do as they please, not use condoms, and not have necessary conversations with their spouses. For women, there is even more reason not to bring up condom use with anyone, particularly with anyone besides a spouse. In colloquial terms, the deck is stacked against the possibility of preventing HIV infection, and against preventing HIV from becoming AIDS—because if you can’t have the necessary conversations or take precautions to reduce the risk of contracting HIV, there can be little doubt as to the outcome being HIV/AIDS. One has only to look at the statistics on Latinos and HIV/AIDS to see that indeed this is the case.
CHAPTER VI
CONCLUSIONS, DISCUSSION, IMPLICATIONS, AND RECOMMENDATIONS

Introduction

The purpose of this study was to explore Latinas’ HIV/AIDS narratives. The research questions guiding this study were: (a) What issues contribute to Latinas becoming infected with HIV? (b) What factors, or confluence of factors, play a role in Latinas living with HIV/AIDS? (c) What does being infected with HIV/AIDS mean to Latinas? and (d) How do Latinas make sense of being infected with HIV/AIDS? Narrative inquiry was used to explore these areas, and data were analyzed following a schema proposed by (Chase, 2005) an adaptation of Polkinghorne’s (1995) narrative- and paradigmatic-type narrative analysis, and the biographic lens proposed by Denzin (1989).

Nine Latino women, seven HIV positive and two diagnosed with AIDS, were purposefully selected and interviewed for this study. Participants came from various medical services clinics and from two AIDS service organizations in the southeastern U.S. The interviews lasted 60 to 90 minutes, were conducted in Spanish, and were held in the participants’ homes, as participants requested. Interviews and informal observations comprised the data sources. Additional data were provided by a research diary that chronicled the time from participant recruitment through completion of the data collection process.
Summary of the Findings

Several themes addressing each of the four research questions emerged from data analysis. Themes reflecting issues that contributed to an HIV diagnosis were lack of education, domestic violence, culturally-prescribed gender norms, and religious tenets. Data analysis also revealed that the factors were underscored and exacerbated by poverty. Themes associated with factors in living with HIV/AIDS included pervasive poverty, HIV/AIDS-related stigma, and immigrant status; data supporting these themes suggested that these factors acted on participants’ lives with both singular and combined effects. Themes congruent with the meanings participants ascribed to an HIV/AIDS diagnosis were being a good caregiver and summoning courage in adversity. Exploring how participants made sense of being HIV-positive or having AIDS produced three themes: the diagnosis as “just one more thing,” a deepened relationship with God, and a resolve to prevent infection in others. It should be noted that both ascribing meaning and making sense of an HIV/AIDS diagnosis were characterized by concrete rather than abstract thinking.

This chapter presents the conclusions drawn from the study findings and discusses them relative to the extant literature on HIV/AIDS and the study’s conceptual framework. The chapter also discusses implications for social work education and practice, and presents recommendations for future research.

Conclusions and Discussion

Analysis of study findings led to three general conclusions: (a) Making a distinction between contributing issues to HIV infection and the factors involved in living with HIV/AIDS creates a false dichotomy; (b) the meaning ascribed to and sense made of
being HIV/AIDS infected are both culturally mediated and congruent with the exigencies of the participants’ lives; and (c) there is an insufficient understanding of the gestalt of the HIV/AIDS experience in the participants’ lives.

*Making a Distinction Between Contributing Issues to HIV Infection and the Factors Involved in Living With HIV/AIDS Creates a False Dichotomy*

The first conclusion in this study is that making a distinction between contributing issues to HIV infection and the factors involved in living with HIV/AIDS creates a false dichotomy. In reality, the relationship between the contributing issues to HIV infection (lack of education, domestic violence, culturally-prescribed gender norms, and religious tenets) and the factors involved in living with HIV/AIDS (pervasive poverty, HIV/AIDS-related stigma, and immigrant status) is sufficiently fluid and dynamic to render a distinction between the two moot. In essence, the contributing issues to HIV infection continued to be present as participants lived life as HIV/AIDS-infected individuals, and vice versa.

In the following section, I will outline the issues and factors inherent in Latina women becoming infected with and living with HIV/AIDS, and explore their relationship within the context of HIV/AIDS. The issues are: pervasive poverty, which is a common thread across other factors, lack of education (formal and HIV/AIDS information), culturally-prescribed gender norms, religious tenets, domestic violence, HIV/AIDS-related stigma, and immigrant status. Since there is a dynamic and fluid relationship between the issues and factors, they are also discussed at points of intersection.

Authors from a range of fields, and via various forms of media, have expounded on the subject of poverty in general and its consequences for adults and children (Bartlett
et al., 2005; Caplovitz, 1963; Ehrenreich, 2001; Kozol, 1995; Lindsey, 2004; Mackenbach et al., 2008). Their positions are captured in a remark by Jeffrey Sachs, PhD, a noted international economic advisor and professor of health policy and management at Columbia University in New York. In an interview given to the *Journal of the American Medical Association (JAMA)* (Friedrich, 2007), Sachs underscored the connection between poverty and the lack of access to fundamental human needs such as basic education, primary health care, adequate nutrition, access to safe water, and the opportunity to earn a living.

Carmen, Paz, Gloria, Valencia, Isabel, Marisol, and Mercedes were relatively poor as children, and some, like Valencia, lived in abject poverty, as exemplified by no running water or electricity in the home. Poverty increased participants’ exposure to all of the contributing issues to HIV infection. For example, when someone was needed at home to take care of the household, other siblings, or an older family member, culturally-prescribed Latino gender norms, upheld by parents, dictated that the young women drop out of school to meet the family’s need. Consequently, the participants acquired insufficient formal education as well as scant HIV/AIDS information. Several researchers (Bowleg, Belgrave, & Riesen, 2000; Organista et al., 1998; Urizar & Winkleby, 2003; West, 2001; Wyatt & Carmona, 2000) have associated insufficient formal education with a low-level of condom use, and with misperceptions about what constitutes HIV risk. Organista et al., for example, found that people with little formal education, and/or with scant HIV/AIDS information, tended to believe that casual contact could lead to HIV/AIDS transmission, and do not think that they are like people “who get AIDS.” None of the participants considered herself at risk for HIV infection, including Susana
and Pilar, who had a college education but knew little about HIV/AIDS. Susana’s comment that “it happens to drug users and prostitutes only, and I am not that,” is representative of how all respondents felt. It is not surprising, then, that only one participant had ever used condoms prior to becoming aware of her HIV/AIDS status, and that was for the purpose of preventing pregnancy.

Aside from the impact on their education, both formal and HIV/AIDS-related, pervasive poverty also led to little or no access to health care throughout their childhood, necessitated crowded and at times substandard housing, and subjugated participants, as well as other family members, to menial labor, such as house cleaning or taking in ironing, to help support their families. This same set of circumstances also impacted participants’ status as immigrants.

Powerful economic and political forces motivate immigration (Engstrom, 2001). Whether directly, or indirectly this was certainly the case for study respondents. Either they or their partners emigrated to the U.S. in search of opportunities that would enable them to feed, clothe, and educate their children. Many were like Marisol, who exclaimed, “If you only knew how in my country I and my babies suffered hunger. We did not have clothes; I had to make them from rags.” Marisol and others decided that the only way to remedy the situation, after trying everything else, was to emigrate to the U.S. Others were like Paz, whose husband periodically traveled to the U.S. in search of work, and then returned home. Still others, like Susana and Mercedes, faced life-threatening circumstances that brought them to the U.S. Susana emigrated looking for life-saving medical treatment, and Mercedes did so to escape an abusive husband who had threatened to kill her.
Immigration, however, does not always bring rewards; it can also entail heartache, even disaster. In *Gender and U.S. Immigration: Contemporary Trends*, Hondagneu-Sotelo (2003) characterized immigration as “one of the most powerful forces disrupting and realigning everyday life” (p. 3). Every participant’s family embodies this description, and particularly in reference to HIV infection. For example, Paz’s husband traveled to the U.S., alone and episodically, to give his family a basic quality of life he could not provide in their native country. Economic need intersected with culturally-prescribed gender norms, in this instance, the macho cultural script endowing Latino men with the power to seek sexual gratification outside the marital relationship. It was during one of his forays to the U.S. that Paz’s husband became HIV infected; presumably his infection was acquired through either hetero- or homosexual contact, as he was neither a drug user nor a blood transfusion recipient. Of greater importance than how he became infected was the fact that upon his return from the U.S., he passed the virus on to Paz. The stories of other participants reflect similar experiences.

Presently, all nine participants live below the poverty line and suffer the attendant consequences as described by Jeffrey Sachs in the *JAMA* interview (Friedrich, 2007). While living in the U.S. affords them access to clean drinking water, work that will enable them to meet their basic needs is never a given. Pilar, for example, depends on a church food bank to supplement what food she is able to buy for herself and her daughter. Paz often does not know from one week to the next if her family will be able to pay the rent for their trailer, at times having to choose between food and rent. And, Isabel’s family frequently does not earn enough money to pay the rent on their apartment, buy food, and send money to El Salvador to support the children living with their
grandmother. The circumstances of these three participants, similarly experienced by the other participants, illustrates why socioeconomic status is such a prominent focus in the literature relative to HIV/AIDS.

Lower socioeconomic status is not only a risk factor for HIV infection, it is also a leading cause in the progression to full-blown AIDS—a likelihood much greater for financially impoverished individuals (Amaro, 1995; Bartlett et al., 2005; Borrayo & Jenkins, 2003; Bowden, Rhodes, Wilkin, & Jolly, 2006; Campbell, 1999; Caputo, 2004; CDC, 2006a; Community Education Task Force, 2006; Dutta-Bergman, 2004; Giordano et al., 2005; Jenkins, 2000; Land, 1994; B. V. Marin, 2003; B. V. Marin et al., 1988; K. R. McKenzie, 2003; United Nations Joint Programmes on HIV/AIDS, 2008; van Servellen, Chang, & Lombardi, 2002). This trajectory is due to the poverty sequelae discussed earlier, particularly lack of access to health care other than HIV-related care. In addition, and for reasons still unknown, lower SES individuals are not always given the more advanced or aggressive treatments available (Lopez, 2007)

The issues and factors addressed to this point have demonstrated the role of pervasive poverty as a contributory issue to HIV infection both singularly and in its intersection with lack of education, culturally-prescribed gender norms, and immigrant status. I have also described pervasive poverty as a factor in living with HIV/AIDS. The complexity, dynamic, and fluid nature among all the issues and factors is clear, though not complete. In the following section, I will focus on culturally-prescribed gender norms, religious tenets, domestic violence, and immigrant status.

Culturally-prescribed gender norms, role expectations, power inequalities, and cultural scripts, such as machismo, marianism, familismo, and personalismo, have been
associated with contextual risk factors for HIV (Amaro, 1995; Davila & Brackley, 1999; Moreno, 2007). Their influence promotes male dominance, female subservience, a requirement for women to be “virgin-like” in their relationships with men, and the expectation that they will tolerate abuse to maintain their marriage and their family (Moreno).

At the same time, it is important to note that both machismo and marianismo may also serve as protective factors. A man who ascribes to the macho role is expected to be a “gentleman” who takes responsibility for his family, for prescribed social responsibilities on behalf of the family, and for not bringing shame onto his mother (Gonzalez-Lopez, 2005). A woman’s marianista characterization implies that she will have only one partner, thus reducing her own and her family’s risk of contracting HIV. This study’s findings are concordant with the literature on culture, particularly as it relates to the respondents’ experiences with HIV/AIDS.

Other than Isabel, Mercedes, and Susana, participants were not only inexperienced when they had their first sexual experience (with the men they married), they were also ignorant about sex, and therefore dependent on their partner for “guidance.” Furthermore, it never occurred to them to question anyone about sex, least of all their mothers or their partners. What the participants did know was that they were expected to be virgins, and, as Valencia shared, “we were supposed to be faithful . . . . And [the men] were also [supposed to be faithful], but they’re not.” The participants understood that asking their partners to wear a condom was tantamount, as Gloria said, “to making them think we were accusing them of doing something [having sex with someone else].” And, the participants insinuated that asking questions would precipitate
negative consequences, including but not limited to their husbands’ anger. Moreover, the fact that the participants were married presumably negated the need for condom use, given that the sole purpose of condoms, as the participants expressed in various ways, was “to prevent pregnancy.” Even participants whose partners traveled to the U.S. for extended periods of time never entertained the thought that there might be cause to go against the marianismo script or, for that matter, to question their partners’ behaviors while away from home.

One culturally-influenced norm that has been fairly well researched as a factor in living with HIV/AIDS pertains to the doctor-patient relationship. It has been demonstrated that the doctor-patient relationship is critical to good outcomes for those living with HIV/AIDS (Reeves & Arnold, 2006); poor communication can prove disastrous given the complexity of HIV/AIDS treatment. Communication difficulties for Latino women are compounded by their view of providers as authority figures who are to be held in high regard and not questioned; communicating with physicians through an interpreter adds to the difficulty of becoming partners in their own healthcare—a concept that is foreign to Latina women but common to medical practice in the U.S. (Burke, 2003; McCoy, 2005; Miller, 2004). The findings in this study are congruent with this research. For example, only Susana has a fairly good understanding of her treatment goals. When she is given information like the results of the regular blood work she is required to have, for example, Susana knows they are a reflection of how well she is doing, and, what “doing well” really means. The rest of the participants, including Pilar, who is well-educated, have limited understanding of their medications and other indicators of their medical status—and they do not ask for explanations.
A finding in this study not found elsewhere in the literature is that participants’ reticence to be assertive with their medical care providers serves them well in the critical task of adhering to medication regimens; many of the HAART regimens require strict adherence for the medicines to be effective (Wolf et al., 2005). Participants reported taking their medications “exactly as prescribed,” and without resistance. Their goal is to stay well, so that “[they] can take care of [their] children,” as Paz and Isabel indicated, or so that they do “not get sick and have to tell [their] mothers [about HIV status],” as Pilar and Marisol related. Religious tenets, however, at times intersect with cultural norms, and, in so doing, sometimes undo the protective factors created by those norms.

Religious tenets, and particularly those of the Catholic Church, exert a strong influence in Latin American countries in many ways. With respect to HIV/AIDS, the Catholic Church is particularly powerful in affecting the politics of public health and education, and, even more directly, the social and cultural lives of its followers (Archundia, 2006; Armus, 2003; Frasca, 2005). The Church has not taken up the subject of AIDS directly but has addressed people’s behavior, specifically underscoring the duty of the fieles (faithful) to remain true to the Church by adhering to its tenets regarding sexuality (Archundia). Catholics are expected to conform to the Church’s teaching that sex is an act of procreation, and to its outright ban on using condoms as a means of contraception. The Church’s presumption is that the edict against sex outside of marriage will negate the need for condom use, and thus act as a protective behavior against HIV infection (Archundia).

Study participants, all raised Catholic and inculcated with the values of the religion, adhered to the teachings regarding sexuality. Only one of the seven married
participants, Isabel, had sex before marriage; the rest experienced their first sexual encounter with either their novio or with their spouse on their wedding night. None of the participants considered using condoms, much less discussed condom use with their partners. When asked about this omission, Paz’s statement that it was “something I just knew I was not supposed to do, probably from Church,” is representative of the other participants’ responses. Pregnancy prevention was accomplished through the use of the church-sanctioned rhythm method, though the act of using this “natural” method of birth control, as with condom use or any other sexual matter, was not something participants discussed with their partners. As the experiences of these participants underscore, religious tenets intersect and potentiate cultural norms that promote women’s subservience to men (Gonzalez-Lopez, 2005). As a result, domestic violence is at times exacerbated.

DV is an insidious occurrence in the lives of those who are victims of such violence, whether it is intra-familial, between intimate partners, or between parents and children. According to the CDC (2006d), the effects of DV can be physical (e.g., broken bones, internal bleeding, head trauma); emotional (e.g., low self-esteem, depression, inability to trust); and/or behavioral (e.g., alcohol or drug abuse, engaging in risky sexual activity). Research (L. S. Carter, Weithorn, & Behrman, 1999; Osofsky, 2005; Ybarra, Wilkens, & Lieberman, 2007) reveals that children who grow up with DV as even an occasional presence in their lives, even if they are subsequently removed from the environment in which the DV occurred, have a greater likelihood of developing the consequences of DV later in their adult lives [TR1]. In addition, children who have been exposed to DV, even when not abused themselves, tend to score lower on verbal
functioning tests, have higher internalizing behaviors, and, at times, become batterers themselves (Ybarra et al.).

The participants’ experiences mirror the findings in the DV literature. Many grew up watching their fathers abuse their mothers; were abused themselves as children either physically, emotionally, or both; or were physically, sexually, and emotionally abused by their partners as adults. Moreover, the violence was often accompanied by alcohol abuse by the perpetrator, thus heightening the impact of the abuse. The consequences of DV are evident in the participants’ acknowledged bouts of depression, anxiety, and self-doubt and were not necessarily or solely related to their HIV/AIDS status. Also, the participants expressed at times feeling helpless to change a particular circumstance in their lives—a common occurrence, according to researchers (Sokoloff & Pratt, 2005), for women who have been abused. For example, after her novio physically and sexually assaulted her, Pilar commented that she “tolerated [his abuse] because I thought I wouldn’t have another opportunity to have a family.” This finding highlights the intersection of DV with culturally-prescribed scripts regarding gender roles, in this case both machismo and marianismo. Machismo and marianismo potentiate DV in that the former promotes the dominance of males over females, and the latter the female imperative to accede to males’ wishes (Gonzalez-Lopez, 2005).

In addition to the impact DV has on individuals, studies (Amaro, 1995; Amaro & Raj, 2000; Campbell, 1999; Davila & Brackley, 1999; Land, 1994) have also identified DV as a powerful risk factor for HIV infection. Researchers have demonstrated a strong, if not direct, relationship between DV and women’s inability to successfully negotiate sexual contact and activity—a necessary protective behavior against HIV infection. All
study participants had some experience with DV, whether from an intimate partner, as in Pilar’s case, or at the hands of a stepfather or a boyfriend, as in Mercedes’ situation.

Some participants witnessed DV in their families of origin and learned behaviors that put them at risk both for being abused themselves and for becoming infected with HIV. Gloria was one such participant. She shared, “there was a lot of abuse in my house . . . My father hit my mother all the time while I was growing up . . . I learned what it was to be a woman from my mother.” When she encountered abuse in her relationship, she “took it . . . I thought that’s what you had to do.”

For at least three participants there was a direct link between DV and HIV, given that their partners initiated the trajectory to an HIV/AIDS diagnosis when they chose to have unprotected sexual intercourse with them. Paz, Susana, and Marisol, after becoming HIV positive themselves, discovered that their partners knew they were either HIV positive or had AIDS when they chose to have unprotected sexual intercourse with them. Five additional participants had a strong suspicion that their partners were aware of their HIV positive status but could not prove it. In some states, including Florida, Georgia, and Missouri, knowingly putting someone at risk for HIV infection is considered a felony, and those who commit such a crime can, and often do, spend significant time in jail (Lambda Legal, 2008). Acquiring HIV in this manner adds to the burden already imposed by HIV/AIDS-related stigma.

There is a great deal of stigma attached to HIV/AIDS in Latin American countries as well as in the Latino community in the U.S. Fueling stigmatization is the disease’s continued association with homosexuality and sinfulness. In the Latino community, there is more stigma attached to homosexuality than to HIV/AIDS (Frasca, 2005; Gonzalez-
Lopez, 2005), though for many Latinos HIV/AIDS and homosexuality are one and the same. Consequently, stigma is one of the major reasons—the other being the taboo against talking about sexual matters of any kind, particularly in public or with someone not an intimate friend or partner (Frasca)—for the lack of frank, straight-forward HIV/AIDS education in the participants’ countries of origin. None of the participants, including those fairly new to the U.S. or Marisol who has resided here 20+ years, knew much about HIV/AIDS; they did not view themselves as being at risk for HIV infection nor were they aware that their partners’ behaviors could put them at risk. This circumstance has been supported by many researchers (Bowleg, Belgrave, & Riesen, 2000; Gutierrez et al., 2000; Organista et al., 1998; Parrado et al., 2005; Urizar & Winkleby, 2003; Wyatt et al., 1998).

It is important to note that the impact of HIV/AIDS-related stigma is compounded by immigrant status. In the U.S., participants’ status impacts all aspects of their lives, particularly with respect to HIV/AIDS infection. The politics of immigration in the U.S., as well as the political and sociocultural aspects of HIV/AIDS in the participants’ native countries, constrain their lives. For example, if not properly and legally documented, one cannot get a driver’s license; not having a driver’s license necessitates curtailing movement for even a minor traffic infraction poses the threat of deportation. Lack of proper documentation also impacts the ability to find gainful employment; often relegated to low-paying jobs, immigrants remain in the vicious cycle of poverty. One in five Latinas in the U.S. lives in poverty (U.S. Census Bureau, 2005), and the figure is higher for those who are not properly documented. Furthermore, if Latinas want to return to their native countries, to see their parents or the children they left behind, they cannot
do so without proper documentation; otherwise, they would not be allowed to re-enter the U.S. And while there might be many positive consequences of being amongst family, in a country with which they are familiar and know the language, it also means risking not having the HIV/AIDS medications needed. In many Latin American countries, including those of Pilar and Susanna, the medications are either not available for purchase, or are available but prohibitively expensive. It is evident that their choices are constrained by their immigration status and because the choices can have such dire consequences, participants find themselves in untenable situations.

In summary, various aspects of participants’ lives have been demonstrated to be risk factors for HIV infection. In addition, many authors (Armus, 2003; Bowden et al., 2006; Campbell, 1999; CDC, 2007b; Dutta-Bergman, 2004; Frasca, 2005; Land, 1994; Marshall et al., 2005; Moreno, 2007; UNAIDS, 2006) have addressed the notion that there is a multi-layered and mutually influential relationship between structural factors (i.e., poverty, lack of education, poor or no access to ongoing health-care), and domestic violence, culturally-prescribed gender norms, and religious tenets when it comes to HIV infection. By extension, it is reasonable to suggest that since issues contributing to HIV infection do not “disappear” once someone is diagnosed with HIV or AIDS, and may be exacerbated by receiving this diagnosis, the relationship between these issues and the factors involved in living with HIV/AIDS is dynamic and mutually influential. At times, it is impossible to say what came first, particularly if one goes back, as Denzin (1989) suggested, to participants’ biographical origins.

_The Meaning Ascribed and Sense Made of Being HIV/AIDS Infected is Both Culturally Mediated and Congruent with the Exigencies of the Participants’ Lives_
The second conclusion for this study, the meaning ascribed and sense made of being HIV/AIDS infected is both culturally mediated and congruent with the exigencies of the participants’ lives, reinforced the centrality of culture in this narrative inquiry study. This is the least surprising of the conclusions, given that individuals’ views, attitudes, and responses towards illness are shaped by the culture in which they live. Within the social work profession, this type of interaction is embodied in ecosystems theory (Kirst-Ashman, 2007), which is a blending of the ecological perspective and general systems theory. The focus of ecosystems theory is on “the interactions between the individual and various systems in the environment” (Kirst-Ashman, p. 24). This locus of attention and action provides fertile ground for generating meaning and making sense of events in life. While ecosystems theory offers a framework for understanding this second conclusion, Kleinman’s theoretical perspective is more to the point in that he posits that illness has culturally-mediated meanings which are particular to individuals.

While the conclusion that culture mediates both the meaning ascribed and sense made of HIV/AIDS in the participants’ lives is not surprising, some of the findings which led to the conclusion stand in contrast to those in other studies where meaning and sense making were also a focus. I should also note that in the early stage of data analysis a peer reviewer commented that the data supporting some of my findings were somewhat “thin.” This motivated me to immerse myself more deeply in the data in order to convey the nuances particular to this study.

Data analysis revealed that the meanings participants gave to HIV infection in their lives were related to being a good caregiver and to summoning courage in the face of adversity. Making sense of the diagnosis centered on thinking of HIV as “just one
more thing” in their lives, developing a deepened relationship with God, and to resolving to prevent infection in others. Both the meaning ascribed and the sense made were culturally-mediated responses congruent with the exigencies in participants’ lives.

Given that being other-centered resides at the heart of identity development in women (Gilligan, 1982) it was somewhat expected that participants would include “being a good caregiver” when asked about what it meant to be HIV positive. For women in general, and in Latino culture in particular, the most significant role of women, and one that the participants valued greatly, is that of caregiver (Campbell, 1999; Clark, 2002; Gonzalez-Lopez, 2005). This puts into context Paz’s first comment when she was asked about the meaning of being HIV positive: “nothing.” When I probed for more detail, she thought for a moment and said, “It means I have to take my medicine [as instructed] . . . so I can stay well and take care of my children.” Other participants responded in very similar ways, including those participants without children; for them, mothers and/or significant others served as the care giving focus.

Further supporting this conclusion is Campbell’s (1999) assertion that caring for their children gives mothers a sense of purpose and hope for the future. Both are ideas central to the teachings of Victor Frankl (2006), whose work focused on how people in concentration camps managed to survive against great odds. Frankl concluded that

The true meaning of life is to be discovered in the world rather than within man or his own psyche, as though it were a closed system . . . . Being human always points, and is directed, to something or someone, other than oneself—be it a meaning to fulfill or another human being to encounter. (p. 110)
Frankl’s quote captures the way participants in this study were able to make meaning of HIV infection. Whether concentrating on her disabled daughter, as did Paz, or thinking how her death might impact her mother, as did Susana, the participants maintained an outward focus. In every case the meaning they expressed was in reference to someone for whom they felt responsible. What is also important to note is that participants saw this responsibility as something required of them—as a woman, a daughter and as a mother.

That participant responses are culturally mediated can be understood when considering how the findings of this study are different from research by Courtenay, Merriam, and Reeves (1998), who looked at how a maximum variation sample of HIV-positive adults made sense of their lives. They found that the meaning-making process included steps in which participants took stock of their lives, discovered what in life is important to them, and re-evaluated their priorities. During these three steps, which took place early in the meaning-making process, participants focused primarily on their own needs. Furthermore, they were able to think about their life in abstract terms. They asked themselves some of the eternal questions, like who am I? Why am I here? Dawn, for example, early on asked herself, "who I was and what I wanted, what kind of contributions I wanted to make and what was important to me" (Courtenay et al., p. 24). This is in stark contrast to the experiences of the Latinas in this study, whose immediate focus was on the needs of others, particularly their children, spouses, and parents, after a brief period of shock and depression post diagnosis, and who thought of life primarily in concrete terms. For example, Valencia, whose HIV infection was discovered during a pregnancy, cried for her unborn child and her husband, “I do not know what is going to happen to the baby.” Another example is Paz, whose main concern since “the shock wore
off . . . [has been] her children . . . I have to stay well for them . . . who will take care of them if I don’t?” Although demographic differences between the samples in these two studies preclude the ability to make other, meaningful comparisons, the difference in focus post diagnosis—self or others—underscores the importance of culture in making meaning of a life-threatening illness.

The meaning of an HIV/AIDS diagnosis also involved summoning courage in adversity. Frankl (2006) found that one of the ways that “we can discover meaning in life . . . is by the attitude we take toward unavoidable suffering” (p. 111). Furthermore, “in some ways, suffering ceases to be suffering at the moment it finds meaning” (p. 111). The participants demonstrated what Frankl is talking about in the way they handled their HIV/AIDS diagnosis. Rather than bemoan the unfairness of becoming HIV/AIDS infected, they responded in the way they typically do in the face of life challenges—by adopting a “can do” attitude that leads to action. When Susana discovered she had AIDS, after a period of a week or so she “got up and went out and got [herself] educated about this disease.” She not only looked for, and found, information she also located medical care, including access to HIV medications with limited availability in her country. When told that there was “nothing else they could do for [her],” Susana, who did not speak English at the time, found a way to the U.S., and once here was able to connect with medical care, including participation in an experimental drug trial. Similar stories by participants are replete with examples of courage in the face of adversity. Carmen clearly captured the attitude of the participants in this study when she said, “[We] don’t have time to think about being HIV positive, and [we] have too much to do. [We] take our medicine and move on.”
Like the meaning ascribed to an HIV/AIDS diagnosis, the sense made of it is mediated by culture and congruent with the exigencies in participants’ lives. The idea that meaning arises out of the lived experiences of those being studied is evident in both the phenomenological and sociological literature. Denzin (1984), in discussing meaning and method in phenomenological research, posited that “experience comes to the researcher in terms of lived experience, thickly embedded in the historical, interactional, temporal, emotional and relational worlds of everyday life” (p. 24). Similarly, Armus (2003), in Disease in Latin America, highlighted the concept that “diseases cannot be examined outside their societal frame” (p. 2) and that “meanings for disease . . . reflect individuals’ own way of producing meaning (p. 2),” with the way of producing meaning influenced by life circumstances. For participants already burdened by poverty and the myriad social circumstances in which their lives are embedded, being HIV infected, is “just one more thing” with which they have to contend. Paz’s worry “about how rent will be paid” and “what would happen if my husband can’t work enough,” is a concern that supersedes other worries, including “making sense” of HIV infection. Valencia shared that “now it means nothing” and she “just takes her medicine.” Making sense of HIV infection, like everything else in her life, is related to how well she can manage what the illness requires of her. Doing what needs to be done so that HIV does not get in the way of other responsibilities is, for Valencia and the other participants, making sense of it. That is why being HIV infected is considered to be “just one more thing” in a life characterized by responsibility.

While I found no studies that specifically discuss the role religion plays in helping Latinas cope with HIV/AIDS, there is research that addresses the role of religion in
coping with other illnesses. One survey study (Addington-Hall, Weir, Zollman, & McIlmurray, 1993) revealed that religious beliefs and practices often reduce the loss of control that individuals living with both acute and chronic illness experience. A study with pediatric cancer patients found that religious patients experience lower levels of pain than nonreligious ones (Yates, Chalmer, St. James, Follansbee, & McKegney, 1981). Kleinman (1988a), in his book on explanatory models of illness, talked about the need to understand—to make sense—of a medical condition, and he explained that religion or faith helps people achieve this goal.

Several of the participants turned to God in response to their diagnosis. Pilar, who felt betrayed when news of her HIV infection was shared by the pastor’s wife with other members of the congregation, left that church, though did not reject God or her religion. She found another church and said that, “I thank God every day and thank you for what my daughter has learned today . . . . I don’t ask for money, what I ask most of God is health and many years of life.” She also thanks God that her daughter “was not born with the virus, it was not there while this little girl was in my uterus.” She counts on God “to help me” and feels that if “I stay true to God, He will be there.”

Marisol and Mercedes have also turned increasingly to God to help them make sense of HIV/AIDS and what it means for their lives. Always a religious person, Marisol commented that she relies on God even more “because who else do I have? If I didn’t have God to talk to, I would talk to no one.” Marisol stated that there is one request, in particular, that she makes of God: help in dealing with the anger she feels to a husband who “could have done this to me (knowingly infected her).” Mercedes, never a particularly religious person though “a believer,” had “a vision of Jesus . . . He came to
me with his hands outstretched . . . and told me I was going to be alright.” Now, she
prays, and “counts on Him,” and shared that “If I am alive it’s because God wants me
here . . . maybe to forgive someone.”

Some of the participants, three in particular, are dealing with HIV/AIDS by
resolving to prevent infection in others. This is not surprising and is well documented in
the research literature (Jacobson Jr., Luckhaupt, Delaney, & Tsevat, 2006; Loue &
Sajatovic, 2006; Neff, Amodei, Valescu, & Pomeroy, 2003). Two participants, Isabel and
Mercedes, attend a support group. Isabel commented that it “gives [her] a chance to help
others,” and Mercedes reported it has “taught me so much that I can now share with
others, so they don’t wind up like me.” Similarly, Carmen noted that she “wants to help
my sisters and my cousins not get sick,” and that she “talks to them all the time and I
don’t care who knows that I have the virus . . . . Maybe they’ll learn from my mistakes.”

There is Insufficient Understanding of the Gestalt of the HIV/AIDS Experience in the
Participants’ Lives

The third and final conclusion is that there is insufficient understanding of the
gestalt of the HIV/AIDS experience in the participants’ lives. This conclusion fits well
with the three theoretical assumptions on which this study is based. The first is that
science is non-neutral and political (Benston, 1989; Foucault, 1994; Harding, 1991; N. F.
McKenzie, 1991b). According to this assumption, analysis of factors such as gender,
race, and ethnicity is essential in understanding the scientific response to diseases such as
HIV/AIDS, as well as in gaining insight into people's experiences with HIV/AIDS.
Amaro (1995) underscored this essentiality in a theoretical paper that noted the need to
address HIV prevention in women in general, and women of color in particular. She
suggested that behavioral approaches to HIV prevention thus far have paid insufficient attention to the ways gender, social status, and women’s roles impact sexual behavior and risk taking, as well as the ability to take the actions necessary to protect themselves against risk.

Other authors have also addressed the issue of gender, race, and ethnicity in relation to HIV/AIDS. Gomez and Marin (1996), for example, acknowledged the importance of considering gender, race, and ethnicity in a study which looked at the relationship between gender, culture, and power in relation to condom use. They determined that condom use not only depended on a woman’s ability and skill to protect herself, but also upon her ability to persuade her partner to use a condom. It is understandable, given the cultural reality of life as Hispanic women, that the participants in this narrative study were not assertive in promoting condom use; they did not feel sufficiently empowered to raise the issue, much less insist their partners use condoms. And the constraining effect of culture is compounded when lack of information about HIV/AIDS is also a factor. Take Marisol, for example. Despite living on Long Island, New York, at the height of the epidemic, she had “never heard of AIDS” and “had no idea” that she could become infected. After all, “[She] was not a prostitute, a drug user, and . . . . did not go with a lot of men.” What is disconcerting, given the HIV/AIDS epidemic has been in existence for more than a quarter of a century, is that the message for women is essentially the same: Even after grappling with societal and cultural forces, and choosing to use a condom, a woman’s ability to fully protect herself from HIV infection continues to be dependent on the behavior of another person—as her partner needs to agree and, as this study demonstrated, they often do not.
In a report on HIV/AIDS and women of color, Land (1994) pointed to the “devastating” (p. 355) effect the HIV/AIDS epidemic is having on African American and Latino women, especially those of child bearing age. She identified disparities in the statistics and related them to issues of poverty, lack of access to healthcare, the impact of economic dependence on a woman’s ability to protect herself from disease transmission, and lack of HIV/AIDS information, including treatment information. All of these issues were dealt with by the participants in this study.

The reason for the lack of success in HIV prevention efforts with Latino women is not due to insufficient data regarding the biographical particulars of this population and context within which they experience HIV/AIDS; much is known and has been known for quite a while. The problem is a lack of understanding of HIV/AIDS infection as a gestalt, that is, an organized whole that has specific properties that cannot be derived simply from summing the component parts. It is the entirety of the HIV/AIDS experience that must be understood, not simply the discrete issues that contribute to HIV/AIDS infection and the factors involved in living with it. The findings of this study underscore what other researchers have long known: The gestalt of the HIV/AIDS experience must be understood and advanced if prevention efforts are to be effective.

This third conclusion is also related to the assumption that diseases occur, are investigated, and treated within societal contexts and require examination within those contexts (Campbell, 1999; Foucault, 1994; Frasca, 2005). Diseases are defined and framed by history, social groups, and individuals. In addition, they are further influenced by factors such as religious and cultural beliefs, gender obligations, nationality, ethnicity, and class (Armus, 2003). The contributing issues to HIV infection, and the factors
involved in living with HIV/AIDS, are not only present in the participants’ lives, the relationship between the two is dynamic, fluid, and multi-layered. This complex of factors acts as a filter through which prevention messages must pass—if this is not understood by those researching or crafting prevention interventions and messages, the likelihood of HIV prevention messages being effective is quite low.

What HIV prevention messages, in effect, have asked the participants in this study to do is “just say no,” and to do so in the face of what their Church tells them they must do, the culture has taught them they ought to do, not only about sexual behavior but also about their role as a woman, and their personal beliefs and desires would have them do; given the statistics for HIV infection in Latino women (CDC, 2006a) it is a message that is not having the desired effect. This study’s findings suggest that the source of the ineffectiveness is not simply that prevention messages rely on “individualistic conceptualizations of behavior” (p. 339), but rather that there is insufficient appreciation and understanding of what the “broader cultural and social context of sexuality” (p. 340) is for the participants of this study. I suggest that while there is an acknowledgement of cultural difference in research, what is understood of the differences is being filtered through assumptions that are not the same as those of the people who are the focus of the research; one needs only to consider the degree of cultural and health disparities in the U.S. to deem this indeed might be the case.

Although the sample in this narrative study is small and purposeful, by providing a detailed accounting of the participants’ lives as the context for the lived experience of HIV/AIDS, it contributes to the knowledge base of what is known about Latino women
living with this illness. It is my hope that their narratives, as rendered in this research, do justice to the complexity of their lives and to the courage required to live them.

Implications for Practice and Education

There is a dearth of studies that focus on Latinas’ experiences with HIV/AIDS, particularly from the perspectives of women living with the illness. Those that do are primarily concerned with preventing infection and focus on discrete factors (e.g., culture) related to the experience of living with HIV/AIDS. In doing so, they fail to address the critical issue that this study has highlighted: the need for HIV prevention initiatives, as well as efforts to assist infected women in coping with the illness, that take into account the entirety of these women’s lives, recognizing and honoring the many influences that shape who they are. A review of the literature did not uncover any study that focused on the emic perspectives of Latinas with HIV/AIDS living in the U.S., much less one that looked at the confluence of factors and issues facing this particular population. This narrative study, in exploring the stories of nine Latina women living with HIV/AIDS, provides a richer depiction of their experiences than exists in the literature to date.

In addition to the theoretical implications alluded to earlier, this study has important implications for the profession of social work, particularly in the areas of practice and education. In addition, many of the implications are relevant for professionals in allied disciplines (e.g., health care), given the emphasis in this study on both the nature of HIV/AIDS and the psychosocial needs of Latino women living with it.

First and foremost, this study may be beneficial for those who work with Latinas who are at risk for HIV infection, Latinas living with HIV/AIDS, or “simply” Latina immigrants. Rothery (2001) noted that social workers most commonly utilize an
ecosystems model in working with clients, in which they are “encouraged to view situations holistically, attending simultaneously to people, their families, and whatever other systems might be important to their needs” (p. 69). To do as Rothery suggested requires having information about the women and their circumstances. Participants’ narrative summaries, the analytic commentaries, and the comparative analysis of the narratives contain a wealth of specific and detailed information about the women and their experiences that is not found elsewhere. While the profiles cannot duplicate those of a social worker’s own clients, the data nevertheless suggest the kinds of issues that clients may present with in both medical and mental health settings.

Second—and the importance of this point cannot be overstated—effective social work practice with Latinas living with HIV/AIDS requires an understanding of and appreciation for the context of their lives. This dissertation illuminates for practitioners how poverty, education, domestic violence, culturally-prescribed gender roles, and religious tenets, singly and in combination, influence not only how others see Latino women but, more importantly, how they see themselves. Because disease does not occur in a vacuum, these influences impact how Latinas will hear and respond to prevention messages and treatment. The steady increase in HIV/AIDS morbidity and mortality among Latinas (see Chapter 1) suggests that they are either not receiving or not heeding existing messages. This dissertation adds to the knowledge base that will help practitioners understand why this is the case and how it can be changed.

Third, for practitioners who counsel HIV/AIDS-infected women, understanding contextual influences provides critical information about what the diagnosis means to their Latina clients and how they make sense of having the disease. That is to say, the
information can help practitioners understand how the women incorporate the diagnosis into their everyday lives, enabling counselors to better assist their clients with this task. In addition, examining context may uncover areas in which the women need to be empowered to take action that is unfamiliar to them, such as becoming knowledgeable about HIV and how it affect their bodies, and exploring treatment options.

This dissertation contains important information for educators as well. Working with Latinas who are at risk for or living with HIV/AIDS requires more than the standard complement of skills (e.g., evaluation, assessment, treatment planning, etc.) that social workers learn in BSW or MSW programs. A surprisingly small number of social work programs offer specialized courses that cover the kind of information contained in this dissertation; many do not teach a course providing even basic information about HIV/AIDS (Humble, 2009).

Practitioners must learn about the dynamics that impact Latinas if they are to respond effectively. They need to be taught how to empower their clients, but more specifically, they need to learn what the impediments to empowerment might be. They need to understand the cultural information contained herein, as well as the ways it impacts Latinas’ ability to advocate for themselves, and educators need to make sure their students are exposed to this information. Lastly, it is critical for practitioners to be aware of the lack of information about how HIV/AIDS acts on and impacts the health of Latino women, as well as this population’s lack of knowledge about available treatment options and what they entail. While practitioners do not prescribe medication, it is increasingly their responsibility to assist clients in adhering to the medication regimens that prevent HIV from becoming AIDS (Lopez, 2007).
Recommendations for Future Research

The purpose of this study was to explore the narratives of Latino women living with HIV/AIDS. Based on this qualitative study, I offer five recommendations for future research.

First, even though the sample in this study consisted of nine, first-generation immigrants from five different countries, they do not represent all Latinas or all women who come from the same country. Also, all participants were of a low socioeconomic status, and only two had attended college in their native countries (none had attended college in the U.S). Lastly, the study took place over a three-month period and participants were interviewed only twice. To address these limitations, the study should be repeated with a larger sample size, with recruitment geared toward achieving maximum variation, to see if the results hold up across a larger number of women with greater demographic diversity. Additionally, it would be beneficial to repeat the study over a longer period of time, with a series of interviews rather than only two. While all the participants warmed up to me and the information they provided suggests that they trusted me, having more time with them might produce richer data.

The second recommendation may be the most important one. Social science researchers must conduct more community-based, participatory research, or research that engages communities in partnership with researchers. Those affected, in this case Latino women, need to be included in all phases of the research to the extent possible, from the development of the grant proposal through subsequent phases of the study. There are numerous benefits to engaging in this type of research, including: (a) focusing on issues that are important and relevant to Latinas; (b) targeting interventions to identified needs;
(c) developing approaches that incorporate Latino cultural norms and values, and are therefore both valid for the community and based on empirical evidence; (d) improving interpretations of findings so that they are sensitive to genuine (but not stereotypical) cultural meanings, and (e) increasing the participation of Latino women in research.

The participants who were recruited for this study were eager to participate and believed they had something to contribute. What engaged them was, first, that as a Latina woman, I “was one of them” and therefore someone they could relate to and trust. Second, the interviews were conducted in Spanish, without the need for an interpreter, and in a place of their choosing (in their homes, and in one case on a private stairwell). Many of the participants commented that this was part of the reason they agreed to participate. Third, I provided a “safe space” for them to share what I was interested in, their personal stories. It was truly surprising how unaccustomed they were to being asked to talk about themselves.

My third recommendation is that until a cure is found, the advancement of HIV/AIDS prevention research should begin with the recognition that the greatest impact on the epidemic will come from effectively preventing HIV transmission in the first place. While this may seem obvious, this matter is complicated significantly by cultural tenets (Vinh et al., 2003) and gender and social inequalities (Bowden et al., 2006; Bowleg, Belgrave, & Riesen, 2000; Campbell, 1999; Gates Foundation for Global Health, 2007; Land, 1994) both in the U.S. and throughout the world. Existing prevention tools are largely dependent on male behavior, rather than being under Latina women’s control. Prevention researchers, then, would do well to follow Amaro’s (1995) advice and
use behavioral approaches that reflect the role of gender and social status in women’s ability to negotiate sexual contact and protect themselves against becoming HIV infected.

My fourth recommendation is that social work researchers should play a larger role in prevention research by advancing non-stereotypical, psychosocial characteristics of Latina women. They should use this understanding as a basis for creating new prevention initiatives while also incorporating it into existing initiatives. In addition, social work researchers can make clear the connection between prevention impediments and their enduring impact on the women’s lives post-HIV infection. Doing so will advance cultural competence in both prevention (Vinh et al., 2003) and psychosocial treatment interventions for Latina women living with HIV/AIDS (Campbell, 1999).

Lastly, social work researchers must aim to ameliorate the circumstances that hinder HIV prevention and fuel HIV infection, while simultaneously calling attention to the expansion of the epidemic in the Latina community. Specifically, research and action are needed in relation to the following areas and issues: (a) demonstrating the impact on women and girls of promoting gender equality and addressing gender norms and relations, while also highlighting the need to involve men and boys in the effort; (b) promoting the links between HIV prevention and sexual and reproductive health; (c) demonstrating the impact on HIV/AIDS prevention and treatment of mobilizing community-based responses throughout the continuum of prevention, care, and treatment; and (d) demonstrating the need to strengthen financial, human, and institutional capacity across all sectors, particularly in health and education.
Chapter Summary

The purpose of this study was to explore Latinas’ HIV/AIDS narratives. I conducted in-depth interviews with nine participants, and analyzed transcripts of the interviews. Based on this narrative inquiry study, there were three conclusions: (a) Making a distinction between contributing issues to HIV infection and the factors involved in living with HIV/AIDS creates a false dichotomy; (b) the meaning ascribed to and sense made of being HIV/AIDS infected is both culturally mediated and congruent with the exigencies of the participants’ lives; and (c) there is an insufficient understanding of the gestalt of the HIV/AIDS experience in the participants’ lives.

I discussed the conclusions while also weaving in a discussion about related implications for policy. I also explored implications for social work practice by discussing knowledge, skills, and goals. Theoretically, this study advances the literature related to Latina women, particularly emic perspectives of living with HIV/AIDS. Practically, it provides educators with suggestions for preparing social work practitioners for work in this field and highlights specific areas that need to be underscored and expanded in social work education programs. Finally, I provided five recommendations for future research.

Concluding Thoughts

Aside from failing to produce a vaccine that would inoculate against HIV, the sheer volume of research on every other aspect of preventing and treating HIV/AIDS is truly astounding; this dissertation alone contains almost 100 citations of disparate types of research on the medical and psychosocial aspects of HIV/AIDS. Yet a recent re-reading of Randy Shilts' (1987) journalistic account of the beginnings of the HIV/AIDS
epidemic, *And the Band Played On*, read like a prophecy. For me it was a *déjà vu* experience, and when I was done, I realized that it is not a mystery, really, how even knowing what we know and possessing the resources we do, there are nevertheless approximately 4.3 million new cases of HIV infection globally (43,000 in the US) and approximately 2.9 million deaths from AIDS (18,000 in the US) (UNAIDS, 2006). The answer lies in the margins of gender, race, class, and ethnicity and in the political context into which HIV/AIDS was born and in which it continues exist. Researchers, practitioners, and service delivery providers need to take this into account in a more comprehensive way.

Shilts (1987) decried the lack of media attention to AIDS until “October 2, 1985, the morning that Rock Hudson died” (p. xxi). By then, however, 12,000 other Americans had died as well (Shilts). The evidence strongly suggested, and continues to suggest in many ways today, that political expediency won out over matters of public health. Recounting the history of HIV/AIDS, Shilts said, “is a tale that bears telling, so that it will never happen again, to any people, anywhere” (p. xxiii). Yet the statistics indicate that it is happening again, particularly in minority communities in the U.S. and across the globe. We need once again to be riveted by the HIV/AIDS epidemic; otherwise, the difference being made by research and other efforts will be of little consequence.
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APPENDIX A1

Escritura de Consentimiento de Proyección

Hola. Soy Sandra Yudilevich, la investigadora conduciendo el estudio de mujeres Latinas viviendo con VIH/SIDA. Me gustaría hacerle unas preguntas a fin de determinar si usted puede ser elegible para la investigación. Antes de que yo comience con las preguntas me gustaría decirle un poquito sobre la investigación. El objetivo de este estudio es explorar la experiencia de mujeres Latinas que han sido infectadas por el VIH/SIDA y los factores que afectan la experiencia.

¿Quisiera usted seguir con la proyección? La proyección tomará no más que 10 minutos. Le preguntaré sobre su estado de VIH/SIDA, su voluntad de participar en el estudio, y algunos factores demográficos. Usted no tiene que contestar ninguna pregunta que usted no desea contestar o la contestación la hace sentir incómoda. También usted puede dejar de participar en cualquier momento. Su participación en la proyección es voluntaria.

Sus respuestas serán confidenciales. Nadie sabrá sus respuestas excepto el grupo de investigación. Si usted no participa en el estudio, su información de preproyección será destruida. Si usted califica para participar en la investigación, y decides participar, sus respuestas de esta proyección serán guardadas en un gabinete cerrado con llave, localizado en una oficina que también será cerrada con llave cuando nadie está allí.

¿Quisiera usted seguir con la proyección?
(Si no, agradezca al individuo y cuelgue)
(Si sí, siga con la proyección)

- ¿Cómo se llama usted?
- ¿Cuántos años tiene usted?
- ¿Es VIH de SIDA positiva?
- ¿Quisiera usted participar en una entrevista de 90 a 120 minutos?
- ¿Estaría usted disponible para participar en una entrevista de 30 minutos si es necesario, persiguiéndola por teléfono o en persona, como sea preferable para usted?
- ¿Dónde vive usted?
- ¿Cómo puedo ponerme en contacto con usted en el futuro para la participación adicional?

Gracias por contestar las preguntas de proyección.
(Indique si la persona es elegible, requiere la proyección adicional, o no es elegible y explicar por qué.)
¿Tiene usted alguna pregunta sobre la proyección o la investigación? Voy a darle un par de números de teléfono para llamar si usted tiene alguna pregunta más tarde. ¿Tiene usted una pluma? Si usted tiene preguntas sobre la proyección de investigación, usted puede llamar Sandra Yudilevich en 706-248-9275. Si usted tiene una computadora puedo darle mi dirección de correo electrónico: syudilev@uga.com.

Si usted tiene preguntas sobre sus derechos como un participante de investigación, por favor llame los Sujetos Humanos UGA en (706) 542-3199.

Muchísimas gracias por su buena voluntad de contestar mis preguntas.
APPENDIX A2

SCREENING CONSENT SCRIPT

Living with HIV/AIDS: An Exploration of Latina Women's Narratives

Hi. I am Sandra Yudilevich, the researcher conducting the study on Latina women and HIV/AIDS. I would like to ask you a few questions in order to determine whether you may be eligible for the research. Before I begin the screening I would like to tell you a little bit about the research. The purpose of this study is to explore the experience of Latina women who have been infected with HIV/AIDS and the factors that impact the experience.

Would you like to continue with the screening? The screening will take no more than 10 minutes. I will ask you about your HIV/AIDS status, your willingness to participate in the study, and some demographic factors. You do not have to answer any questions you do not wish to answer or are uncomfortable answering, and you may stop at any time. Your participation in the screening is voluntary.

Your answers will be confidential. No one will know your answers except for the research team. If you do not participate in the study, your pre-screening information will be destroyed. If you do qualify for the research, and decide to participate, your screening answers will be kept in a locked cabinet located in an office which will also be locked when no one is there.

Would you like to continue with the screening?
(If no, thank the individual and hang up)
(If yes, continue with the screening)

- What is your full name:
- How old are you (in years):
- Are you HIV or AIDS positive?
- Are you willing to participate in a 90-120-minute, face-to-face interview?
- Are you willing to participate in a 30-minute, follow up interview by phone if it is necessary?
- Where do you live?
- How can I contact you in the future for further participation?

Thank you for answering the screening questions.
(Indicate whether the person is eligible, requires additional screening, or is not eligible and explain why.)
Do you have any questions about the screening or the research? I am going to give you a couple of telephone numbers to call if you have any questions later. Do you have a pen? If you have questions about the research screening, you may call Sandra Yudilevich at 706-248-9275. If you have a computer I can give you my email address: syudilevich@gmail.com. If you have questions about your rights as a research subject, please call the UGA Human Subjects at (706) 542-3199

Thank you again for your willingness to answer my questions.

Date: __________________________________________
Outcome: _______________________________________
Next appointment: ________________________________
APPENDIX B1

Viviendo con VIH/SIDA:
Un Estudio Para Mujeres Latinas

¡Ayúdanos aprender como darles mejor cuidado!

Usted esta invitada a participar en un estudio de investigación donde tendrá una oportunidad de compartir su historia de la vida con HIV/AIDS en una entrevista durando no mas de dos horas, y grabada en audio. Recibirá un vale de $40 usable en Wal-Mart por su participación. Además, tendrá la satisfacción de saber que su historia podrá ser beneficiosa para otros atravez de ayudarles a los proveedores crear programas que mejor cubren las necesidades de mujeres Latinas con VIH/SIDA.

Participación es confidencial; su nombre no aparecerá en conexión con el estudio

¿Quienes pueden participar en el estudio?

- Mujeres Latina que son por menos 18 años de edad
- Tienen una diagnosis de VIH/SIDA
- Hablan Español o Ingles
- Son de América del Norte, América del Sur, o Méjico, y en los E.U. no mas de dos generaciones
El estudio está siendo conducido por una estudiante doctoral Chilena en la Escuela de Trabajo Social de la Universidad de Georgia. Esta aprobado por el Comité Examinador Institucional de la Universidad. Supervisión del estudio es proveído por Patricia Reeves, Ph.D., Profesor Asociado, Escuela de Trabajo Social de la Universidad de Georgia.

Para participar u obtener más información contacte:
Sandra Yudilevich
(706) 248-9275 (telephone)
syudilev@uga.edu (e-mail)
The University of Georgia School of Social Work, Athens, Georgia 30302
APPENDIX B2

Living with HIV/AIDS: A Study of Latina Women

Help us learn how to best care for you!

You are invited to participate in a research study where you will share your story of living with HIV/AIDS in an audio-taped, two hour interview. You will receive a $40 gift certificate to Wal-Mart for participating. In addition, you will have the satisfaction of knowing that your story may benefit others by helping providers to create better programs to meet the needs of Latina women with HIV/AIDS.

Participation is confidential; your name will not be used in connection with the study.

Who can participate? Latina women who are at least 18 years of age
- Have an HIV/AIDS diagnosis
- Speak Spanish or English
- Meet other requirements. The researcher will determine if you qualify for the study during a short telephone interview
The study is being conducted by a Chilean PhD student at The University of Georgia, School of Social Work. It is approved by the University’s Institutional Review Board. Study supervision is provided by Patricia Reeves, PhD, Associate Professor, The University of Georgia School of Social Work.

For more information contact:

Sandra Yudilevich
(706) 248-9275 (telephone)
syudilev@uga.edu (e-mail)

The University of Georgia School of Social Work, Athens, Georgia 30302
APPENDIX C1

Apertura de Declaración

Tengo mucho interés en lo que la vida es para mujeres Latina que son infectadas por el VIH/SIDA. Estoy interesada por muchos motivos, pero uno de aquellos, es espero familiarizarme con sus experiencias, y con el aprendizaje ser capaz de ayudar mejorar la habilidad de proveer cuidado a usted y otras mujeres enferma como usted, de a la gente que quienes la cuidan ahora.

Me gustaría hacerle preguntas sobre sus experiencias antes y después de conocer que usted era VIH positiva (o fue diagnosticada con el SIDA). Aunque yo hare preguntas y buscaré respuestas, quiero que usted se sienta libre de tomar su tiempo en la contestación de las preguntas. También, siéntase libre de rechazar contestar cualquier pregunta que no se siente comoda de responder. Mi intención es aprender sobre su historia. Me encanta escuchar y hablar y espero que esta entrevista sea interesante y útil a usted al mismo tiempo

Quiero recordarle que la participación en esta entrevista es voluntaria. Si usted decidiera que usted no quiere terminar la entrevista, por favor sólo avíseme. También, haré todo lo posible para asegurar que usted y su nombre no tienen que ver con la cinta de su entrevista. Su nombre no aparecerá en ninguna parte además de en la forma de consentimiento, que no será guardada juntos con la cinta de lo que usted dice.

¿Tiene usted alguna pregunta sobre el estudio o sobre mí? (Antes de empezar la entrevista contestaré cualquier pregunta hacen las participantes).
APPENDIX C2

Opening Statement

I am very interested in what life is like for Latina women who are infected with HIV/AIDS. I am interested for many reasons, but one of those, is I hope to learn about you and your experiences, and be able to help the people that take care of you, do as good a job as possible.

I would like to ask you questions about your experiences before and after finding out that you were HIV positive (and if diagnosed with AIDS, since being diagnosed with AIDS). Although I will be asking questions and seeking answers, I want you to feel free to take your time in answering the questions. Also, feel free to refuse to answer any question. My intention is to learn about your story. I love to listen and to talk and I hope that this interview will be interesting and useful to you.

I want to remind you that taking part in this interview is voluntary. If you decided that you do not want to finish the interview, please just let me know. Also, I will make every effort to ensure that you and your name are not associated with the tape of your interview. Your name will not appear anywhere other than on the consent form, which will not be kept together with the tape of what you say.

Do you have any questions either about the study or about me? I will ask any questions they might have before beginning the interview.
APPENDIX D1
FORMA DE CONSENTIMIENTO

Yo, ____________________________, consiento participar en un estudio de investigación titulado “Viviendo con VIH/SIDA: Una exploración de narrativas de mujeres Latinas” conducido por Sandra Yudilevich, LCSW, de la Escuela de Asistencia Social en la Universidad de Georgia (706-542-6513) bajo la dirección de Patricia Reeves, Escuela de Asistencia Social, Universidad de Georgia (706-542-5451). Entiendo que mi participación es voluntaria. Puedo rechazar participar o dejar de participar en cualquier momento, sin dar cualquier razón, sin consecuencia, y sin perdida de beneficios a cual tengo derecho attravers de mi participación. Puedo solicitar para tener que los resultados de mi participación, al grado que pueden ser identificado como los mio, quitado de los archivos de investigación o destruido.

El motivo para este estudio de investigación es explorar los narrativos de mujeres Latinas viviendo con VIH/SIDA. Veinte mujeres en total serán entrevistadas, cada una a su propio tiempo y en un lugar confidencial. Si consiento participar en este estudio, seré pedida hacer lo siguiente:

1) Contestar preguntas sobre mi vida en el presente y tambien antes de venir a los EE.UU., y sobre viviendo con VIH/SIDA. La entrevista durara entre 90 y 120 minutos.
2) Participar en una segunda entrevista si es necesario. Esta entrevista durara no mas de 30 minutos y puede ser vía Teléfono o personalmente, como usted desee.

Recibiré un certificado de regalo de 40 dólares a mi supermercado local al final de la primera entrevista.

Las ventajas para mí serán: (a) la oportunidad de hablar de mis experiencias y viaje personal de vida, y (b) aportar al cuerpo de investigaciones que pretenden ayudar a otras mujeres que viven con el VIH/SIDA.

Ningún riesgo es esperado pero puedo experientar un poco de tensión emocional o psicológica hablando de mis experiencias de vida, en particular aquellas relacionadas con tener el VIH/SIDA. Si siento que la contestación de una pregunta me hace incómoda, puedo decidir no contestar la pregunta o discontinuar mi participación en cualquier momento.

Con mi permiso, la entrevista será grabada attravers de un registrador de voz digital. Sólo el equipo de investigación tendrá acceso a la cinta, que ellos transcribirán, quitando cualquier identificador durante la transcripción.

Los investigadores guardarán mi identidad confidencial. Ninguna información de identificación sobre mí, o proporcionado por mí durante la investigación, será compartida con otros, a menos que no requerido según la ley. Seré adjudicado un seudónimo y este nombre falso será usado en todas las etiquetas, transcripciones, y notas. Si los
investigadores usan citas de mis entrevistas en informes de investigación, publicaciones o presentaciones, mi nombre y cualquier información que se identifica individualmente serán quitados.

Las cintas de la entrevista y cualquier información que se identifica individualmente y coleccionada de mí serán guardadas en un archivo cerrado con llave al cual sólo la investigadora tendrá acceso. Después de que la investigación se completa, la investigadora destruirá la grabación de audio y la lista que une mi nombre al seudónimo (nombre falso).

La investigadora contestará otras preguntas sobre la investigación, ahora o durante el curso del proyecto (706-248-9275).

Entiendo que consiento por mi firma en esta forma en participar en este proyecto de investigación y entiendo que recibiré una copia firmada de esta forma para mis archivos.

Sandra Yudilevich, LCSW

Teléfono: 706-248-9275
Email: syudilev@uga.edu

Nombre del Participante

Por favor firme ambas copias, consérvese una y devuelva la otra a la investigadora.

Preguntas adicionales o problemas en cuanto a sus derechos como un participante deben ser dirigidos al Presidente, Comité Examinador Institucional, la Universidad de Georgia, 612 Centro de Investigación de Estudios de Boyd Graduate, Athens, Georgia 30602-7411; Teléfono (706) 542-3199; Dirección de correo electrónico: IRB@uga.edu
APPENDIX D2

CONSENT FORM

I, ____________________________, agree to participate in a research study titled “Living with HIV/AIDS: An Exploration of Latina Women's Narratives” conducted by Sandra Yudilevich, LCSW, from the School of Social Work at the University of Georgia (706-542-6513) under the direction of Patricia Reeves, School of Social Work, University of Georgia (706-542-5451). I understand that my participation is voluntary. I can refuse to participate or stop taking part at any time, without giving any reason, and without penalty or loss of benefits to which I am otherwise entitled. I can request to have the results of my participation, to the extent that it can be identified as mine, removed from the research records or destroyed.

The reason for this study is to explore Latina women’s narratives of living with HIV/AIDS. A maximum of 20 women will be interviewed, each at a separate time, and in a confidential setting. If I volunteer to take part in this study, I will be asked to do the following things:

1) Answer questions about my life now and prior to coming to the U.S., and about living with HIV/AIDS. This interview will last between 90 and 120 minutes.
2) Participate in a follow-up interview if needed. This interview will last no more than 30 minutes and can either be by telephone or in person, as I wish.

I will receive a $40 gift certificate to my local supermarket at the end of the first interview.

The benefits for me will be the opportunity to discuss my personal journey and experiences and contribute to the body of research aiming to help other women living with HIV/AIDS. No risk is expected but I may experience some emotional or psychological stress when discussing my life experiences, particularly those related to having HIV/AIDS. If I feel uncomfortable answering any questions, I may discontinue at any time or choose not to answer the question.

With my permission, the interview will be audiotaped. Only the research team will have access to the tape, which they will transcribe, removing any identifiers during transcription.

The researchers will keep my identity confidential. No identifying information about me, or provided by me during the research, will be shared with others, unless required by law. I will be assigned a pseudonym and this fake name will be used on all labels, transcripts, and notes. If the researchers use quotes from my interviews in research reports, publications or presentations, my name and any individually identifying information will be removed.

Tapes of the interview and any individually identifying information collected from me will be kept in a locked file which only the researchers can access. After the research is
complete, the researchers will destroy the audio recording and the list that connects my names to the pseudonyms (fake names).

The investigator will answer any further questions about the research, now or during the course of the project (706-248-9275).

I understand that I am agreeing by my signature on this form to take part in this research project and I understand that I will receive a signed copy of this form for my records.

Sandra Yudilevich, LCSW                Signature                        Date

Telephone: 706-248-9275
Email: syudilev@uga.edu

Please sign both copies, keep one and return one to the researcher.

Additional questions or problems regarding your rights as a participant should be addressed to The Chairperson, Institutional Review Board, University of Georgia, 612 Boyd Graduate Studies Research Center, Athens, Georgia 30602-7411; Telephone (706) 542-3199; E-Mail Address IRB@uga.edu
APPENDIX E1

Guía de la Entrevista

**Preguntas demográficas**

Edad _____________

Nivel Educacional _____________  Habla Español/Ingles

Estado Civil _____________  Estado Socioeconómico

Numero de Niños _____________  Edades

Religión _____________  Cuanto tiempo en los EU.

**Preguntas sobre su país nativo**

1. ¿Háblame sobre el país de cual vienes? (es decir clima, cómo vive la gente, qué hacen para el trabajo, y así sucesivamente)
2. ¿Vienes de una familia grande?
3. ¿Como era tu vida en _______?
   a. ¿Con quien ivies?
   b. ¿En que trabajabas?
   c. ¿Hasta qué grado atendiste a la escuela?
   d. ¿A ti se permitió tener novios? ¿Como te fue esa experiencia?

**Preguntas sobre venir a los Estados Unidos**

1. ¿Que te hizo decidir venir a los Estados Unidos?
2. ¿Como es estar tan lejos de tu país para ti?
3. Describe la experiencia de venir a un país diferente de tu país natal:
   a. En que manera son los dos diferentes
   b. En que manera son los dos similar
   c. Describe cómo pudiste haber cambiado desde venir a este país – por ejemplo en cómo piensas de tus relaciones con los hombres, o sobre la familia, o la educación, etc…
   d. ¿Tienes familia en este país?
   e. ¿Has hecho amigos desde llegar en este país?

**Preguntas sobre su experiencia de la vida con VIH/SIDA**

1. ¿Cómo descubriste que eras positiva?
2. ¿Describe como fue la experiencia?
3. ¿Quién te ayudó o apoyó durante ese tiempo?
4. ¿Quién sabe sobre tu estado de HIV/AIDS?
5. ¿Háblame sobre estar en medicamentos de HIV/AIDS? ¿Si no estas tomando medicamentos, por qué no?

6. ¿Cómo ha cambiado tu vida el hecho de vivir HIV/AIDS positiva?
7. ¿Qué o quién le ayuda en su vida diaria, especialmente ahora que vive con HIV/AIDS?
8. ¿Te puedes cuidar tal como quieres, o como deberías hacerlo? ¿O como el doctor dice que deberías hacerlo? ¿Si no, cuáles son los factores o las cosas que impiden tu abilidad de cuidarte como deberías hacerlo?
9. ¿Qué piensas que son HIV y AIDS? ¿Tienes pensamientos sobre si significa algo que tienes HIV/AIDS?
APPENDIX E2

Interview Guide

Demographic Questions

Age

Educational Level

Martial Status

Socioeconomic Status

Number of Children

Ages

Religion

Time in the U.S.

Questions to establish rapport

1. Tell me about the country you come from.
2. What was your life like in ___________ (their native country)?
3. Tell me about your family and your relationship with them.

Questions about coming to the U.S.

1. Describe the experience of coming to a place so different from your birthplace.
2. What is it like for you to be so far from home?
3. Describe how you may have changed since coming to this country – especially in how you think about your relationships with men, or about family, or education, etc.

Questions about their experience of living with HIV/AIDS

1. Tell me about your experience of finding out you were HIV positive or had AIDS.
   Probes
   a. How did you find out you were HIV positive or had AIDS?
   b. What was that like?
   c. What did you know about HIV/AIDS before being diagnosed?
   d. Can you tell me about discussions you may have had with others about HIV/AIDS?
   e. What do you think may have better protected you against becoming infected with HIV or diagnosed with AIDS?
   f. Describe other factors that may have had an impact on your ability to protect yourself from HIV infection or an AIDS diagnosis?
g. How did factors such as machismo, marianismo, religion impact your ability to protect yourself, if at all?

2. What did being diagnosed as having HIV/AIDS mean to you at the time?

3. Describe how being infected with HIV/AIDS has impacted your family and your relationship with family members…
   
   **Probes**
   a. Are there people in your family who do not know of your status?
   b. Describe in what ways they are supportive
   c. Tell me about what you might like from your family that you are not getting

4. Describe your medical care and how you feel about it
   
   **Probes**
   a. Tell me about your care providers and your relationship to them
   b. Describe your medication regimen and how you feel about it, including how you are able to get your meds
   c. If not on meds, why not?
   d. Describe how you are able to follow your doctor’s instructions

5. How has living with HIV/AIDS changed your life?

6. What kinds of things help you as you go about your daily life?

7. What do you think HIV/AIDS is (are)?

8. Describe how your thoughts about having HIV/AIDS have changed over time
APPENDIX F1

Conclusión de la Entrevista

Si usted siente cualquier fatiga nerviosa o emocional debido a las experiencias de cual ha hablado en esta investigación, hay ayuda. Los consejeros y las agencias siguientes pueden ser un recurso valioso para usted. Se especializan en los puntos que surgen de vivir con VIH/SIDA. Algunos de los siguientes tienen consejeros que hablan español y otros no.

**Absolute Wellness**
2484 Briarcliff Road
Suite 22-B
Atlanta, Georgia 30329
(404) 329-2315

**The Center for Counseling Services**
1847-A Peeler Road
Atlanta, Georgia 30338
(770) 394-5447

**AID Atlanta**
1605 Peachtree St. NE
Atlanta, Georgia 30309
(404) 870-7700

**Family Counseling Service, Inc. (Athens & Winder)**
1435 Oglethorpe Avenue
Athens, Georgia 30606

**AIDS Athens**
112 Park Ave.
Athens, GA 30601
(706) 542-2437

**First Metropolitan Community Church of Atlanta**
1379 Tullie Road
Atlanta, Georgia 30329
(404) 325-4143

**AIDS Survival Project**
139 Ralph McGill Blvd. Suite 201
Atlanta, GA 30308
404-874-7926
Toll Free 1-877-AIDS-444

**Positive Impact**
139 Ralph McGill Blvd NE # 301
Atlanta, Georgia 30308
(404) 589-9040 (Hispanic Outreach)

**Atlanta Interfaith AIDS Network, Inc.**
139 Ralph McGill Boulevard NE
Atlanta, Georgia 30308
(404) 874-8686

**Samaritan Counseling Center of Northeast Georgia**
1690 South Milledge Avenue
Athens, Georgia 30605
(706) 369-7911

**Care and Counseling Center of Georgia**
1814 Clairmont Road
Decatur, Georgia 30033
(404) 636-1457
APPENDIX F2

Debriefing Statement

If you experience any emotional or psychological stress due to the experiences brought up in this research, there is help. The following counselors and agencies can be a valuable resource to you. They specialize in issues pertaining to living with HIV/AIDS. Some of them have Spanish speaking counselors and some do not.

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