A CRITICAL FEMINIST CASE STUDY: HIV PREVENTION EDUCATION FOR WOMEN

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PREVENTION EDUCATION

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COMMENTARY

When I began writing and collecting data for this dissertation, I believed that HIV was a behavioral disease. I thought women were becoming infected because they engaged in unprotected sex with an infected partner, or utilized injecting drug paraphernalia that was used by someone who had HIV disease. After listening to the participants' stories, I now believe that HIV is a disease of the oppressed.

Through the women's stories I came to understand that life changing circumstances, economic disenfranchisement, gender inequality, chemical use, sexism, racism, and a chronicity of abuse contributed to the barriers to self-protection. The women in this study were not able to accurately perceive health dangers. They had limited economic resources which further encouraged dependence on their partners, further limiting prevention options. Many women described the struggle of living an oppressed life-style complicated by fear and abuse. I can understand how many of the women in this study turned to relationships and chemicals that provided some form of immediate gratification.

The assumption that HIV is a behavioral disease implies that women can change behavior through knowledge about HIV disease and skill building dialogue about condom usage, or sterilization of syringes. However, the assumption that HIV is a disease of the oppressed implies a monumental problem that needs to be addressed on the individual, community, national, and global level. To combat this problem society must find new ways of promoting women as equal members of society. This means offering women HIV prevention messages that address the root causes of disease such as oppression, childhood sexual abuse, domestic violence, economic inequality, sexism and racism. HIV prevention must be linked to a social movement that recognizes the hazardous outcomes of male hegemony and the unequal status of women.

Interviewing women living with HIV disease made me more aware of my own privileged health and empowered status, juxtaposed to the severely isolated status and ill health of the participants. One participant had a shunt in her chest enabling her to receive life-sustaining medication. Another participant had a severe white plaque engulfing her mouth causing her pain when she spoke. Another participant weighed around eighty pounds and was frail, and often too weak to eat or speak. Another participant was bald and voiced embarrassment concerning her current appearance. Many participants suffered from flatulence from the multiple medications they were ingesting.

There were many times when I felt I needed to be around vibrant and healthy people to balance my feelings of sadness and social injustice. I thought about how easy it would have been for the participants not to grant an interview, or to reschedule, or cancel the session. Never once did this happen. Instead I met with the participants to hear their stories and write about their experiences which may not have otherwise been told.

I sincerely hope the reader(s) of this dissertation will think about the rising seroprevalence in women and the designated categories of HIV disease transmission. I ask the reader to remember the participants' stories.

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CHAPTER I

INTRODUCTION TO THE STUDY

Introduction

The year was 1979, and the United States was suffering abroad and at home with runaway inflation that made Americans feel penniless. Iranian fanatics threatened our military intelligence and caused feelings of powerlessness. It was against that backdrop of economic and political turmoil that Ronald Reagan campaigned for the presidency and promised us a bright new horizon. But, there was something else on the horizon and that something else was dark, mysterious and deadly. That something was AIDS. The story of AIDS is a story of agony, despair, intrigue, genius, passion and exhilaration. This story begins in 1969 with gay liberation and chronicles how Human Immunodeficiency Virus (HIV), that can cause a paralyzing disease known as Acquired Immune Deficiency Syndrome (AIDS), continues to spread and affect our lives, communities, and our nation.

The social and sexual revolution of the sixties engendered free love and for some, passionate liberation. For homosexuals, this era was a political awakening. On the last weekend of June 1969, drag queens, fed up with years of abuse and oppression, attacked police as they harassed people in a gay bar called the Stonewall Inn in Greenwich Village. Perhaps, it was this riot that inspired legislators to repeal historical prejudicial laws against homosexuals. The lives of gay men and lesbians were about to change. The growth of a newly non-apologetic gay community recruited public figures to fight millenniums of discrimination. Many gay men now viewed open sexual expression as a political statement. This new radicalism, with in your face courage and non-contrite political position, challenged homophobia (Wilton, 1997). Although it took until 1975 for The American Psychiatric Association to remove homosexuality from its list of clinical disorders, (Bloomer, 1995) it was clear, gay life was becoming more mainstream.

Places like Fire Island in New York exploded with gay men who felt liberated to explore desires openly that they previously had to hide. Castro Street became the heart of San Francisco's homosexual ghetto where gay pride became personified with parades, exotica, nostalgia and bathhouses. By 1973, 9000 gay men moved to San Francisco, and by 1978 an additional 20,000 homosexual men relocated to the Bay area. By 1980, approximately 5,000 homosexual men were moving to the Golden Gate area yearly (Shilts, 1988).

But, this exhilaration was soon to quiet. By the end of 1979, young homosexual men started getting sick with illnesses that doctors couldn't cure. Symptoms included swollen glands, fever, rare pneumonia, skin cancer, intestinal problems and severe fatigue. The first cases appeared in New York, San Francisco, and Los Angeles. The doctors were baffled. The medical community searched for a cure as young men coast to coast started to waste away and die.

In San Francisco all cases of Sexually Transmitted Disease (STD) were reported to the Health Department. Dr. Selma Dritz noticed an unusual amount of amoebic dysentery in gay men in the bay area. Bathhouses on Castro Street were filled with homosexuals who felt free to explore sexuality. Was there a connection between gay life style and enteric pathogens? Dr. Dritz interviewed these men and found that many of the men were having multiple sex partners in one night during visits to bathhouses. But what did sex have to do with intestinal disorders? Dr. Dritz quickly learned from her gay physician colleagues the realities of gay sex that consisted of not only anal and oral sex but also "rimming" (oral anal contact). As sexual appetites became more exotic, rimming became fashionable and a parasite ingested orally was an efficient way to contract such enteric pathogens. Shilts (1988) described Dritz as cool and businesslike.

> Her calm admonitions to gay men about the dangers of rimming and unprotected anal sex were well rehearsed. The sheer weight of her professionalism, however, made Dritz immensely popular among gay doctors. Her children teased that she was the sex queen of San Francisco and den mother of the gays. (p. 39-40)

The more of an expert Selma Dritz became on gay health, the more concerned she became. As chief of Public Health for the San Francisco area, she was alarmed at the increase in Hepatitis B in gay men and a host of other sexually transmitted organisms. These diseases were challenging to control because they had long latent periods. Specifically, gay men were spreading the disease to many others long before they knew they had a dangerous illness or had any symptoms. "Too much is being transmitted here," Dritz kept saying. "We've got all these diseases going unchecked. There are so many opportunities for transmission that, if something new gets loose here, we're going to have hell to pay" (Shilts, p. 40).

Dermatologists in New York were puzzled with gay men who had Kaposis sarcoma (KS), a rare skin cancer usually found in older Jewish and Italian Mediterranean men. The only clue the doctors had was that patients were gay and had low white cell counts of a specific type, namely T cells. Doctors from New York called doctors in the

Bay area of California and found that coast to coast young gay men were dying of this unusual skin cancer. In 1981, the Centers for Disease Control (CDC) reported 26 cases of KS in immunosuppressed homosexual men (MMWR, 1981).

In 1980 doctors in Los Angeles noticed serious problems in the gay community as well. Young men were getting Pnumocystis Carnii Pneumonia (PCP). PCP is found in every person's lungs. However, as immune systems become weakened, this fungus can multiply and become uncontrollable as it diminishes the capacity for individuals to breathe. Up until 1980 there were so few cases of this type of pneumonia that CDC dispensed a drug called Pentamidine to physicians and hospitals to inhibit its growth. CDC began dispensing the drug to physicians and hospitals to control the pneumonia but became baffled as additional cases in gay men in other cities were consistently being reported (MMWR, 1981). What was this new mysterious disease plaguing gay men? Why were gay men experiencing depleted immune systems? These men were otherwise healthy. All of these men had low T cells. What was happening in the lives of gay men to cause such infection and devastation?

The CDC's job is to monitor infectious diseases and track new epidemics. CDC became involved in AIDS perhaps by accident. In 1981 Dr. Jim Curran, head of the CDC, noticed a huge request for pentamidine for young gay men. On June 5, 1981, the Morbidity and Mortality Weekly Report (MMWR, 1982), published by Centers for Disease Control, described cases of otherwise young healthy homosexual men with PCP. Subsequent issues of the MMWR documented additional cases. By the end of 1981 scientists had a new name for the syndrome plaguing gay men called GRID, or Gay Related Immune Deficiency.

In 1982 CDC documented thirty-four cases of opportunistic infections in Haitians similar to the symptoms that were seen in gay men (MMWR, 1982). Many of these reported cases were in women. Injection drug users were also being hospitalized with weakened immune systems, and symptoms of GRID. Infants born to injection drug users or who were born to a mother whose partner was an injection drug user were showing failure to thrive, weakened immune systems, and rare infections. Men with hemophilia started presenting a collection of syndromes that were mimicking the medical maladies of gay men and injection drug users. As of September 24, 1982, 593 cases of people with GRID had been reported to the CDC; 184 people had died. In this issue, Morbidity and Mortality Weekly Review reported cases among women for the first time. Thirty-four cases, or 5.7 percent of total GRID patients, were among women (MMWR, 1982).

Scientists at CDC argued that the name GRID had to be changed. After all women and infants were now among the population infected. Acquired Immune Deficiency Syndrome (AIDS) was the name chosen to replace GRID. Scientists were sensitive to linking the disease to the gay community. And yet, by the end of 1982, mainstream media had published many articles on the new immune deficiency disease that affected not only gay men, but also the "innocent victims" such as infants and hemophiliacs (Roth & Hogan, 1998). How had mainstream media missed the reality that women were also targets? Is it possible that the media wanted us to believe that this was a gay disease? Michael Foucault (1976) poignantly spoke to the issue of silence when he said, "There is not one, but many silences, and they are an integral part of the strategies that underlie and permeate discourse" (p.27). Perhaps AIDS discourse helped the public feel safe by limiting the disease to homosexuals, heroine users, Haitians and hemophiliacs.

In 1982 I was working as a Medical Technologist in a Tulsa hospital. Medical Technologists examine and test bodily fluids via microscopes and auto analyzers to ascertain body fluid values needed by physicians for treatment and care of ill people. AIDS was a new disease, and it was unknown that this virus could be transmitted through occupational exposure. There were no standard operational procedures to instruct hospital workers on occupational safety. I did not wear gloves as I analyzed and sometimes aspirated and pipetted blood, semen, and vaginal secretions. Although I was an incessant hand washer, latex-gloves were an unknown commodity. I can remember shedding my uniform, lab coat and shoes in the garage and proceeding directly into the shower before greeting my husband and young children.

I had a degree from City University of New York in Medical Technology. I did my internship at Queens County Hospital where I saw individuals who had blood diseases ranging from sickle cell anemia to rare blood cancers. I was amazed at the courage and endurance of people who were too poor to have private insurance and had to access public transportation to seek medical care. Individuals waited for hours, as they cradled screaming children; sometimes mothers nursed in a large crowded wait room. I graduated college knowing that I would find work in indigent health care. In a small way, I was able to feel like I was contributing to my community through the interaction with ill patients; many were less fortunate than I was. Somehow I knew that this career was a danger to my physical health and yet essential for nourishing my soul.

I recognized my privileged status as a Jewish woman whose family had escaped Nazi Europe. I did not have numbers tattooed on my wrist, and unlike so many people I knew, I was far removed form the pernicious effects of Hitler and the Third Reich. It was my pleasure and duty to help in the repair of the world by working in indigent health care. My family had come to the U.S. to be free from the evils of discrimination. I learned early in life the world needed repair, and I knew that I was privileged to be alive and free to discern my own destiny. The gift of Judaism lies in its powerful ideas and so the Hebrew concept of "Tikkun Olam," or repair of the world, was an accepted practice.

I can recall one female patient who was trying unsuccessfully to become pregnant. She was the partner of a man who injected illegal drugs. She had a severe skin rash. I drew her blood without gloves. I analyzed her white blood cells without gloves. I checked her vaginal secretions for yeast and other fungi. It was years later when I was working as an alcohol and drug counselor that I saw this woman again. She looked ill and pale. Her skin rash had blossomed into huge red blisters and her infant lay dying of AIDS in the pediatric ward. I knew then that I had been occupationally exposed to a virus that caused a deadly disease. I picked up her infant, and she whimpered as I held her; she was too weak to cry. I remember thinking that if there was a God to please help this woman and her baby. How could this be happening? And what might I do to help repair the world of this mother and child?

Background of the Problem

Surveillance data from Centers for Disease Control and Prevention (CDC) informs us that at the end of 1995, 311,381 persons living in the United States had died from AIDS. An additional 189,929 individuals had been diagnosed with AIDS, and it is estimated that nearly one million persons are currently infected with HIV, the virus that causes AIDS in the US (MMWR, 1995) . The trend of the epidemic has changed from men who had sex with men, to individuals who inject drugs, and to women who engage in heterosexual sex, sometimes with injection drug users (CDC, 1997).

Women are now the fastest growing population being infected with HIV. The number of AIDS cases among women is doubling about every two years. In the US in 1996 AIDS deaths among women increased 3%, while among men they declined 15%. Today, women comprise 18% of the AIDS cases in the U.S. Black and Latina women respectively account for 56% and 21% of the new cases reported (HIV Frontline, 1997).

Could the increase in infection be due to the fact that women maintain a historically disadvantaged position? The industrial revolution, which caused economic and social changes, provided a climate for the rise of women's rights because the disparity between male and female roles became much more apparent. For example, males became much more aligned with the public sphere that included politics and economics. Females became aligned with the private sphere of the home and children (Pinchbeck, 1993). The transformation of producing handicrafts, which women had worked on at home for no pay, into machine powered mass production meant that women of lower socio economic stature could work in factories. This, theoretically, meant that women could be financially independent, although their pay was lower than their husbands and the money was typically controlled by their husbands. Women could not own property during this time in history. This discrepancy in roles and asymmetry of power contributed to the first wave of feminism (Encarta, 1995).

The number of working women increased substantially during and after the two world wars, but women still had lower paid positions and their positions were usually female occupied vocations like school teachers and clerical workers. Once men came home from war, little opportunity existed at universities, in politics, government positions, and the scientific research arena or in medical schools for the advancement of women. An equal rights amendment to the constitution of the United States to remove legal, economic and social restrictions on women was introduced into Congress in 1923 but made no progress (Levine, 1995).

By the 1960s changing demographic, economic and social patterns encouraged a resurgence of feminism (di Leonardo, 1991). Lower infant mortality, soaring adult life expectancy, and the availability of the birth control pill (after 1960), gave women greater freedom from childcare responsibilities. These developments, combined with the inflation experienced in the United States and rising divorce rates propelled women into the job market due to economic necessity.

As women encountered discrimination in many forms, the women's movement gained momentum. In 1964 the Civil Rights Act, initially intended only for African Americans, was extended to women. In 1972 the Supreme Court declared that abortion was legal, and the Equal Rights Amendment was passed by Congress and sent to the states for ratification (Franklin & Moss, 1980) . Turner, Scadden, and Harris (1990) were concerned that the English language itself, by reflecting male dominance in its word forms, was perpetuating the problem.

During the contemporary women's movement, women began to question social institutions and moral values. Much of the feminist struggle today focuses on gender inequity. For example, women have not been compensated for staying home with children and have, in many circumstances, adopted obsequious roles to their male counterparts. Indisputably, there is a significant level of gender asymmetry in corporate management and women remain underrepresented in positions of power within government and social institutions (Morgan, 1984; Seager & Olson, 1986).

Women's disempowered status has contributed to domestic violence and also creates situations where women feel unable to protect themselves. This has manifestated itself in woman's sexual interaction with male partners.

Gomez and Marin (1993) argued that women are afraid of their partner's anger in response to requests to use condoms (condoms prevent the spread of HIV, the virus that causes AIDS). Furthermore, among women who inject drugs, the experience of violence and abuse is normal life style. These women are perhaps, at the greatest risk for disease (Gomez & Marin, 1993).

Amaro (1995) believed that environmental and economic barriers contribute to the rising tide of infection for women. For example, women who maintain a lower socioeconomic stature, who perhaps are addicted, fearful of domestic abuse, and lack job skills, may turn to sex in order to survive. In addition, a large portion of chemically dependent women report a history of childhood or adult mental abuse, incest and rape (Benward & Denson-Gerber, 1975; Hickok & Jemelka, 1992; Schafer & Evans; 1987; Walker, et. al.,1992). These alarming and traumatic circumstances are likely to impact a woman's ability to negotiate protective health measures.

I am reminded of a young woman living with HIV disease. She described her father as a wrestler, statuesque with bulging musculature. He would demand oral copulation from the time she was seven years old until she ran away at fifteen for life on the street. I became acquainted with her while she was incarcerated on drug related crime. She was living with HIV disease and attending the university through correspondence courses. She developed her own voice while in prison and began a journey of self- exploration as she examined her life. Was it the sexual abuse that drew her into homeless culture? Was it the emotional pain and torture that lured her into drug abuse? If this woman were of relatively functional parents, would she be infected? Given a different childhood environment, would she be in prison?

Juxtaposed to the common assumption that disenfranchised women are at risk for HIV because of lack of empowerment and economic dependence is the assumption that women engage in unsafe sex because of the cultural ideals associated with a loving heterosexual relationship (Miller, 1976; Sobo, 1995). It may be that women feel so emotionally and socially dependent on heterosexual relationships that their perception of being at risk is not real.

Jean Baker Miller (1976) spoke to the subordinate social pattern in women's lives and stated that "the patterns of the female's development are not the same as male's and that the same terms do not apply" (p.86). Hence it may be that the female organizes her life in many senses to "maintain affiliations and relationships " (p.83). The need for women to be connected within the relationship is of utmost importance. Does this mean that being connected makes her put her partner's needs first?

For many years, I have listened to the stories of women who are infected with HIV. Some of them have developed AIDS and have died. Many are still alive and living productive lives. Many of the women are incarcerated; many are free. However, their stories are similar. They became infected although they knew how to protect themselves. Many were involved with someone they cared for and trusted. In many cases he took care of her. The relationship and her dependence on his affection and support were paramount.

These women never thought of using a condom; they trusted that their lover was not infected. He told her so.

Statement of the Problem

As the number of new cases of HIV begin to level off in men, the number of new HIV infections in women continues to rise. Minority women are now the fastest growing population to be infected with HIV (CDC, 1997). Surveillance data from CDC (1998) indicates that women now comprise 45% of new HIV reported cases. Has society perpetuated the myth that only gay men and drug users are at risk? If I examine the AIDS pandemic through a critical feminist lens, I see the "womyns" body viewed by science as a mere vector of infection to her unborn child or to her male partner. Is it only when women are pregnant that we "research" in order to see how drugs will impact the fetus (Deren, Davis, Tortu, Beardsley, & Ahluwalia , 1990). When a woman can become infected with a life-changing virus that is preventable, I can only surmise that prevention efforts have miserably failed. Treichler and Warren (1998) noted, "What different representations, language, educational approaches, spokespeople, or cultural models might have produced a different outcome?" (p. 110)

Purpose of the Study

The purpose of this study is to understand HIV positive women's perceptions of the causes of the virus and barriers to prevention. Further, the study seeks to develop an HIV prevention model for women not currently infected.

Guiding Questions of the Study

The succeeding questions have aroused my curiosity as I search the literature that is feminist and non-government related. They are indefinite, as my intent is to utilize a post-positivistic, praxis oriented perspective drawing on critical feminist, and postmodern and/or post-structural philosophy. These philosophical lens are premised on a transformative agenda for the individuals participating in the study (Lather, 1991; Reinharz, 1992). This means that women participating in the research will maintain decision making power over the structure of the interactive individual and group interviews. Participants will have many opportunities to interpret data and negotiate meaning and build a theoretical model contributing to the field of HIV prevention for women.

To attempt to achieve an egalitarian relationship, I plan to use a client-centered approach during the interview process, and engage in mutual dialogue (Rogers, 1969). I seek to build on the experience of those living with the disease and, discover a theory that is grounded in the experiences of the participants. Lather (1991) refers to this as "dialectical theory building" (p.61).

Focus Questions

1. What are HIV positive women's backgrounds and perceptions of the causes of HIV disease in women?
2. What are HIV positive women's experiences concerning barriers to prevention?

3. How do HIV positive women make sense of their lives?

Related Questions

1. How have women been constructed in the media portrayal of the HIV epidemic?
2. How have women been constructed in the health education theoretical models that have been employed for HIV prevention?

Rationale for the Study

Through this study, I hope to explore the lived experiences and barriers to prevention of women who are now HIV positive. Many prevention educators agree that prevention literature that has guided praxis has been developed for men, specifically, gay men (Amaro, 1995; Monti-Catania, 1995; Quina, Harlow, Morokoff & Saxon, 1997). First, by examining the perceptions to barriers of prevention that are germane to women, a new prevention model will emerge. This knowledge may provide insight as to the focus that HIV prevention must take to address the needs of women. Further, it may provide understanding into how women perceive their risk, view the notion of self-esteem, and expose the realities of unsafe sex. With this generally unexplored approach to HIV prevention, educators may be able to suggest alternative intervention approaches. Until prevention science can develop a method of protection controlled by the female, (i.e., a comfortable female condom or foam that will kill the virus), knowledge about human behavior, and gender relations in particular, appears appropriate.

Second, this study may be helpful to counselors and therapists working in community-based organizations whose clients are chemically dependent. It has been suggested that women use an excess of alcohol and drugs as part of the ambiance created to enhance relationships (Amaro, 1995). These drugs also act as a conduit to HIV disease because of breaks in the skin due to injecting drugs. In addition, alcohol and other drugs can cause loss of inhibition that may lead to denial of the need for protection.

Recent acknowledgment of the importance of relationships to the lives of women, as in the Self-In-Relation Theory (Jordan, 1997), highlight the nature of female development. Knowledge gained from this study may provide insight for women on how relationships are constructed, and if gender and power controls risk reduction measures. In other words, if a woman has been subjected to abuse from her partner can she realistically negotiate protective measures to reduce her chance of getting infected? This study may also provide some understanding to prevention educators and behavioral scientists about the power of the bond of the relationship. As Gilligan (1982) explained, "women define themselves in the context of human relationships" (p.17). What this may mean is that the relationship is paramount and HIV prevention is secondary, or perhaps not even a consideration.

Third, I envision this research bringing the voices of HIV infected women to the literature which possibly has the opportunity to change praxis, both on a local and national level, by addressing the root causes of HIV disease. It is possible that gender inequality, economic disenfranchisement, and notions of women's need for connection, contribute to the barriers to prevention and actually increases the risk for HIV. Fourth, theory must inform practice and praxis must continue to develop and in turn inform theory (Swanson, 1997). These domains must work interdependently to enrich the prevention profession as a whole. In HIV prevention work, failure to address the connection between lived experiences and theory means that people may continue to become infected. Fifth, the value of this study is its use of multiple theoretical frameworks in understanding the complexities of HIV prevention for women.

Through a critical feminist perspective, and by being informed of postmodernism, I deconstruct and see HIV prevention education as disempowering rather than empowering. I envision this research to contribute new knowledge not only to the field of HIV prevention education but to other researchers seeking to establish new paradigms, new paths for research, and establishing new methods for the body of knowledge for everyone. On the one hand, HIV prevention calls for condom usage, especially with multiple partners, sex with an unknown partner, or with a steady lover who is unfaithful. On the other hand, prevention educators have advised against multiple partners, implying that safety comes within a relationship based on the principle of monogamy (Bolton, 1992; Sobo, 1995). Many of the women infected have been involved in a relationship they thought was monogamous, and condoms were not seen as necessary.

Rationale for a Qualitative Design

I choose a qualitative research approach because I envision gathering life histories and raw experiences from women living with HIV disease. I will collect this data through interviews and a focus group. My hope is to help the insider interpret her perceptions and meanings. Another characteristic of qualitative research is that the researcher is the primary instrument for data collection (Merriam, 1998). I plan to conduct three interviews on ten women living with HIV disease. I am hoping to work with the participants during a focus group to discover an emerging model rich in relevant contextual categories that will be useful for identifying barriers to prevention for women not currently infected.

Currently there is not an HIV prevention model specifically based on the needs of women. Although there have been studies which speak to how women are coping with HIV disease (Lather & Smithies, 1994), there is nothing in the literature that I am aware of that speaks to prevention for women. This study may have a profound effect for researchers and behavioral scientists and for women who are at high risk for the virus. It seeks to find a path for women juxtaposed to the silence permeating much of the prevention literature. A qualitative approach allows the researcher to engage in an iterative process of data collection, analysis, and additional collection. Through this iterative approach, I am able to work with the participants to build a context-bound prevention model.

According to Guba (1990) "Qualitative researchers work hard to control what is precise and verifiable and what is interpretative and judgmental"(p. 310). Because naturalistic research cannot avoid observer bias, I will strive for reflexivity between participant and researcher, participant and data, and data and the development or modification of theory. I will do this by checking out my interpretations of the narratives and by asking the participants to clarify and explain important timelines in their lives. I will do this at several different points during the interview process. These member checks will take place during the interviews by using an interview technique called paraphrasing. Paraphrasing is a technique used during the interview process to clarify any preconceptions that may be incorrect or may need further exploration (Evans, Hearn, Uhlemann & Ivey, 1988). During the interview and after the analysis of the interview, I will ask the participant if what I perceived seemed accurate to her.

I think it is important to note that truth to the qualitative researcher is not a universal truth, but a local truth (Miller & Crabtree, 1992). This means that the information gleaned from the interviews, and the prevention model, may not be generalizable except for women who have precise similarities to those women who participated in the study. A thick description of each woman participating in the prevention model will be disclosed in Chapter IV.

As a qualitative researcher I am interested in the data being credible, dependable and confirmable. To achieve this task, I will triangulate the data, using long interviews and a focus group. I will engage in numerous member checks and search for disconfirmations during the interviews. In Chapter IV, I will provide thick descriptions of the participants and self-disclose my bias as suggested by Zyzanski, McWhinney, Blake, Crabtree and Miller (1992).

It is important to note that I am mistrustful of some of the information determined through quantitative measure. My dilemma with positivism stems from growing up within a culture where people had numbers tattooed on their wrists. This of course serves as a metaphor for the injustices and evils of society. Although I do not share the experience of the virus with women who are infected, I do bring a passion to represent their voices and a history of not being on the "inside" of society.

The number of women who have tested positive for the virus remains relatively low in the state of Oklahoma. Therefore, funding for prevention in women is almost non existent. Although CDC project officers have recommended that our state use more qualitative data to determine the number of women who actually have the disease, (i.e., stories from infected women and talking to case managers who care for infected women) only quantitative analysis is currently being employed. Studies have suggested that women fear domestic violence if their partners find out that they have tested positive for the virus (Zierler, 1997).

A Qualitative Case Study

Merriam (1998) conceptualized the case study as an "intensive, holistic description and analysis of a single unit or bounded system" (p. 12). Case study is often equated with qualitative data according to Merriam (1998). However, quantitative case studies also exist. Case studies in education are often associated with fieldwork, participant observation, qualitative analysis, grounded theory or exploratory research. Merriam's definition of a case is "a thing, a single entity, a unit around which there are boundaries" (p. 27). The single entity of this case study is that all of the women involved with this study have HIV disease.

An Interpretive Case Study

This study will contain rich description of timelines and events in the participants' lives that the participants believe contributed to infection. These descriptive data will be used to challenge the traditional assumptions about HIV prevention. The conceptualizations gleaned from the analysis of the data will be used to construct an HIV prevention model. Merriam (1998) noted that "the level of abstraction and conceptualization in interpretive case studies may range from suggesting relationships among variables to constructing theory" (p. 39).

I choose a case study design because women who live with HIV disease will provide descriptive data that may challenge prior assumptions about HIV and common prevention notions. For example, the current theoretical models for HIV prevention do not adequately provide contextual prevention messages for women. The case study is used when researchers are interested in insight and discovery as opposed to hypothesis testing. As already stated, I am interested in working with the participants to discover prevention insights for women not currently infected. Finally, case study is used to illuminate the upper and lower boundaries of the case, giving the reader a range of human experience that may be useful for understanding the multiple barriers to prevention in these women's lives.

A Critical Feminist Research Approach

Critical feminism is concerned with thoughtful action and liberatory praxis designed to deconstruct and free us from limited ways of knowing (Lather, 1991). Critical feminism strives to find women's voices, experiences and perspectives as a means of discovering self, addressing inequity of power relations, and resisting hegemony (Elias & Merriam, 1995). Critical feminism struggles to discern the relationship between women's oppression and oppression of all people in general. It is through the lens of critical feminism that I question the status quo and deconstruct what is said and what has been eliminated from the research and literature on women and AIDS. I am committed to remaining conscious of the social status of women, regardless of their race, religion, sexual choice or orientation.

Critical feminist theory is not monolithic and uses strands of postmodernism and/or poststructuralism, as well as Feminism, and critical theory. Critical theory is interested in transforming the production and dissemination of knowledge (Lather, 1984). Critical theorists critique the way in which people are constrained to behave and identify themselves in terms of particular social situations. Critical theorists explore the notion of hegemony and how it helps to sustain authority that can be unjust or repressive. Critical theory has origins in the Frankfurt School and recognizes the concept of "praxis" which is a combination of reflection and action (Ashley & Orenstein, 1985). Critical theory contributes to a postpositive research methodology by deconstructing quantitative analysis and by showing how method can be read to reflect passion, context, and political text (Agger, 1991).

From the critical perspective, I utilize the philosophy of Paulo Freire. According to Freire (1970) traditional education approaches assumed that the learners were like empty bank accounts into which the facilitator made deposits. Participatory education assumes that people gain control over their lives through dialogue and critical thinking that lead to identifying and analyzing the social and historical roots of problems, envisioning alternatives, and bringing about social change (Wallerstein, 1992; Wallerstein & Bernstein, 1988). However, this study also explores the social world of women from diverse cultures and seeks to understand what they have come to learn from their own experience. Therefore, this study employs postmodern and/or poststructural perspectives to ensure human diversity and to represent varying perspectives.

A postmodern design has roots in aesthetics, science, and architecture (Harding, 1991; Lather, 1991; Tong, 1989). A postmodern perspective encourages an emerging paradigm rich in diversity that has multiple layers of truth and understanding. Persons who employ a postmodern perspective strive to understand the many truths and perspectives germane to a particular context and understand the relationship between power and control and how this plays out in the political and social decision making process. This philosophical view recognizes deconstruction as a method of comprehending language, society, culture, and history. Postmodernists do not believe in objectivity because they feel it is impossible to gather data without a particular perspective on a specific topic. Postmodernist thought denies the credibility of metanarratives like use of a condom to stay safe from the virus.

Overlapping and somewhat similar to postmodern thought is postructuralism. Poststructuralism can be described as a "theory of knowledge and language" (Aggar, 1991). Poststructuralism and postmodernism challenge the positivist way of doing research, and are interested in the literal translations of what the participant(s) has come to know. This means that paternalistic and eurocentric ways of understanding can be broadened to include individuals from diverse race, gender and socioeconomic stature. The meshing of these three philosophical perspectives offers innovative ways of constructing methodology. By combining critical theory with strands of postmodern and/or poststructural, I am able to deconstruct current HIV prevention models and work with a diverse group of women to discover new assumptions about HIV prevention for women not currently infected.

HIV prevention education has largely focused on men. Because critical feminist theory seeks not only to emancipate the oppressed but also to represent human diversity, my research will be devoted to women who remain underrepresented in the research arena on HIV and AIDS. Lather (1988) contended:

> I engage in feminist efforts through empirical research designs which maximize a dialogic, dialectically educative between researcher and researched . . . What I suggest is that our intent more consciously is to use our research to help participants understand and change their situations.

I draw from Lather (1991), Reinharz (1992), and others to envision a study where there is improvement in the lives of the participants and knowledge is contributed to the community. This study is participatory because the researcher and participants are together on a learning journey to discover and explore uncharted territory into the world of prevention for women and to explore why prevention education has been silent to the needs of women. Drawing from a critical feminist theory that includes the postmodern and/or poststructural perspective will enable me to deconstruct the literature and work with infected women to tell their stories and to develop specific prevention strategies.

Significance of the Study

Currently there is not an HIV prevention model developed by women specifically based on the needs of women. Although there have been studies which speak to how women are coping with HIV disease (Lather & Smithies, 1994), there is nothing in the literature that I am aware of that speaks to prevention for women. This study may have a profound effect for researchers and behavioral scientists and for women who are at high risk for the virus. It seeks to find a path for women juxtaposed to the silence permeating much of the HIV literature. In addition this study seeks to deconstruct the prevention literature and prevention models to see what messages are missing that could be helpful in keeping women not currently infected safe from the virus.

Definition of Terms

My language throughout this text will be very deliberate, and I write with what I consider to be reflexive knowledge for I have worked within the HIV/AIDS community for the last ten years. Much of my formal training began in 1991 when the Oklahoma State Department of Health, HIV/STD Service employed me as supervisor of disease intervention. CDC trained me about the etiological agents that cause sexually transmitted infections and how to sensitively interact and counsel with individuals living with such disease. Approximately one year later I received a master's degree in behavioral studies with a specialty in community counseling. I furthered my graduate training in therapy under direct supervision with a psychologist. This post-graduate supervised training was a two-year process. In 1994 I successfully passed the professional counseling board examination and alcohol and drug counselor exam enabling me to be a licensed therapist and certified alcohol and drug counselor.

In referring to the HIV/AIDS epidemic, I use varying definitions for I am more than aware of the political and psychosocial implications of the disease. Many clinicians speak to the issue of AIDS as "HIV disease" or "HIV related conditions," I think because it is less threatening to the patient. Perhaps people associate AIDS with death, and perhaps, society has socially constructed the word AIDS to infer that the individual is a homosexual, homeless person, heroine user, hooker or Haitian individual.

Acquired Immune Deficiency Syndrome (AIDS) – AIDS is a collection of symptoms or infectious diseases occurring because the immune system is damaged and unable to fight off organisms that are generally considered normal flora to the human body. As the immune system weakens, opportunistic infections develop placing more of a strain on the body and the complications of these infectious organisms sometimes lead to death (Bennett, 1986). The clinical diagnosis of AIDS according to Centers For Disease Control and Prevention (1993) has expanded in response to complaints that the original definition excluded conditions that were specific to women such as invasive cervical cancer.

Antibody Positive (HIV Positive) – A test that indicates that antibody to the virus is found in the blood. It indicates HIV infection and the potential for transmission to sexual or needle-sharing contacts and mother-to-infant transmission (Flaskerud & Ungvarski, 1992; Martelli, Peltz, & Messina, 1987).

Human Immunodeficiency Virus (HIV) – HIV is a retrovirus introduced into a human being through a break in the skin or through a mucus membrane. The fluids that carry the virus are blood, semen, vaginal secretions and possibly mother's milk. HIV attaches and destroys a certain kind of white blood cell called a T cell. A reduction in the amount of T cells weakens the immune system. Scientists working at the National Cancer Institute in the United States and the Pasteur Institute in France identified this retrovirus in the latter part of 1983 (Bartlett, 1997). Through the discovery of the virus, researchers were able to develop a test for the antibody to the virus, follow the transmission of the virus, and study the mechanism of the disease. Psychologists, social workers and sociologists tracked the emotional impact of the disease on the individual and society.

Counselors studying behavioral science continue to develop theories on preventing the disease, but as we will see, the seroprevalence of HIV continues to rise and change afflicted populations.

<u>Immune System</u> – It is a mechanism by which an organism protects itself from infection, toxins and malignancy (Koop, 1986).

<u>Immunosupression</u> – When an individual has AIDS, the immune system is suppressed by the activity of transmissible virus (Bartlett, 1997).

<u>Kaposi's Sarcoma</u> – A tumor in the walls of blood vessels. Usually appears as pink to purple, painless spots on the skin, but may also occur internally in addition or independent of the skin lesion. Death may occur if there is major organ involvement (Bartlett, 1997; Tabkin, Remien & Wison, 1994).

<u>Opportunistic Diseases/Infection</u> – Diseases or infections caused by agents that are naturally present in our bodies or the environment, but that cause disease or infection only when there is an alteration from healthy conditions. Healthy conditions usually deteriorate when the immune system becomes depressed (CDC, 1993).

<u>Pneumocystic Carinii Pneumonia (PCP)</u> – Pneumocystic carinii pneumonia is a lung infection seen in individuals who are experiencing immunosuppression. Common protozoa that are normally controlled by healthy immune systems cause it. People who develop PCP are susceptible to reoccurrence of the disease, and the outcome could be fatal (CDC, 1996; Slavin, Hoy, Stewart, Pettinger, Lucas & Kent, 1992).

<u>Postmodernism</u> – A form of epistemology that rejects absolute statements. In postmodernist discourse many truths are accepted. There are no meta-narratives. Knowledge is contextual and scientists problematize, modify and warrant the constitutive

norms of their own practice even as they engage in it. Postmodernism rejects the notion of scientific objectivity developed during the Enlightenment era. Postmodernism can be described as a theory of history, culture and society that disputes modern understanding of western civilization (Noddings, 1995, Lather, 1991, Tong, 1989).

Poststructural – There is not one single theory. Knowledge is socially constructed through language. One is able to identify, deconstruct and critique macrostructures that appear to foster inequality, injustice, and hegemony (Frasier & Nicholson, 1991; Lather, 1991; Foucault, 1982).

Seroprevalence – A term denoting the number of individuals whose blood serum contains the antibody to a specific agent, for example, the number of people who have the antibody to HIV disease (Bartlett, 1997).

T4 Cells – This cell is sometimes called a CD4 lymphocyte cell. It is the primary host cell that becomes infected with HIV. It is an important surrogate marker for integrity of the cellular immune system (Rabkin, Remien & Wilson, 1994).

Summary

As we approach the 21st century, the number of people who will develop AIDS as the result of HIV disease will continue to rise. Although the scientific community has made great strides in developing medications that slow the progression of the virus, these drugs are extremely expensive. Only those with medical and prescription insurance are able to afford the annual expense of around $16,000 a year to stay relatively healthy. These financial figures do not take into account the unexpected opportunistic infection that will require hospitalization bringing the yearly cost of such infectious disease to around $100,000.

It has been said that an ounce of prevention is worth a pound of cure. In the case of HIV prevention, this is true yet unfulfilled. However, as we have seen through the development of this research, the prevention messages have recognized the context in women's lives. It is imperative for the psychological and physical well being of our nation that we pursue HIV prevention for women and stop the silence that has become inculcated into our society.

Both the mainstream media and scientific community have done little to encourage women to challenge abusive relations, gender asymmetry and unequal pay status. These constructs may in fact be conduits to the disease and at the same time act as barriers to prevention. Little or no prevention theory has been connected or grounded to women's lives, leaving much to be desired of our prevention education.

The remainder of this dissertation builds on the themes suggested in this first chapter. Chapter II critically investigates the prevention literature and deconstructs current HIV prevention theory, models, and praxis. This includes the work of Kristeva and her theory of AIDS and abjection. Chapter III focuses on the theoretical and pragmatic aspects of qualitative research and case study used to develop this research. Chapter IV begins to analyze the data and uses concepts such as women's developmental theory, and feminist theory to build a tacit prevention model. Chapter V offers a synthesis of the research findings, limitations of the study, suggestions for praxis and policy, and suggestions for future research.

CHAPTER II

REVIEW OF THE LITERATURE

Introduction

A principal responsibility of this review of literatures is to inform the reader what is available about the topic under study from many domains and theoretical perspectives. Although AIDS is a medical malady, the psychosocial, political and educational components of HIV prevention appear somewhat unique. Society continues to support prevention and treatment of cancer and different kinds of infectious diseases, with relative compassion. However, AIDS is somewhat novel because of the intimacy involved in transmission, and because of the way the contributors to the literature and members of society have framed its discourse. Many people seem to feel comfortable believing that homosexuals, heroin users, hookers and homeless people are the sole populations infected. Overall (1991) has suggested that understanding the AIDS epidemic and AIDS discourse requires:

> An awareness of the social and political dimensions of HIV infection; the cultural construction of AIDS language, images, and representations; the pervasive effects of racism and homophobia; the scapegoating and marginalization of groups such as gays, prostitutes, and intavenous drug users; the oppression of women; the power and authority of the medical and scientific establishment (p. 8).

For example, in 1998 federal funding is available for school and religious curricula that will teach abstinence only programs. In September 1998 I attended Oklahoma's governor's conference entitled CALM. This acronym stands for Choosing Abstinence Lifestyle until Marriage. In a personal correspondence I received from Governor Frank Keating on September 25,1998, he wrote:

> The current national discussion over matters of personal morality and sexual behavior once again challenges us to think and speak clearly about fundamental values. While there are vital and important clinical aspects to be addressed at this conference, we must remember that the issues surrounding teenage pregnancy and STD's are also a matter of character and faith.

The conference centered on postponing sex until marriage to lower rates of STD's and HIV, teen pregnancy, and to speak to the tragedy of premarital sexual involvement. Speakers and brochures advocated living God's Christian principles to help resist the tide of disease, death, family tragedies, and broken lives. There were no workshops or dialogue that included same sex relationships. Homosexuality was clearly a taboo topic. The concept of waiting to engage in sexual activity until marriage created the perception that it is safe to have sex with one person who is known because they couldn't possibly be infected. Bolton (1992) and Nichols (1990) contended that it is exactly this type of prevention discourse that has caused women to contract HIV disease from long-term partners, not from casual relationships.

In the book Troubling the Angels, Linda, a woman living with HIV, wrote:

He took me to summer one winter day

Landed my ass in downtown LA

Yes, he had the virus, that flu

You know the kind you don't live through.

He smoked reefer, loved Budweiser,

Found he shot up too

To top it all off, boy he could screw.

He left me alone to contend with this

Needless to say- Yes I got pissed!!!

To think I must do another lonely day

I'm sure his spirit's

Downtown LA

I can't sit-boo hoo and cry!

I must stay strong, healthy and spry!

So I can warn all you fools

That this too can happen to you.

Don't let yourself get this flu!

Take care of yourself, spend some money

Check him out good before you call

Him honey! (Lather & Smithies, 1997, p. 107)

Merriam (1988) contended that

> no problem in education exists in isolation from other areas of human behavior. Consequently, there is always some research study, some theory, something related that can be reviewed to inform the study at hand (p. 63).

Although a plethora of information exists on the topic of HIV prevention education, this literature review focuses on deconstructing what has been written because much of AIDS discourse is directed to gay men. Women are either omitted from the literature or prevention strategies designed for gay men now are replaced with the words "for women." In a way, heterosexual men have also been recognized with reluctance. Men seem to be characterized as homosexuals, homeless people, heroin or injecting drug users, or users of prostitutes, something other than "masculine men"(Wilton, 1997). Perhaps the notion that AIDS is a gay disease helps men to act unsafe and deny the consequences of the emotional and physical scaring it causes.

Many feminist writers question the notion that simply taking the prevention education available, and adding "woman" cannot excuse the deeply enmeshed historical silences that pervade the literature. Wingood and DiClemente (1996) conducted a search of HIV prevention interventions targeted toward women using the MEDLINE, ERIC, and PSYCHLIT online databases for the years 1984-1995. They concluded that there was a "paucity of published literature targeting prevention toward women and fewer published reports evaluating their effectiveness" (p. 209).

Roth and Hogan (1998) searched the HIV prevention literature and contend:

> This collection weaves together theoretical, critical and practical perspectives to question the idea that simply taking AIDS and adding "women" will provide the insights necessary to stem the spread of HIV. We claim that this ineffectual tokenism seriously overlooks the intricate processes and conceptualizations of gender that may have kept women repressed within the discourse and treatment of HIV. Scholars have shown repeatedly that perceptions of HIV infection coded as "male" are directly linked to the distorted representations of Women in medical research, outreach and treatment (p. 15).

HIV Education Definition

Prevention for the Uninfected

Educational programs for the prevention of HIV include information and knowledge about the prevention and transmission of disease. Specifically, individuals are taught what behavioral steps they can take to stop or reduce transmission. Many educational programs have focused on the correct and consistent use of condoms. Educational messages to injecting drug users often include how to clean syringes to decrease the chance of transmitting blood. Some states have needle exchange programs to eliminate the sharing of needles altogether. Sexual negotiation skills are taught to people unprepared to deal with sexual advances. All of these approaches to HIV prevention is termed primary prevention because its objective is to prevent disease before it starts. Primary prevention is designed for individuals who are not infected, but at risk for disease.

Halting the Further Spread of Disease

Secondary prevention refers to stopping the spread of disease by infected people to their sex and needle sharing partners who are not yet infected. It is targeted to people already infected with HIV. These individuals learn specific strategies designed to prevent the transmission to other individuals. Additionally they are taught to create an atmosphere with low stress and to maintain the disease through medical management to prevent the onset of opportunistic infections that lead to AIDS. Vocational counseling and the development of particular skills (e.g., learning computer programming) so infected persons may work at home are not uncommon at this stage of disease process.

Learning to Prolong Life

Tertiary prevention offers learning strategies and procedures for people living with the HIV disease so that persons may live healthier and more productive lives even if their infection has digressed to AIDS. Tertiary prevention encourages good diet, exercise, and a team approach to care management. Very often a physician, nurse, therapist and group support system is utilized. Environmental reengineering is learned so those patients remember to take medication and do not have to walk steps unnecessarily. At this stage of disease patients may be in pain due to peripheral neuropathy caused by the disease or side effects from medication. During this phase of disease, people are taught to get their fiscal affairs in order and to make peace with loved ones, as death may be inevitable. When death approaches, therapists teach to accept it with peace (Hay, 1988).

Pedagogy for Professionals

Professional HIV education for nurses, physicians, and therapists presents an ever-changing body of information as the medical and social science communities learn new facts about the disease. The need for HIV education at every level of the health professions has been an impetus to a number of educational changes. In essence, HIV accelerated the need for innovative and interactive educational processes that help learners achieve higher level knowledge, attitude, and skills. These learning methods encourage active participation; defining, resolving, and critically questioning current praxis; and managing complex problems. Many current learning strategies encourage learners to reassess old information, attitudes, and skills (Gallagher, 1996).

HIV Prevention Theories and Models

There are many HIV behavioral scientists who believe that primary prevention programs must be based on sound theoretical models if behaviors are to be changed (Fisher & Fisher, 1992; Holtgrave, Valdiserri, Gerber & Hinman, 1993). For this reason service providers, educators and counselors should consider theoretical models when they develop HIV prevention interventions. Behavioral science explores the psychosocial, behavioral and cultural influences that elucidate why people put themselves at risk, and why people are continually becoming infected with this disease. Research on human sexuality is paramount to understanding how people change risky sexual behaviors and can help in designing program interventions (Kelly & Kalichman, 1995). Behavior change theory provides a conceptual framework to help understand why and how people change risky behaviors. Behavioral scientists insist that using behavior change theories can help educators when crafting interventions (Valdiserri, West, Moore, Darrow, & Hinman, 1992).

As an educator and therapist for Oklahoma State Department of Health, HIV/STD Service, I am in a position to access federal and private dollars for program development, enhancement and evaluation. I know that grant money will not be allotted without some kind of theoretical model used to guide the prevention/intervention design. For example, recent research has suggested that childhood sexual abuse is a predictor for risky sexual behavior as an adult (Wingood & DiClemente, 1997). Knowing this important factor, counselors and educators can incorporate this information on early childhood trauma into needs assessments, add a segment on childhood abuse to multi-session educational interventions, develop new projects for adults who were abused as children, or give specialized training to direct service providers on the topic of sexual abuse issues.

This next section focuses on the most commonly used health education theoretical models. These models are: The Health Belief Model (Janz & Becker 1984); The AIDS Risk Reduction Model (Catania, Kegeles, & Coates 1990); Theory of Reasoned Action (Ajzen & Fishbein, 1980); Social Cognitive Theory (Bandura, 1977); Stages of Behavior Change (Prochaska & DiClemente, 1983); and Empowerment Theory (Wallerstein & Bernstein, 1988). I will outline each behavior theory, deconstruct its application to HIV prevention, and indicate what is known about its effectiveness, if evaluation of the model is available.

Health Belief Model

The Health Belief Model (HBM) is one of the most widely accepted theoretical models of behavior change. This theory maintains that three factors are necessary for health-related behavior change to occur. First, individuals are motivated to change behavior when they believe they are susceptible to the disease. In other words, they believe that HIV is a viable risk and they are willing to change behavior. Second, people have to believe that HIV poses an actual threat to their personal health and well being. Sometimes watching a friend die of this disease has caused people to make a change in their behavior. Third, people must believe that following a prescribed set of behaviors which will result in a benefit will outweigh the effort of the adjustment. For example, people must believe that using a condom actually prevents the transmission of disease (Rosenstock, Strecher, & Becker, 1988).

The HBM model suggests that a specific stimuli or "cue to action," is often required to move the individual into the behavior change process (Petosa & Jackson, 1991). Examples of cues to action include media messages, messages from the medical and social service community, the illness of a friend or relative, peer education and other health interventions.

Petosa and Jackson (1991) specifically described the HBM's applicability to HIV intervention. They believed that personal beliefs about safer sex methods are influenced by individuals' perceived susceptibility to HIV/AIDS, the consequences of the disease, and the effectiveness of safer sex practices in diminishing the rate of transmission. According to HBM, individuals need to understand what safer sex is all about and have the ability to engage in safer sex practice. For example, a female who distrusts condoms and has a partner who is opposed to using them is unlikely to adopt condom use behaviors. The HBM calls for counselors, educators and other medical and social service providers to increase people's perception of their risk, increase their knowledge about HIV disease, and reduce barriers to self-protecting behaviors.

Evaluation researchers of HIV intervention programs who have used the HBM generally support its ability as a model to modify individual behavior. By using this model, educators and social service providers can target the beliefs necessary for behavior change (e.g., personal risk, self-efficacy, benefits of being disease free) and dialogue about the barriers to prevention. The HBM can be used to design prevention education and change the target population's behavior as long as the messages are culturally appropriate (Abraham & Sheeran, 1994).

Deficiencies of the HBM are obvious. Although its focus on health attitudes and beliefs is pragmatic, it does not consider other aspects and psychosocial factors in peoples' lives (McCusker, Stoddard, Zapka, Mayer, 1989). In addition, the HBM depends on the awareness of "cues to action" or the availability of prevention intervention in people's lives. This necessitates vast and diverse interventions for targeted communities whose outcomes have yet to be evaluated. Because the HBM strives to change attitudes and beliefs, it has limited effectiveness in changing addictive behavioral patterns that have very intensive biopsychosocial consequences. For example, programs modeled on the HBM may only minimally affect HIV risk associated with injection drug use (IDU) or chronic alcoholism. In addition, studies have not indicated whether this model is effective for behavioral change in women or whether it can effect risk behaviors in the general female population (Deren, Tortu, & Davis, 1993; Catania, Coates, Kegeles, Thompson-Fullilove, Peterson, Marin, Siegel, & Hulley, 1992).

Social Cognitive Theory

Social Cognitive Theory, formerly known as Social Learning Theory (Bandura, 1977) hypothesized that peer reinforcement, supportive community norms, and perceived self-efficacy are important for behavior change. Social Cognitive Theory (SCT) interventions stress role model stories, personal interactions, and multiple contacts with message givers. In Dallas, two sets of low-income housing projects that contained a large population of individuals who injected drugs were targeted for HIV prevention (Freeman & Krepcho, 1993). Peer educators identified role model stories that were published in a quarterly community tabloid. More than forty community volunteers distributed the tabloids that emphasized contextual HIV prevention messages, and reinforced indicators of positive behavior change (e.g. not sharing needles and syringes and encouraging the use of condoms). Stores in the neighborhood distributed the materials to increase exposure to the education prevention messages and to show engagement on the part of the community. The distribution of materials from community stores served as support for behavior change as well as the social support implied by merchants willing to hand out this material.

Educators worked in pairs around the neighborhood facilitating one-on-one street education which consisted of condom distribution, tabloid stories, bleach to clean needles, or information distribution, whichever seemed appropriate during the non-traditional educational encounter. The educators listened to their contacts' stories for the recruitment of future role models and enlisted potential volunteers. SCT emphasized a reciprocal interaction of behavior, social, and physical factors and maintained that a change in any one of the three factors influences the others. The primary forces that influenced change are what Bandura (1977) called expectancies or incentives.

The SCT concept of expectancies focused on individuals' perception of disease susceptibility, threat, and severity. Expectancies, in this context, are what a person believes will happen if they engage in unprotected sex with an infected partner, or share needles with someone who may have the virus. The SCT concept of expectancies is very similar to the HBM's focus on an individual's perception of disease susceptibility, threat and severity. Of course, the individual has to have the information or knowledge about the ways HIV is transmitted, and it should fit within the cultural norms and beliefs of the person. When program interventions are designed to use SCT, people's beliefs about three specific areas are thought to affect behavior change. First, environmental factors, such as beliefs about the general cause and effect relationship of HIV disease must be understood. For example, the person must comprehend that safe behaviors decrease the opportunity of HIV infection. Second, the individual must understand the consequences of personal actions, especially how behavior can determine one's own health. Third, The person must have self-efficacy or the belief that he or she can perform the desired behavior to stay safe from the virus.

Whereas expectancies are individual thoughts, beliefs and internal factors, incentives are reactions to the external world regarding behavior and behavioral change. This model suggests that incentives reflect community values germane to health beliefs and actions. A community that promotes healthy living for longevity of mental and physical strength is more likely to positively intensify health–promoting and health maintenance behaviors (Rosenstock, Strecher, & Becker, 1988). For the purpose of HIV prevention, SCT asserts that people are more likely to practice safer sex and drug using behaviors if there is an incentive, and if they actually think there is a relationship between behavior modification and decreased HIV risk. For example, an HIV prevention incentive is living a long healthy life without the severe complications of a life threatening disease.

According to SCT, HIV-related environmental expectancies are beliefs that current unsafe sex and or drug use behaviors are a threat to a person's health or other valuable characteristic like appearance, or independence. If an individual is likely to believe that the outcome of safer sex and drug using behavior will reduce transmission of disease then she is likely to adopt such practices. The model calls for continued self-efficacy or the belief or vision that the person can implement said changes.

There have been few evaluations of HIV prevention programs that have employed SCT concepts into their program design (O'Leary, Goodhart, Jemmott & Boccher-Lattimer, 1992). However, these evaluations have indicated that SCT is useful, especially, in determining perceived self-efficacy to negotiate condom use with partners. Specifically, SCT has proved a strong predictor of sexual behavior change among gay men (Emmons, Joseph, Kessler, Wortman, Montgomery, & Ostrow, 1986; Mckusick, Coates, Morin, Pollack, & Hoff, 1990), adolescents (Hingson, Strunin, Berli, & Heeren, 1990) and college students (Basen-Engquist, 1994).

It is important to note that the SCT model focuses on the person and it does not suggest strategies for changing group or community norms. It is known that when a community can influence social outcome expectancies to expand social norms to include safer sex and drug using behaviors, HIV risk-taking behavior is affected positively (O'Leary, Goodhart, Jemmott & Boccher-Lattimer, 1992). A model that has an individual focus limits the extent to which the community can participate and therefore remains short sighted about its application. Additionally, the model does not address the complexity of alcohol and drug using behaviors or the profound biopsychosocial and psychological affects of addiction.

Although this model helps predict perceived self-efficacy for condom use, it does not address the role of contextual and cultural differences and their effect on sexual behavior (Wingood & DiClemente, 1996).

AIDS Risk Reduction Model

AIDS Risk Reduction Model (ARRM) developed by Catania, Kegeles and Coates (1990) has specifically emerged from HIV prevention work. This model consists of three stages and is helpful for clients, counselors and educators to understand the process of behavior change. ARRM combines aspects of the health belief model and social learning theory to describe three stages of behavior change. The first stage, called labeling, means that an individual must consciously identify a particular behavior as a risk factor for HIV before they will consider making a change. The second stage, commitment, suggests that people must commit to change in order to implement the desired behavior. The third stage, enactment, consists of facilitating the plan of action to remove or reduce barriers to the desired behavior change and then actually making the behavior change. These stages are presented sequentially, but the authors contended that people might move among stages at different times in their lives, and move among stages in any order. Factors that may contribute to the movement among stages include person anxiety about threat of disease, social norms, peer pressure and changes in relationships.

For HIV prevention to be effective, this model has the service provider increase awareness among members of the targeted population about their risk for HIV disease and emphasize commitment to safer sex and drug use behavior. In addition, the model calls for removing community barriers so the targeted population can actually proceed with the intended behavior change. Communities and AIDS service providers can increase risk reduction methods by providing condoms to at risk populations and needle exchange programs to injecting drug users, and working with social justice committees to provide the legislative body with information on barriers to prevention.

Catania, Kegeles and Coates (1994) evaluated the usefulness of their model in a research study that investigated the determinants of condom usage among the heterosexual population. Generally, they determined that this model could be used for understanding the behavior change process. They found that if participants were able to label their behavior as risky, then they were able to commit to condom use. The evaluation indicated that factors, such as personal beliefs, and social norms, were important components of whether people would move from one stage to the next.

I believe that human behavior, especially, sexual behavior is more complex than any model could suggest. Behavioral scientists know that knowledge about HIV or even the skill to negotiate condom use does not sufficiently describe the contextual factors that affect women's ability to engage in safer sex (Amaro, 1995). A recent report from Institute of Medicine (1994) suggested:

> The U.S. population as a whole has failed to incorporate prevention messages into sexual behavior. In fact, a consistent observation from many studies is that many of those at risk for HIV infection whether through sex or drug use do not recognize the danger they face… and that, even when they do, knowledge alone is not enough to effect behavior change to reduce their risks (p. 83).

Stages of Change Model

The Stages of Change (SOC) Model was based on the transtheoretical behavior change model that considers the dynamic aspects of human behavior (Prochaska, Norcross & DiClemente, 1994). The transtheoretical model suggests that different people may be at different stages of their lives with respect to changing any particular behavior. This approach mentioned five stages of change that an individual went through when changing behavior. The precontemplation stage was when the individual was aware that the existing behavior was harmful. Contemplation, was the next stage where the individual was emotionally aroused and cognizant of self- reevaluating behavior. The third stage, was preparation, and the client became committed to behavior change. The fourth and fifth stages were combined into action and maintenance. It was during these phases that the person understood the rewards involved in making the behavior change and relied on social support for maintenance of the desired behavior.

In one neighborhood that had an elevated rate of teen pregnancy, drug abuse and STD's, peer advocates received continuing education through in-service training, case conference, and ongoing review of an SOC model to help them facilitate a prevention program among their peers. The advocates worked with clients to help them change one or more specific behaviors, or to reinforce and support the risk reduction changes that the women had already made. Advocates developed rapport by meeting with their clients from one to three times. During the rapport phase, advocates ascertained the clients' needs and strengths. Advocates had the flexibility to take the client out for coffee, meet the client in the clinic, or offer the client various referrals. By the end of this first phase, the advocate identified her clients psychosocial needs as well as her current stage of readiness to change the intended targeted behavior. For example, the advocate ascertained whether the client was ready to persuade her partner(s) to use a condom(s), or whether the client was ready to clean her works (syringe and needle) or stop using drugs (Cabral, Galavotti, Gargiullo, Armstrong, Cohen, Gielen & Watkinson,1996).

Advocates were trained to use the SOC counseling manual which consists of self-contained modules that described characteristics of clients at each stage of change and objectives to reach the next stage of change. Peer advocates were trained to ask a series of assessment questions that reportedly identified the key influencing factors that determined the counseling interaction. The SOC manual prescribed a set of counseling activities and influencing factors for each stage. Interventions were flexible so the advocates were able to diverge from the manual when appropriate. For example, an advocate may have concluded that a client was at risk for becoming infected with HIV. The peer would then tell a story about a woman who was infected and how she became alienated from friends and family.

According to the SOC Model, emotional-cognitive influencing factors are most important in early stages, and interventions should focus on manipulating these factors for people in the precontemplation and contemplation-preparation stages. HIV prevention intervention at the precontemplative stage requires raising awareness of susceptibility and the consequences of behaviors that can put an individual at risk for disease. HIV prevention at the contemplation phase of behavior change includes skills' training (e.g., negotiating skills for condom use, appropriate cleaning of needles and syringes) and self-efficacy nurturing to minimize barriers and help strengthen beliefs in the person's capabilities. People often revert to old behaviors, therefore, intervention for people at the action and maintenance stages focus on reinforcement of the behavior and other prevention methods (Valdiserri, West, Moore, Darrow & Hinman 1992).

This enhanced intervention model, delivered by peer advocates, suggests that interventions that fit a person's stage of readiness to change are more effective than interventions that are more germane to prevention in general (Prochaska, 1989). Although professional staff designed the (SOC) counseling manual, it was the paraprofessional peer advocates who administered the assessments of their clients. It was the advocates who ascertained the stage the women were in and then performed the appropriate counseling intervention.

Few prevention projects based on this theoretical model have been formally evaluated. However, preliminary results provide support for its effectiveness. The primary strengths of this model are its elements for understanding that behavior change is dynamic, the recognition of environmental and social norm influences on behavior, and the acknowledgment that people revert back to risk-taking behaviors. Valdiserri, West, Darrow and Hinman (1992) contended that the above factors, and the individual stages, pointed to diverse approaches to HIV prevention strategies based on age, gender, race/ethnicity and socioeconomic status. However this model, similar to other prevention paradigms, is based on the sometimes-inaccurate assumptions that sexual behaviors and sexual encounters are controlled totally by the individual. In the case of sexual coercion, rape, and gender inequality, women are clearly disadvantaged. There is a need for models that address gender asymmetry and how this issue is relevant to HIV risky behavior in women.

It is important to note that the circumstances of targeted populations must be known before attempting to prescribe an appropriate intervention. This model acknowledges the importance of individual and group differences. Because potential members of a target population may have members at different stages (e.g., precontemplation and maintenance), HIV providers need to target only the members at a particular stage, or design an intervention program that can work with individuals who are at different stages.

The different types of interventions that may be required to assist individuals, who are in various stages, may require a range of service providers and service organizations. Valdiserri (1989) asserted that public health departments might access knowledge about HIV intervention prevention by assigning the responsibility of prevention activities to community-based organizations that are typically trained to work with specific sub-cultural groups. For example, in Tulsa, Metropolitan Substance Abuse Services receives funds from the Department of Mental Health and Substance Abuse to outreach to injection drug users. Staff from this community-based organization then reports to the health department which interventions appeared successful and in turn, the health department can monitor new cases of HIV infection in this demographic area.

Theory of Reasoned Action

The Theory of Reasoned Action (TRA), developed by Ajzen and Fishbein (1980) focuses on the translation of beliefs about a behavior and perceptions regarding threat to health into appropriate behavior change (Abraham & Sheeran, 1994). Whereas many behavioral theories actually target the individual, portions of the TRA incorporate the social and interpersonal aspects of human behavior. DeWit, Teunis, VanGriensven and Sanfort (1994) found this model to be very useful for intervening with sexual behavior that is social in nature (e.g., homosexual men).

The components of TRA are attitudes, subjective norms, and intentions. Attitudes are individually determined and mirror beliefs about consequences associated with performing a behavior and evaluations of those consequences. Subjective norms are socially determined, usually by peers' and role models' perceptions of what an individual should do about a specific behavior (Jemmott & Jemmott, 1991). Intentions to change a particular behavior are determined by ones personal attitude and the subjective norm toward that particular behavior. Behavior, according to TRA, is ultimately a direct result of an individual's intention to change a certain behavior.

An HIV prevention program based on the TRA addresses attitudes and subjective norms in order to influence people's intentions to change their behavior. For example, HIV related attitudes that might be targeted include beliefs about whether condom use will prevent HIV and whether condom use with one's main partner will be perceived as an act of mistrust. Expanding upon this example, an HIV prevention program would aim to change the entire group norm if it was known that a particular community commonly practiced unprotected sex with primary partners because of strong values linking condom use to partner mistrust.

The TRA has been shown to provide an important link between health beliefs and behavior change actions. Its expansion upon other theories to include social and interpersonal aspects of behavior is an important strength. Components of the TRA have proven important predictors of safer sex behaviors. Specifically, studies have shown that attitudes toward condoms are predictive of intentions to use them, perceived norms are predictors of HIV prevention intentions and behaviors, and perceived condom use norms are predictive of adolescents' intentions to use condoms (Abraham & Sheeran, 1994). The TRA focuses on attitudes and subjective norms and suggests that HIV interventions on the community level need to influence perceptions of cultural and sub-cultural norms.

The TRA does not provide a comprehensive perspective for behavior modification. Its focus on attitudes and intentions, while predictive of some behaviors, does not address the dynamic nature of human behavior, including gender inequality, and it particularly neglects issues of reverting to unsafe sexual behaviors and behavior maintenance. Additionally, larger social and environmental issues are not emphasized as influences on norms and behaviors (e.g., drugs and alcohol).

Empowerment Theory

Empowerment theory is based on the philosophical principles of Paulo Freire. According to Friere (1970, 1990), traditional health education approaches assume that the learner is like an empty bank account into which the educator or facilitator makes deposits. On the other hand participatory education assumes that people gain control over their lives through dialogue and critical thinking that lead to identifying and analyzing the social and historical roots of their problems, envisioning alternatives, and, taking action that can change personal conditions and bring about social change (Wallerstein, 1992; Wallerstein & Bernstein, 1988). Research has determined the link between a person's lack of sense of control over his or her own life circumstances and illness. Empowerment Theory employs the ideas of Popular Education and seeks to promote health by enhancing people's feelings of power and sense of being in control (Wallerstein & Bernstein, 1988).

The tenets of Freirean empowerment have been used in conjunction with needle exchange programs across the country to decrease transmission of HIV in injecting drug users. Programs utilizing this philosophical lens, offer clean needles and syringes, condoms, referrals for detoxification and counseling for interested people. By working with clients, who may intend to stop injecting drugs, providers build trust and assist clients to decrease risk (Lurie, Reingold & Bowser, 1993). Similarly, in a penal peer education project in an Oklahoma prison, health department personnel work with offenders to establish democratic curricula needed for dialogue, personal empowerment and emancipation.

The Oklahoma State Department of Health, HIV/STD Service facilitates several HIV Peer Education Programs for Incarcerated Women, (AIDS & Public Policy, 1997; Marwick, 1997; Richards, 1997). This program utilizes funding from Centers for Disease Control and The Tulsa Community AIDS Partnership to furnish a classroom in the local city-county jail where peer education is facilitated. In another state health department sponsored penal program at the Eddie Warrior Correctional facility in Taft, Oklahoma women earn college credit to become peer educators through Tulsa Community College. The program at the jail and prison utilize the educational pedagogical theory of Paulo Freire for a form of adult educational praxis committed to radical change for the empowerment of women. The project uses dialogue to learn about the root causes of HIV. Women involved in the project determine topics for dialogue, participate at their own comfort level, develop materials to be disseminated throughout women's prisons' in many states and teach their peers how to stay safe from the virus while incarcerated and once released.

For the radical philosopher Paulo Friere, the opposite of humanization is dehumanization or oppression which is found in prisons (Freire, 1970). The autocracy of the states' correctional department monitors what women eat, what offenders wear, and how many sanitary napkins they can have each month during menses. I have helped incarcerated women to develop peer education programming in the women's prison system for several years. Although funding has not permitted outcome evaluation of these projects, process evaluation studies have indicated positive value of the program and several states have emulated the concept. For this model to be successful the teacher must be willing to relinquish control of the classroom and become a listener, learner and partner.

Peer educators at Eddie Warrior Correctional Facility have developed a twenty-minute video entitled "AIDS Is Not My Only Problem." This video depicts women telling their stories of abuse, neglect, chemical dependency, incest and rape. The women are strong, articulate, and although physically not emancipated, their spirits are free and empowered to give voice to let other women know they are not alone with issues of oppression.

Because there are no documented outcome evaluations' of interventions based on Empowerment Theory in the literature, little is formally known about its effectiveness.

Given the complex issues surrounding HIV disease no single theory can be expected to encompass the intricacy of human behaviors and the environmental and psychosocial components that represent caveats to primary prevention. A well-designed intervention will be inclusive of the culture and gender of the target population, and not be expected to support or test theoretical models at the expense of the people. Empowerment theory allows the target population to design their own perspectives on prevention, and modify prevention notions and practice to meet the needs of problematic issues as they arise.

Where Are the Women? The Pursuit for Visibility

In a discussion of the prevention models used specifically for women, Wingood and DiClemente (1996) asserted:

> A continuing challenge is to understand the implications of previous research for the development of more tailored gender relevant behavioral interventions. For instance, while SCT has provided a promising theoretical framework for developing skills training interventions proven to be effective in enhancing women's condom use, this model does not entirely address the role of contextual and sociocultural variables such as gender, class, and ethnicity and their influence on sexual behavior. These social structures shape the reality of risk for HIV infection and potential for adopting HIV-prevention strategies by women. Gender roles, cultural values, and perceived norms, for example, are highly influential in affecting the behavior of women and the nature of their heterosexual relationships in which sexual activities occur (p.213).

Similarly, in a recent study on gender and AIDS, Schieman (1998) revealed findings that suggest several dramatic differences among a sample of women and men that may have implications for education and prevention efforts. The main findings indicate that women's behavior matters more for their perceptions of personal risk. That is, the number of sexual partners women had in the past year had a positive influence on their perceived susceptibility to HIV.

> There was an interaction effect, however, such that the level of condom use among women conditioned the association between partners and susceptibility. In contrast, the same interaction was not found among men in the sample (p.276).

Could it be that gender differences affect the ways men and women perceive AIDS related psychosocial processes? If this is so, then AIDS prevention programs need to focus on these differences while emphasizing the perceived susceptibility within the context of gender as an integral component of prevention efforts.

In addition to gender insensitivity, the models presented have an individual-focus that limits their utility by ignoring the environmental factors such as the social context of where the individual, family and community. Furthermore, these models assume that all behaviors can be weighed in a cost/benefit analysis. Essentially, these models disconnect the person from the environment even though interacting with the wider social environment may entail situational and emotional hardship for the individual (Choi, Yep, & Kumekawa, 1998). An example may be individual peers who are heavily invested into the drug culture, and may cultivate barriers to HIV risk reduction efforts.

Amaro (1995) pointed to the absence of discussion about gender roles in current prevention models and said:

> A growing number of investigators have recognized that gender differences influence HIV risk behaviors and barriers to behavior change. However, these studies have been based on theoretical models that do not provide an explanation for the expected and observed gender differences. Their results suggest a need to look closer at values, beliefs, and practices related to the roles of women and men and their sexuality, as well as the implications of those HIV risk behaviors and behavior change strategies (p.441).

An example of the attitudinal differences in genders can be explained through the theoretical construct of "self-efficacy." It is interesting that self-efficacy beliefs, which is a paramount component in many of the described prevention models, are not significantly associated with condom use for women. Self-efficacy is a construct associated in the literature with gay men (Catania, et al. 1992). More specifically, the Health Belief Model, Social Learning Theory, Theory of Reasoned Action and the AIDS Risk Reduction Model have guided somewhat effective prevention projects targeting the individual's knowledge, beliefs, norms, and attitudes related to HIV in men who were having sex with men. However, the effectiveness of these models when applied to female prevention projects has not been investigated.

Kelly, Murphy, Sikkeman and Kalcihman (1993) noted that the increase in AIDS-related knowledge was insufficient to bring about behavioral changes needed for HIV prevention. For the second decade of this pandemic, they called for a need to target not only the individual but also prevention projects that target environmental factors.

I believe a community prevention approach to decrease domestic violence would impact HIV transmission for women. Programs must also acknowledge the aggression that occurs among lesbian partners (Waterman, Dawson, & Bologna, 1989). Lesbian women must have access to community support and be able to challenge "the lesbian myth of healthy, violence-free, egalitarian relationships" (Coleman, 1994, p.139). Community prevention programs need to include information on women's studies that explain the historical, political, and religious aspect of gender inequality. If women had the power to refuse unprotected sex without the fear of domestic violence transmission rates for women would decrease. Similarly, women have told me that their male and female partners encourage drug use, and that they often are fearful of refusing to participate in said behaviors. When this type of coercive drug use is part of the relationship, women are at risk. Curriculum would have to include the meaning of parity in the lesbian and heterosexual relationship, and the consequences of a society where women are exploited, abused and vulnerable to disease. Program pedagogy would need to include information about gender equity.

The Myth of Lesbian Immunity

The exclusion of women who have sex with women as a risk category for HIV disease speaks to the CDC's AIDS reporting protocols and to the exclusion of women in the HIV literature. CDC uses a protocol of exposure categories to determine how HIV was transmitted. If a woman has more than one possible exposure, she will be categorized by the highest risk only. For example, CDC's hierarchy of exposure for women is:

1. Injection drug use,
2. Heterosexual contact with an HIV infected partner (or partner that is high risk for HIV),
3. Recipient of blood or blood products, and
4. No identified risk (CDC, 1994).

In other words, female to female transmission is not available as a possible exposure category for women, although vaginal secretion is a fluid that is known to transmit the virus.

It is precisely this form of paternalism that fostered feminists to embrace an awareness in the lives of women, namely women's experiences, their subjectivity, and sexuality. Alexander (1994) wrote on the history of feminist reflection and said, "we need a history of our own, a language of our own, and the right to determine our own sexuality" (p.272). The denial of female to female HIV transmission is problematic from a critical feminist perspective. First, it mandates a heterosexual orientation totally disregarding lesbianism. Second, the invisibility of lesbianism influences what Rich (1980) called "compulsory heterosexuality." Compulsory heterosexuality makes penile-vaginal intercourse the only real form of sex (Chalker, 1994). Conceptually, this denies lesbians equal access to community resources like testing for HIV and other STD's. Third, this type of sexual discourse oppresses women because it takes away their right to alternative sexual orientations and strengthens male hegemony keeping the dominant gender in control. Hoogland (1994) posited that lesbianism is made invisible by and within heteropatriarchal discourse because they make up an "alarming subject."

> The persistence with which the lesbian is erased from the phallocentric conceptual universe is not so much incidental as overdetermined, and thus motivated. As such it can and should be read "symptomatically" as a discursive knot or "nodal point" in the text of phallocentric culture as a whole (1994, p.21).

Is it not the Anglo male that initiates heteropatriarchal discourse to reflect and reproduce the dominant culture and to keep the (other) subordinate?

A Critical Feminist Perspective

Harding (1991) spoke to the issue of how we come to knowledge. Feminist theoretical approaches direct us to start our research and ways of knowing from the perspectives of women's lives. The reviewed models come from researchers and behavioral scientists from the dominant group. Although the models mostly address the lives of men having sex with men, these men are mostly white, Western and economically advantaged.

There is a need for a critical feminist approach to writing prevention programs for women. Critical feminism is concerned with thoughtful action and liberatory praxis designed to deconstruct and free us from limited ways of knowing (Lather, 1991). It strives to find women's voices, experiences and perspectives as a means of discovering self, addressing inequity of power relations and resisting hegemony (Elias & Merriam, 1995). Critical feminism struggles to discern the relationship between women's oppression and oppression of all people in general. It is through the lens of critical feminism that I question the status quo of these models and wonder why there is not a model specific to the prevention needs of women.

Because feminists believe that women are different with regard to race, culture and socioeconomic status, a model or several models, perhaps, are needed that addresses the multiple dimensions of the female experience. Spender (1985) defined feminist ways of knowing:

> At the core of feminist ideas is the critical insight that there is no one truth, no one authority, no one objective method which leads to the production of pure knowledge. This insight is as applicable to feminist knowledge as it is to patriarchal knowledge, but there is a significant difference between the two: feminist knowledge is based on the premise that the experience of all human beings is valid and must not be excluded from our misunderstandings, whereas patriarchal knowledge is based on the premise that the experience of only half the human population needs to be taken into account and the resulting version can be imposed on the other hand. This is why patriarchal knowledge and the methods producing it are a fundamental part of women's oppression, and why patriarchal knowledge must be challenged and overruled (pg. 5-6).

Poststructuralism deals with interpreting power and culture and claims no knowledge is final. Cleavages like gender, race, socioeconomic levels and sexual orientation are categories created by dominant culture used to explain the human condition. Sometimes, categories form linkages, which lead to resistance through agency. For example, it was the AIDS activist organization "ACT UP" (AIDS coalition to unleash power) that forced the food and drug administration to conduct clinical trials on AZT. And, it is the AIDS community and various "agencies" that lobby congress so that triple combination drug therapy will be available for developing countries. Resistance can be identified in many gay and AIDS related agencies. Resistance comes from telling one story. However, where is Act Up for women and the resistance needed to foster social change?

Commenting on the absence of voice and representation, Mackinnon (1982) said, "we need a woman's point of view that criticizes all the ways we have been created by being excluded and kept down but that also claims the validity of our own experience" (p.142) . Serving as an illustration of Mackinnon's perspective is the alcohol and drug research arena where women for the most part have been excluded. For many years it was assumed that research done on Vietnam veterans who were abusing alcohol and other drugs could be generalized to women. This research demonstrated that a genetic proclivity for drug and alcohol abuse existed in men. It has been assumed in the name of "bad science," that women also had a genetic proclivity for alcohol and other drugs (Amaro & Hardy-Fanta, 1995).

Alcohol and drug counselors have been treating alcohol and drug problems in women with a model that included their genetic propensity for abuse. When researchers actually studied pregnant women who were addicts and alcoholics, they found strong support to show that male partners introduced them to drugs and alcohol and later to hard drugs. In most cases there was no genetic relationship between women's alcohol and drug use and the alcohol and drug use patterns of their parents. Women used drugs and alcohol as part of the ambience in the relationship and these substances help to braid the connectedness to their lovers (Amaro & Hardy-Fanta, 1995; Blume, 1990). A recent National Institute of Drug Abuse (NIDA) study (Bowersox, 1996) suggested that gender would become an increasingly important consideration in drug abuse clinical studies and treatment strategies.

If I examine the AIDS pandemic through a critical feminist lens I see the "womyns" body viewed by science as a mere vector of infection. Research has been slow to conduct clinical drug trials on women (Sperling, et al., 1996). Is it because women who are infected are seen as promiscuous drug users? Is it only when women are pregnant that we "research" in order to see how drugs will impact the fetus ? (Deren, Davis, Tortu, Beardsley & Ahluwali, 1995)

Harding (1986) suggested that feminists challenge the categories of Western thought and the yearning for "suspect universalization" and move beyond the categorical to find multiple ways of knowing others. Poststructural research practices are seen as messages or evocative portraits from people (subjects) that help us understand some "truth," or that represent other voices as opposed to an objective method of data collection that reveals one universal truth (Foucault, 1985; Lather, 1991; Marcus, 1993). When Lather (1997) represented women living with HIV disease in Troubling the Angels, she drew on an eclectic group of narratives. Her intent was not to construct theory or conceptual frames but to look at available discourses. Her emphasis was on the dynamics of power, language and meaning, and how women challenged with HIV made sense of what was happening to them.

Rethinking HIV Prevention Models

Morrison (1975) writes of her two heroines in Sula,

> Because each had discovered years before that they were neither white nor male, and that all freedom and triumph was forbidden to them, they had set about creating something else to be.

As researchers and counselors look at prevention for women, theoretical models that incorporate gender and psychological studies must be addressed. Amaro (1995) outlined four points that need to be addressed for understanding women's high risk sexual behaviors: (a) women's unequal social status as a factor for risk, (b) women's developmental theory, fear of disconnection and how this is critical for women's risk, (c) women's male partners and their risk factors, and (d) women's experiences with domestic violence, sexual abuse, and fear of violence and how these elements form barriers to prevention in some women.

Women, Sex and Drugs

Women's unequal status has been an ongoing theme in the feminist literature. To highlight gender asymmetry, this next strand of literature will represent research and voices from women involved in the sex- for-drugs culture. It is important to consider that many women who are now infected grew up from the mid-1960s to mid-1980s when drug addiction was taking a horrific toll on community. During this time, the availability of inexpensive drugs such as cocaine products, made euphoria possible without the risk of HIV due to needle exposure (Bourgois, 1989; Hamid, 1990). Essentially these drugs became popular because they didn't have the expense of heroin and people didn't believe they would lead to HIV infection. Paradoxically, the sexual thrill and need for multiple partners that these drugs produced, perhaps lured more people into irresponsible sex culminating in higher rates of HIV than ever thought possible through non-injectable drugs.

The new expansion of cocaine products (crack and cocaine hydrochloride) increased demand for safer forms of more intense drugs. This expanded drug scene created opportunities that exceeded the capability of older drug networks and permitted women to circumvent many of the gender barriers to selling drugs (Baskin, Sommers & Fagan, 1993; Fagan, 1992; Johnson, Hamid, & Morales, 1990). During the era of heroin, women were banned from sales and so crimes typically associated with gender, like prostitution prevailed. Men lured women into heroin use (Blom & van den Berg, 1989; Stephens, 1991), sold heroin to them, and were their pimps (Hunt, 1990; Miller, 1986; Rosenbaum, 1981; Miller). Occasionally, women were allowed to be "holders" of the drug, and then prostitution was more lucrative. As more and more men in major cities were convicted and sent to prison for drug sales, young women became heads of households. These contextual changes had great cultural significance for women who were living in extreme poverty. Many of them now had the need to earn more money.

Anderson (1994) argued that many of these young women made the choice to enter the drug culture and to sell drugs because it was something they knew how to do. The social change from heroin to the cocaine economy, and an increasing service economy created opportunities for women within street drug networks. The male hegemony that once excluded women from selling drugs was replaced with a culture with a wider array of street drugs that needed a constant network to supply the huge demand. The expanding cocaine economy neutralized the social processes that kept women *out of the business* and gender neutralized the dope economy. Unfortunately, the addictive nature of crack cocaine led women back into prostitution to accommodate their frequent crack use. Women's occupation in the drug market grew to manufacturing, selling and crew bosses. Their jobs became intertwined with their social world as they became marginalized from licit work. Their options for education or training became more limited the more addicted they became and their enmeshment into street networks reinforced their trail into a life of illicit activities.

The sex market that grew out of the cocaine economy was phenomenologically different than more traditional forms of prostitution. Ratner (1993) characterized this form of the sex trade as a "volatile disorganization." There was price-cutting, vicing (robbing customers) and violent and abusive sex practices (Maher & Curtis, 1993). The higher level of degradation and debasement inflicted on these crack-addicted prostitutes was perhaps secondary to increased rates of STD's and HIV (Bourgois & Dunlap, 1993). However, the price-cutting was only a small problem that arose out of the expanded sex-for-drug trade.

Women's risk for violence and victimization increased as the protective structures of madams working in brothels and pimps were replaced by drug dealers or operators of crack houses who had little regard for these women. One crack-addicted prostitute named Yvette offered the following account in a recent publication on women and crime in America (Baskin & Sommers, 1998):

> The crack makes people fearless at certain points and also gives you a "you don't give a fuck" attitude. So you know, they will hurt you, they really will. And you have no one lookin' out for you. One time this happened

> around twelve at night around midnight, this guy I know he only came with nine dollars, and asked if I could do him for nine dollars. But he doesn't wait for me to answer. I would have done him for anything. So he says to me, since he doesn't wait for the answer, "Since you can't do it for nine dollars, I'm gonna take everything" and he took my crack. He pushed me against the wall and I was fighten' him. So he punched me and cut my eye open. I got ten stitches. He had a cane and he hit me with the cane. He broke it over me. Then, he body-slammed me. Then he started he started hitting me with the cane until my eye was messed up. He took, uh, sixty dollars and four vials (pg. 97-98).

Research on the community context of crime claimed that neighborhoods directly influenced behavior, attitudes, values and opportunities (Bursik & Grasmick, 1993; Harrell & Peterson, 1992; Wilson, 1987). Hence, it is almost easy to understand how selling drugs, although a criminal career, provided a choice for women offering a higher income. It was a reachable goal for women coming from vulnerable neighborhoods and very much acceptable in their environment. Furthermore, their involvement and success within the drug culture positioned them in a context that offered status, excitement and commodities otherwise unavailable to them (Adler, 1985; Anderson, 1990). However, their involvement with the sales of drugs also led to the taking drugs that enmeshed them to a life of violent prostitution and elevated rates of STD's and HIV.

Sexual exploitation is related to crack addiction. Corea (1992) spoke to the notion of "tossing" or bartering sex for drugs with prostitutes. She claimed that it was a different form of prostitution because it involved a smaller payment, less negotiation on the part of the female with regard to money and condom use, and a degraded social position. The intense euphoria experienced by these women induced them to do almost anything for one hit of crack. In Corea's book entitled The Invisible Epidemic (1992), an addict revealed the depth of debasement and humiliation:

> I sucked his dick, and he came in my mouth and I was spitting it out-and he gave me $4. I was crying and shit because I knew how bad I had gotten. I was like, oh my god, $4 and I was out there begging for a fucking dollar" (p. 4).

Control issues are germane to addicts. When an addict loses all sense of reality, the drug is in control. The primary relationship for the individual at this point is with the drug, and all sense of needs for food, shelter, appearance, and self-preservation is lost to the narcissistic craving for that unadulterated high. Women addicted to crack blame themselves not only for the shame and guilt associated with the addictive process, but for loss of "womanhood." Their children have been taken by the system or by their families. They have lost the gender battle, so to speak, because they are unable to be mothers, wives and respected lovers.

I am reminded of my own experience as an alcohol and drug counselor. I remember Mary; she was released from prison and employed as a french fry maker at McDonald's, and it was payday. She proudly cashed her check and picked up her children from her mother's home. She promised them pizza and pop. She stopped at the crack house for just "one hit," and left her two sons in the hot car. Mary couldn't stop at one hit, and kept hitting the pipe to reach that unreachable euphoria she longed for while incarcerated for prostitution. She hit the pipe over and over until a passer-by called the police as her children screamed for her in the heat of the summer evening. I saw her later that week in the county jail. She was sad, depressed and shameful. But, she was lucky. Her children were unharmed and safe in the custody of The Department of Human Services. I, too, was sad and felt her shame for treatment centers are unavailable for the marginalized and disenfranchised populations like Mary. Drug-addicted women are viewed as evil and dangerous prostitutes. They are seen as mere vectors for sexually transmitted infections and a deadly virus commonly known as AIDS. Yet, the system and society deny them the basic elements of human dignity.

Drug and alcohol addiction is a woman's issue. The magnitude of this problem must be addressed within the larger context of how the female role is shaped within society. An additional complication facing female addicts is the "fact that male-run medical establishments still assumes, for the most part, that the male body is the norm" (Tessier, 1997, p. 144). Women need to have treatment programs help them to explore the causes for their drug addiction, and rehabilitation programming that will provide child-care or residential facilities for their children. Women must have access to information that explains the importance of relationship and connection in their lives, and how this interacts with alcohol and drug use.

All things are connected.
Wildlife
Wild sex, wild death
Wilderness (Le Guin, 1986, p.193).

A "Theory" of Development for Women

The most notable psychological betrayal of women came when Freud in the late 1880s was studying hysteria. It was during this time that Freud heard over and over again how, in their childhood, his female patients' fathers had seduced them. At first Freud believed that these were repressed memories of childhood incest and after the onset of puberty these memories created neurotic behavior culminating in hysteria. Freud then discerned that these memoirs were fantasies on the part of these women patients suffering from chronic hysteria. He then hypothesized that the incestual seduction never took place and that the fantasies were merely a form of unconscious desire. When women insisted that it was not fantasy causing their traumatic state Freud pointed out that a man had more opportunity to engage in sexually perverse thought, and a woman's sexuality is restricted by society. Hence, the woman must be content with neurosis and repressed sexual ideas that are basically forbidden (Jordan, 1997; Mitchell, 1993)

However, Freud's betrayal of women was perhaps just the beginning of a century filled with developmental theories that elevated notions of independence and autonomy as the pathway to sane and normal personality function. Theories of psychological development have stressed independent decision making, overshadowing empathy and communal responsibility. Psychologists like Freud (1920) and Erickson (1963) have framed the concept of "self" to establish the significance of personal autonomy. The importance of the sanctity of freedom has been linked to a healthy and prosperous mental state, whereas women, who have been needy of attention and relationship, have been viewed as hysterical, neurotic and labeled with psychoanalytic personality disorders.

Judith Jordan is a feminist psychologist and professor at Harvard University. She has been an advocate for trying to better understand the developmental pathways in women's lives. She has given voice to women's experience and how we grow and develop in relation to others. Jordan (1997) has been highly skeptical of traditional theorists. She asserts:

> Freudian theory stressed the power of innate instinctual forces and the development of increasing internal structure and freedom from dependence on others for gratification of needs. Relationships were seen as secondary

> to or deriving from the satisfaction of primary drives (e.g. hunger or sex). Intrapsychic development was seen as the ultimate area of interest; and "self-development" (or ego development) was seen as a process of internalization of resources from caretakers and others to create an increasingly unique, separate, and self-sufficient structure: the self. Connotations of control, ownership of action, and mastery over both impulses and outer reality abound in this model (p.11).

Theorists like Miller (1986), Gilligan (1982; 1993) Jordan (1997) and Noddings (1995) have questioned male models of development and have supported female developmental theories founded on relationships with others. These female theorists posit that women are nourished through relationships with others. They believe that an ethic of care involves mutual understanding and empathy. I must digress for a moment and question any theory that categorically explains women's behavior or experiences, including a feminist view of growth and development. It is exactly the diversity in women's cultural lives and experiences that have led critical feminists to question any universal truth. With this in mind, I will attempt to explain female development through a unique lens.

Gilligan (1982) explained that "women define themselves in the context of human relationship" (p.17). This perspective of connection to others is participatory, synergistic and empowering to women. As women develop an interdependent and relational connection their goals about life cycle issues become clear. Jordan (1987) used the term "clarity in connection" to describe how the relational self can positively influence and support the direction that creative and productive energy can take. Of course, the full understanding of relational development depends on mutual empathy between the partners of the relationship and the flow of mutuality. Jordan (1997) contends:

> An individual must be able to represent his or her own experiences in a relationship, to act in a way which is congruent with an "inner truth" and with the context, and to respond to and encourage authenticity in the other person. Participation with another person(s) leads to a jointly created "feeling-milieu" and contributes to effective action for both (or all) people. In an authentic and mutual relationship, one will not be too accommodating (i.e. self-sacrificing). Often what people refer to as difficulties in "self-function" (so called "co-dependence," "masochism," or "self-defeating behaviors") are really failures of mutuality in the relationship. Importantly, mutuality involves commitment to engage in the development and support of both people; it involves respectfully building a relationship together that both sustains and transcends the individuals engaged in it (pg. 32-33).

It appears that this connected epistemology emerges through care of others and may explain why some women are reticent to negotiate protective measures, especially if they think it may impact the man negatively (e.g. the man may not be able to sustain an erection with condom use). We know that negotiation and consent are critical to keep women safe from the virus. Could their desire for connection and intimacy serve as barriers to prevention? If we assume that at least some women develop in a relational way, then it is obvious that they need love and nurturence within a relationship.

One outcome of gender roles is a difference, first noticed in childhood, in communication and conflict resolution styles. Boys are more likely to use physical superiority and girls to use verbal skills. As gender roles become more amd more socially inculcated, females are often at great disadvantage in sexual encounters with men (Charlesworth & Dzur, 1987; Jacklin & Maccoby, 1978; Maccoby, 1988). When discussing sexuality Judith Jordan (1997) often asks her female clients if they can tell their partners what they want or what pleases them; few can. Perhaps conventional femininity requires having a different voice, or no voice at all (Gilligan, 1982). If conventional feminine goodness means being voiceless as well as selfless, how can women learn to speak up and protect themselves?

Recently data has suggested that women over forty-five years of age are a relatively new category of infected women (Gordon, & Thompson, 1995). Women who become infected during mid-life may not have been aware of their partner's sex or drug activities. Husbands or partners of these women who grew up knowing that homosexuality was taboo may be experimenting sexually with men and putting these women at risk through unprotected sex. In a recent study from project AWARE, data confirmed that women, who think that they are in a mutually monogamous relationship, but are not, might be at greater risk than are women who are not monogamous.

During middle age, women have failed to protect themselves or even acknowledge that protection is necessary especially if they are post-menopausal or have had surgery to protect them from becoming pregnant (CDC, 1995). Many women reaching mid-life may think they are not at risk for the virus since older people have rarely been included on the list of people "at risk." In the following account, Carol, a forty-five-year-old infected woman spoke of years of not feeling well. She went from physician to physician who insisted her depression was a result of "empty nest." Her doctors continued to prescribe Valium or Xanax to help her cope with her neurotic behavior (Goldstein & Manlow, 1998):

> In retrospect I now realize I had harbored suspicions regarding my husband's fidelity since the earlier period when I had coerced Michael into couple's counseling. We had discussed, if infrequently, the threat AIDS posed to sexually active adults who didn't protect themselves. But we never discussed the issues that had prompted me to question him that night. I was terrified to sunder the secrets that lay between our sheets; I buried my doubts along with the opportunity to breathe some honesty into our

> relationship. If I asked the questions, I would have to deal with the answers; I was afraid to jeopardize our marriage further. I loved my husband but resented his inability to empathize with my fears, resented his overt dismissal of my disgust with the medical establishment (p. 414).

If women grow and develop through being connected, then fear of abandonment is understandable. Carol did not confront her husband's suspected unfaithfulness. Perhaps, she was fearful of abandonment or loss of relationship. In another account, a care provider of infected women expressed how women have told her that they are fearful that no one else but their abusive partner will want them once infected. "A violent relationship is better than no relationship at all" (Zierler, 1998, p214). Sarah, an HIV positive woman in Troubling the Angels, (Lather & Smithies, 1997) wrote:

> I went out with a guy who was HIV positive. I got it from him; we weren't living together then. I knew him ten years ago and we were lovers for a brief time and it was really wonderful. It was a surprise to both of us that we fell in love again and at that point he didn't know he was HIV positive. But his lover had died of it and he had never been tested. So I told him I wanted him tested and then we knew that he had it and we were sort of careful and sort of not careful. Sometimes we would use rubbers and other times we would not, but we would always use withdrawal. But I got it anyway and that was a challenge for the relationship. We decided to live together and went through some stuff after that, but it didn't change. I never felt that way in my life and I still feel that way. He is a wonderful person. It's a good relationship and I feel really lucky (p. 107).

It is obvious that many women are active participants in sexual decisions. Studies suggest that there is a positive relationship between unsafe sex and emotional and social dependence on men (Sobo, 1995). Because condom use is associated with infidelity and deceptive behavior, using them possibly implies that partners are not truly connected (Pivnick, 1993). Admitting that your partner is having other sex partners, regardless of whether they are men or women, is probably emotionally painful. Condom use is avoided because such a barrier interferes with sexual intimacy and a loving trusting relationship.

Condom use implies that someone in the relationship is having another sex partner or partners. This lack of connection in the relationship may cause an obstacle to growth and development for the female.

Gilligan described what she called "a different voice" in the female's ability to reason about moral dilemma. Reasoning in this different voice requires feelings and paying attention to the quality of life. Maybe some women become infected with this disease knowing their partners are putting them at risk Maybe the relationship, the importance of intimate connection and the ethic of care for their partner's feelings is more important than life itself.

I recall fifty-one year-old Elizabeth who found out she was HIV positive when she entered the penal system for sales of heroin and cocaine. She self-disclosed that she never sold drugs to kids and that she became infected through unprotected sex with her boyfriend. She said she asked him to use a condom because she knew he "shared needles." "I'm not infected," he replied. She believed him. "I needed the love and closeness" she told me. I understand Elizabeth and all the women who have the need for intimacy and connection to their partners. I do not understand the notion of sharing the virus with a partner as part of the connection desired by women. Is it an issue of female socialization, self-esteem, women's development, socioeconomics, domestic violence or some postmodern theme yet to be discovered? How can we help women from dying of a disease that is preventable? We must help women to understand that being connected to self is primary and then, connection to others is possible.

Will there be angels

When I open the door

Walk through

To the other side

Will they take my hand?

Walk beside me in the light?

Will I close my eyes

And dream of angels?

Will they take me in their arms?

Will there be angels? (Chalgren, 1994)

Kristeva's Theory of Abjection

The Union of AIDS and Abjection

The Ryan White Care Act became Public Law 101-381 in 1990. This law authorizes the use of federal dollars to provide care and services to infected individuals and their families. In responding to our nations response to the AIDS epidemic Senator Jesse Helms threatened not to re-authorize the Ryan White Care Act in 1995. He referred to AIDS as a gay man's disease that was spread by "disgusting, deliberate and revolting behavior" (New York Times, 1995). During that same year our military recommended that HIV positive individuals be released from command. And, the revised Ryan White Care Act strongly encourages antibody testing on all prenatal women. In other words

Ryan White funding for states not testing all prenatal women, regardless of their HIV risk, is in jeopardy (Journal of American Medical Association, 1995).

The above policies and recommendations add to the negativity surrounding AIDS discourse. Such discourse serves to abject individuals that need resources and services. These policies serve to drive individuals underground because they fear the prejudice and discrimination society develops when they learn of an individual who is infected. However, this discourse also validates the needs of dominant society not to feel that they are at risk for such body pollution. If most of the AIDS cases are in homosexual men, injection drug users, and minority women, then those people in power, and their wives, daughters, and heterosexual sons do not need to worry. Social order is contained by such thought.

The succeeding body of literature explores Kristeva's theory of abjection. In her book, first published in France, Powers of Horror: An Essay on Abjection (1982) Kristeva explained abjection. Abjection is a ubiquitous method through which we create individual, social and political order. This process allows us to individuate ourselves from others on a personal and collective level. Although power relations existed long before AIDS was born, it is yet another reason to exclude and categorize the uninfected as uncontaminated.

Kristeva spoke of *exclusionary rituals* by which we make sense out of the social order of society. Zivi (1998) described Kristeva's three stages of abjection:

> 1) the identification or coding of that which is threatening to order (the abject); 2) mechanisms for separations and divisions that function to jettison the abject (abjection); and 3) the production of a realm of beings or "objects" which are abased (objected). (p.35)

In other words, AIDS represents the twentieth century categorization of fear, disease, exclusion and identification. The conceptualization of AIDS is congruent with the conceptualization of abjection.

As previously defined, abjection is a process of isolating that which threatens the individual and the universe. In the past public health has been responsible for separating people with diseases like small pox and tuberculosis from the healthy. In order to protect the general public, those who are sources of infection are not only stigmatized but also isolated and sometimes, as was in the case of tuberculosis, quarantined. Many individuals might even contend that their rights were infringed upon in the name of public health. These practices often labeled the afflicted as guilty, immoral, and impure. Social order was thus maintained and the identity of those not infected maintained a category of strength and power

In our society continued abjections are necessary to keep the abject in a state of marginality. The exclusionary rituals are necessary for the survival of society. Although abjection is historical, as in the case of communicable disease, it is a ritual or taboo intended by the individual and society to keep away that, which threatens the social order. These boundaries between the pure and impure are often associated with food, bodily fluids, waste and other forms of pollution. Purification rituals serve as a function to divide groups and exclude filth, maintaining the power of those who are clean and in control.

The Mystery of Surveillance

HIV and AIDS are reportable diseases in thirty-one states throughout the US, including Oklahoma. This means when a person's HIV antibody test is positive their name is reported to the state health department. Their name, demographic information, sexual orientation, risk factor and other specific information are recorded in a confidential database. Once immune systems deteriorate and these individuals digress to AIDS, their names are taken out of the HIV database and recorded in the AIDS database.

The rituals of surveillance track the population that is infected and categorizes them according to age, races, sexual orientation, drug using behaviors, and sexual practices. The structure (e.g. the health department) is remunerated from the federal government for such surveillance activity and the health department publishes the categories of infected people. AIDS is the abject and surveillance constructs borders between the pure and infected. AIDS is the abject because it threatens the unity and identity of the individual and social order (Zivi, 1998). Callen (1989), a noted activist, described the visceral aspects of AIDS:

> AIDS is about . . . loss of control – control of one's bowels and bladder, one's arms or legs, ones life . . . AIDS is the moment to moment management of uncertainty. It's a roller coaster without a seat belt. Once this ride begins, there is never a moment when the rush of events that swirl around you stops long enough for you to get your bearings. AIDS is like motion sickness except you realize that you'll never stop moving; one way or another, you'll be dealing with AIDS for the rest of your life. (pg. 975)

The above citation describes the abased or the abjected. The abjected have been categorized as homosexuals, hookers and heroin users, unclean and impure. Categorized unlike us, these other people have patterns of behavior that cause fear, dirt and pollution. When AIDS is conceptualized within this context, purified heterosexuality, designed to procreate and secure social order, is not at-risk for disease. As Trechler (1992) suggested "AIDS and death is the price one pays for anal intercourse and for violation of natural difference" (p. 26).

The Exception to Abjection

Ryan White was a young boy when he contracted HIV through a blood transfusion. I have heard his mother Jeanie tell his story many times, and am familiar with the Ryan White clinic at the Oklahoma Osteopathic Hospital in Tulsa, where medical professionals provide treatment to infected persons. At first, Ryan was ridiculed and ostracized from his friends and schoolmates. He was teased, excluded from school, and the community in which he lived which threatened the fabric of his family's life-style. Essentially, he was coded or categorized as abject.

However, by the time of Ryan's death in 1990, he had a national law named in his honor. Michael Jackson visited Ryan in his final hours, and Elton John sang at his funeral. Ryan remains a hero and represents the innocent victims of this pandemic. Is he an icon because he was infected through a medical procedure? Is it because he was not a homosexual, hooker or heroine user? Is it because Ryan was clean and proper; and the need to code him as abject was not necessary? Is it because Ryan didn't threaten the social order with behaviors that make society uncomfortable? Is Ryan an example of the type of journalism used to taint society's perspective? Is it possible that Ryan didn't pose a threat to the moral fabric of the powerful majority that feels forced to abject to maintain individuality and social order? The Ryan White story serves as a metaphor for hope that humanity and society will learn to celebrate diversity and reject abjection for the exclusionary and marginalizing practice that it represents. Ryan's mother travels internationally hoping his story will deter discriminatory practice against people living with HIV and AIDS.

The Myth of La Loba

I believe archetypal stories can inspire people to take control of their lives just like theorists believe that their models prevent HIV, and mothers of infected sons believe that their stories dissuade discrimination. Many counselors and therapists have embraced the notion of archetypal psychology to help women discover their innate feelings and to encourage them to reconnect with their inner selves. Carl Jung was a noted psychoanalyst and disciple of Sigmund Freud. Jung (1961) stated that archetypes appear in folk culture and myths and that "these myths are the first and foremost psychic phenomena that reveal the nature of the soul" (pg. 6). Jungian therapists believe that concepts gleamed from myths and simple stories can unite humankind with wisdom about the past that may have set the stage for their current actions and behavior. Once individuals are able to understand intergenerational dysfunction they may be able to work on issues that are preventing them from moving forward in their lives. More specifically, women who are struggling with alcohol and drug addiction or who have lost their souls to prostitution can find a renewed hope for strength and courage.

As women listen to stories of women who represent strength, dignity and a renewed sense of hope for a brighter future, they search for their lost uniqueness. This uniqueness is sometimes hidden in a world of chronic addiction, prostitution, HIV disease and the untamed instincts of all that long for the freedom to explore and discover self. The myth of La Loba is one such story that women in a San Francisco recovery facility process to find inner strength, soul, dignity and reconnection. SAGE (Standing Against Global Exploitation) was founded in 1995 by a recovering prostitute who has turned her life around and now helps other women, many of whom are HIV challenged to recapture their lost sense of self and dignity (Foglino, 1998). The story of La Loba is a symbol of the wild woman archetype described by Jungian analysts (Estes, 1992).

The wild woman archetype relies on the symbol of the wolf for its lust for freedom and uninterrupted rhythms. The wild woman visits us through events, stories and night dreams. Bone people bring the dead back to life restoring both humans and animals. La Loba is one such metaphorical story depicting a bone woman who searches for dead souls and restores them back to humanity.

There is a myth that in the desert the spirit of women meets the spirit of wolves. La Loba is a creature who has both human and wolf-like characteristics. She is known to crackle and crow, generally making more animal than human sounds. Some say she lives in the desert of Arizona. The sole work of La Loba is the gathering of bones, especially, wolf bones. La Loba is called by many names, the gatherer, the bone woman and the wolf woman. She is known to collect the bones of those who are in danger of being lost to the world.

La Loba's cave is filled with bones of all matter of desert creatures like wolves, rattlesnakes, and crow. But, her specialty is said to be the gathering of wolf bones. When she has assembled and put together an entire skeleton, she sits by the fire and contemplates which song to sing. When she is certain, she stands over the creature raising her arms and sings a special hymn. And that is when the creature begins to grow hair and breathe life. As La Loba sings more deeply, the wolf opens its eyes and begins to move, and then runs into the sunset. The wolf is then suddenly transformed into a laughing woman with long hair of different colored streaks. It is then, that the spirit of the wild woman metaphorically meets the spirit of the wolf.

The bones in this story represent the indestructible force that in archetypal psychology represent the soul that cannot be destroyed. If you are lost to abuse or oppression, La Loba may take a liking to you and breathe new life into your soul helping you to be free. The story demonstrates the power of the human spirit and the potent constitution of the soul. Yes, the soul can be damaged or spoiled by postmodern culture that is abundant with drugs and diseases that are unable to be cured. However, women who become connected to their animal side can begin to understand their quest for freedom and need for individuality.

The story of La Loba is an example of an archetype that restores the human soul. The animal portion of the psyche or the desire to be free is possessed within each woman, and her instinctual nature must be recovered and restored for the soul to be truly free. When the instinctual nature is lost to oppression or gender inequality, boundaries become blurred and the soul can become lost to unhealthy behaviors. Through strong archetypes, like La Loba, women who are disconnected can rediscover themselves, allowing them to transcend constricting roles. Women are then able to persist in their struggle to achieve equality and to find their heroine within.

The wild woman archetype visits me often through dreams, stories and unbridled passions. As we run like wolves, she encourages me to have defined boundaries and to disseminate knowledge and power to women less fortunate than me.

Summary

I have presented a variety of theoretical approaches to the HIV prevention literature for women. Much of the literature has been developed for gay men and is assumed, incorrectly to be reliable to prevent disease in women. As the number of cases of HIV infection begins to rise in women, researchers are realizing that women need prevention messages that reflect the issues that are significant to females. I have deconstructed current models of prevention and presented the evaluation research pertaining to their efficacy. I have blended the poetry and stories of women who are infected with HIV into the literature review so that infected women can be represented with reflexivity and without pity. An archetypal story has been used to illustrate the power of the female soul, and how stories can be used to help women find strength and a path to the recovery process.

Contributors to the literature eluded that gender asymmetry, the drug pandemic, dysfunction family life including incest and abuses are all barriers to prevention. In addition, the theory of abjection has crystallized the need for those in control to maintain social order by using the power of AIDS discourse to further isolate the infected. Researchers are looking at how women develop, and how the need for connection and relationship is often paramount in the lives of women. Yet much of the prevention models are based on an individualistic theory of fear of disease.

However, women have lived in fear from the beginning of time. Aren't women careful to not walk alone at night for fear of being assaulted? Women always have feared the effects of unwanted pregnancy, childbirth, sexually transmitted infection and the price of losing men. Marginalized women are often fearful of the welfare system, and that their children will be taken to foster care. Women have always lived with fears, and so it is not surprising that the current HIV prevention models have had little impact on the rate of infection.

These strands of literatures mesh together for several reasons. First, they deconstruct agency through a critical feminist and poststructural perspective by exposing male ethnocentricity and the need for categorization. In other words, community-based organizations, CDC, and state health departments have taught said prevention models without even questioning their lack of efficacy for women. Second, women's developmental theory has typified a need for prevention researchers to reevaluate and redesign prevention education for women that is inclusive of their needs for connection and relationship. Third, the literature has explored the crack epidemic's debasement of women, and how this further negates negotiation skills for money and safer sex within the sex for drugs population. And, finally, this review challenges society's quest for social order by exposing alienating practices and AIDS discourse that have been ineffective in curtailing HIV disease in women.

CHAPTER III

METHODOLOGY

Introduction

In this chapter the researcher outlines the methodological and theoretical frameworks used to analyze and interpret the narratives of women living with Human Immunodeficiency Virus and Acquired Immunodeficiency Syndrome.

Rationale for a Qualitative Study

I came to qualitative research as a way of working with women challenged by HIV disease. I have been working for a government agency that uses statistical data to analyze the trends of the disease and to distribute prevention funding. This impersonal form of data collection strips away context; it reduces the information to numbers and does not require our clients to share their perceptions of disease or their experience with barriers to prevention. My willingness as a therapist and educator to change current prevention principles based on women's personal stories has been a continuing journey. This journey has encouraged women with little individual or societal voice to talk back when traditionally they have been silenced (Hooks, 1989).

Qualitative research was a natural fit for me. I came to the AIDS epidemic eager to learn and to defend our government's position on HIV prevention education. Soon I learned of the Tuskegee syphilis research experiment, and of our public health system's surveillance reporting requirements for HIV and AIDS. How were the Tuskegee experiments different from the experiments performed at Auschwitz or Bergen Belsum? How similar are we to the German people whom silently inhaled burnt flesh, when we are silent about agency that abjects those who need help the most? Is our current HIV/AIDS surveillance system a form of sexual McCarthyism?

A Critique of Positivism

Recently, I was at a training sponsored by Centers for Disease Control and the American Psychology Association for behavioral scientists. Out of twenty-two invited therapists only three of us had not yet earned doctoral degrees. The other two doctoral candidates were conducting quantitative dissertation studies. I sensed that most of the other behavioral scientists believed in *truth* that could only be justified by quantitative rigor, such as validity and reliability. I know this because the belief in quantitative analysis was articulated, and as a group we explored the ridiculous rigidity of the meaning of truth to the positivistic researcher. Many notable researchers who had published in prestigious scientific journals presented the latest literature in HIV prevention intervention.

All of the literature presented was empirical data that enforced the idea of condom use to prevent disease. The interventions were designed to help people recognize that they were susceptible to HIV and that they could do something about it. Most of these studies were randomized and controlled. At the end of a several week group intervention, the people who received the intervention had fewer sex partners and used condoms more frequently when compared to the control group.

The researchers had conducted lengthy outcome evaluative studies to *scientifically* prove that their interventions were a sound method for the promotion of condom use, and ultimately disease prevention. One could infer from the data that when individuals accessed certain educative interactive sessions that they then, had the efficacy needed to use, or have their partner use a condom.

I questioned these methods. What was the context of these interventions? Were the participants' men or women? Had the participants engaged in drug using activities, and if they did, what kind of drug was used? Did the participants have a history of chronic physical, emotional or sexual abuse? What encouraged the participants to partake in the intervention education? Were the researchers sensitive to gender issues, and were women included in the study? How had their disconnection to the participants impacted their studies? Why did the intervention appear to be effective to these positivistic researchers?

A Qualitative and Postpostivistic Design

Qualitative postpositive research assumes that multiple realities exist, and there is a collapse of grand theory known as the metanarrative. There is no single truth but multiple truths driven by diverse experiences and perceptions (Crabtree & Miller, 1992). Qualitative data cannot be described or understood in terms of separate independent and dependent variables; rather data is interrelated and clustered to construct a pattern of truths. It is these patterns that must be sought out for the sake of human understanding and egalitarianism (Guba & Lincoln, 1981).

Deconstruction as a Postmodern Notion

Deconstruction focuses on the binary oppositions within a text (Powell, 1998). In the case of HIV prevention one binary is noted as central, natural, and privileged (e.g. men) while the other binary is repressed and marginalized (e.g. women). This study contains postmodern strands because it utilized the technique of deconstruction to expose the underlying meanings and perceptions that had structured prevention for women. Deconstruction is an integral piece of postmodern design and it allowed me to see the modernist ideas that are not working theoretically or practically. By exposing the patriarchy involved in HIV prevention, I have elucidated the need for a feminist, neo-Marxist, poststructural and postmodern research strategy (Farganis, 1994).

When I deconstruct the continued debate at Oklahoma State University, CDC, the American Psychological Association and probably other universities over qualitative approaches versus positivistic research methods, I often ask myself "where lies the truth in science?" Many scientists think quantitative analysis is more rational and truthful. Rationalistic approaches are based on the assumptions that phenomena exist in one reality that can be controlled through the environment and by manipulation of variables. The research hypothesis is defined at the beginning of the investigation and findings from these studies are generalized to larger populations (Guba & Lincoln, 1981). The researcher is disconnected from the participants she is studying to reach the ultimate objective truth.

Qualitative Research and the Constructivist Paradigm

Crabtree and Miller (1992) used the metaphor of "Shiva's Circle" to demonstrate how the qualitative researcher informs epistemology by constructivism. Shiva, the androgynous Hindu, Lord of the Dance and of Death enters the circle much like a qualitative researcher, "performing an ongoing iterative dance of discovery and interpretation" (p. 11). Qualitative researchers must be rooted to the context and part of and separate from the dance. No one truth and no objective reality exist to the qualitative researcher. Reality becomes what the actor thinks, feels, and says that it is (Dooly, 1995).

Guba and Lincoln (1989) asserted that qualitative researchers are linked to those they are inquiring about through the findings of the investigation. The inquiry itself is a literal creation of the research process – a subjective epistemology. In retrospect, the forthcoming analysis is qualitatively hermeneutic because it involved a continued dialectic, and iteration of life stories, events and member checks for the emergence and construction of a female driven prevention model (Guba & Lincoln, 1989). It was the interaction between myself and the research participants that created the data that emerged.

A Qualitative Case Study

I chose the case study design because its inquiry is concerned with discovering new information, insights, and interpretations. According to Merriam (1988) "The qualitative case study in education is useful in presenting basic ideas where little research has been conducted" (p. 27).

Juxtaposed to the experimental design, field research is sometimes referred to as qualitative research. Field researchers are personally and directly involved with the participants they are working with. The goal of qualitative research is to "generate holistic and realistic descriptions. The field is viewed through the experimentally engaged and perceptually limited lens of the researcher using a qualitative filter" (Crabtree & Miller, 1992, p. 5). Field research does not have a step-by-step procedure that must be followed. Rather, the data collection methods, sampling procedures and analysis are used to create an emerging research method that often takes the form of a case study (Merriam, 1988).

Howard Baker (1970), a fervent follower of the Chicago School wrote:

> To understand individuals behaviour, (sic) we must know how he (sic) perceives the situation, the obstacles he believed he had to face, the alternatives he saw opening to him. We cannot understand the effects of the range of possibilities, delinquent subcultures, social norms and other explanations of behaviour which are commonly invoked, unless we consider them from the actor's point of view. (p. 64)

I have chosen the case study to illuminate the barriers to prevention, and to give women an opportunity to use their infection as a voice of social activism. I have explored a relatively uncharted issue, and through the women's narratives, developed a model for feminist action. Women living with this disease represent an important heuristic because they have identified deficiencies in patriarchal prevention messages, and demonstrated the need for additional research between individual lives and societal expectations.

The incidence of HIV/AIDS seroprevalence rates is growing rapidly in the female population nationwide. In order to prevent further transmission we must recognize that prevention education must be tailored to fit the diversity within the female population. Seroprevalence data does not speak to the barriers to prevention, nor does it tell us why prevention education does not appear to be effective. The case study is a kind of naturalistic, qualitative inquiry and may be a practical approach for finding out information that quantitative methods do not address. A qualitative case study assumes that multiple realities exist. The case study design was chosen because this investigation was concerned with discovering new information, insights, and interpretations. Women living with HIV/AIDS have a disease that binds them together as a distinct group of people. Thus, women who participated in this study represent a distinct group whose views form the focus of this prevention paradigm. The case study method used for this dissertation reflects a variety of experiences of a diverse group of women bound together living with a life threatening disease.

Qualitative Data Collection

For this study I interviewed ten women, three times, for a period of one to three hours. Most of the interviews took place at the home of the participant. However, a few interviews took place in state correctional facilities and one set of interviews took place in an AIDS Hospice. Particulars of the interviews are discussed in the interview section. In addition, a focus group was conducted so that the participants could work together on HIV prevention strategies for women not currently infected. The specifics are discussed in the focus group section.

All of the interviews were recorded by a cassette player, and I also took field notes. I anticipated that the note taking would serve as a back up for the recordings. The tape recordings proved to be the primary source of information for providing precision in the responses used for the data analysis found in Chapter IV. The interviews were of conversational nature and the exact words of the participants were captured on the tape. I personally conducted all of the qualitative data collection.

My approach to postpositivist, praxis-based research draws on themes from feminist theory, specifically multiplicity of research methods and the desire to put the epistemological construction of gender at the heart of this inquiry. Reinharz (1992) described multifaceted information:

> Feminists choose multiple methods for technical reasons, similar to mainstream researchers, and for practical feminist concerns that reflect intellectual emotional, and political commitments. Feminist descriptions of multimethod research express the commitment to thoroughness, the desire to be open-ended, and to take risks. Multiple methods enable feminist researchers to link past and present, data gathering and action, and individual behavior with social frameworks. In addition feminist researchers use multiple methods because of changes that occur to them and others in a project of long duration. (p. 197)

I utilized individual interviews, a focus group interview, numerous member checks, and continued to collect data until new information became redundant to obtain credible data used for this qualitative case study. The data was collected from September of 1998 through July 1999.

Dialogic interactions are considered qualitative because instead of reporting data in numerical form, case studies use literary techniques to describe, elicit images and analyze situations by documenting quotes from the interviews. Women living with HIV/AIDS have a story to tell I call narratives. From the participants' narratives I gained awareness of how to facilitate HIV prevention for uninfected women and how social conditions could be improved for the health and well being of all women.

The purpose of this study was to explore and explain the realities of women's lives infected with HIV/AIDS and to identify the barriers to prevention they experienced. The point of the narratives, and our collaborative analysis of them, is to show that specific experiences led to HIV disease and to identify formal strategies used to prevent the uninfected from becoming infected. HIV intervention strategies for women not currently infected are an outcome of the women's narratives that emerged, and formed a prevention model for those not currently impacted by the virus. The construction of this model places attention from the knower to the known (Baudrillard, 1981). In other words, instead of academicians and HIV prevention theorists constructing theory, women who know from experience have contributed to a form of poststructural thought and interpretation of prevention education. Additionally, through semi-structured interviews and dialogue, the participants gained an opportunity to speak their minds about their lives, and their needs, and tell of their experiences of abjection through agency.

The prevention paradigm that will emerge in chapter four presents a feminist model that can be used for HIV prevention education. The prevention paradigm is a product of the construction of meaning, developed through negotiation and mild confrontation with the research participants. This model is an example of emancipatory thought and liberatory praxis because the participants are not objects, rather active researchers who want to help themselves and other women to understand and change their situations (Lather, 1991).

> There, in the nexus of that dialect, lies the opportunity to create reciprocal, dialogic research designs which both lead to self-reflection and provide a forum to test the usefulness, the resonance, of conceptual and theoretical formulations. (Lather, 1991, p. 61)

The Participants

The participants created the boundaries of this investigation and provided a lens for the reader to examine the world of women living with HIV disease. Moreover, this study was guided by the belief that the participants engaged in this study were truthful human beings interested in contributing to the HIV prevention education of other women. Their participation was strictly voluntary, and I believe they participated as a form of Tikkun Olam or the altruistic desire to help in the repair of the world.

The women in this study share commonalties and are ethnically diverse. Two women are African American, two are from Native American ancestry, five are Anglo-American, and one woman is European American. The women were between the ages of twenty-nine and fifty-two years of age. Four of the women injected drugs and all of the women became infected through unprotected heterosexual intercourse. Participants in this study were living in the state of Oklahoma but resided within three different counties.

Signed consent forms were obtained and informed consent was explained orally. Participants were told several times that participation was voluntary and they would have an opportunity to tell their stories and hopefully benefit their own lives as well as the lives of other women. I told the participants that I felt privileged for having the opportunity to work with them, and I hoped we would learn together about constructing an HIV prevention design that had the capability to prevent disease in others. I hoped to establish an egalitarian relationship and stressed that I was interested in their life experiences. Care and attention were given to entry, reciprocity, ethics and confidentiality.

The Interviews or the Inter Views

Where language and naming are power,
silence is oppression, is violence. (Rich,1977)

All of the interviews were conversations with women living with HIV disease or AIDS. Case managers and social workers working in community-based organizations told their clients they were free to call me if they were interested in telling their story and developing prevention strategies for women not currently infected. From the beginning of the research I explained that participation was strictly voluntary and that my interests were to understand why women were becoming infected. In addition I wanted to provide an accurate portrayal of grass-roots prevention notions from a population that tended to be overlooked or misrepresented. I told the participants that I was interested in hearing about their life experiences. Unlike in quantitative research design, the participants were self-selected. My availability and visibility in the AIDS community helped in enrolling participants for the study.

My intention was to interfere as little as possible in the creation of the narrative, but to mildly confront when incongruity was perceived during the interview. Three groups of semi-structured interviews and a focus group interview were conducted. The first group of questions focused on breaking the ice, getting to know you, and a conversation about childhood experiences. During this round of conversation, relationships with our parents and loved ones as a topic were introduced (see Appendix A). The second grouping of queries centered on life stories leading up to infection (see Appendix B). I worked with the women to establish a time line that was shaped by key life events. In the final interview, the dialogue was more focused on the barriers to prevention and what women not currently infected could do to prevent disease (see Appendix C). Like all of our lives, their lives were filled with contradictions. I believe as Geertz (1973) did "it is not as fatal as is sounds, for in fact . . . it is not necessary to know everything in order to understand something" (p. 20).

A client-centered approach to the interviews was employed, a method I was familiar with from prior training as a licensed therapist (LPC), nationally certified alcohol and drug counselor (NCADC) and certified criminal justice specialist (CCJS). The client-centered approach called for a relationship consisting of positive regard, unconditional acceptance, support and empathy. I knew that my experience as a therapist would help me to be an effective interviewer and help me to recognize countertransference.

Many feminist researchers use semi-structured interviewing as a way of hearing and understanding different voices from their participants (Belenky, 1978; Gilligan, 1982). Open-ended questions were framed so participants could not answer with a yes or no, but instead had to use explanatory phrases. This technique is often used in therapy and encourages the revealing of experiences and perspectives (Rogers, 1969). During the interviews I would use literary prompts, such as, "and then what happened?" If I wanted more information I would be silent and encourage conversation through eye contact and body language, such as looking into their eyes and moving my head up and down. Rubin and Rubin (1995) proposed the semi-structured as unit of conversation and collaboration:

> Feminist researchers emphasize the need for interviewers to avoid dominating the interview. They argue that a more open, loosely research methodology is necessary to learn about women, to capture their words, their concepts, and the importance they place on the events in the world. An interview, the feminists said, should not involve a scientific instrument

> sterilely applied to a passive object, but should resemble normal conversation in which the interviewee influences the exchanges. (p. 37)

There was a major difference in conducting these interviews and interviewing clients I have seen in therapy. As a licensed clinician I was trained to only self-disclose when it could be viewed as beneficial for the transference process. During these interviews or perhaps, dialogue, I self-disclosed on a regular basis to make the interaction more realistic and conversational. I wanted the women to know that although I am not infected, I remain very much affected by HIV disease. Although I was hesitant to compare my own history with the challenges of women living with HIV disease, I wanted them to know my story, and how reflections of the holocaust molded my life and shaped my destiny. I wanted them to know that my family survived Nazi persecution so that they may live to tell their story of marginalization and abjection. I have always understood that the intergenerational effects of the holocaust remain an integral part of who I am. It has provided me with clarity, empathy, insight and strength. These characteristics were used during interviews to process information, to illuminate areas of strength in the participants and to acknowledge the wounds they experienced.

I drew from my personal experiences as a therapist working with HIV/AIDS patients and CDC trained Disease Intervention Specialist to develop the interview questions. In addition, dissertation committee members contributed insight about what questions needed to be explored. My experiences in HIV/AIDS enabled me to have an understanding of what information was needed. Reinharz (1991) refers to feminist researchers who adopt this methodological standpoint as researchers who "draw on a new epistemology of insiderness" (p. 260). Life and work are intertwined, and many feminist researchers developed this rich link and the product has been their life work (Millman, 1980; Rich, 1976; Theodore, 1986). "Starting from the female experience" is a postmodern notion that developed as a reaction to positivism and androcentic social science (Reinharz, 1991). Commenting on the absence of voice and representation Catharine Mackinnon (1982,) said,

> we need a woman's point of view that criticizes all the ways we have been created by being excluded and kept down but that also claims the validity of our own experience. (p. 142)

From my own experience I saw that our national foundation for HIV prevention was paternalistic. Perhaps, this inadequacy and hegemonic pedagogy helped to create the mounting number of new HIV cases in the female population.

My personal qualifications and experiences with HIV/AIDS were disclosed to participants. They understood that my tenure for the HIV/STD service began eight years ago, and that I had worked with infected women, some who had been incarcerated. Some of the participants had heard me speak at conferences or community meetings and knew I was an advocate for social issues and women. Some of the women I vaguely knew from the detoxification facility and women's prison.

I interviewed ten women, three separate times. The interviews lasted from one to three hours and were held mostly in the participant's home. Occasionally a participant would want to explore a new surrounding like the park or my office. I tried to discourage using my office for fear that the official appearance of the health department would intimidate the participants. However, it appeared to have the opposite effect. I think all the postmodern posters, inside my walls, depicting gay and lesbian lifestyle, and people injecting drugs made the women see that I was a person who respected individuality and alternative life style. They wanted to come to my office, as I wanted to go to their homes. They wanted to know who I was, as I wanted to know who they were. They wanted a relationship, a friend, someone who understood they were not abject or a social pariah.

The women were encouraged to choose a different first name as part of the coding procedure to ensure confidentiality of information. Their actual names were cross referenced with letters from the alphabet and locked in a safe deposit box with the tape recordings, coded transcripts and contact summary forms. However, all of the participants insisted on using their own first name. I believe this speaks to their convictions to be heard, and for some of the women this was their first opportunity to express their thoughts on how one makes sense of such a disease. All first round interviews were tape-recorded, transcribed and coded. Second and third round taped interviews were transferred to contact summary forms to avoid the cost and time of transcription. Contact summary forms allowed lengthy documents to be appropriately clarified and summarized. In addition, I attached each contact form to the tape recording and kept them in a locked box. Document summary forms (see Appendix D) were coded for analysis and rapid retrieval of themes, categories and information pertaining to the study (Miles & Huberman, 1992). In addition to the contact summary forms, I wrote field memos of pertinent events that were happening during the interviews and notes concerning nonverbal behavior and mannerisms of the participants. Miles and Huberman (1992) stated their perspective on transcription:

> Some transcripts can be thick, but many can, and probably must be thin. And transcriptions often erase the context along with some crucial nonverbal data. What you see in a transcription is inescapably selective. A critical theorist sees different things than a deconstructivist or a symbolic interactionist does. The instrument, too, will selectively determine much of

> the data collected. Informants themselves are selective, too, sometimes deliberately, sometimes unwittingly. They may gloss over important parts of their behaviors and perceptions, and the researcher may not be aware of this. (p. 56)

Obviously, it was not possible to capture every non-verbal and significant occurrence that transpired. However, Spradley (1980) proposed one such framework that I incorporated into this research design. Spradley recommended that field notes describe the physical places where the interviews occurred, the actions of the participants during the interview, the goal of the interview and the feelings that were expressed. Similarly, Bogdan and Biklen (1982) suggested that researchers document all of their reflections of their respective interviews and record any ethical dilemmas or conflicts. For example, during some of the interviews it was obvious that sometimes women engaged in sexual intercourse without condom use. As a therapist for OSDH, I am supposed to council of this danger and quote the house bill that describes the legal penalty for knowingly and intentionally infecting others. At first I was cautious not to admonish the participants for this behavior for fear they would no longer trust me and not tell me relevant information. In other words I experienced countertransference and found myself processing this issue, confidentially, with another therapist. What I learned was to relinquish my role and training as a health department employee, and try to hear what the participant was telling me through another lens. As a result of this issue, I decided not to write the actual field notes in the field, but while the tape was recording I often jotted down my feelings and experiences with countertransference. The paramount issue-surrounding field notes, interviews, and research for me was not to inflict harm on any of the participants in this project.

Lincoln and Guba (1989) argued that the forms of harm include not only lack of confidentiality, but also the loss of dignity and self-esteem that participants felt if they thought they had been duped or used. I was extremely cognizant to paraphrase statements so as to understand all of the participant's contextual knowledge. To the qualitative researcher this is called member checks. This technique served as validation that I cared enough for the participant to let her know that I was actively listening to her every word, and checking out assumptions if I was unclear about an issue. I was respectful and empathic, and mildly confrontive when I heard contradictory statements.

The Focus Group Interview

As already mentioned, a focus group was conducted. Most of the women were unfamiliar with each other. During the focus group interview, emancipatory theory building was negotiated between the women and myself. The open environment facilitated asking focused questions that encouraged discussion and the expression of differing opinions and points of view (see Appendix E). The focus group offered an opportunity for the participants to talk about how they perceived barriers to prevention. It gave them an opportunity to have their ideas and words form a framework for the restructuring of HIV prevention for women.

Initially, the focus group was planned to satisfy the notion of data triangulation. However, the women articulated that they wanted to meet each other. First, women in the study expressed the desire to come together as a celebration of life and accomplishment. Second, the women wanted to hear of each other's treatments and if anyone knew of any new medication on the horizon. Third, the group came to hear the congruities and incongruities of the data. Professors reading this probably question how women inexperienced at looking at data could actually understand or make sense of it. Here lies the beauty of postmodern and/or poststructural theory. Its emphasis on the search for a new presentation or representation of what the data means to the un-represented is most meaningful, and necessary for emancipatory theory building.

Although all the women voiced a desire to attend the focus group, only seven were able to attend. A few women were physically too ill to make the journey. An AIDS service organization was gracious in supplying the room where we were able to gather, eat lunch and work together to negotiate meaning, learn from each other and gradually construct a prevention model for women.

Critical Feminism

> Feminist theory is neither subjective nor objective, neither relativist nor absolutist: it occupies the middle ground excluded by oppositional categories . . . Absolutism and relativism both ignore the concrete functioning of power relations and the necessity of occupying a position . . (Grosz, 1988)

According to Elias and Merriam (1995) feminist theory incorporates numerous lenses that attempt to explain women's oppression. Several fundamental principles relating to feminist theory grew out of critical theory and vice-versa. First, feminist theorists and critical inquiry challenge the assumption that positivism represents ways of knowing the *Truth* based on empirical knowledge. Second, both theories argue that the ways in which we come to know are value-laden and therefore impact how we do research in the postpositive era (Lather, 1991). Third, some Frankfurt critical theorists (e.g., Habermas) argued that "Marx failed to distinguish carefully enough between knowledge gained from causal analysis and knowledge gained from self-reflection and interaction" (Agger, 1991, p. 110).

Critical theory has origins in the Frankfort school and challenges beliefs, values and human interests to look beyond dominant thought. Critical theory is concerned with the analysis of social conditions and inequality and seeks mutual humanization for the oppressed. Notions about the inequity of racism, classism, and sexism are raised to promote consciousness and dignity. Critical theorists like Antonio Gramsci (Eley, 1984) examined the ways in which dominant groups exercised cultural hegemony over marginalized and disenfranchised populations.

One of the distinctions between critical theory and critical feminism is the notion of action and social change. Critical theorists have sometimes been criticized for their lack of political and ethical involvement needed for transformation of oppressed populations (Collins, 1991). Although critical feminism is connected to critical theory, much feminist research is connected to social change and critical policy questions (Reinharz, 1992).

My critical feminist perspective, and the desire to give women an opportunity to have voice in the development of a prevention paradigm, shaped the neo-Marxist, feminist, postmodern and poststructural methodology used for this study. In addition, the inclusion of feminist voice became an issue of social justice in my personal and professional life. Some individuals have argued that a feminist postmodern perspective is not feasible (Di Stefano, 1990). If feminism represents a permanent partiality then we have acknowledged a hegemonic metanarrative that is modernistic in its discourse. Reinharz (1992) has reminded me that "feminism's mandate for change is as broad as saving life itself. It does this by working to prevent lovers from battering heterosexual, lesbian and bisexual women" (p.175). This prevention paradigm is not intended as a metanarrative. It is intended to help uninfected women from becoming infected with HIV and to help all women realize the potential danger caused by dysfunctional relationships rooted in gender inequality.

Bridging Theory and Practice

As a practicing clinician, I am often amazed at the lack of connection between theory and practice within the therapeutic and academic milieu. The current HIV prevention models are examples of male developed material. Theoretically they are not working because they are individualistic and fear based. Practically, these models lack notions of what is important to women, a gender/power component and the understanding of the need for connection germane to many women.

Theory and practice must be congruent and address problems within the context of gender, age, race, and socioeconomic and religious beliefs. In the case of HIV prevention, overcoming barriers to prevention, means that women can stay safe from disease. Theory and practice must work to inform each other. For example, how do we help the Latina population to stay safe when their religion in many cases, forbids condom use?

Feminists posit that we must hear the voices of those who have been traditionally silenced, or who have not been asked about their relationships and experiences, if we are to collaboratively develop theoretical constructs and praxis that are useful (Lather, 1991; Oakley, 1974; Reinharz, 1992). If knowledge is socially constructed, then, the woman who knows, is an intimate part of what is known.

A Blending of Philosophical Lenses

True to neo-Marxist philosophy, postmodernism, critical feminism, and poststructuralism, some qualitative researchers examine distribution of power, issues of social injustice and inequalities relevant to gender. Neo-Marxism allows for transformative praxis by accepting and listening to those who have been abject and traditionally powerless. The issue of relevance for me from neo-Marxist philosophy are the "purposes of emancipatory knowledge-building and the empowerment of the researched" (Lather, 1991, p. 55). However, true to other neo-Marxist researchers, I did not perceive myself as the interpreter or exposer of false-consciousness. I viewed the participants of this study as active women self-empowered to understand and if they desired, able to change their situations. Meanings were negotiated, constructed and jointly resolved between the research participants and myself. I used an egalitarian approach to the semi-structured interviews by self-disclosing my personal experience with a verbally abusive, and sometimes physically abusive father. This dialogue guided consciousness-raising concerning the historical roots of patriarchy, male violence and gender inequality to engage the women about their lives and the barriers they encountered to effective HIV prevention.

In our exploration for meaningful praxis we ask, "What is to be done and how do we go about doing it?" Postmodernism does not address these questions but seeks to understand cultural differences and how roles are defined by society. A critical feminist lens affords qualitative researchers the luxury of exploring the participants and the systems that benefit from those that have been abjected. The critical feminist moves to an emancipated consciousness by deconstructing history, juxtaposing mechanistic and interpretive design. The models explained in Chapter II are behaviorally driven, male egocentric, and lack the notion of context, critical to feminism, critical theory and postmodernism.

I also drew from the Marxist and radical philosopher Paulo Freire. He promoted a liberatory dialogue and participatory education praxis among oppressed individuals that included women. His notion was to limit the banking experience of depositing knowledge so those students were free to explore and become co-learners and co-teachers with the facilitator. Freire maintained that participatory education empowered and transformed individuals through their own creative style. Individuals were then free to become "beings for themselves" (1970). Freire called the condition of oppression the culture of conscience (Elias & Merriam, 1995). Although Freire has been criticized for sexist language, strong Christianity and for declaration of a one way of reaching oppressed populations, his emphasis on working with individuals in a relationship of equality is worth noting. Freire engaged in liberatory praxis through dialogic communication with his students. However, unlike researchers who may impose theoretical imposition, the forthcoming prevention model is not based solely on my own interpretations of data. I relied on a process of emancipatory-theory building. Emancipatory-theory building is premised on a "deep respect for the intellectual and political capacities of the dispossessed" (Lather, 1991, p. 55).

Similarly, Freire's educational philosophy presupposes action research. His dialogical theory sets the stage for researchers to learn from their participants, and for the participants to engage in political activism. I drew from Freire's principles and set the stage for dialogue and emancipatory praxis where the participants changed and I as a researcher changed as well. Critical feminism and postmodern/poststructural principles formed the theoretical lens I used to dialogue with the participants of this study on issues of relationship, life, and oppression. The dialogue between myself and the participants formed the narratives used in the forthcoming chapters. These narratives were then jointly negotiated to create an HIV prevention theory.

The Poststructual Connection

I defined poststructuralism in Chapter I as not one single theory but interpretative frames reflected through language. Knowledge is socially constructed through language. One is able to identify, deconstruct and critique macrostructures that appear to foster inequality, injustice, and hegemony (Foucault, 1982; Frasier & Nicholson, 1991; Lather, 1991). I used postructuralist methodology to seek not the fixed meaning of the narratives, but interpretations as defined by the women who created such texts.

The women in this study have engaged in dialogue to get to the foundational barriers of HIV prevention. The worth of their efforts within this framework, I believe, is that it offers other women who recognize hegemony in their relationships, a means of understanding the context of their situations. These women are in a position to identify the social structures that have oppressed them, and to take the responsibility for reforming praxis and initiating change. Poststructuralism recognizes that the dominant group (e.g. white men) has had the authority to create AIDS and HIV prevention discourse.

Too Weak to Speak

When I recognized that a participant needed to further explore additional health and human services, or medical care management, I facilitated appropriate referrals, and offered to provide transportation or childcare. One of the ladies in our study looked like she was starving. She was sick from the medication and unable to afford a diet rich in fruits and vegetables needed to help digest the medicine. I drove her to the food bank and helped her acquire the items she so desperately needed. These stories sound patronizing and in a sense condescending because I would have helped any individual needing services regardless of whether they were a research participant. How do you reciprocate to women who bargain with God to be allowed to live long enough to enjoy their children's sport events, eat a nutritious meal without nausea, or delight in the warmth of the sun? Is reciprocity a theoretical construct of academia designed to make the researcher appear ethical? I find it difficult thinking about reciprocity without feeling the crushing sense of the injustice that this disease inspires.

> She must learn again to speak
> starting with I
> starting with We
> starting as the infant does
> with her own true hunger
> and pleasure
> and rage. (Piercy, 1978, p.38)

Feminist Reciprocity: Personhood or Academic Ethics?

Reciprocity implies a give and take relationship. The positivist design demands that the researcher be detached to obtain objectivity. In feminist research, researchers are connected to their participants. They form a trusting relationship that transcends the formality of the experimental design and develop a mutual rapport for one another. Lather (1991) expanded the definition to include "a mutual negotiation of meaning and power. It operates at two primary points in emancipatory empirical research: the junctures between researcher and researched and data and theory" (p. 57).

Negotiated meaning or (re) presentation is a tool used to speak to the notion of reciprocity. It is paramount to this study because theory emerged as a result of trust, rapport and a collaborated interpretation of data by participants and researcher. I was very aware of countertransference issues or how the participants were reading my reactions as a result of our dialogue and negotiated meaning. When I sensed they were telling me what I wanted to hear, I addressed the incongruity. Without the participants' honesty, willingness to become the teacher, and ability to engage in collaborative theory building we would not have had a reciprocal relationship. Feminist theory emerged from the participants lived concerns, fears and hopes for the future not only for themselves, but also for the future of other women including researchers. Lather, (1991) wrote,

> Emancipatory theory serves as an energizing, catalytic role. It does this by increasing specificity at the contextual level in order to see how larger issues are embedded in the particulars of everyday life. The result is that theory becomes an expression and elaboration of progressive popular feelings rather than abstract frameworks imposed by intellectuals on the messy complexity of lived experience. (p. 61-62)

An example of reciprocity in research design can be found in the work of Jane Addams who conducted research with immigrant participants. This research helped social planners and community organizers meet the needs for health and welfare services for many people who could not speak English (Knowles, 1994). Without the participants' stories, intellectuals such as Jane, would have been blindly discerning the needs of people. Community-based organizations may then have provided services based on what the intellectuals thought the people needed. All of these resources would have been developed from research on what services the researchers thought were lacking. The common hegemonic practice of researchers asking the questions that they want to know to satisfy the validity of their hypotheses, keeps the structure (organization) strong and provides necessity for categorization and abjection. Participatory praxis provides a framework for voice and inclusion of often marginalized populations that can lead to emancipatory thought and action. If disenfranchised populations became the intellectuals, whom then would intellects study?

Barbara Saunders (1998) is an offender at the Dr. Eddie Warrior Correctional Center in Taft, Oklahoma. Barbara and I are co-teachers and trainers for the award-winning HIV peer education project that we facilitate together for prison inmates. This project was chosen as the 1997 winner of the STD/HIV Innovative Project of the Year for the 3M Company (Richards, 1997). Barbara has been incarcerated for more than four years and recently published the following poem. I include her sensitive prose in this dissertation to exemplify the attainable power that can be obtained by the disenfranchised when given opportunity to express voice and individuality. Her poem is entitled Therapy.

Two years ago I was a seed cast among the rocks,
in an alien environment.
Over time and with the help of the waves
nudging me
or crashing against me,
I gained purchase
on receptive soil.
I could choose
to burrow below and find the darkness
and richness of the earth
or lie above, rot and die.
For whatever reason
I burrowed below
seeking the dark
solitude and the unknown.
I stayed beneath the earth for a year,
twisting, turning not ready
to seek the light.
At last I began my slow crawl
to the surface,
to light and air.
The first tiny shoot of my almost white,
translucent green head

now peaks cautiously

at the surrounding area.

It is an environment

I may survive,

a challenging place

to grow strong.

There are no protectors offering

shade or shelter,

I am on my own.

But the choice to survive,

to seek the light,

to try to grow was mine. (Saunders, 1998, p.120)

Mary Daly coined the term methodolatry to warn feminist researchers that adhering to rigid procedure could result in not getting needed information. Daly (1973) wrote:

> The tyranny of methodalatry hinders new discoveries. It prevents us from raising questions never asked before and from being illuminated by ideas that do not fit into preestablished boxes and forms. The worshipers of method have an effective way of handling data that does not fit into the respectable categories of questions and answers. They simply classify it as nondata thereby rendering it invisible. (p. 11)

To help the participants become the teacher and the knower I would often say during our conversations, "What have we left out? What else do we need to talk about?" This sharing of ideas for the quest for new knowledge between researcher and researched braided, and became a shared responsibility for data collection, and analysis, a process rich in reciprocity.

Issues of Rigor and Catalytic Validity

In order for data to be credible, the researcher must find ways to establish data that is seen as trustworthy. As already mentioned, a variety of methods such as personal interviewing, group interviewing and collaborative interpretations were utilized to triangulate data. Most of the interviews obtained in the field form links and is corroborative. Ultimately, the narratives form a broader picture of the whole (Guba & Lincoln, 1981).

Developing systemized reflexivity or determining how theory has been developed or modified is essential for credible research (Lather, 1991). In the following chapter, portions of the participants' dialogue are represented so that readers may hear the participants' voices, converging thoughts and inconsistencies. I draw from their voices, my own experiences, and the theoretical frames presented in Chapter II to analyze and deconstruct the data. The prevention paradigm that emerged is not intended as a metanarrative, and it represents the researcher's experiences and knowledge, and the lived experiences of those who know.

The main criteria for credibility was catalytic validity (Lather, 1991). In other words, how have the women changed as a result of being a participant in the research study, a teacher, and contributor to the field of HIV prevention? What social action have they taken as a result of this study? How has their new knowledge helped or hindered them? Has raised consciousness, self-reflection or emancipatory thought occurred as a result of participation? Answers to these questions are addressed in Chapter V. I use the lived experiences of the participants to demonstrate social action.

I envision that the interpretations drawn from this study will contribute new knowledge to the field of HIV prevention education, and that the methodology will provide resourceful insights to critical feminists who are seeking new research paths.

CHAPTER IV

ANALYSIS OF THE INTERVIEWS AND FOCUS GROUP

Introduction

To explore HIV positive women's perceptions of the causes of HIV disease in women and to identify perceived barriers to prevention; and to understand how women make sense of their infection data were derived from two sources: (a) the in-depth interviews provided a timeline of key life events that led to HIV infection, and (b) the focus group gave the women an opportunity to look at the similarities and differences in their lives. Then, the women constructed an HIV prevention model for women. The purposeful statements that form this prevention model address perceived barriers to protection for women.

I did not have problems finding women to tell their stories or to talk during the interview process. Two HIV care managers, working at AIDS Service Organizations, recruited volunteers for me. However, six of the women in this case study called or approached me at community meetings or forums. They had heard of the study and asked me if they could participate. All of the women wanted to tell what they had come to know from their experiences. They hungered for someone who would listen to all that they had been through.

This qualitative case study uses narratives from ten HIV positive women to provide data about how they construct the causes of HIV disease in women. The stories describe their experiences and perceptions about the barriers to prevention, and how they now make sense out of their lives. In-depth interviews were encoded and categorical information was established delineating common themes. I listened to the tape-recorded interviews and listed common words on a grid that were spoken by the participants. The coded categories reflected the participants' narratives that were used to analyse the interview questions. Coffey and Atkinson (1996) posit that when

> qualitative data is analyzed with close attention to detail, understood in terms of their internal patterns and forms, should be used to develop theoretical ideas about social processes and cultural forms that have relevance beyond those data themselves. (p. 163)

The information derived from the in-depth interviews and focus group, provide profiles that are the basis for the analysis of the data. The analysis of this data is informed by my own experiences as a licensed therapist and HIV prevention educator. In addition, the participants of this study informed the analysis through constant member checks.

Before I begin the analysis of data and responses to the research questions, I present an archetypal story rich in metaphor. Coffey and Atkinson (1996) contend that

> Metaphorical imagery can provide a useful way of thinking about and interpreting textual data. Metaphors are a figurative use of language, a ubiquitous feature of a culture's or an individuals thinking and discourse. This is accomplished through comparison or analogy. At its simplest, a metaphor is a device of representation through which new meaning may be learned. (p. 85)

The Metaphorical Bluebeard

Estes, noted Jungian analyst, author, and cantadora (Latina storyteller) told the story of Bluebeard in her award-winning book, Women Who Run With The Wolves (1995). Bluebeard was a mysterious and frightening looking man who set out to court three sisters who were initially afraid of him. One day Bluebeard invited the three sisters and their mother to a picnic. The youngest sister decided that Bluebeard was not so scary and threatening after all, and became intrigued with his attention and persistence of her affection. She eventually became his wife.

One day Bluebeard left his young and impressionable wife alone in his hundred-room castle. He left her a huge key ring and instructed her to enter any room in the castle except for the room that had to be opened by the smallest key. During Bluebeard's absence the young woman's sisters visited the castle. They tempted her to disobey Bluebeard, and encouraged her to enter the room that Bluebeard forbid. Later that evening, the young woman entered the forbidden room. The key that opened the mysterious room began to bleed. The young woman began to scream as she looked around the secret room and found blood, bones and the remains of human skeletons.

When Bluebeard returned home he noticed that the smallest key had been soiled with blood, and knew his wife had disregarded his orders. He became enraged and told her that the blood and bones in the room were the remains of his previous wives whom he had murdered. The young woman began to beg for mercy and screamed out for her older brothers to come and rescue her. Boryysenko, (1996) interpreted Estes version of the Bluebeard tale.

> The young wife in the story represents the creative energy within a woman's soul which, in it's naivete', tries to borrow prestige and power from a man. The process of handing over our power to the inner masculine archetype of Bluebeard, the archetype that wishes to keep us in submissive positions, dampens the intuitive knowledge that is a lethal choice. The more injured we are in childhood, and the more in need of external verification, the more unconscious we are of our own inner life and in the danger of Bluebeard's power (p. 114).

The key to the room where the dead bodies laid can be interpreted as the key that unlocks conscious understanding. Estes (1995) wrote of four basic questions that a woman who is involved with a Bluebeard type character must ask herself. "What stands behind the forbidden door? What is not as it appears? What do I know that I wish I did not know? What of me has been killed, or lays dying?"

When abandonment and abuse have shamed children, they lack self-trust. As the shame continues, children learn to stop trusting their own instincts, judgments, feelings and desires. These instincts form our basic human power, sometimes called self-esteem. Estes (1995) and Borysenko (1997) recognize these phenomena and have challenged women to use the key to open the door to the unconscious to gain inner power and peace.

I believe that women can find their inner strength and power while maintaining honesty, integrity and a sense of connection to themselves and those they love. I believe that all of the women in this study have been shamed, and that their low self-esteem contributed to the contraction of HIV disease.

Bluebeard's young heroine can contribute to an understanding of this study's analysis. When she realized that Bluebeard was evil, she found her authentic power that eventually saved her life. She was able to see, know, and hear what was real, as opposed to living a constricted life where someone else was taking care of her.

The Demographics and Selected Histories of Participants: The Shaping of Lives

Three interviews were conducted with ten women. The interviews lasted from one to several hours often depending on the strength and stamina of the participant. The following eight areas were explored through the dialogic and semi-structured conversational interviews.

1. Demographics: (a) age, (b) religion, (c) marital status, (d) number in household, (e) employment, (f) income, (g) current benefits and (h) highest grade completed.
2. Drug/alcohol history: (a) drug of choice, (b) frequency of use (c) age at first use, and (d) who introduced the drug.
3. Physical/mental health history: (a) medical problems associated with HIV infection, (b) treatment for mental health, and (c) current medication.
4. Family history: (a) mother living, (b) father living, (c) parents married, (d) parents' relationship, (e) relationship with parents growing up, (f) closest family member, (g) sibling relationship, (h) quality of childhood, and (i) family member(s) alcohol/drug use.
5. Marital history: (a) number of marriages, (b) children during marriage; and (c) custody of children.
6. Legal histories: (a) current legal status, (b) drug related arrests, and (c) current or prior incarceration(s).

7. History of abuse: (a) childhood sexual abuse, (b) childhood physical abuse, (c) childhood emotional abuse, and (d) adult sexual assault or domestic violence.
8. HIV/AIDS history: (a) mode of transmission, (b) method of receiving results, and (c) reaction to results.

Demographics

Demographics of the ten female participants included: (a) age, (b) religion, (c) marital status, (d) number in household, (e) employment, (f) income, (g) current benefits, and (h) highest grade completed.

Age – The majority of the participants were between the ages of 31 and 44. Three of the ten participants were between the ages of 51 and 53.

Religion – Five of the participants indicated that they were very connected to religion and Christianity. Seven of the ten participants suggested that they were connected to spirituality, and one woman identified herself as Catholic. Four of the ten participants suggested nondenominational religious affiliations.

Marital Status – Eight of the participants were single at the time of the study. Two of the participants were legally married, but separated from their spouses. One woman in the study had never been married, and nine women had been married at least one time.

Number in Household – One woman was incarcerated during all three interviews and lived in a dormitory type room with another woman. One woman was released from prison after the first interview and was living temporarily with her mother. Four participants lived by themselves, and three respondents lived with a child.

Employment – Of the ten participants in this study, two were employed and eight were unemployed. Those employed were full time employees working in AIDS-related service organizations.

Income – Eight participants had an annual income of less than $10,000, and two respondents earned between $18,000 and $21,000 per year. Eight participants indicated that they grew up within middle income. Two African American women and one Native American woman disclosed that their families were of lower socioeconomic status.

Current Benefits – Five respondents received Social Security income, and seven of the participants received food stamps and other benefits from AIDS-service organizations. Seven of the participants received housing benefits and nine of the participants received some form of free medical related services. The woman who remains incarcerated pays the penal system $2.00 per prescription. The money for these life-saving drugs comes from an AIDS-service organization.

Highest Grade Completed – Ten of the participants completed the 12th grade, and two women graduated from vocational nursing programs. Two women earned college credit while incarcerated, and two participants completed 1 year of post-secondary education.

Drug/Alcohol History

The drug/alcohol data addressed (a) drug of choice, (b) frequency of use, (c), age at first use, and (d) who introduced the drug.

Drug of Choice – Participants self-disclosed drug usage and choice of preferred drug(s). Alcohol was used by all of the women in the study. Seven of the participants in this study also used marijuana and two participants injected methamphetamine. Three other participants indicated heroin as their drug of choice, and all injecting drug users had ceased using injection drugs prior to infection. It is important to note that all injecting drug users made a point during in-depth interviews to note that they had tested negative for HIV antibodies six months after using needles. One injecting drug user never shared needles or syringes. Prior to severe HIV disease, four participants also used cocaine, and one participant was addicted to crack, a derivative of cocaine. In summary, all participants used alcohol with one or more drugs.

Frequency of Use – Seven of the ten participants indicated that they used drugs or alcohol on a daily basis prior to infection. Three participants indicated that they used drugs and alcohol several times a week prior to infection. I did not ask the participants if they were currently using illicit drugs. However, three women volunteered they currently used marijuana because it helped them "feel hungry."

Age at First Use – Five out of ten participants indicated that they started using drugs and or alcohol during adolescence. Two women started drinking alcohol during childhood. These women also indicated that unstable family systems encouraged substance abuse. Three women starting using drugs and alcohol during their early 20's.

Who Introduced Drug – Introduction to the drug of choice by a friend was indicated by 6 of the 10 participants. Two participants were introduced to alcohol by their parents and two women indicated that curiosity led them to drugs.

Physical/Mental Health History

The physical/mental health data addressed (a) medical problems, (b) treatment for mental health, and (c) current medication.

Medical Problems – Ten of the participants shared medical problems associated with HIV disease ranging from moderate to severe. All of the women had experienced HIV-related neuropathy (e.g., numbness and pain in extremities) and had acknowledged moderate to severe body pain.

Treatment For Mental Health – All ten of the women reported treatment for mental health. One participant lived in-patient at an alcohol/drug rehabilitation center prior to HIV disease. She left the facility free of the virus. One participant disclosed that she had bipolar disorder. Another term for bipolar is manic depressive disorder. All of the women indicated feeling depressed during portions of their lives. I did not make a distinction between mental health treatment, and substance abuse treatment because the issues that become illuminated during therapy overlap.

Current Medication – Ten of the participants were taking various kinds of anti-viral and HIV-related medication. However, these drugs are constantly changing because of advanced scientific development, and the need to alter drug combinations due to drug resistance and gastric intolerance. Eight of the ten women complained about the number of pills required for sustaining life. During a third interview, one woman self-disclosed that she refused to take any more AIDS-related medication because it was making her too exhausted, and unable to care for her son. However, she continued to take the medication that helped control her manic and depressive states. It is important to recognize that anti-depressants are often prescribed for patients living with HIV disease regardless of depression. It is for this reason that I did not report the number of women taking anti-depressant medication. Anti-depressants permit more of the chemical serotonin to circulate the system allowing a feeling of general well being for the individual.

Family History

The family history data consisted of the following information: (a) mother living, (b) father living, (c) parents married, (d) parents relationship, (e) relationship with parents growing up, (f) closest family member, (g) sibling relationship (h) quality of childhood, and (i) family member(s)' alcohol/drug use.

Mother Living – Of the ten participants, four indicated that their mother was still alive. Only one participant had a close relationship with her mother. Three other participants reported close relationships with their mothers who were now deceased.

Father Living – Five of the participants said that their father was still alive, although none of the participants' had a close relationship with their respective fathers.

Parents Married – All ten respondents indicated that their parents were no longer married. Of the ten participants, nine women came from broken homes due to parental death or divorce. One participant who did not come from a broken home. She was raised by her mother and stepfather. Her stepfather is now deceased. Her biological father abandoned her mother during pregnancy.

Parent's Relationship – This data addressed the way in which parents related to each other. Four participants disclosed that their parents had a good relationship, but the relationship was interrupted by the death of the husband. Five women indicated that their parents divorced when they were children or adolescents. All women of divorced parents reported that their parents had violent and dysfunctional relationships. Seven of the participants disclosed that at least one of their parents had mental health problems. One woman reported that her conception was the product of her drunk father raping her mother and that she had only met him three or four times before his death.

Relationship with Parents Growing Up – Four women indicated that they had close relationships with their mother. Three women indicated their mothers did not approve of the men in their lives because it took time away from the mother-daughter relationship.

Two women indicated they had close relationships with their father. However, one father was actually her stepfather. This participant was an adult before she knew that he wasn't her biological father, although she questioned how he could have another daughter, from a previous marriage of about the same age as herself. The other participant indicated that her father's best friend sexually molested her from age twelve to eighteen, and that she never disclosed this information to her father for fear that he would not believe her.

Closest Family Member – One participant indicated a parent to be the closest family member. Five participants did not have a close family member. Three participants disclosed being close to their children and one participant indicated that she was closest to her grandchild.

Sibling Relationship – Three participants indicated that they had no siblings. Three participants were middle children and indicated they had good relationships with their siblings. Two participants were the youngest daughters and had poor relationships with their siblings. One participant was the oldest child and lived in foster homes, which alienated her from her siblings. Another participant was the oldest child and indicated fair relationships with her siblings.

Quality of Childhood – Eight participants indicated a problematic childhood. Two women indicated that they had a good childhood. However, these women also experienced severe childhood trauma.

Family Member(s)' Drug/Alcohol Use – Three participants claimed that their mother did not use drugs or abuse alcohol; five indicated that their mother did use drugs and/or alcohol. Two participants indicated that their mothers had used prescription nerve medication. Alcohol abuse was defined as more than two drinks per day. Eight participants indicated that their father did use drugs and/or abused alcohol.

Marital History

Number of Times Married – One participant never married. Three participants married one time. Six participants' married multiple times. None of the participants were living with their husbands at the time of the interviews. Two participants were married, five were divorced and two participants' respective husbands had died from AIDS.

Children – Nine of the ten participants had children. One married participant did not have any children. Five participants had at least one child with their first husband. One participant had a child with a man with whom she was not married. Three participants had a child or children during their second or third marriage. Of the nine participants who had children, five participants indicated that they had good relationships with one or some of their children. Five participants had at least one child they had not seen in more than three years.

Custody of Children – Five participants had lost custody of their children. They all verbalized that alcohol and drug use had contributed to their loss of custody. One participant had two children who were adopted by another family, and two participants had children living with other family members. Two participants lost custody due to incarceration.

Legal History

The legal history data set addressed (a) current legal status, (b) drug related arrests, and (c) prior incarceration.

Current Legal Status – Eight participants indicated a fair or good legal status at the time of the study. However, one participant was incarcerated, and one participant was recently released from prison and on parole.

Drug-Related Arrests – Arrest due to drugs was indicated by six of the ten participants.

Prior Incarceration – Six of the ten participants had prior or present incarcerations. Reasons for incarcerations were for possession with intent, grand larceny, and distribution of cocaine, robbery and prostitution. Three of the participants received long-term prison sentences, greater than one year. Three participants served their sentence in jail.

History of Abuse

The history of abuse data addressed (a) childhood sexual abuse, (b) childhood physical abuse, and (c) adult sexual assault or domestic violence.

Childhood Sexual Abuse – Of the ten participants, eight were victims of childhood or adolescent sexual abuse. Victims stated that they were angry, experienced loss of self-esteem, and assertiveness, suffered isolation, shame, and problems with intimacy as a result of the abuse. Five of these participants expressed feelings of early betrayal in response to their mother's request for them to forget about what had happened to them. Of the eight participants who were sexually abused, five were between the ages of four and twelve. Three were between the ages of thirteen and seventeen. Four participants had more than one abuser. One participant indicated that her pastor began molesting her at age seven, and that his attention was welcomed because she didn't have a father. She disclosed that his attention made her feel special at the time, but later caused her shame.

Childhood Physical Abuse – Four respondents were victims of childhood physical abuse. In one case, the participant's mother would severely beat her and tell her that "she wished she was never born." In another case a father would take out his rifle, chase his daughter and say, "you better think of a reason to let you live."

Adult Sexual or Domestic Violence – Nine participants were victims of adult sexual or domestic violence. The women indicated that drugs and/or alcohol abuse brought about violent relationships and drug-induced rages.

HIV/AIDS History

The history of HIV disease data addressed (a) mode of transmission, (b) method of receiving results, and (c) reaction to receiving an HIV positive antibody test.

Mode of Transmission – Ten of the participants indicated that they became infected from unprotected intercourse with an infected male. One participant knew her husband was infected and thought that if they shared the disease they would be bounded together for the rest of their lives. One participant was certain that her husband did not know he was infected and transmitted HIV to her unknowingly. Eight participants were not sure if their partners knew they were infected. None of the participants were angry with the men who infected them, although, two participants indicated a period of anger that had passed with time.

Method of Receiving Results – Five participants were told that they had been exposed to the virus after their partners suffered from life threatening opportunistic infections. These women, then, tested voluntarily, and received their results through a health department or hospital. One participant was checking her antibody-status regularly at an anti-body test site and told of her infection. Another participant was about to enter a serious relationship and elected to test for the virus. She too tested at a local health department. Another participant was mandated to test upon entering the penal system, and another mandated test was performed on a participant for life insurance purposes. One participant was selling her plasma, and was tested without her knowledge. Because nine of the women were connected to a structure, (e.g., health department, hospital, prison or antibody test-site) social and medical services were made available. The efficacy of said services goes beyond the scope of this study.

Reaction to Results – One woman felt relieved when she finally tested positive. The other participants grieved, and were saddened and shocked. Four of the women expressed that HIV was just another challenge to their already difficult lives. Two women expressed that this was God's way of helping them to clean up their lives. One woman saw it as an opportunity to pay back God for all the wrong things she had done during her life. Five women experienced mild to severe depression and two women reported suicidal ideation.

Summary

The women in this study living with HIV disease tended to be middle-aged, separated or divorced from her partner, and been the victim of childhood sexual abuse and adult abuse. The participants who reported sexual abuse also indicated problems with intimacy. All of the women reported that they contracted HIV through unprotected sex with a male partner. A majority of the women have spiritual and religious affiliations and are not employed. Around half of the women in this study have served time in a jail or prison and have lost custody of their children.

Research Question One

What Are HIV Positive Women's Perceptions of the Causes of HIV Disease in Women?

I now turn to the voices of the participants. Sandi was 41 years old at the time of the interviews and of Native American descent. She had an abusive alcoholic father who would awaken her in the middle of the night and make her dance for his amusement. Although her mother lived at home Sandi claimed "she couldn't control him, no one could when he was drinking." Eventually Sandi's mother left and moved to California. Sandi's father re-married a much younger woman who was unable to conceive a child. According to Sandi, one evening her father was intoxicated and hit her sister over the head with a bottle of Old Charter. "He wanted to do it like in the old west," she said. Sandi became increasingly concerned about his violent rages and was scared for her life and the life of her sister. She disclosed that she was left alone in the house often, and was raped in her living room by her cousin's friend at age thirteen. "My dad wasn't there for me," she reiterated. Her father's behavior was inappropriate and he would come into the bathroom while she bathed and invaded her private space with touch. She became pregnant at age fifteen and her parents accused her of being a slut and a whore.

> My father and stepmother took my baby away from me and raised him as their own son. My father used to get the gun out at night and said, "you better give me a good reason to let you live." So, I ran away from home.

Sandi's life story contained a pattern of abuse. Sandi married several times and was an individual who experienced sexual, emotional, and physical abuse throughout most of her adult life. She admitted that she was attracted to men that engaged in alcohol and drug use, and eventually participated in the drug scene to the point that she became addicted to alcohol, and methamphetamine. Her response to how she perceived the cause of HIV disease is as follows.

> I had no parents to help me and to teach me right from wrong. I had no morals. My parents ridiculed me my whole life, and called me fat. I needed someone to love me even if I was under bondage and control. I knew my husband was infected, but I thought if I got it too, we would take

> care of each other and he would never leave me. I had no self-esteem, and never received training on how to behave.

Lori is another participant whose life history has markers that resemble circumstances in the life of Sandi. Both of these women had abusive parents who abandoned them emotionally and physically. Both of these women connected with abusive men. Lori's parents divorced when she was in grade school. Lori described her parents as "drinkers and smokers of marijuana." Neither of her parents wanted custody of her when they divorced and so she moved in with a foster family who had other children her age. Lori remembered her mother's words, "Don't call me mother anymore because I look too young to be your mother."

When her mother re-married, Lori was a teenager, and she returned to live with her mother and stepfather. Her grades began to decline and she missed the love and unconditional acceptance of her foster family. Lori's stepfather molested her at the age of fifteen. This went on for about a year until Lori's mother decided she wanted a divorce. Lori never told her mother about the sexual abuse because she feared that she would once again be abandoned. About a year later her mother and stepfather divorced and Lori met her first husband at age sixteen. Lori insisted that the "molestation was insignificant" when compared to the abandonment issues she suffered as a result of her parents not wanting her. "It has effected my self-esteem for all of these years."

Lori stayed married for seven years. Her husband drank heavily and abused her verbally. When he began physically abusing her, she left him. Lori started back to college and met her second husband. He was an injection drug user who swore that he "never shared needles." Lori described her life with her new husband as "chaotic."

> He was a recovering addict at the time. When he started using again, he would split for several days. He would be gone for three or more days and then come home and crash. I was afraid to say much because I was afraid he would leave me.

Lori and her husband have two children who are now in her mother's custody. The police raided their apartment on a "drug bust." Lori and her husband served six months in a local jail for possession of methamphetamine. Although Lori did not inject drugs, she did self disclose that she drank a lot of beer in the past, and when she does currently drink she drinks to "get drunk." Lori said, "I had no idea there was (sic) any drugs in the house because he never used around me or the kids."

Lori's husband is now incarcerated and the district attorney is still examining her case. When Lori's husband entered the Department of Corrections, he found out that he had antibodies to HIV. Lori was then notified that her husband tested positive for HIV in prison. She was tested and found out that she too had the virus and was infected.

> He swore to me that he would never share needles. While he was lying in the hospital with Pneumonia, he looked me in the eye and told me that he hated what he had done to me. He said he needed a fix and any drug user would share if they had to.

Lori currently has an attorney who is trying to persuade the courts to allow her to regain custody of her children. Lori acknowledged that the theme of abandonment has continued throughout her life. She offered the following information on her perception of why women were contracting HIV.

> Women don't want to believe that they can get infected. I wasn't out there using drugs. I was doing what society wanted. I was being a good wife and having sex with my husband. The prevention literature talks about not using drugs. There is nothing out there that talks about if your husband is a user. Women are not taught to say no. I was sticking by my man and that is what society tells women to do. Women are not taught to have

> individuality. Our whole society, school, and the church regiment us to be followers not leaders (sic).

Like Sandi, Lori survived a dysfunctional family system, molestation, abusive husbands and ultimate betrayal. She is fighting the courts to regain custody of her children and lives with a possibly deadly disease. She has developed survivor behaviors. For example, she readily admitted not leaving a husband that was an injection drug user because she thought she was being a good wife, and that he might change as a result of her support. She was reticent to confront his drug using behaviors because she feared abandonment. Bradshaw (1998) described survivor behaviors.

> As the child from the dysfunctioning family grows up, those survival behaviors continue even though they are now disconnected from the original form of distress. These survival behaviors feel normal since they are the patterns the family member used every day of her life in order to survive. As an adult they are not only unnecessary, they are actually unhealthy. While once they were protective, now they are destructive (p.184).

I believe abandonment and the bible skewed Lori's notion of love. In passive-dependent love, the highest act of love is self-sacrifice. Many religious leaders teach that the highest form of true love is to set aside one's physical, emotional, and intellectual needs to take care of others. From this perspective martyrdom and long suffering are the ways to attain goodness. When self-esteem is poisoned by sexual and emotional abuse, learning to have a healthy sense of self is almost impossible. Lori yearned for parental support and approval, and looked for it in other relationships. Unfortunately, the partners she chose were unavailable (just like her parents). She connected to an unhealthy relationship that ultimately caused familial abandonment and her HIV infection.

Jane, another participant, was in her early 50's at the time of the interviews. She has been living with HIV for ten years and claims that "at the time of my infection only gay men and junkies were getting it." She spoke of the pain involved with being African American, impoverished, and living in a racist society. Jane's father abandoned the family before she was born. Jane was the product of her father brutally raping her mother while he was heavily intoxicated. Her mother kept this a secret, but played out her hostility to Jane through chronic abuse. Her mother worked long hours as a house- keeper and supported Jane and her two older sisters. Jane's mother physically and emotionally abused her, and expected her to attend to all household duties. Jane was sexually molested as a child and raped as an adolescent. Jane drank alcohol as a child, smoked marijuana as an adolescent, and used heroin as an adult. Jane admits that she was on a "self-destructive path." She finally "became clean" of illegal drugs, and gained self-worth in the army. Jane was beginning to be assertive and comfortable with self when a new officer, who she emphasized "was from the south," became in charge of her unit. Jane had a verbal disagreement with this officer and was honorably discharged from the army. Jane claims that discrimination robbed her of an education and a career in the army.

Jane spent five years in a drug rehabilitation center. She learned to live without alcohol and drugs. During therapy she was able to process the sexual and physical abuse that contributed to her emotional pain. Eventually she found strength and facilitated group process for women who were newly admitted to the program. She learned that her life circumstances and the dysfunctional family secrets had contributed to her drug dependency. Jane was now able to understand that the childhood molestation was not her fault. She spoke about the state of affairs surrounding her infection.

> I hadn't had sex in five years, and needed love and affection. I needed to feel my sexuality. The sex wasn't about him, it was about me. I became infected because I needed someone to validate me.

Jane talked about her perceptions of the causes of HIV disease in women.

> This disease and low self-worth and self-esteem go hand in hand. The media doesn't tell you things. I thought only White gay men and drug users were at-risk. We must address self-esteem during small group workshops. Women believe they can't live without a man. I know now that this is bullshit. I know that women supplement their income from their boyfriends. They aren't going to jeopardize this income by insisting on condoms. Our society has always dictated that the female be subject to the male's wants and needs no matter what they are. There are a lot of women who don't know any better. HIV prevention messages are not enough and not designed to meet the needs of women, especially Black women. Prevention educators need to be more honest. I'm sick of them being so politically correct. I'm damn tired of them acting like they understand Black women. Women need to learn alternative ways of satisfying themselves sexually.

Ronnie highlighted a different perception of the cause of disease in women. She had been infected for more than ten years at the time of the interviews. She was extremely ill with several AIDS defining diagnoses when we spoke. At times she seemed so frail, I felt reticent to bring up painful memories in her life. Ronnie insisted on finishing the interviews and said that the "stories made her cry, but she felt like she was accomplishing something." Although Ronnie described herself as a middle child who had "a good childhood" her story reveals conflicting information. Ronnie described her father as a "workaholic who was never at home." Her father's best friend molested her over period of around six years. She was reluctant to tell her father of the abuse because she was afraid "to ruin the lifelong friendship he had with this man, and didn't want to be the cause of upsetting him." Ronnie finally told her mother of the chronic sexual harassment and abuse. Her mother insisted on keeping the abuse a secret. "Mother never asked any questions about it, and would send me to a show or to a friends house when he would come over." Ronnie described her mother, who is now deceased, as her best friend whom "never approved of any of my male choices because it took time away from our relationship." Ronnie described her father as a drinker "who would drink when mother wasn't around."

> I had always been real close to my mom. Dad was killed in a plane crash a day before my eighteenth birthday. I had already had my oldest daughter and was married to a man twelve years older than me. The marriage didn't work out. Mother didn't care for him. I was sixteen and he was twenty-eight when we married. But, then again my mother didn't care for anyone I ever had a relationship with. She didn't want to lose me. We were so close and did everything together. I really believe she was jealous of other relationships I had.

Ronnie had three children, all from different men. The man that infected her was no longer alive, and was not the father of any of her children. Although she had periods in her life when she "drank heavily" she wasn't able to consume alcohol presently because of the anti-viral medication she was taking. Ronnie described her husbands as either men who "drank or who ran around with other women." Her first two husbands were twelve years older than she was and she described them also as "emotionally abusive." Ronnie said that her first husband would "take off to the oil fields for weeks." She divorced her first two husbands because they were "extremely controlling." "I would always run home to mother and allow her to control me."

> Mother also raised my kids. If I told them they could do something and mother told them not to, you could bet that they would listen to their grandma. You could say I never really grew up. She was in total control of all of us. I'm like the referee and like to make everyone happy. I don't like to make waves and so I always kept mother happy. I'm a real people pleaser. If I would have listened to mother and gone off to college my life would have been different.

When Robbie's third husband was killed in a car accident she drank heavily and she experienced alcoholic blackouts. She explains her perceptions of the cause of HIV.

> I went crazy and wanted to die too. I never wanted to go home. All I wanted to do was drink. I ended up having a nervous breakdown. I met this guy and took off with him. His wife was a heroin user. She eventually died of AIDS. He told me he tested negative but then became sick from Pneumonia and found out he was positive. He called me from the hospital and told me to get tested. I tested positive too. I don't have any animosity for him. My mother thought he lied to me and that he knew he was infected. It really doesn't matter to me. He was there for me when I needed him. I still think that he was a good person.

Ronnie described physical abandonment by her father and first husband. Her second husband abandoned her through infidelity and her third husband abandoned her through death. In a sense, her mother also abandoned her when she refused to confront Ronnie's sexual perpetrator. Similar to Sandi, Lora and Jane, Ronnie experienced emotional and physical abuse by the men in her life. Ronnie's relationship with her mother was enmeshed and unbalanced.

Bradshaw described the role of second-position siblings and how family enmeshment is dysfunctional (1995).

> Second-position siblings respond to the emotional maintenance needs of the family system. They try to see to it that each family member's emotional needs are met, and they feel especially responsible for the mother. Second siblings are especially aware of the elements implicit in family rules and relationships. They will probably pick up the family secrets faster than their siblings, especially the mother's secrets. Second siblings absorb other people's feelings as if they were their own. They often perceive issues in polarized terms. Second children need acceptance as people to establish clear boundaries.

When Ronnie was growing up she kept the trauma of sexual molestation a secret to keep peace in the family. She was the only daughter and had two brothers, one older and one younger. She learned early on that her needs were less important than the needs of other family members. By keeping the molestation a secret she was unable to be her true self. Her developmental dependency needs were denied for the sake of others. She was unable to set her own boundaries because someone who had physical strength and power stole them. Her true self was not permitted to shine because the family system wasn't able to cope with the stress of a child who was sexually abused and the betrayal of a best friend. Robbie learned to trade off awareness for security and to mesh reality and fantasy. She was used by the family to maintain balance so that the family could have the appearance of being normal.

Perhaps we will never understand why family secrets mold our lives. However, like Sand, Lori, and, Jane, Ronnie harbored secrets that were painful for her to remember and self-disclose. I can't imagine living with such secrets or surviving their impact. Although her parents did not physically abandon her, Ronnie's story exemplifies the problems associated with emotional abandonment and inappropriate parental bonding. The issue is that Ronnie's parents were not there to satisfy her needs. But, Ronnie was there to satisfy her parents needs and the needs of the family system.

Lisa was another participant who also bonded inappropriately with her mother. Unlike most of the other participants in this study, she was not sexually abused as a child. However, she was neglected and emotionally abused. I met Lisa in a correctional facility. She was incarcerated for distribution of marijuana and received a sentence of five years. She was confined in a medium security state penitentiary. Lisa had a similar family pattern to the other women in the case study. She and her parents came to the United States from Holland when she was around four years old. Her father died of a massive heart attack when she was eleven years of age. He was ill most of her childhood. After her father died, her mother would work all night long and Lisa spent six nights a week sleeping alone in the house. Her mom would call first thing in the morning to awaken her and to make sure she was getting dressed for school. She was an only child and spent her childhood and adolescence "being lonely." Lisa now thinks "this loneliness caused my drug dependence. When I was using there was (sic) always tons of people around." Lisa's mother struggled with the English language and didn't know how to drive a car. In order to support herself and Lisa, her mother got a job at a nearby nursing home. She rode her bicycle to work. Lisa inappropriately bonded to her mother. Like Ronnie's mother, Lisa's mother never liked any man who took time away from her relationship with Lisa.

> I married a good man. I'm sorry to this day that I divorced him. I wouldn't have been in prison if I stayed married to him. He took good care of me and was eight years older than me. My mom wanted me all to herself, didn't want to share, and never liked any man that I was ever around. I couldn't please her. That's another reason why I left him. I wanted to please her and I couldn't please her staying married to him. We got married and moved to California. Six months later mom moved to California and asked why I stayed married to that good for nothing. He was always good to me. She wouldn't have liked any man I was with. She didn't want to share me and wanted me all to herself. I wound up taking care of her and selling drugs to support her Alzheimer's care. That's why I'm incarcerated and have AIDS.

Similarly, to the other women in this case study Lisa was physically and emotionally abused by several men. She would leave a relationship if "the guy hit" and she had a part time job and made money from selling marijuana. "My house was a twenty-four-hour seven day a week party house. I liked the company and being the center of attention. I know I liked it because I was alone so much of the time when I was young." However, a man who injected drugs betrayed her. He promised her he was not infected. She questioned him before having unprotected sex and he assured her he "was not infected." Some time later, Lisa learned that his wife had died of AIDS. While Lisa served time in prison, he sold all her belongings and her parents' antiques from Holland. He used the money "to shoot up with." Lisa claimed that, "serving time and living with AIDS has caused her to reevaluate her life and drug using patterns." She voiced that the "loneliness" and "abandonment" she experienced as a child contributed to her drug using behaviors that ultimately caused her HIV infection. Like the other women in the study Lisa did not use injection drugs.

Lisa responded to her perceptions of the causes of HIV disease in women.

> After I got my divorce, I got involved with physically abusive men. My sons lived with their dad. I went from one relationship to another. I went from the best relationship into the gutter. I went so far into the gutter and then kept doing pot, and eventually methamphetamine, and crack. Then, I didn't have sex for five years because I was so drugged out. Eventually I got off the crack. I wanted to have sex. I was lonely. I couldn't face having to take care of a mother with Alzheimer's. I had all these parties going on at my house. I kept doing more drugs so I didn't have to face what was going on with my mother. I finally met this guy. He swore he was clean. He infected me. I wasn't thinking. The drug scene took its toll on me. Now that I'm in prison I think a lot. If I wasn't on drugs, I would never of had sex with him. I needed to be needed. My perception of him was unrealistic. It's crazy because I weighed 92 pounds and thought I looked really good. His wife was a heroin addict and she died of AIDS. Before I came to prison, he admitted to me that he knew he was HIV positive.

Summary

Women living with HIV experienced many similar childhood events. They were abandoned and abused as children. Sometimes, a parent(s) was present, but unavailable emotionally. These women were unable to have their developmental dependency needs met because their parents were unavailable and they experienced low self-esteem, and shame throughout their childhood. These participants did not have the opportunity to form a healthy connection within the family. Their parents did not mirror mutual empathy or healthy notions of being connected within a relationship. The women mood-altered with alcohol and other drugs to mask the pain caused by severe family dysfunction. These women had adult relationships that were characterized by additional abuse and abandonment. Often, they were attracted to partners who had similar behavioral patterns to their primary caretakers. The relationships they experienced with their intimate partner(s) were often an outcome of loneliness. The women in this study desired companionship and affection. They wanted someone, a man, they thought would take care of them.

Conclusion

The family is the source relationship that helps us to learn about ourselves. When family dynamics are riddled with abuse we learn to protect ourselves. We repress our feelings and create illusions of love and connection. We learn to deny the painful memories and disassociate through chemicals. Then, we become numb and unable to recognize dysfunctional practices. These behavioral patterns are described by Bradshaw (1996) as "Adult Children of Dysfunctional Families" (p.192). Bradshaw (1996) offers a checklist of traits that describe these common phenomena (192-193):

A	Abandonment issues
D	Delusional and denial
U	Undifferentiated ego mass (carry the desires of other family members)
L	Loneliness and isolation
T	Thought disorder

C Control madness (masking control issues by being helpful)
H Hypervigiliant (high level anxiety)
I Internalized shame
L Lack of boundaries
D Disabled will
R Reactive and reenacting
E Equifinality (no matter where you begin, your life seems to end at the same place)
N Numbed out

O Offender with or without offender status
F Fixated personality

D Dissociated responses (out of touch with feelings)
Y Yearn for parental approval
S Secrets
F Faulty communication
U Underinvolved
N Neglect of developmental dependency needs
C Compulsive/addictive behaviors
T Trance (carrying the family spell)
I Intimacy problems
O Overinvolved (drawn to needy people, think you can fix them)
N Narcisstically deprived
A Abuse victim
L Lack of coping skills

F False self
A Avoid depression through activity
M Measured (unrealistic expectations of self and others)
I Inhibited trust (lack of trust in self)
L Loss of own reality (weak boundaries)
I Inflated self-image (live according to an ideal image, rather than a true identity)
E Emotional constraint
S Spiritual bankruptcy

Many of the participants in this study have traits that fit the pattern of Adult Children of Dysfunctional Families. These traits are outcomes of the poisonous pedagogy created by the dysfunctional family. Miller (1983) posits that poisonous pedagogy is a model of parenting that demands the direct obedience of children. This form of parenting is intergenerational, meaning, dysfunctional parenting style is passed from one generation to another. In essence, this parenting style demands that one group of people, parents, are in absolute control over another group of people, children.

No child, regardless how abused she may be, wants to realize that her parent(s) was inadequate. Adolescents begin to use drugs when the pain and intense anxiety elucidated from dysfunctional family dynamics affects the ability to function successfully. The women in this study bonded with men who they felt comfortable with. Men whom they thought would take care of them and protect them. What is familiar is often comfortable and the family dysfunctional patterns were repeated. I believe that these internalized traits caused barriers to the prevention of HIV disease.

Research Question Two

What Are HIV Positive Women's Experiences Concerning Barriers to Prevention?

I met Corena in a correctional facility. The first interview was conducted while she was incarcerated. Subsequent interviews were conducted in the back room of a local pancake house. Corena does not fit the typical characteristics of woman living with HIV disease, nor does she match the typology of women who are incarcerated because she was not physically or sexually abused as a child. However, she participated in the drug culture and was eventually incarcerated on drug related crimes. Corena was not sexually or physically abused by her mother or stepfather. Corena described her mother. "She was addicted to nerve medication and had wild mood swings." She acknowledged that her mother emotionally abused her by hiding the identity of her biological father and by keeping the circumstances around her birth a secret. She was 21 years old before she found out that a sailor whom her mother never saw again impregnated her. Corena reenacted this family secret by becoming pregnant at 19 years of age by a man she did not see again. Corena claims that her mother has hurt her the most in life.

> She has never accepted me for who I am. She was always more concerned about what the neighbors or other people were thinking about me. She could have helped me when I was an unwed mother, but instead she continued the lie.

Corena is similar to Sandi and Lori. Her parents gained custody over her son. Similar to the other women in this study, Corena did experience domestic violence with the man that infected her.

Corena met the man who infected her at a club in Dallas. They dated for a long time. Corena had a history of injection drug use, but never shared needles with anyone. She eventually gave up injection drugs and limited her euphoria to cocaine, alcohol, and marijuana. She and the man who infected her did coke together and started an intimate relationship. As the relationship began to become more intimate, Corena suggested that they both be tested for HIV antibodies. He had proposed marriage and was willing to help raise Corena's two sons. Corena knew that having a man to help her raise her sons was important. Corena described preparing for their marriage and how the topic of AIDS was in the newspaper daily. Corena said:

> I knew I hadn't shared needles and he wasn't an injecting drug user. However, he had started to disclose his background to me. He was sexually abused by a man and I got the feeling that he could have been bisexual. I even caught him dressing in my clothes one time. He said it turned him on. But, when I talked to him about testing, he would say he didn't want to have the test. He then asked me if I had it. I remember thinking that's a man for you. I don't think I had it before him. We didn't get tested at that time, but four years after we were married he developed

> this bad rash and started getting real sick. The doctor tested him and he had it. The very next day I was tested and was positive too. But, he was so sick and died soon after. He was in much worse shape that I was. In retrospect, he had it long before we started dating. I wish now that I made him get tested before we had unprotected sex. I should not have asked. I should have just told him, we are getting tested. At the time I just wrote it off.

Corena was accommodating and co-dependent. She was putting the needs of her lover before her own. She needed her lover to be a father to her sons, and in a way her sons' needs also came before her own. Women's Developmental Theory posits that women grow and develop through relationships (Jordan, 1997). However, in a relationship where authenticity and mutual relationship exist one cannot be too self-sacrificing. A mutual relationship transcends the individual and is committed to the developmental and support of both people. In other words, Corena knew that her lover had risk factors. What she didn't know was that he wasn't committed to a mutual relationship. After they were married, he beat her to the point that she needed to be treated by a plastic surgeon.

She wanted both of them to test for the virus. Her lack of assertiveness interfered with her intuition. She continued to play out her co-dependent behavior by taking care of the man who she believed infected her throughout his illness.

Lin highlighted a similar perspective relating to the importance of asserting self. Lin is an African American nurse around 50 years old. She is similar to Sandi, Lori, Jane and Ronnie because she was sexually molested, and abandoned by her parents. Lin's father died when she was 3 years old. Her mother took care of other people's children and cleaned houses. Her molestation and eventual rape began at around eight years of age. She described her childhood sexual abuse and lack of assertiveness.

> If my father wouldn't have died and my mother wasn't cleaning other peoples' houses maybe he wouldn't of (sic) been able to snatch me. He was always able to grab me on my way to the swimming pool and not be seen. I was so intimidated, I wasn't about to tell anybody. He would give me nickels, dimes, and a few quarters afterwards and send me on my way. I was afraid to tell mama (sic). He made it sound that I came because of the money, and because I was fast. He said I was a bad little girl and that nobody would believe me. He made me believe it. If this didn't happen maybe I would have been more assertive and aggressive. Because of this I didn't accomplish my goals. I wanted to be something. I wanted to help Black people, especially Black women. I always wanted to have a voice. Yes, I am a nurse, and that is helpful. But, I did not accomplish my goals.

I conducted three interviews with Lin at an AIDS hospice. We would have our discussions in a room containing a large wall hanging of Jesus Christ nailed to a cross. Lin weighed around 85 pounds, and I would bring her soft and nutritious food to eat. Allow me to digress and share some of Lin's medical condition with you. Lin is an example of how HIV medication is failing women. She talked about this concept at great length during all the interviews. For example, Lin had a high T-cell count, and a low HIV viral count. Theoretically she should have been feeling well. Unfortunately, she is suffering from wasting syndrome. Her complaints about clinical trials in women transcend the scope of this dissertation, but I promised her that I would include her voice about this important topic.

After the interviews were over, I would hold her by the arm and walk her around the hospice. She told me of her life as a socioeconomically disenfranchised Black woman. She struggled as the only minority in her vocational nursing class. She was smarter than most, but too intimidated to voice her despise of a system rooted in discrimination and oppression. The juxtaposition of her frail stature and mental strength was profound. When she left the hospice to return home to rural Oklahoma, I missed our talks. She had suffered the pain of sexual abuse, abandonment, discrimination, abusive relationships, and now her feeble body was not responding to medication. Yet, her forthcoming account of her perceptions of the barriers to prevention is insightful.

> If I had been more assertive, I would not have let my lover get away with all that womanizing. I guess, maybe I was lazy and complacent too. I knew he was going to take care of all the financial responsibilities and he wasn't going to slap me around or do anything physical. I gave up monogamy for financial security and peace of mind. He was good to my son. It makes a big difference when you are a young Black woman raising a child on your own. I knew I was physically safe with him. We had a special chemistry. I guess I never said "no" to a man.

Lin talked about the relationship with her lover. He was kind and a good provider. He made his living as a drug smuggler. He was incarcerated in a foreign country and in the US during their relationship. He wove in and out of her life for 20 years and he is the only father her grown son had ever known. The last time she saw him he was sick with what she thought was the flu. She had made him chicken soup, they had gotten high on marijuana, and engaged in unprotected sex. After he left, she took antibiotics from her medical cabinet. She knew he had other sex partners. She wondered if he had a temperature from a sexually transmitted infection. She told me she thought that maybe he had gonorrhea.

The next time she spoke to her lover, he was calling from prison. He told her he had tested positive for HIV antibodies. His infection explained her continuous weight loss, lack of energy and upper respiratory infection. Then, she tested positive for the virus. Her physical problems were an indication of acute viremia, or her body responding to the invasion of HIV disease. Lin admitted she was a "little angry" with her lover, but, she knows in her heart that he did not give her this virus purposefully.

> I have written some letters to him. I told him that if he would have made some adjustments in his life, we could have avoided all this. Now, I see no point in being angry.

Similar to Sandi, Lori, Jane, Corenaa, and Ronnie, Lin was a drug abuser. She was addicted to prescription pain medication for many years and saw a psychiatrist to help her through all the shame she had experienced. Her barriers to prevention were numerous. The molestation caused her to lose voice and become disconnected. She lived with this hurtful secret and only after intense treatment was she able to divulge this truth. Like many of the women in this study, Lin was missing pieces of relational development with her lover. She needed him to be a part of her life and help her with finances, and raising her son. Similar to Corena, Lin's boundaries were blurry. And, similar to the other participants, Lin experienced shame and a sense of relational impossibility. Her shame caused her to be dependent and vulnerable. Miller (1988) has voiced her analysis of shame and calls it "condemned isolation" or "being locked out of the possibility of human connection." (p. 9).

I am conscious of the intersection between Lin's lack of mutual relationship with her partner and the discrimination she experienced. Mutual relationship or mutual empathy requires that one knows the other, be connected to the other, and develop the relationship with the other. Similar to Jane, the racism Lin experienced, taught her about the failure of mutual empathy (Jordan, 1997).

Summary

The barriers to the prevention of HIV disease are complex and numerous. Certainly alcohol and drug abuse interferes with personal judgment and provides a barrier to healthy thought and practice. In addition, women have historically been disenfranchised economically. When we add contributing factors, such as discrimination, family secrets, abandonment, betrayal, domestic abuse and the internalized shame involved with feeling permanently flawed, prevention barriers become synergistic. Although needing a man to help support the family is a piece of the barrier to prevention, the cumulative effects of the abuse in these women's lives are paramount.

It is also important to recognize that both Lin and Corena were not assertively angered by their belief that their partner infected them. Similarly, Ronnie, Jane, and Lori did not engage in dialogue that would bring me to believe that they were angry with their partners or abusers. When anger in a relationship is processed between mutual partners it can become a shared understanding. Miller (1983) and Stiver (1988) posited that anger in the relationship's subordinate member often becomes suppressed. This theoretical lens supports the notion that relationships that are not mutual are emotionally disconnected relationships. Being in a connected relationship means one person in the relationship does not objectify the other, but engages in affecting and being affected by the other. Each individual is interested in being known by the other and knowing the other. Participants in this study experienced disconnected relationships.

Conclusion

Participants in this study reported betrayal, domestic abuse, substance abuse, internalized shame, need for help with finances, and male support to help them raise their children. Many of the participants came from dysfunctional families whose parents were substance abusers and single parents themselves. The theme of silence and lack of voice was carried through childhood into their adult years.

Adult issues like the need for male support, superceded questions relating to monogamy and their partners' sexual practices. The ability to process anger was not part of the relationship. I believe these women had suppressed feelings of anger. These suppressed feelings emanated from their childhood experiences with abuse, neglect, shame and the lack of their parents' protection. Through appropriate processing anger can be moved to constructive and creative action. These participants chose to move their lives in a direction that they were able to control. They chose to tell their truth, and not harbor emotions of anger. Half of the participants decided to make sense out of their infections through a meaningful relationship.

Research Question Three

How Do HIV Positive Women Make Sense of Their Lives?

Barbara was 34 years old at the time of the interviews. She learned of her infection when attempting to sell her plasma for money to buy diapers. Barbara's parents divorced when she was a child. She lived with her father who she described as a "workaholic who was never around," and she described her mother as "an addicted speed freak" who eventually lost custody of her sisters and brothers.

> I was in the eighth grade before I ever stayed in the same school for a full year. Dad was in construction and we would move where there was work. And, mom and dad would run up bills that they couldn't pay for, so we would pack up and leave town in the middle of the night.

Barbara claimed that her uncle and maternal grandfather sexually molested her and other siblings and that the family had a long history of intergenerational incest. Barbara left her fathers' home at age fourteen and opted to live with foster parents. Barbara asserted that her dad was never home and that when he was home "he would try to make me get down on my knees, and pray to him. He thought he was Jesus." Barbara claimed that her foster parents were physically abusive and they reported her to the Department of Human Services (DHS) for "not minding." Barbara spent time at Radar Institute and Shadow Mountain Institute for psychological evaluation. Barbara never told the therapists' she spoke to about the victimization and trauma of sexual abuse. She was eventually released undiagnosed and lived in numerous foster homes. When Barbara reached the age of eighteen she became a dancer and was able to support herself. It was in the dressing rooms at various exotic dance clubs that Barbara learned that many other women had shared her secret of incest and sexual abuse.

Barbara described her abusive relationships.

> My husband would pimp me (sic) on the streets so he could buy drugs. When I refused, he would beat me until I was purple. I tried running away several times but he would find me and threaten to kill me. I am still scared of him. I eventually ran with my two biracial children to a small out of state town. There were no Black people living in this small Indiana town. I couldn't get a job or childcare. Eventually, someone complained to the Department of Human Services, because we had no food. They took my kids away. I heard a Black family adopted them. I never saw them again.

Like Sandi, Lori, and Corena , Barbara had her children taken away from her. She eventually moved back to Oklahoma, and remarried. When she received her results at the plasma center the doctor said to her, "you have AIDS and you will die within the next six months." Barbara desperately begged the doctor for bus fair or tokens to return home, but he refused. That happened five years ago. She didn't know what AIDS meant. When her infant son became very ill the doctor diagnosed him with HIV disease. She and her son, who is now five and one half years old, began treatment. Barbara began to learn about the virus that had invaded her body. Her husband refused to get tested, left the state and has refused to pay child support. The Department of Human Services is unable to find him. Barbara talked about her dreams. Her dreams explain how she makes sense of her infection.

> I have dead baby dreams. I'm going to visit my friend and I am pushing a baby stroller and I'm crying. I knock on my friends' door and tell her my baby died. I then push the covers back and there is this dead decayed body and his head falls off and rolls down the sidewalk. The other dreams I have had are even worse. I dreamt that I was in this building and there are a lot of people in there, adults and children. The building was full of terrorists and they were killing everybody. I had other kids, and I could see the significance of that since I have other kids I haven't seen in a while. These other kids were killed, but I begged the terrorists to let me hold Seth (her son living with HIV) while they killed him. Seth was saying the Lords Prayer and the whole time he's praying the terrorist gun won't go off. But, as soon as he finishes the prayer the gun goes off and Seth is dead.

Barbara's dreams exemplified the awareness that death and the loss of her children were a reality. The violent themes in her life were typified in her dreams. Barbara and Seth are relatively active and vital life still remains. They are connected by the maternal child bond, a common secret that must be kept in rural Oklahoma, and by dreams in which they are abandoned. Barbara continued speaking about Seth's dead mommy dreams.

> Seth is going to be six years old in a couple of days. He doesn't get a chance to forget he has AIDS. He takes medicine six times a day and he's angry. In his dreams he dies first and he tells me when he awakens, "Mommy I don't want to leave you all alone. Mommy sometimes I dream that you died. I don't want you to die first because then I will be alone." I tell Seth "I'm not going anywhere." I just want to hold him. You see I must be here to take care of Seth. I make sense out of this infection by staying alive for Seth. Seth needs to have someone to take care of him.

Dr Christiane Northrup, M.D., recently published a book on women's emotional and physical health (1996). In one chapter she described how feminine intelligence can help to heal the body, and how dreams serve as beneficial directions toward the place we wish to focus upon. Dr. Northrup wrote:

> The mind and the body are intimately linked via, the immune, endocrine, and central nervous systems. Today, mind/body research is confirming what ancient healing traditions have always known: that the body and the mind are a unity. There is no disease that isn't mental and emotional as well as physical. (p. 25)

Although Barbara's dreams are disconcerting, she continued to live throughout the horror of watching her children suffer. Barbara has survived a life of chronic abuse, abandonment, victimization and betrayal. Researchers have documented that women who survived childhood sexual abuse engage in self-destructive behaviors (Briere, 1989; Courtois, 1988; Dolan, 1991; Waller, 1992). These behaviors interfere with psychosocial interactions at the individual and community level. These behavioral reactions are demonstrated through chemical dependency, low self-esteem, psychological numbing, hypervigilence, guilt and shame (Bradshaw, 1996).

Obviously, Barbara has played out her life with some of the qualities characteristic of incest survivors. She has suffered long term consequences from incest, unbalanced relationships, and HIV disease. However, she has transcended victimization by developing a supportive relationship with Seth and by taking control of her present situation. Barbara's triumph is her survival, and her passion is making sure that Seth is provided with the best possible medical care. Recently, Barbara decided not to continue taking her medication. It was making her too weak, and therefore, she was unable to care for Seth.

Tara is another participant in this study. I met her about seven years ago. She had an insurance physical for life insurance and was unknowingly tested for antibodies to HIV. Her test indicated that HIV antibodies were present and that she was infected. Tara had just gotten married. She was approximately 40 years old. She was different than most patients I had seen in the clinic. She presented well dressed, articulate, and interested in accessing health and human services.

Her newly wed husband appeared to be the source of her infection. Several years ago he had a sore on his penis. It was probably herpes. He had also remembered having a number of sex partners. The herpatic sore made the transmission of HIV more sufficient. His T count was very low and he was very ill. He died a few years later.

Around six months ago Tara sent a message to me. She had heard about this research and wanted to be represented in the study. I went to her beautiful and immaculate home. She had just returned from a vacation in Mexico with her fourteen year-old-daughter. She was vibrant, happy and engaged to be married again. She was different than the other women I had interviewed because she appeared to have more material possessions. However, her life story was similar in other ways to the other women in this study.

Tara was the oldest of three children. She shared that her mother had bipolar disorder and obsessive compulsive disorder. Her father was an abusive man who beat the family puppy to death when she was around five years old. He later abandoned the family and married Tara's second grade teacher. Tara's mother went to work and all three children were responsible for cleaning the house daily. This entailed dusting every gadget, moving furniture out of every room, and vacuuming all the corners. Tara's mother remarried a man who worked three jobs to give Tara and her siblings everything they needed. This man molested Tara when she was a teenager. Her mom refused to believe her. Tara claims that she drank moderately and has always taken pain prescription pain medication for migraine headaches. Tara described her mother as her "best friend, but after she accused me of lying we fought like cats and dogs." Recently, Tara's younger sister disclosed that her stepfather repeatedly molested her for many years. Tara's parents are now deceased, and her stepfather is still alive. Her mother committed suicide around ten years ago and her father had a stroke while addicted to alcohol and prescription nerve medication.

Tara described her previous five husbands.

> I have been married a total of seven times, but I married two husbands twice. My first husband was physically abusive, alcoholic, very rich, and had teenage lovers who were boys. I had two children with my second husband who also drank heavily and beat me. He owned his own business. My third husband had a similar pattern. He drank a lot of alcohol, was physically abusive, had another female lover, and gave me anything I ever wanted. I always had one waiting in the wing. I thought I couldn't live without a man. The husband who infected me was kind. He was the love of my life and the best lover. I do not hold him responsible for my infection and I am not angry with him. I miss him so much and wish he was still alive. He was my one true love.

Tara describes herself as a very religious Christian who puts a lot of trust in God. She regularly visits her stepfather who is now elderly. He has admitted that "I have hurt you girls very much and I owe you both a lot." Tara described him as a religious Christian. Tara claims that "most girls have been molested." Tara said, "I don't hate anyone, you need to let go of hate."

Tara described how she makes sense of her infection:

> I am targeted all the time on Jesus. I behave the way he would want me to be. I have changed inside because of HIV. I have always been a Christian, but became baptized after HIV. I live a Christian life style. I do everything to help my kids. I want my kids to learn from this disease. I want my kids to learn not to get married to everyone. When you marry make sure that person is your soul mate and a Christian. Only my son knows of my infection. My daughter is only 12 years old, and she knows I am sick. If I tell her, I'm afraid she will tell everyone. I must be around to help my children cope. I will eventually tell my daughter.

Similar to Tara's perspective of infection, is Sandi's understanding of how she makes sense of this virus. Sandi feels like she must be around to help raise her grandchildren. She iterated that "nobody ever modeled proper behavior for me. I want to be around to show my grand kids right from wrong." Sandi is also very religious and feels like "this virus has helped put me on track."

> I no longer drink or do drugs, and I can think now. HIV was a wake up call. I gave my life to the lord, and stopped having all these wasteful relationships. My spirit was wounded before HIV. I want to be with my family the way God ordained. I now see how blessed I am. I have my kids. I want to survive.

Ronnie offered a similar view.

> Death is sitting on my shoulder. I feel the reaper sitting right on my shoulder sucking the life force right out of me. It's hard sometimes. I try and go on. I concentrate on my kids. I center on them instead of myself. God has a plan for me and I have to remember that when I'm ready to go he will take me. I was not a very nice person before I got HIV. Who knows where I would be if it wasn't for HIV. I was a pretty wild card. Maybe this is God's way of helping me to see all the good things in my life, like my kids. I can actually say that I'm a better person because of HIV. I'm not selfish anymore. I am more giving, patient, and understanding.

Lisa offered a different perspective on how she makes sense of her life with HIV.

> I don't ever think about HIV. I get no support from the staff, medical or other inmates. Prison is the worst thing that has ever happened to me. I need to get out of here. I need some decent food, and a decent bed. I need some privacy. I just want to live long enough to get out of here. Maybe I will buy a plant store. I have a little money left. Once I leave here

> I will be able to get support from the community. These people in here, they just don't give a damn. There ain't (sic) nothing in here for me, just nothing. It's like I don't even have HIV. If I am in pain or something, nothing can be done. Maybe I'll live long enough to get out of here and see my boys again before I die.

Lisa can't make sense out of her infection because her disease is secondary to her will to survive prison life. I believe that she needs all of her energy to walk across the yard to consume the nutrition to sustain life. She barely receives medication and if she complains about her health she will be sent to the maximum-security woman's prison. The maximum-security has an infirmary and physician. And, the prison is surrounded with barbed wire, fences and armed guards. An inmate cannot move throughout the prison grounds without permission. The oppression would be daunting to a free and easy spirit, like Lisa. Lisa longs to have a relationship with her grown sons. She hasn't seen them in the four years that she has been incarcerated. Lisa makes sense out of her infection by living long enough to be a free woman.

Summary

Women living with HIV feel the need to live the remaining portions of their lives by being connected to those they love. Participants have taken responsibility for HIV disease and try to make sense out of the disease through love of a higher power, the need to be giving, and not repeat the dysfunctional patterns of their own family of origin. Many of the participants feel like the disease has caused them to have a greater understanding of what is important to them, mostly their children. The participants in this study want to go on living.

Conclusions

Participants in this study did not express self-pity for living with HIV disease. Mostly, they chose to make the remaining time that they had meaningful by connecting to a relationship. HIV disease is a dis-empowering affliction that destroys the immune system and the availability of vital organs to function. However, the participants seemed more in control of their lives than when they were in an addictive state or living their life under the control of another person. HIV offers freedom in a sense. Many of these women are frail, and have lost the luster of healthy skin, body and vitality. Their honesty is profound because they have lost their attractiveness to men, the drug scene, the workforce and society. They are mostly isolated, abject, and free to think about themselves. They are no longer in dysfunctional relationships or exhibiting co-depended behavior where everything they do is for the benefit of someone else. Now, they are able to live their lives the way they want, without fear of reprisal. These women are survivors of severe trauma. The trauma they have experienced has taught them to be courageous.

Summary of Research Questions

Using descriptive qualitative measures, the three research questions were addressed through in depth, long interviews that were semi-structured. Data for question one included demographic information as well as the life history of the participants', drug and alcohol abuse, physical and mental health, family dynamics, and history of abuse. Data for question two described the barriers to prevention and looked at the participant's familial/social relationships. Data for question three was gathered through individual interviews and explored women's need for spirituality, and relational development. Data was subjected to a coding scheme to account for which participants indicated similar or differences in their responses.

The Focus Group

The focus group was held at an AIDS service organization in Tulsa, Oklahoma. Six women attended the group. One woman was incarcerated, and three women were unable to attend. I called three of the women and gave them the information that resulted from the group meeting. The women listened, and one absent participant added to the list of risk factors suggested by the group. During the focus group we discussed the similarities and differences of the demographic information and the similarities and differences in the life histories of the participants.

Then, as a group we listed all the risk factors women face pertaining to HIV disease. We engaged in a dialogue about the barriers to prevention. Women attending the group mentioned the following risk factors for women:

1. If you have experienced child sexual abuse (including incest).
2. If you have experienced domestic violence (adult or childhood).
3. If you abuse alcohol and/or other drugs.
4. If you have childhood and adult abandonment issues.
5. If you are in a relationship where you are disrespected because you are female (gender inequality).
6. If you need a partner to support you.
7. If your partner is bisexual.

8. If you have suffered from oppression.
9. If you think that the prevention messages portrayed by the media are not meant for you.
10. If you are suffering from Post -Traumatic Stress Disorder (PTSD).

Individuals who have experienced a traumatic event oftentimes suffer psychological stress related to the incident. In many circumstances PTSD reactions are normal happenings to abnormal situations (Tannenbaum, DeWolfe,& Albano, 1999). The following are symptoms of PTSD and have been expressed by the participants in this study.

A) Recurring thoughts or nightmares

B) Feeling emotionally numb, withdrawn, disconnected or different from others.

C) Having difficulty making decisions.

D) Feeling depressed, sad and having low energy.

E) Experiencing anxiety and fear, especially when exposed to events or situations reminiscent of the trauma.

A formal assessment for PTSD was not included in this study. I did not want to include PTSD in the prevention model because it is a clinical term used by therapists and psychologists for diagnostic purposes. However Mona, the tenth participant in this study, insisted that it be included. Her life history is very similar to the other women in this study. She was sexually abused, abandoned by her mentally ill father, unaware that women were at risk for infection and had bi-sexual lovers. However, Mona is different. She was lured into the drug scene by the "poetry and music of the 70s." She claims she "was determined to be an addict, by age 15, and loved the drug scene." Mona was a sex worker who supported her own drug habit. She spent time in jail, lived in a homeless shelter, and never relied on a man to support her or her habit. Mona does not have a formal education, but is extremely knowledgeable. Today, Mona is a licensed practical nurse and is probably correct in her assessment. PTSD appears to be a risk factor for women. Mona explained her position.

> In retrospect, I know I had Post-Traumatic Stress Disorder from being molested and raped. My mother wanted me to just forget about it. She was too busy concentrating on her own love life to pay attention to me. I defied her by escaping into the drug scene. I ran away from home, and was constantly depressed. I liked being an addict, and I always held my own stuff. Guys came to me if they wanted drugs. Towards the end, I was going down from all the speed. I was pathetic, paranoid, and lost everything. Trust me addicts' escape the real world through drugs. They need to escape because the real world is so painful. Addicts go through life being in shock from all the abuse and shame. It's a vicious cycle.

Mona's poignant statement highlighted the severe anxiety she experienced. Mona carried the secret of sexual abuse so that her mother could avoid the shame and embarrassment that going public would have caused. Mona was obedient to the rigid rules and hierarchical control, until she was old enough to run away from the poisonous pedagogy of the dysfunctional family system. She felt flawed as a human being and engaged in self-destructive behaviors. She experienced boundary issues. Mona would not let a man take care of her, but engaged in sex work when she needed money to buy drugs. Her testimony during the focus group added insight to the prevention model, and stressed the notion of oppression as a barrier to prevention.

I had hoped during the focus group meeting we would determine a name or acronym for our model, but one did not emerge. However, a month later I was at the

National HIV Prevention Conference in Atlanta. This was the most exciting and stimulating conference I have ever attended. Researchers from all over the country presented the latest in HIV prevention, treatment and care. Later that evening I was thinking about how the presenters were focused on the importance of contextual messages and language. I imagined the name of the prevention model. I returned to Tulsa and called the participants in the study. They all agreed that the prevention model would be called WARN, Women At Risk Now.

CHAPTER V

SUMMARY OF FINDINGS, RECOMMENDATIONS FOR FUTURE PRACTICE, THEORY POLICY AND RESEARCH

Introduction

At the National Human Immunodeficiency Virus Prevention Conference, I met an HIV prevention educator, and psychologist whose job was to speak with Jewish communities concerning the prevention of disease. He told me that in New York some Chasidic men were infecting their wives and that the women were "going underground" to learn about where, and how, to access HIV medical-related services. He reported that the women were afraid of their husbands and the domestic abuse that accompanied dialogue about HIV disease. I then called my sister-in-law who is a reading specialist at a Jewish day school in New York. She teaches some children who are of Chasidic ancestry. She told me that she knew of the underground domestic violence shelters for Chasidic women. She iterated what the psychologist in Atlanta had told me about the sex practices of the Chasidim. Multiple sex practices are sanctified for the dominant gender within this sect of people. She told me what I had remembered about orthodox Judaic practice. It is difficult to attain a *get* if you are a woman. A get is a divorce in Judaism.

I am disappointed that my own people could be this provincial, and I remain saddened for the Chasidic women who are abject and marginalized. I am reminded of the statistics that imply that one out of every three adult women will be a victim of domestic violence (Flitcraft, Hadley, Hendricks-Mathews, McLeer & Warshaw, 1992). I am reminded of the women in this study and the abuse that has permeated their lives. Given this information, and the HIV prevention models that have been deconstructed in Chapter II, it is imperative that HIV prevention educators abandon prevention practices that are not applicable to women. In addition, new theories must constantly evolve as the disease changes course, and women become the category with the highest HIV seroprevalence.

Summary of Findings

Childhood sexual abuse, familial dysfunction, low self-esteem, and domestic violence were common experiences among participants in this study. In addition, the women in this study experienced childhood neglect and chemical use and dependency. Male dominance, or the unconditional need for a man, was also a common thread for women participating in this study. Women in this study lacked assertiveness in relationships with men, were victimized, abandoned, and displayed survivor behaviors. They were reticent to question their male lovers about past sexual history and sexual orientation. They were willing to be connected to a man, even if he was not mutually involved in their lives or the relationship.

Many participants indicated that they needed a man for sex, drugs, or income. This information fits with Amaro's (1996) understanding of high risk factors for women reported in Chapter II. She outlined four points that need to be addressed for understanding women's high risk sexual behaviors: (a) women's unequal social status, (b) women's sexual behaviors: (c) women's male partners and their risk factors, and (d) women's experiences with domestic violence, sexual abuse, and fear of violence. The information gleaned from the participants' experiences speaks to the perceived economic disenfranchisement of women, and the perceived need to have patriarchal presence when raising children.

Half of the participants expressed the need for connection to loved ones in their lives. They made sense of HIV disease by being mentally and emotionally present for their children. They wanted to spend the remainder of their lives in relationships where they were free from the violence and maltreatment they had experienced in past relationships.

The women in this study are literally and figuratively survivors. Naming and acknowledging HIV disease, sexual abuse, abandonment, chemical abuse, and dysfunctional familial patterns seem to have lifted the shroud of secrecy, abjection and silence in these participants' lives. For example, Chew (1998) wrote on the victim to survivor identity.

> As the victimization experience is identified, its impact is explored, and steps in the healing process are gradually taken. The individual acknowledges the presence of inner strength and the ability to cope. These resources may have existed well before the counseling process itself. As a result, personal and political change can be realized (p. 18).

It is important to note that naming and identifying language, such as victim and survivor, places feminists in a framework of "replicating a traditional mental health paradigm" (Anderson & Gold, 1994, p. 7). It is not my intention to categorize the women in this study, but rather to demonstrate the power of story, and how it can provide a pathway for change. Although all of the participants in this study received mental health counseling prior to the interviews, some continued to change throughout the interview and focus group process. This personal movement "toward knowing reality in order to transform it" has been identified by Lather (1991, p. 68) as catalytic validity.

Catalytic Validity

Toward Self-Reflexivity

Before recognizing the movement of many of the research participants, I would like to take this opportunity to disclose how praxis-oriented research has helped me to transform the way I facilitate HIV prevention education. Although I recognized that the prevention models are male ethnocentric, I did not realize they were rooted in utilitarian instrumental philosophy. In other words, said models weigh the cost of HIV disease against the benefits of not contracting such a medical malady. By listening to the women's stories it became understandable how such utilitarian philosophy was an unknown construct, or that it was so abstracted that it was unavailable for process. The participants' lives had been ridden with neglect, abandonment, and abuse, disqualifying them from the pragmatism needed to practice life-sustaining behavior. I believe the participants in this study experienced reality-changing life events that became barriers to prevention. HIV disease is an outcome of the oppressive circumstances they have experienced.

Theory can help people to understand the current state they are in and can help to move them out of their current situations and into a more healthy space. A common language helps people to name what has happened in their lives. Often these names such as child sexual abuse, domestic violence, abandonment, chemical dependency and low self-esteem were the barriers to prevention in the participants' lives. Contemporary theories need to change and reflect said experiences of women. Participatory research is needed for participants to understand the sociocultural demographics that have had a realty-altering impact on their lives. Current theories need to espouse the causes of HIV disease in women from those who have come to know from their own situations, not solely from the data collected by the researcher. However, by combining the lived experiences of the participants and the empirically driven data of the researcher, theory and application can be assessable to at-risk women and prevention educators.

Our Evolving Lives

Not all of the participants in this study had change in the course of their lives as a result of this research. However, the following examples indicate movement in the lives of some of the participants. In some cases the movement has affected more than the individual and branched out to affect individuals living in the community.

Sandi – At the 1999 Women, Children's, and AIDS Conference, Sandi spoke in front of approximately 400 women. This was her first speaking engagement in which she told her story. About a month later Sandi spoke at another public forum. Nabisco corporation officials were in Tulsa. They were giving the food pantry a grant to help HIV challenged people to attain nutritious food that otherwise would have been unaffordable. Sandi spoke in front of the television cameras and explained how most services were designed for men. She complemented Nabisco on supplying funding for a service that would benefit women and children.

Sandi continues to be vocal about lack of medication that is available and helpful to women. Her growth is amazing and cannot be totally attributed to this study. However, our dialogue helped her name the issues in her life that prevented her from being safe from the virus.

Ronnie – Ronnie had been telling her neighbors that she was living with cancer. During our conversations she told me "I am tired of lying." I suggested that she come to the women's conference and attend one of the round table discussions that was going to be facilitated by HIV positive women. I gave her the telephone number of the AmeriCorp workers who were arranging scholarships for HIV positive women. At a conference-planning meeting, I heard that Ronnie participated in the opening film. The film was shown during the conference. Ronnie voiced what it was like living with HIV disease for more than ten years and what it is was like to live in a state of isolation. She later told me that her brother was furious with her for self-disclosing the truth on camera. Nevertheless, Ronnie told me she felt "good about coming out."

Mona – Mona now works at an AIDS service organization. Her job is to outreach to female injection drug users. She offers clients HIV antibody testing, and if positive, she links them to treatment and care. Mona sits on the state's HIV planning committee, and influences how dollars are spent for HIV prevention and care.

Lori – Lori worked for an AIDS service organization when we interviewed. However, she has now changed her presentation and is no longer articulating the "use a condom message." Lori speaks to high school students and now uses the Women At Risk Now Model to identify high-risk teens. She carries with her a book of resources and refers those requesting additional health and human services.

Barbara – Barbara and her son, Seth, also appeared in the film that debuted at the women's conference. Barbara spoke at the women's conference about her risk factors. She warned women to take care of their sexual health and to seek help if they had circumstances in their lives that would place them at risk. This was the first time she spoke about her disease in public. She is now speaking out about the lack of HIV-related medications for women at public health forums. More importantly, she has accessed counseling services for herself, and her son.

Lisa – Lisa is now taking a role in the peer education program for women who are incarcerated. She facilitates monthly meetings where she speaks about her drug use, and its connection to HIV disease. She speaks about her perceptions of the causes of HIV disease in women and has input into the curricula for the peer education program.

The Human Condition

Six of the women in this study have demonstrated inner change or movement toward social justice as a result of the interviews and new prevention model. Four of the women are very weak and are suffering from wasting syndrome. However, they continue to speak to me about the lack of helpful medication. They want others to know that the medicines are not helping them, and that more research is needed on women that will lead to drug efficacy. They continue to question "why" the drugs appear to help men and not women. Their doctors have admitted that very few clinical trials exist for women. I will continue to carry their message, especially when I address state legislators this year, and work to help others understand the importance of the inclusion of clinical trials for women.

One woman is using addictive drugs again. She has engaged in unprotected sex with her lover, and has abandoned her children. She has run away from home and her lover has sought counseling in the community. I believe that she is shamed over her addiction to crack cocaine and other drugs. I know that her physical condition has deteriorated, and that the thought of impending death must be contributing to her need to emotionally and physically escape. Although she has exposed her lover to the virus, he still does not know if he is infected because of the six-month window period. She must feel shamed, thinking that she may have infected him. Who will take care of her sons if the father figure becomes ill? The more she thinks of the pain that she has caused her sons, and her lover, the more she masks her own terror through chemical abuse. This woman is an example of how the media has portrayed a chemically dependent woman, who has an even more complex illness named HIV.

Before moving to the practical, theoretical and policy implications of the study, I address the Related Questions of the study.

Related Questions of the Study

Question One

How Have Women Been Constructed in the Media Portrayal of the HIV Epidemic?

By now all of us have heard of Rock Hudson, Ryan White, Greg Louganis, Liberacci, Freddie Mercury, and Magic Johnson. These icons have been used by the media to engage in discourse about HIV and AIDS. But, where are the women? From the beginning of the naming of this disease women have been infected, but the media has focused on the gay life style of this disease. Few exceptions to the homophobic media portrayal have existed. As mentioned in chapter two, Ryan White is an exception. Like Ryan, Magic has been portrayed as blameless. Magic is an exception to the abjection experienced by many gay men and injecting drug users. However, other than Kimberly Bergalis, who was portrayed as a helpless victim of psychopathic behavior, women remain relatively invisible.

As late as 1985, the surveillance definition of AIDS did not include gynecological symptoms as an AIDS defining diagnosis. Gynecological manifestations began to develop in women infected with HIV, such as, chronic yeast infections, cervical dysplasia and cervical cancer. Still, women were omitted from clinical trials, and these gynecological problems were not added to the list of AIDS defining diagnostics. This meant that women could not receive any benefits from social security, Medicaid, or AIDS Service Organizations. I know of several infected women who were dying of cervical cancer, and who were unable to access housing needs. These omissions inhibited recognition of disease in women, and allowed for more dollars to be spent on infected men (Tessier, 1997). In other words, women were invisible to the epidemic. Research projects that studied the manifestation of disease in women were few in numbers.

In 1985 a group of female physicians decided to include women in research. They conducted a study on HIV positive women in San Francisco. The study was referred to by male colleagues as, "The Prostitute Study." However, less than one third of the participants were sex workers (Corea, 1992). The naming of women with HIV, as "prostitutes" was not only a form of abjection, and sexism, but it pathologized women as the vector of disease transmission to men and children. Another example of the media's portrayal of the female infected prostitute can be seen in the case of Elizabeth Prophet. She was an imprisoned sex worker and drug abuser who was being considered for parole. The media did not voice a concern for Elizabeth's health, but rather voiced a concern for the men who would use her (Corea, 1992). It is obvious that the media's discourse portrays women as sexual dangers. This theme has historical significance. For example, around 3,000 BC the Israelites were at war against the Midianites. The victorious Israelites captured and raped the Midianite women, resulting in an unidentified STD, commonly thought of as Gonorrhea (Llewellyn-Jones, 1985). The men were quarantined until they were well, while the women were put to death (Wilton, 1998).

A more modern version of the woman as a source of contamination can be seen in posters of syphilitic women. These images lined army barracks during the world wars, warning men of the dangers of sexually transmitted diseases and the promiscuous women who served as vectors of transmission. Today, women are portrayed as the transmitters of

HIV disease. Corea (1992) noted "the intense irony of blaming women for spreading a disease while simultaneously reassuring them they are unlikely to get it" (p. 128).

Summary

Juxtaposed to the woman as vector of disease is the invisibility of the woman with HIV. From 1981 until 1993 the CDC did not recognize any opportunistic infections found in women that could indicate an AIDS diagnosis. In 1993 the epidemic was 12 years old. Centers for Disease Control and Prevention changed the AIDS defining definition to include opportunistic infections found in women. I can remember a poster that read "Women don't get AIDS. They just die from it." Failure to recognize women as a high-risk group contributed to a lack of awareness for women, and physicians.

This lack of awareness, fostered by the media and medical community has dramatically contributed to the increase of HIV in women. Further, the number of women infected heterosexually with HIV increases each year (CDC, 1998). Reports suggest that women are likely to die from advanced HIV disease earlier than men. One reason for this is that women are often misdiagnosed with other illnesses and learn about their HIV status well into the advancement of the disease.

An example of the lack of awareness can be seen in the case of Judith Billings. Judith is an attorney and former superintendent of Washington State Public Schools. She was becoming weaker and more ill each passing day. She was hospitalized more than a dozen times and still no diagnosis was conclusive. Judith is White, married, and of upper socioeconomic status. In 1994 Judith developed severe pneumonia and was dying. The doctors were baffled. A physician suggested that Judith test for HIV. Judith was not a sex worker. She did not use injection drugs. She believed her husband of twenty years was monogamous. She later disclosed that she had been unsuccessfully artificially inseminated in 1987, before donor guidelines were implemented. Judith tested positive for antibodies to HIV. However, it was too late for the drug cocktails to be beneficial; she already had digressed to AIDS. Judith now works for President Clinton and is chairwoman of his advisory board on AIDS. I saw her recently. She was frail and suffering from wasting syndrome. She told me, "If only I tested sooner. I just didn't know that women could become infected."

Conclusion

The media has left women out of AIDS discourse. For many years women went undiagnosed and eventually died of AIDS. Their unique infections did not constitute an AIDS diagnosis. This left infected women with little or no resources. When they are included, words like "prostitute" and "drug user" are employed to describe women as the sources of infection. This form of abjection further marginalizes women and pathologizes their existence.

Question Two

How Have Women Been Constructed in the Health Education Theoretical Models That Have Been Employed for HIV Prevention?

Women have not been constructed in the health education theoretical models that have been employed for HIV prevention. Prevention educators have taken many of the theoretical models described in Chapter II, and adapted them for women. The models have been used for women who inject drugs, and to give women communication tools for condom negotiation. However, as the number of women infected with HIV continues to rise, I question the efficacy of the models. I challenge the notion that women without economic power can actually negotiate effective condom usage. In addition, through personal stories of women who inject drugs, I have come to understand that when a woman is in need of a fix "the cleaning of works," to inject drugs, is less than paramount. The omission of the unique needs of women in the HIV prevention models has contributed to the turning tide of infection for women, and is congruent with women's disenfranchised position in society.

HIV prevention educators often have an authoritarian approach to HIV prevention. The use of male centered HIV prevention models is an example of a top down approach. Professional public health educators often teach the models to women who access county health departments. The implication is to live a good clean life for the families' well being. The notion is that women should be good wives and mothers. The needs of women have been excluded in the health education theoretical models that have been employed for HIV prevention. However, women are expected to change their behavior according to the expectations of the models that have been designed for men.

In contrast, men have been the theorists of the health education theoretical models that have been employed for HIV prevention described in Chapter II. Because of the hegemonic and unequal axis of gender power relations, health education materials have been designed to fit the needs of men. These male texts promote ideology that calls for philosophy rooted in utilitarianism to keep safe from infection. Messages like "use a condom," and "do not share works," are employed to help individuals understand the cost of the virus as compared to the benefits of not becoming infected. In addition the models speak to the issue of self- efficacy and self-preservation. They do not consider women's developmental theory, relational concepts, economic inequality, sexism, or racism. The models do not consider the historical unequal status of women.

Summary

Unfortunately, HIV prevention models have focused on an individualistic notion of behavior change. These models were initially designed for men and do not consider the context of women's lives. Equally abandoned by these models are the effects of sexism, racism, and economic disenfranchisement. The noted prevention models call for behavior modification without considering the oppressiveness surrounding the context in women's lives. Women have not been given a voice in said models, and the prevention messages attached to these models discount the structural influences that place women at risk.

Conclusions

Women have been encouraged by the prevention models to be the providers of good clean living for their husbands and children. Women who are perceived to be the vectors of disease transmission are expected to modify their behavior using a model of behavior change rooted in patriarchal philosophy. The objective of the behavioral models is to help women to recognize their risk, and to change their behavior for the protection of men and unborn children. There are no acknowledgments that women have needs that are not connected to being a wife or mother.

Women are now contracting HIV disease more frequently each year. Prevention models need to focus on the contextual issues in women's lives, and must implement effective strategies to cease the rising seroprevalence in women. The following sections contain recommendations for future practice, theory, policy development, and research.

Recommendations for Practice

1. Provide culturally sensitive, gender sensitive, and diverse sexually orientated HIV prevention education materials.
2. Expand HIV prevention to comprehensively address issues germane to women such as childhood sexual abuse, domestic violence, substance abuse, socioeconomic imbalance, and family dysfunction.
3. Provide resources that are woman-centered and that can address the traumas in women's lives.
4. Provide parenting classes that support the notion of a functional family system.
5. Provide HIV materials that address gender and power inequality.
6. Incorporate participatory research methods to develop HIV curriculum.
7. Design HIV curriculum that is problem posing.
8. Provide HIV prevention and treatment clinics that are facilitated by women and that are sensitive to the needs of women with respect to race, class, and sexual orientation.
9. Use peer education to disseminate HIV prevention messages.

10. Include women who have sex with other women in HIV prevention messages.
11. Develop human sexuality curriculum that is conceptualized on the basis of female parameters.
12. Provide education for women that includes methodology on self-sexual gratification.
13. Provide education that gives women the option of transforming the meaning of sex from sexual penetration to sexual pleasure.
14. Prevention educators need to take social responsibility for change by identifying oppressive structures and changing the way we present HIV prevention discourse.
15. Offer HIV prevention education in penal facilities, and alcohol/drug treatment centers.

Summary

The increase of HIV disease among women suggests that current public and private prevention efforts are insufficient. HIV prevention messages for women need to be purposefully designed to meet the comprehensive needs of all women. Women who represent diverse ethnicity, socioeconomic level, and sexual orientation need to participate in the development of HIV prevention and intervention strategies that are designed to fit the holistic needs of women. HIV prevention must be designed to help women acknowledge, and overcome the barriers to prevention such as sexism, poverty, patriarchy, racism, and violence.

Conclusion

From the beginning of the HIV/AIDS epidemic, women have had to try and understand HIV prevention messages designed for men. For women the co-factors for disease transmission include, the dysfunctional family system, childhood sexual abuse, poverty, gender inequality, domestic violence, substance abuse and racism. Yet, our current prevention initiatives do not consider the co-factors in the development and implementation of prevention programming. Women must link with one another to find more comprehensive, and alternative ways of delivering HIV prevention messages.

An example of an alternative way of teaching HIV prevention to women can be found in feminist literature. Richardson (1993) posits that we should redefine forms of sex that are often seen as second best. Instead of prevention educators promoting that sexually active females carry condoms, educators could encourage new meanings for sex. Prevention educators could teach adolescent females to focus on discourse related to erotica, and on strengthening the relationship through intimacy and dialogue. This form of communication could help young women to avoid, or at least minimize contact with violent young men, and increase the opportunities for female sexual choice.

Recommendations for Theory

1. Challenge the notion that HIV prevention theory designed by members of the academy is confirmable and transferable for all women.
2. Explore the context of patriarchal structures that develop HIV prevention theory for women.

3. Incorporate participatory research methodology into the development of HIV prevention theoretical models for women.
4. Explore the experiences that have been used to generate HIV prevention theory.
5. Develop HIV prevention theory that is contextual to the needs of the diverse female population and develop theoretical models that fit the lives of women who have been traditionally silenced, and perceive themselves as powerless.
6. Use language in HIV prevention discourse that is culturally appropriate.
7. Develop alternative ways of collecting and analyzing data for theory development.
8. Explore ways to include multiple philosophical perspectives when generating new theory.
9. Challenge the existing categories developed by Centers for Disease Control and Prevention that determines the mode of HIV transmission.

Summary

The aim of HIV prevention theory for women is to help women understand, and be conscious of the issues, concerns, and barriers surrounding the prevention of HIV disease. For this to occur, prevention educators, and theorists must work with women from diverse economic, racial and sexually oriented backgrounds to bring about dialogue that leads to meaningful and purposeful prevention messages. These messages must be applicable and accessible to the women who remain at risk for disease. All women need to have access to meaningful prevention messages.

Conclusion

New theories and new theoretical models must be developed to meet the challenges of the changing face of the HIV epidemic. One way to accomplish this task is to apply conscious raising notions during HIV prevention workshops. Then, theorists can evoke women's own ability to think and critically analyze their own experiences, by comparing their own situation with the other women in the group, and also with the experiences of the theorist. Barriers to prevention may emerge that then begin to broaden HIV prevention for a group of women that traditionally have not experienced voice. Banzhaf and Bellamy (1998) posit that "a conscious recognition of one's own oppression is part of the process of empowerment" (p. 104). A participatory theoretical design used for the developmental of HIV prevention for women, challenges the distinct role of theorist because the theorist is going to have to self-disclose her own experiences to make the dialogue more meaningful.

The WARN model is an example of a participatory research project that resulted in the construction of a theoretical HIV prevention model for women. This model will now be used to identify high-risk women. Theories need to be designed and implemented with the notion that that they are not metanarratives. I believe theorists should incorporate multiple theoretical lens when designing HIV prevention theory.

I am aware that I was unable to split my psychological/counseling orientation and training from the notions espoused in poststructural/postmodern theory. For this reason, I believe that theorists need to acknowledge the way that we categorize diverse theoretical perspectives, and begin to incorporate new ways of combining and looking at diverse theoretical perspectives. Because, without the use of empathy, I would not have been able to attain the highly personal and implicit information used to develop the WARN model.

Recommendations for Policy

1. HIV/AIDS prevention policy agenda must reflect the realities in women's lives, including the impact of childhood sexual abuse, domestic violence, substance abuse, racism, and women's unequal economic status. Funding from local, state and national government must be spent for the development and implementation of woman-centered research that includes the prevention and care of women living with HIV disease.
2. Effective HIV prevention messages must reflect gender and power analysis. Local government needs to mandate the State Department of Education to incorporate gender and power relationships into school curriculum.
3. Women who notify their partners of their positive HIV serostatus must be protected against violence. Although the women in this study were not victims of violence because of partner notification, this recommendation could benefit like women.
4. Women living with HIV/AIDS need to be self represented in government and must be involved in prevention planning, and treatment for HIV/AIDS, at the local, state and national level.

5. Policy should provide resources for the development of new prevention methods. Women must have prevention methods that they can control without their partners' knowledge.
6. HIV prevention messages for women must be contextual. Racial and ethnic differences do not put women at risk, and are not barriers to HIV prevention. Racial differences and ethnic pride can be sources of empowerment for women. Funding should be made available which fosters interventions that promote ethnic pride.
7. Funding for new curriculum needs to be developed that promotes woman-centered HIV counseling, treatment and care.
8. Partnerships between government and community-based organizations need to be developed so they can provide medical services that are in the interests of women.
9. Treatment for women must be holistic and reflect the comprehensive physical, emotional, and spiritual needs of women.
10. Mandatory testing of pre-natal women must be recognized as an attack on women's reproductive rights and criminalization of prenatal transmission must be explicitly exempt by legislation. Although the women in this study were pregnant prior to infection, or childless, these recommendations could help like women.
11. Policy needs to mandate that penal systems provide medication for those offenders living with HIV/AIDS.

Summary

In 1995, Public Health Service published guidelines focusing on universal counseling and voluntary testing of pregnant women (CDC, 1995). The American Medical Association has chosen mandatory HIV testing for all pregnant women and newborns (Institute of Medicine, 1998). Mandatory HIV testing is a violation of human rights and will have a disproportionate negative impact on low-income women, especially who are of minority ethnicity. Minority women have been traditionally devalued and have been burdened with the brunt of punitive reproductive health policy. Mandating HIV testing will further abject, marginalize and ostracize those women needing support the most.

We live in a society that is permeated with sexism, racism, and unequal economic opportunity for women. These social injustices' further magnify the female risk factor for HIV disease. Therefore, it seems reasonable that policy makers provide resources that will foster women's health. Policy implementations need to reflect primary, secondary and tertiary prevention for women. For example, funding should be available to provide woman –centered prevention, and treatment centers. In addition, funding should be generated to develop gender/sexuality education for women. Comprehensive treatment for women who are victims of domestic abuse should be available, regardless of their HIV serostatus, and incarcerated women who are infected should have access to medication. Women need to have access to services that address women's issues that are void of patriarchal discourse and practice.

The intersection between HIV disease and violence perpetrated upon women has broad implications for lawmakers and policy makers. The formulation of policy that addresses HIV prevention and care, needs to reflect the perspectives of women, in all their diversity, to ensure the just and fair treatment of all women. The burden of educating the public of the need for woman-centered prevention and treatment should be fostered by policy development from all levels of government.

Conclusion

To guide the changes suggested by said policy recommendations, HIV prevention advocates of women must educate state, and federal legislatures. These recommendations provide a framework for considering HIV policy initiatives at the local, state, and federal level that respond to the comprehensive needs of women. Ultimately, local, state and federal policies must reflect an increase in funding for the development and implementation of woman-centered comprehensive HIV prevention, and treatment initiatives. These initiatives are needed to stop the permeated oppression that has formed the barriers to HIV prevention for women, and to provide the necessary treatment for women.

Recommendations for Future Research

1. Focus research for the prevention of HIV disease in women, that emanates from the perspectives and experiences of women.
2. Design research for the prevention of HIV disease that addresses the multiple dimensions of the female experience.

3. Allow women to participate in the clinical trials for HIV prevention, and HIV-related medications.
4. Develop new medications and develop new HIV combination therapies used to treat women who are infected with HIV disease.
5. Provide research to ascertain the efficacy of needle exchange programs. Even though the women who participated in this study did not become infected through the sharing of drug paraphernalia, this research could help like women.
6. Provide research opportunities that would explore new methods of gathering information needed to develop HIV prevention curriculum for women, and human sexuality curriculum from the perspectives of women's lives.
7. Provide research that would explore the efficacy of woman-centered HIV prevention and treatment centers.
8. Provide research to explore the outcomes of teaching gender and power issues for the prevention of HIV disease in women.
9. Provide research that explores the efficacy of participatory research, and how to engage women who have been traditionally disadvantaged into the research design.
10. Provide research for women which is meaningful and insightful about behavior change in the lives of women.
11. Provide research on how women who have experienced childhood sexual abuse, dysfunctional family systems, domestic violence, abandonment,

post-traumatic stress disorder, and substance abuse can learn to practice healthy behaviors.

12. Provide research that focuses on how women's values, beliefs, and practices related to gender and sexuality effect barriers to prevention.

Summary

Women have been omitted from research relating to HIV prevention (Wingood & DiClemente, 1996). Women are often excluded from clinical trials surrounding HIV prevention and treatment. In Tulsa, Dr. Ralph Richter is part of a national HIV prevention vaccine clinical trial. Men can become research participants by stating they are high risk for HIV disease because of their sexual behaviors. In contrast, a woman wanting to participate in this research must bring documented proof that she has had three STD's within the last year. I have discussed this sexist practice with Dr. Richter many times. He does not set the research criteria. The criterion is constant for all seventeen states participating in the research design. This sexist practice is an example of the kind of discriminatory practice that excludes women in clinical prevention studies.

In addition, women have been excluded from clinical drug trials. It is my experience that women have been excluded because of their potential to become pregnant, and harm to the unborn fetus may occur. However, if women continue to be excluded from clinical trials we will continue to lack the data needed to find combination drug therapies that are effective for women. Similarly, we have no data on the outcomes of teaching human sexual relations combined with gender and power issues, and HIV prevention for women.

Conclusion

The HIV/AIDS epidemic has increased most dramatically among women, especially during the last decade. The impact of HIV disease has been disproportionate in the African-American and Latino female communities. AIDS is now the leading cause of death of women ages 25-44 and the leading cause of death among African-American women. Of the reported AIDS cases in 1997 among 13-19 year olds, 49% were women. Women account for 32% of adult cases of HIV infection reported from July 1998 through June 1999. Reports suggest that women are likely to die from advanced HIV disease earlier than men (CDC, 1998).

Researchers must focus prevention efforts on the root causes of disease in women to halt the increase of female transmission. Causes such as poverty, childhood sexual abuse, chemical dependency, domestic violence, and the promotion of women's role in society must be further explored, and combined with HIV prevention. Prevention messages must be contextual and fit the needs of the diverse female population. Women must work together to engage with the needs of all women (e.g., heterosexual and lesbian) for education about the barriers to HIV prevention that is accurate, explicit and useful.

Women researchers must work to alter the criterion set forth by male hegemony that excludes women in clinical trials. In addition, woman-centered counseling and treatment programs must be researched and evaluated. The barriers to HIV prevention for women are interrelated. Research and analysis must be brought to public attention to help shape prevention messages that will fit women's lives, in all of their diversity. Finally, researchers must listen to the women who are on the front lines of the epidemic. This means using more qualitative research, and women's stories to promote effective and useful HIV prevention for women.

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APPENDIXES

APPENDIX A

FIRST ROUND INTERVIEW QUESTIONS

First Round of Interview Questions

1. What is your full name?
2. What is your date of birth and where were you born?
3. Tell me something funny about your childhood.
4. Tell me something funny about your parents.
5. Describe a typical family dinner.
6. What do you remember about the town where you lived?
7. How many siblings do you have, and what role did you play within your family?
8. How would you describe your relationship with family members?
9. How did the members of your family get along with one another?
10. Describe your first date.
11. When you were an adolescent, what did you do on the weekends?
12. What is the best thing you remember about your childhood?
13. What is the worst thing you remember about your childhood?

APPENDIX B

SECOND ROUND INTERVIEW QUESTIONS

Second Round of Interview Questions

1. What is the best thing you remember about being a teenager?
2. When was the first time you used alcohol and other drugs?
3. What do you remember about how you felt when you were high?
4. Who did you do drugs with?
5. What qualities did you look for when you were looking for a partner?
6. How are you different now?
7. What was the worst part of being a teenager?
8. Describe the life events that led to your infection.
9. Describe the circumstances in your life when you became infected.
10. How did you find out you were infected?
11. What were your physical and emotional reactions to the virus?

APPENDIX C

THIRD ROUND INTERVIEW QUESTIONS

Third Round of Interview Questions

1. How do you understand or make sense of your life now that you are living with HIV?
2. How do you view your infection?
3. What were the barriers to infection when you became infected?
4. How can HIV prevention serve women so they may overcome barriers to infection?
5. If you could move back the hands of time, from before you became infected, what do you wish you would have changed about your life?
6. What would you like to tell women about HIV prevention?
7. What kind of changes have you made in your life as a result of the counseling you have received?

APPENDIX D

CONTACT SUMMARY FORM

Contact Summary Form

A Critical Feminist Case Study: HIV Prevention Education For Women

Date:______

Contact: _______

1. What were the main issues or themes that struck you as a result of this contact?____

2. Summarize the information you got on each of the questions you had for this contact.____

3. What else struck you as salient, illuminating or important during this contact?____

4. What new or remaining questions do you have when considering the next contact with this individual?

APPENDIX E

INSTITUTIONAL REVIEW BOARD (IRB)
APPROVAL FORM

OKLAHOMA STATE UNIVERSITY
INSTITUTIONAL REVIEW BOARD
HUMAN SUBJECTS REVIEW

Date: 08-08-98 **IRB #: ED-99-004**

Proposal Title: A CRITICAL CASE STUDY: UNDERSTANDING HIV PREVENTION EDUCATION FOR WOMEN

Principal Investigator(s): James A. Gregson, Melanie Spector

Reviewed and Processed as: Expedited

Approval Status Recommended by Reviewer(s): Approved

ALL APPROVALS MAY BE SUBJECT TO REVIEW BY FULL INSTITUTIONAL REVIEW BOARD AT NEXT MEETING, AS WELL AS ARE SUBJECT TO MONITORING AT ANY TIME DURING THE APPROVAL PERIOD.
APPROVAL STATUS PERIOD VALID FOR DATA COLLECTION FOR A ONE CALENDAR YEAR PERIOD AFTER WHICH A CONTINUATION OR RENEWAL REQUEST IS REQUIRED TO BE SUBMITTED FOR BOARD APPROVAL.
ANY MODIFICATIONS TO APPROVED PROJECT MUST ALSO BE SUBMITTED FOR APPROVAL.

Comments, Modifications/Conditions for Approval or Disapproval are as follows:

Signature: Thomas C. Collins

Interim Chair of Institutional Review Board
and Vice President for Research

Date: August 17, 1998

cc: Melanie Spector

VITA

Melanie Saitz Spector

Candidate for the Degree of

Doctor of Education

Thesis: A CRITICAL FEMINIST CASE STUDY: HIV PREVENTION EDUCATION FOR WOMEN

Major Field: Occupational and Adult Education

Biographical:

Personal Data: Born and raised in New York City and moved to Oklahoma to work in the field of Public Health in 1976. Married for 28 years to Ira Norman Spector, with two grown children, Jeremy Micah and Shana Ann.

Education: Received Associate in Applied Science degree from Queensborough Community College, Queens, New York in 1971; received Bachelor of Arts degree from Langston University, Langston, Oklahoma in 1988; received Master of Science degree from Oklahoma State University, Stillwater, Oklahoma in 1992. Completed the requirements for the Doctor of Education degree at Oklahoma State University in December 1999.

Experience: Employed with the Oklahoma State Department of Health, HIV/STD Service since 1991. Worked as the Tulsa Director of Disease Intervention from 1991-1996. Currently work full time as a prevention educator/therapist. Certified by the American Psychology Association (APA) to offer continuing education courses to clinical psychologists in the area of HIV/AIDS and Psychology; HIV/AIDS, Chemical Dependency and Psychology. Adjunct faculty member of Langston University and Tulsa Community College. Facilitate course work in social research, feminist theory, alcohol/drug education, and human sexuality.

Professional Memberships: Licensed Professional Counselor, Certified Alcohol and Drug Counselor, Certified Criminal Justice Specialist, and member of the Oklahoma Public Health Association.