In Harms Way:

The Lived Experience of HIV for Women

By

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To Women Living with HIV

"Sharing the Stories is Part of Surviving."

I am honored to have been entrusted with your lived experience of this epidemic.

I dedicate my work to ending the silent epidemic - the HIV infection of women.

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CHAPTER I

INTRODUCTION

Background of the Study

The Human Immunodeficiency Virus (HIV) epidemic is changing and women are now the fastest growing group to become infected. According to the Centers for Disease Control (CDC), of the 79,674 people over 13 years old who reported with AIDS in 1994, 14,081 (18%) occurred among women (CDC, 1995). In 1991, 10% of reported cases were women. As the number of women infected with the HIV increases, so does the need for health care professionals to understand how infection with the virus and progression of disease to Acquired Immunodeficiency Syndrome (AIDS) is unique for women. This is especially true considering that the chance of an infected woman dying of AIDS is 30% greater than it is for a man (Melnick & Sherer, 1994). In order to affect this increased probability, information about how women experience HIV/AIDS differently than men is currently needed.

There is growing concern about HIV in women; however, it is predominantly focused on the management of their clinical disease, because part of why women die faster than men is because they are farther in the progression of their disease when they present themselves for care. Another reason for the focus on clinical management is that women were essentially excluded from HIV/AIDS research because of concerns about their reproductive status in clinical trials (Pham, Freeman, & Kohn, 1992). This changed in 1993 with an expansion of the definition of AIDS and recognition within the National Institutes of Health concerning the lack of information on the clinical care of women (Kelly, 1993). Of relevance to this study is the fact that efforts to focus research on women are primarily concerned with the diagnosis and management of active disease. In a time of playing catch-up to the epidemic as it has moved into populations of women, the focus is on women having problems in the more acute stages of the disease. Research is needed on HIV as a woman's experience including all aspects of the disease.

The CDC does include women in its prevention and education efforts; however, its efforts are targeted at high risk population groups in high incidence areas. Women who are part of the outer perimeter of the epidemic, such as those in this study who live in low prevalence areas, do not have priority for scarce intervention resources. Very little is known about their experience in the epidemic.

Essentially, most of what is currently known about HIV and AIDS concerns homosexual and bisexual men. This is expected because they have dominated the epidemic since it began in 1981. A knowledge base currently exists concerning the lived experience of AIDS for men. This has not been fully developed for infected women. The proposed study will not include men and will address the concerns of infected women who live in both rural and metropolitan areas in the Pacific Northwest.

Purpose of the Study

The purpose of this study is to describe and understand the lived experience of HIV infection for women. This includes their lives before they became infected as well as during the entire process of being an infected person. This is achieved by focusing on life circumstances, experiences, and relationships as women describe and understand them. Through understanding a group of individual women, an explication of the meanings they have in common is possible. An interpretive phenomenological methodology will be used to achieve this.

The literature suggests that infected women share life experiences that influenced decisions they made which put them at risk for HIV. Experience in clinical practice suggests social and cultural attitudes about HIV infected women currently affect their abilities to care for themselves. The purpose of the study is achieved through developing an understanding of the whole experience of HIV infection that women have, and this is done through explicating what all the factors of the epidemic mean when they coalesce in women's lives.

Aims of the Study

This study has two aims. The first is to describe the specific life experiences women believe had an influence on their decisions to participate in the risk behaviors that led to their HIV infection. The second is to explicate the interpersonal concerns and background meanings HIV has for infected women, as they are revealed in women's efforts to live with and manage their HIV disease.

Significance of the Study

The significance of this study rests in part on its focus on women who represent a small but steadily growing segment of the HIV epidemic. They are predominantly white, lower middle class women living in communities that do not consider women to be at risk of HIV disease. Women do not consider themselves to be at risk. The concerns and common experiences of African-American and Hispanic women living in large metropolitan areas has been recognized. The literature reveals increasing attention concerning how to reach these women and provide services to them and their families. At a minimum, attention is focused on all the ways their needs are not being met. The hope is that as their numbers grow there will be resources available to help them.

In the Pacific Northwest and specifically the Willamette Valley in Oregon, the population demographics do not include large numbers of African-Americans or Hispanics. The minority people who do live in this area are not identified to be at any greater risk of HIV than the population of the area generally. This may be an incorrect assumption; however, there is currently no way to dispute it (Oregon HIV Annual Report, 1994).

The interpretive approach used in this study will enlarge the predominantly clinical focus seen in the literature. Because clinicians mainly see women as their disease progresses and they have symptoms and opportunistic infections that require management, the main concern in infected women's care is their current medical management.

The significance of this study is that through a greater understanding of the lived experience of HIV disease for these women, we can more effectively meet their needs for care in communities that are unaware that a need for such care exists. Additionally, through learning from women who are already infected we can develop targeted messages and strategies directed to women in similar circumstances to prevent them from becoming infected.

The use of this methodology provides information that is not available in other ways. Interpretive research provides information from reflection on lived experience already lived (Van Manen, 1990). The methodology reveals the ways people know and understand what has happened to them in their lives and how it affects their lives currently. These are valuable insights for clinicians because the psycho-social dimension of care management is an important factor in the success of care.

There is also a need for new models of care and prevention. Because women are now the fastest growing group becoming infected, clinicians and educators are challenged to readjust their thinking to include women in their planning. Interventions that are successful with homosexual men may not work for women. Even interventions designed for minority women in large metropolitan areas may not address the needs of white women living in rural areas. New models of care and prevention have to integrate the background meaning HIV has in these new environments where people do not accept that the HIV is there, and if they know it is, they reject the people who are infected. The findings of this study may assist in these efforts.

The data from this study can make another significant contribution if they are used to enlarge people's understanding of who gets infected by the HIV. The personal data from the lived experience of women, who could be friends or neighbors, may help people look at the moral meanings and judgments found in the stereotypes that cause hurtful things to be said and done to infected people. A major need exists to carefully look at the socially constructed meanings and cultural understandings of HIV in the context of the epidemic (McCusick, 1993).

The interpretive naturalistic research context also provide an opportunity for individuals to reflect on their experiences and discover what has been worthwhile, what they would change, and what is regretted. The research context is a focused, nonjudgmental environment where a person has a chance to talk about their life experiences to an attentive listener who they know values their opinions. When these insights are shared with health care providers, they may encourage another approach to understanding why people do things the way they do. The focus is not from the top down, or from the problem to the etiology. It is not a reductionistic process of the elimination of potential causal or influential factors. Rather, it is a deep broad look at the entire complexity of a health problem, from the perspective of the person it affects the most.

Overview of the Research Report

Chapter II includes a review and critique of research and other literature relevant to the HIV/AIDS epidemic as it concerns women. Chapter III describes the philosophical background, process, and use of the interpretive phenomenological method. The sample and circumstances of the study are provided.

Chapter IV includes the results and a discussion of the major findings of this study. They were revealed through the application of the interpretive process to the narratives of the women in this study. The analysis was guided by four broad aspects of experience that help shape the meaning HIV has for women: (a) the importance of personal life histories, (b) the cultural context of the epidemic, © the importance of relationships, and (d) the complexity and uncertainty of the disease.

An effort was made to provide sufficient technical background to the reader to create an understanding of the physiological and treatment complexities of the epidemic. This is necessary to understand the women's experience with a mutable, infectious agent.

The final chapter presents a summary and discussion of the findings. It includes implications of the study for practice and further research.

CHAPTER II

REVIEW OF THE LITERATURE

This chapter includes a review and critique of the literature on women infected with the HIV and discusses gaps in the knowledge base. It includes the published literature, conference presentations, publications of the HIV/AIDS activist community and anecdotal reports. The review is focused on literature which concerns the unique physiological challenges and psychosocial experiences of women with HIV disease. It does not address the extensive medical treatment or clinical management research in any detail. The review begins with the literature concerning how the epidemic is changing and trends that specifically impact women. The physiological and psychosocial issues unique to women are then reviewed including opportunistic infections, pregnancy childbirth and parenting, mental health concerns, and finally; the impact of HIV and AIDS on womens roles.

Epidemiology and Change in the Epidemic

The World Health Organization (WHO) predicts that by the year 2000 over 13 million women will have been infected by HIV and 4 million will have died. "A decade ago women and children seemed to be on the periphery of the epidemic," said WHO Global Program on AIDS Executive Director Michael Merson, "Today they are at the center of our concern" (INR News, 1993).

In 1995 the CDC issued a report on the changing epidemic. The report included the following information. In the United States women are being diagnosed with AIDS more rapidly than men. AIDS continues to affect men primarily (82%); however, this percentage decreased from 93% in 1985. At the same time, in 1994 18% of AIDS cases occurred among women, nearly a threefold increase from the 7% reported in 1985. The epidemic also disproportionately affects African American and Hispanic women (76%) in two regions of the U.S., the Northeast (44%) and the South (36%). The two primary modes of transmission among women were injection drug use (41%) and heterosexual contact (38%). Heterosexual transmission increased from 35% in 1993 making it the most rapidly increasing category of transmission in women.

Other trends indicate that a greater number of adolescents than adults with AIDS are female (29% vs. 11%) and that the number of young women reported from small cities and rural areas is growing (National Pediatric & Family HIV Resource Center, 1995). The increasing numbers of people infected with the HIV in rural areas creates many new challenges for care providers (Marron, 1991; Morrison, 1992).

Similar trends are reported in Oregon as revealed by a comparison between 1987 and 1994 (Oregon Health Division, 1994). The number of AIDS cases reported annually almost doubled during this period of time from 300 to 599. Cases among homosexual men decreased from 89% to 73% while the proportion of cases among women increased from 3% to 8%. Heterosexual intravenous drug users (IVDUs) increased from 3% to 11% and other heterosexuals from 1% to 5%. The proportion of women with new HIV infections has increased each year since 1989 when females accounted for 7% of new infections, to 15% in 1993, and 17% in 1994. In Oregon heterosexual transmission accounts for 52% of cases among women. Women with AIDS were younger than men, 32% were age 20 to 30 compared to only 19% of men. African Americans comprise 2% of Oregon’s population and 9% of female AIDS cases. White women comprise 85% of Oregon’s cases.

Heterosexual transmission and sex with men who use IV drugs are the predominant risk factors for women. Hamblin and Reid (1994) link women's sexual HIV risk factors to women's status socially and culturally. They state that the link between powerlessness and the risk of exposure to HIV provides the key to understanding the source of women's vulnerability to HIV infection. They go on to say that women are infected because they do not have the power to determine how their sexual relationships with men take place, and that women accept the risk of HIV infection rather than risk the rejection or violence of their sexual partners. A study by Jemmott and Jemmott (1991) confirmed that to be the case among African-American women as well.

The use of condoms is the main prevention strategy promoted by public health programs to protect both men and women. There is reason to believe the message is being heard according to a 1996 study which reviewed the data from two independent, representative samples of heterosexual adults between 18 and 49 years old. Their use of condoms from 1990 to 1992 was compared and found to have increased from 11% to 20% (Choi & Catania, 1996). The change was mainly noted among young people with less than a high school education, and not among women, whites, people in their 20s to 40s and people who had never been married. The use of a condom is not the only issue for women. A review of condom effectiveness in practice showed an effectiveness level across 16 studies of only 69% (Center for Women Policy Studies, 1994). The research is being used to support the development of HIV prevention options that can be controlled by women, such as microbicides. Campbell (1995) agrees that a change in focus is needed because prevention efforts that make women responsible are failing, as evidenced by rising rates of infection. She argues that current efforts actually undermine women's relationships with men because sexual relations become situations of negotiation. She advocated "refocusing on men, as individuals responsible for their own health and the health of women" (Campbell, 1995, p. 197). Women know they are not well protected and 50% of heterosexually transmitted HIV infections were detected because of a woman's self-perception of risk and request for a test (Carpenter, Mayer, Stein, Liebman, Fisher, & Fione, 1991). Women's ability to protect themselves with the use of condoms has long been known to be inherently ineffective (Worth, 1989). Carpenter et al. (1991) also maintain that the future of heterosexual infection for women is not going to be an issue of their promiscuity or the number of partners women have, but rather will be women having monogamous relationships with a growing number of HIV infected heterosexual men.

Another concern in a consideration of the changing epidemic is the fact that the increasing number of women being discovered to have HIV later in their disease than men, and this has consequences for their survival rates (Buehler, Peterson & Jaffe, 1995). The CDC reported in 1995 that 44% of women who learned they were infected did not find out until they developed obvious signs of an AIDS opportunistic infection, which meant they had been infected for a long time. This relates directly to the fact that HIV infected women have a 30% greater chance of dying from AIDS illnesses than men (Melnick & Sherer, 1994). This is disturbing because recent treatment advances confirm that with early care people infected with the HIV are living longer and HIV is now considered to be a long term chronic disease (Holzemer, 1992). AIDS professionals are encouraged that "recent scientific findings and therapeutic developments converge to favor an aggressive interventional strategy early in the course of HIV-1 infection" (Ho, 1995, p. 450). The current situation in how women are diagnosed may not allow women time to benefit from recent treatment advances.

HIV also affects women of all ages. The CDC reported in 1993 that 14% of women with AIDS are over 45 years of age. Older women who are sexually active are at increased risk of HIV because they equate inability to get pregnant with being able to have unprotected sex (Ogu & Wolfe, 1993). If they think they may be infected, they have difficulty accessing care because they "feel they have far more to lose than to gain by discovering or revealing their HIV status, at least until they are too sick to have any choice" (Cohen, 1993, cited in Ogu & Wolfe, 1993, p. 2).

Issues Unique to Women

HIV in the Female Body

The physiological process of HIV disease usually takes between 7 and 11 years from the discovery of HIV to a diagnosis of AIDS (Valenti, 1992). Some researchers verify that the disease runs a faster course in women (Williams, 1992). It has not been established whether this is due to a biological difference, a social difference based on access to care, or a combination of factors.

Women with AIDS have the same opportunistic infections (OIs) as men, however have more epithelial malignancies and are more likely to present with pneumocystis carinii pneumonia (Williams, 1992). The main physiological difference obviously concerns a woman's reproductive system (Lovejoy & Rumley, 1992). The symptoms associated with women's reproductive tract include persistent Candida vaginitis, human papilloma virus infections, and cervical dysplasias (Mayer, 1993). Women also have a higher prevalence of Candida esophagitis as their presenting AIDS diagnosis (Mayer, 1993). Women's HIV OIs are considered to be diagnosed later than is optimal because gynecological care is not always included in routine care and is often segregated from general medicine (Marte & Allen, 1991).

This is problematic because infrequent visits to gynecologists are the primary source of reproductive health care for many young women and the standard of care for HIV infected women is a pap smear and exam every 6 months (Public Health Service, 1994; Melnick & Scherer, 1994).

Pregnancy, Childbirth and Parenting

Pregnancy and childbirth continue to be important options for infected women. However, the longer a woman is infected the likelihood of her choosing to bear a child is decreased, possibly because of the onset of illness or symptoms. (Kline, Strickler, & Kempf, 1995). Recent research is also having a impact on women's decisions to become pregnant. In 1994 the results of a large clinical trial of the drug Zidovudine revealed that its use before, during and directly following the birth of a child reduced the risk of maternal infection from 30% to 8% (CDC, 1994). This was good news for infected women who desire to have children. It has stirred debate among public health professionals and politicians regarding the potential value of mandatory HIV testing of all pregnant women. Others are concerned about women's rights to privacy. At the present time the standard of care is to offer an HIV test to any pregnant women (Coodley & Coodley, 1995). HIV testing and pregnancy have become closely linked. When discussing obstetric care, it is important to note that women are often discovered to be HIV positive during routine prenatal screening. This was revealed in Minnesota where two-thirds of women with HIV were detected by prenatal screening rather than as a result specifically testing for HIV or through routine medical care (Brettle & Leen, 1991).

Mental Health Considerations

Assessment of mental health status is an important part of the standard of care for women with HIV disease (McCusick, 1992). Depression is recognized as the major problem and is associated with "alcohol or substance use, loss of social support, advancing stage of illness or newly diagnosed disease, stigmatization, occupational disability, loss of friends or loved ones to the disease, pain, and debilitation" (Bishof, 1995, p. 4). Women respond to HIV infection differently based on prior personality and behavior patterns. Pergami, Gala, Burgess, Durbano, Zanello, Riccio, Invernizzi, and Catalan, (1993) studied 57 women with HIV and found that alcohol misuse and an external locus of control accounted for 29% of the variance of psychiatric distress. When psychiatric problems disrupt a woman's ability to adequately manage her life, appropriate referral for mental health care is important (Allen & Marte, 1992; PHS, 1994). This may not always be possible for people living in rural areas where it is difficult to access HIV mental health services (Herz, 1995). People living with HIV often help each other, and activities that provide positive social stimulation are seen as being useful for improving the mental health of infected people (Bartlett & Finkbeiner, 1991). Additionally, it has been shown that the psychological distress of HIV disease is positively affected by an assertive coping style which can be used to alter negative emotional states often observed in patients with a life-threatening illness (Bounous, 1995). Stress, depression, and feelings of hopelessness have been shown to have negative effects on the functioning of the immune system and affect a person's activities of daily living and interpersonal relationships (Bounous, 1995). Stress management and counseling are recommended to assist HIV positive people in assuming assertive coping styles when their HIV disease threatens their mental health. Professional therapy and the use of psychoactive medications is an option which is available through mental health professionals and for which patients should be referred as needed (Weston, 1995).

Impact of HIV on Social Role Expectations

The next concern affecting HIV positive women is their roles as care givers. The care giving role is an important consideration in understanding the experience of HIV infected women. Women spend an average of 17 years caring for their children and 18 years caring for their parents (Corea, 1992). Women experience psychological stress because they are often single parents and the sole source of support to their children. Not being able to fulfill the caregiving role through the growth of one's children to adulthood is extremely distressing to women (Carpenter, Mayer, Stein, Leibman, Fisher, & Fiore, 1991). The health of an infected woman's children is usually more important to her than her own health (Stoll, 1992; Aseltyne, Cloutier, & Smith, 1995; Coodley & Coodley, 1995). Simpson & Williams (1993) discussed the care giving matriarchal role in relationship to women with HIV disease. They observed that even women with low self-esteem still took great pride in motherhood. They found that women remain isolated because they do not trust their communities and fear disclosure of their HIV status because it may threaten their family or children. One of the most difficult aspects of having HIV for women is knowing their care giving role may end prematurely and arrangements have to be made for the guardianship or adoption of their children (Stoltenberg, 1994). Finally, caring for an infant that the woman infected is the most difficult of all (Simpson & Williams, 1993).

Another aspect of care giving concerns women caring for someone else who is infected with the HIV. This may be a friend or sexual partner. The emotional distress HIV women face may include the disability and death of her partner (Coodley & Coodley, 1995). Women may be criticized for caring for a "dying, drug-abusing, abusive husband." They say they do it "because there was no one else to do it" (Maier, 1986, cited in Pizzi, 1992 p. 1023).

Women not only have to go through the emotional distress of losing their partners, they often must also endure the criticism of their families and friends.

Risk Behaviors and History of Abuse

A history of sexual abuse is increasingly seen by researchers as a potentially important factor in whether or not a woman becomes HIV infected (Allers & Bentjack, 1991; Fullilove, Lown, & Fullilove, 1992; Fullilove, Fulliove, Smith, Winkler, Michael, Panzer, & Wallace, 1993; National Association of People Living With AIDS [NAPLA], 1992; Zierler, Fiengold, Laufer, Velentgas, Kantrowitz-Gordon, & Mayer, 1991; Cassese, 1993).

Epidemiological surveys estimate that 20% to 25% of women in the general population have a history of sexual abuse (Paone & Chavkin, 1993). A national study conducted in 1992 of 4,009 randomly selected women found that 61% of all reported rapes occurred before the victim reached age 18 . . . 29% of all rapes occurred when the victims were younger than 11 years old" (Paone & Chavkin, 1993, p. 13).

Relationships are being established between a history of abuse and the subsequent sexual and drug using activities that put people at risk of HIV infection. Zierler et al. (1991) studied 86 people concerning abuse and HIV high risk behavior and found half the women and 20% of the men reported a history of rape. Twenty-eight percent of the women had been sexually abused as children, and they were four times more likely to be working as prostitutes than women who were raped as adults (Zierler et al., 1991). The researchers conclude that assessing for sexual victimization may be an important part of identification of those at risk for HIV infection. It may also be an important part of an HIV infected woman's personal history which affects her ability to care for herself.

Understanding the prevalence of sexual abuse is important because HIV education and prevention initiatives are designed around the concept of consensual sex. People with a history of sexual abuse may not relate to the concept and may be threatened by images of negotiated sexuality (Kidman, 1993). Debra Haffner, Executive Director of the Sex Information & Education Council of the United States testified to the National Commission on AIDS in 1992 about the connection between abuse and HIV:

> It is also important for us to remember that not all adolescent sexual behaviors are voluntary. One in four girls and one in six boys report that they have been sexually assaulted. Recent studies report much higher rates of sexual intercourse among teens who have been abused, including higher rates of pregnancy and multiple partners. It is extremely important for us to incorporate this knowledge into current HIV education efforts.

Fullilove et al. (1993) are currently studying the abuse trauma experienced by women who also use intravenous drugs and crack cocaine. These women are considered to be at serious risk of HIV infection due to both their IVDU and drugs-for-sex-exchanges. Their research at the HIV Center for Clinical and Behavioral Studies at Columbia University suggests that sexual trauma profoundly shapes sexual identity. Using drugs to dissociate and engaging in dangerous sexual activities as an extension of the abuse may be contributing to women becoming the fastest growing group becoming infected. Research evidence concerning this problem has been difficult to obtain due to the social taboo around sexual abuse. Providing an opportunity for infected women to describe their lives may contribute to our understanding of the connection between abuse and high risk behaviors.

Allers and Benjack (1991) studied 52 HIV infected adults and found 65% reported physical or sexual abuse in childhood. Behaviors and dynamics associated with unresolved childhood abuse included: (a) revictimization; (b) sexual compulsivity; © chronic depression; and (d) alcohol and other drug abuse. The study concluded that childhood abuse plays an important role in the HIV epidemic. Herman (1981) studied father-daughter incest and expressed concern that it will remain extremely difficult to affect this behavior as long as society supports fathers in their roles as head of households and does not support daughters and mothers who try to stop the abuse. There are differences of opinion regarding when human service agencies and the criminal justice system have a mandate to intervene in family life. The possibility of positive outcomes in the care of infected women may increase if their abuse history is taken into consideration in both the public discussion of HIV risk behaviors and in clinical care.

Stigmatization and Social Judgment

Stigmatization is not new to the HIV epidemic. However, unlike homosexual men with HIV, most stigmatized women do not have access to well organized socio-political sub-cultures which advocate on their behalf and attempt to empower them to seek care and care for themselves. Herek and Glunt (1988) consider AIDS an epidemic of stigma essentially based on the fear of AIDS as a deadly disease and preexisting prejudice against gay men, drug users, racial minorities, or outsiders in general. This prejudice is experienced by infected people in many ways including: being harassed or judged, being discriminated against in employment or housing, or losing insurance coverage (Green, 1995; Alonzo & Reynolds, 1995). For women there is the additional fear that such disapproval will lead to the loss of their children.

The global AIDS epidemic has a moral dimension because of the fact that most methods of transmission are associated with lifestyles that many cultures have regarded as sinful, such as commercial sex, homosexuality, and drug use (Caldwell, 1995). This causes victimization of people with such lifestyles because they are considered not only different, but dangerous, due to the infectious nature of the virus. The concept of social judgment involves socially constructed evaluative labels that are put on people (Johnson & Webb, 1995). The term social judgment is defined as the apparent judgment of the social worth of a person by others and it happens in every culture and society. The problem for the AIDS epidemic is that when a social judgment is made there is usually a "moral consequence," which is stigmatization and rejection (Johnson & Webb, 1995).

Alonzo and Reynolds (1995) discuss the experience of stigmatization for HIV infected people as being a stigma trajectory. They describe four phases in the stigma trajectory. They are: (a) at risk: or pre-stigma, which is the worried well; (b) diagnosis: when one confronts an altered identity; © latent: the time of living between illness and health; and (d) manifest: the passage to social and physical death. Each HIV infected individual goes through the trajectory. They personalize the illness, encounter dilemmas in interpersonal relationships, use strategies to avoid or minimize stigma, and use subcultural networks and ideologies to construct and adapt to having an HIV identity (Alonzo & Reynolds, 1995).

People living with HIV/AIDS deal with both the actual stigmatization and judgment they experience as well as what they fear. Some believe their fears are excessive. Green (1995) compared the judgment regarding AIDS between 300 men and women of all ages and 42 men and women with HIV. He discovered that the general public actually have relatively liberal attitudes; however, they do feel infected people's activities should be restricted when they put others at risk. People with AIDS had the most liberal attitudes and underestimated the acceptance of the general public. The study took place in Scotland.

The notion of HIV infected people as different or somehow "other" is still strong. This was revealed in the press in 1993 when the National Research Council issued a report on the status of the epidemic and the chairman of the study was reported to have said, "AIDS has devastated the personal lives and social communities it has touched, but the epidemic has little effect on American society as a whole or its way of doing business." This was because the report concluded that the epidemic was, "concentrated among homosexuals, drug users, the poor and uneducated" (Haffner, 1993). It called them "socially marginalized groups." Kleinman (1988) would see people with HIV/AIDS as doubly marginalized because he considers people living with chronic illnesses as already living on the margin of society.

Corea (1992) specifically uses the idea of being discounted, or "other" concerning women living with HIV. She believes women in general are treated as "other" by male dominated medicine, as evidenced by the separation of gynecological care from routine primary care. She quotes Sandra Erkin from the video *AIDS Is About Secrets*.

> Otherness is the notion that we don't need to care for the worthless 'others' afflicted with AIDS. They have only themselves to blame. Nor need we take the decisive, effective action to prevent any further spread of AIDS among them. Certainly we don't have to worry about catching AIDS ourselves if it's something 'others' get. (Corea, 1992, p. 5)

Some see the prevailing depiction of women as "vectors of HIV disease" as an example of how the epidemic has discounted women's experience of it. This was graphically revealed at the second National HIV in Women conference held in 1995. At the meeting, a representative of the National Institutes of Health apologized to the women at the conference and acknowledged that research in the past has focused on women as vectors of disease to men and children as opposed to women as human beings with an illness (Wheeler, 1995). It was indicated that this focus would change in the future. It was acknowledged that this depiction has perpetuated a misperception that women with AIDS were mainly prostitutes.

Issues of stigma and judgment toward women with HIV/AIDS also include the attitudes of health care providers. Longo, Spross, and Locke (1990) researched the major concerns of people with AIDS and found the attitudes of health care providers to be a problem. Subjects reported the most significant difference between AIDS and other major illnesses, aside from the certainty of death, was the degree of "social unacceptability" associated with the disease. "When patients were asked what would help health care providers and nurses better care for them, the majority of the subjects responded that empathy (24%) and acceptance (18%) would be most helpful" (Longo, Spross, & Locke, 1990, p. 25). Research indicates that even when nurses believe all patients are entitled to the same care (97%), 49% preferred not to care for people with AIDS (Larson-Presswalla, Rose, & Cornett, 1996). A study of 600 nurses in Oregon in 1991 confirmed that 20% of nurses preferred never to care for AIDS patients, 23% preferred to defer care, and 53% were willing to care for people with AIDS (Colligan, Noble, Roman, & Kaufman, 1992). This study needs to be replicated and updated, however observation in clinical practice confirms these attitudes as being current in 1996.

A final aspect to be mentioned involves the role of political and religious ideologies in promoting the stigma and judgment of people living with HIV. In the current social context in Oregon there exist conservative Christian organizations that specifically target people with a homosexual sexual preference. By association, anyone with AIDS is considered to have unacceptable lifestyles or behaviors. This makes living in small communities and rural areas very difficult because these values predominate there. Aggleton, O'Reilly, Slutkin, and Davies (1994) recognize this problem in their consideration of the social and community factors which are critical to consider when evaluating the context in which risk behavior education can occur. One of the factors to consider is: "political and religious ideologies that seek to artificially restrict information about the full range of safer behaviors in favor of promoting only those that may be considered morally or politically acceptable to vocal minorities." In

Oregon a vocal minority has succeeded in creating a highly judgmental environment for people with HIV who live outside the Portland metropolitan area.

Changing Models of Care

The AIDS epidemic has fundamentally changed the way we deliver health care (Mann, 1993). This has happened at a time when a basic restructuring of health care generally is being considered. The 1993 National Research Council of the Academy of Sciences issued a report on the impact of AIDS in the United States. The report included the delivery of health care services in its assessment and determined that the impact of the epidemic has been pervasive and has prompted a critical examination of traditional public health practices (Haffner, 1993). The report stated, "AIDS is the most profound challenge to the care of patients that has faced the health care provider community in modern times" (cited in Haffner, 1993). "AIDS presents a major challenge to hospitals, nursing homes, physicians, nurses and other direct providers of health care services" (cited in Haffner, 1993).

Stevens (1993) is among those who feel it is essential to examine marginalized consumers' experiences with health care because as systems are changing she is concerned that the process needs to include more than just cost containment. Her concern is access to care, which is a major concern of women living with HIV. She verified that for single women, not having health care coverage was devastating. Women in Oregon may be eligible for the Oregon Health plan if their income becomes low enough to meet eligibility requirements; however, the plan does not cover everything.

One of the ways people living with HIV/AIDS have accessed care and medications throughout the history of the epidemic has been through research and clinical drug trials. As mentioned previously, it is now recognized that women have been excluded from access to

HIV/AIDS research. Long and Leger (1995) verified the extent of this exclusion in an analysis of women's participation in AIDS Clinical Trials Group (ACTG) studies. They found that by November of 1993 women made up only 11% of all participants in ACTG trials. This included women in trials to assess HIV's effect in pregnancy and women in trials for their infected children. In phase I trials of primary HIV infections, where free treatment and evaluation is provided, only 9% of participants were women. This is important because the role of research in the management of HIV disease has been significant, especially since there was no known treatment at the time the epidemic began. Women have not been included in this critical element of the epidemic. Levine, Neveloff, and Levine, (1991) discussed the rationale for exclusion of women. They indicated it was because: (a) women had the potential to become pregnant; (b) as primarily being members of minority groups, women lack access to the health care system; (c) as possible IVDUs, women may be non-compliant; and (d) women may be excluded because the trials focus on the disease of AIDS, and women may not have a clinical diagnosis. Most of these reasons have been exposed as being based on assumptions that do not necessarily apply to women and certainly not to all women, or to any individual woman all the time. Pham, Freeman, and Kohm (1992) provide an alternative model which does include women, the Community Based Clinical Trials. They verify that women can be successfully included and that it is important to obtain clinical information on the difference in responses to treatment between men and women. Kelly (1993) goes so far as to say that, "women's participation in clinical trials is essential. Factors such as age and weight affect drug metabolism; it is inaccurate to assume that female-specific factors - hormones, percent of body fat, menstrual cycle changes, and other less tangible influences - have no impact on drug efficacy" (p. 1). This information is needed for HIV/AIDS specialists and primary care providers alike if women are ever to have equity in the delivery of health care services.

One area of health care which women have not been excluded from is the use of alternative and complimentary treatments. The NIH Office of Alternative Medicine recommends all persons living with HIV take an active role in the management of their disease and they see the use of alternative therapies, in conjunction with conventional medicine, as an opportunity for persons living with AIDS to be proactively involved in their treatment (NIH, 1994). Furnham and Beard (1995) compared health beliefs, coping style preferences, and mental health between patients using orthodox and complimentary medicine. They found no differences in coping styles or mental health, however people using complimentary therapies scored higher on positive beliefs about future health. A balance needs to be achieved because prolonged self-treatment may contribute to the problem of women presenting themselves for primary care late in their disease.

What is missing from the literature is research in the naturalistic tradition. O'Sullivan & Thompson (1992) say a need exists for research on the natural history, the personal consequences, of HIV in women. The focus has been on the disease process and the circumstances necessary for people living with AIDS to access quality medical care. Some attention has been paid to socio-cultural, economic, and political concerns of at risk groups. The fact that the epidemic began as "GRID", gay reduced immunity disease, created an ongoing perception among both clinicians and the public that this was a disease of homosexual men. A side consequence of the epidemic has been an increased understanding of the community and lifestyle of homosexual men. This awareness has enabled the Centers for Disease Control and Prevention and state and local health departments to specifically target prevention and testing interventions to the gay male community. The knowledge gained in learning how to intervene with gay men does not necessarily translate to women with HIV, especially single mothers. Womens concerns revolve more around their family roles and they do not coalesce into an identifiable community in the way gay men do. More needs to be known about the personal experience of HIV infection for women. Then interventions developed specifically to address their concerns and lifestyles can be developed.

CHAPTER III

METHODS

The methodology chosen for this study was interpretive phenomenology. This approach was chosen because interpretive phenomenology provides a method which is grounded in the life world of every day experience and allows the meaning of the experience to be explicated and revealed. The purpose of this study is to understand the lived experience of HIV infection for women. This method uses a qualitative, naturalistic approach to inductively and holistically understand women's HIV experiences in the context of their lives.

Philosophical Origins of the Research Approach

Interpretive phenomenology has its roots in the tradition of hermeneutics. Hermeneutics originated as the study of mythical and sacred texts and was concerned with how people found meaning in a text that had existed over many centuries (Winograd & Flores, 1991). Within hermeneutics a debate exists between those who place the meaning of the text within the text and those who see meaning as grounded in a process of understanding in which the text, its production, and its interpretation all play a part. Martin Heidegger supported interpreting the text and proposed that hermeneutic phenomenology is the method best suited to the study of human action and meaningful human phenomena in his work *Being and Time* published in 1927 and 1965 (Packer, 1985).

Heidegger made distinctions between the practical, theoretical and reflective modes of engagement that people have with their world and called them ready-to-hand, unready-to-hand, and present-at-hand respectively. This reflects the primary origin of knowledge as being found in direct, everyday practical involvement with things, situations and people. It includes no context free elements. Heidegger's method is *hermeneutic* because there is a need for interpretation when one is explicating human experience and the ways people engage in their lives. Using a hermeneutic approach also treats human action as though it has a semantic and *textual* structure that can be recorded, interpreted, and understood (Packer, 1995). Essentially, hermeneutics is "recognized as a philosophy that supports an interpretive approach to people through research methods that focus on meaning and understanding in context" (Thompson, 1990, p. 224). Additionally, "hermeneutic philosophy emphasizes the historical and social nature of inquiry and argues that understanding cannot be separated from the social interests and standpoints we assume as a result of being cultural agents" (Thompson, 1990, p. 228). Hermeneutics provides a philosophical base for research methodologies that are committed to an interpretive approach to understanding human experience. This includes our social interests, our values, our language and concepts, and our time in history. The goal is to understand our situatedness as human beings in the world of shared background practices and familiarity. Out of this shared background our individual possibilities and potentialities are found and articulated (Plager, 1994). Within the tradition of Heidegger's hermeneutic philosophy various terms are used to describe it. It is interchangeably called interpretive (Denzin, 1992), hermeneutics and phenomenology (Van Manen, 1990), and interpretive phenomenology (Benner, 1994).

Hans-Georg Gadamer was a student of Heidegger and extended hermeneutics to make language central and crucial to the philosophy and methodology. In his view we create our world through the language we use and share. The language we speak determines how we acquire new knowledge, understandings and meanings within our social and cultural systems (Thompson, 1990). Interpretive research fixes language in text and allows us to know another person's lived experience through understanding the meanings found in their narratives.

Denzin (1992) articulated underlying assumptions that guide interpretive researchers. He speaks from an anthropological interactionist perspective that is particularly useful in thinking about the HIV epidemic because of the socially constructed meanings which have been created around particular social acts and the effect they have on the lives of HIV positive women.

1. Human beings create the world of experience they live in.
2. People do this by acting on things in terms of the meanings things have for them.
3. These meanings come from interaction and they are shaped by the self-reflections persons bring to their situations.
5. Symbolic interaction (the merger of self and social interaction) is the chief means by which human beings are able to form joint social acts.
6. Joint acts, their formation, dissolution, conflict, and merger, constitute the social life of a human society.
7. A society consists of the joint social acts which are formed and carried out by its members. (Denzin, 1992, p. 25)

Denzin (1992) describes the goal of the interpretive researcher to be making the world of lived experience directly accessible to the reader by capturing the voices, emotions, and actions of those studied. He describes the use of interpretive research to study what he calls moments of epiphany. These are events in a person's life that affect their personal identity and self-meanings and reconfigure how they relate to the structures of their social life.

> Epiphanic experiences rupture routines and lives and provoke radical redefinitions of the self. In moments of epiphany, people redefine themselves. Epiphanies are connected to turning-point experiences. Interpretive interactionists study epiphanic experiences. They locate epiphanies in those interactional situations in which personal troubles become public issues. (Denzin, 1992, p. 34).

They focus on those life experiences that alter the shape of the meanings persons give to themselves and their experiences.

This study concerns the epiphanic experience of HIV infection for women and how it changes the meanings of their lives personally and socially. The phenomenological interpretive method provides a means whereby the shared meanings of this experience can be revealed for 18 women. This is done through a process of exploring and understanding the particulars or instances as they are encountered in each woman's lived experience (Van Manen, 1990).

The Aims of Phenomenological Research

Phenomenology has as its ultimate aim, the fulfillment of our human nature; to become more fully who we are (Patton, 1990). The goal of understanding the world, ourselves, and others is achieved by studying persons, events and practices in their own terms (Benner, 1994). The phenomenological account makes explicit our understanding of some aspect of the human experience by providing interpretation and creating an understanding that makes sense in the current context.

Phenomenological research is about the lived-in world and tries to provide insights into how one inhabits that world. The effort is to reveal the world as it is experienced, not as an external conceptualization of what it appears to be (Van Manen, 1990). This includes the common meanings, relationship concerns, and activities of everyday life. It also includes understanding when things break down and normal human activity is interrupted (Benner, 1994).

The aims of phenomenological research are achieved through the use of an interpretive methodology which is based on the underlying philosophical assumptions of hermeneutics, as has been discussed. The methodology used in this study is guided by the work of Packer and Addison, Van Manen, and Benner (1994). Benner's work provided the most specific guidance for the conduct and analysis of this study. The next section addresses the application of the philosophical orientation directly to the concerns of this study. It includes the essential aspects of the methodology, exploration of sources of commonality, and the process of inquiry.

Essential Aspects of the Methodology

Phenomenological methodology situates the involvement of the researcher in the study in a way that allows for ongoing interpretation. The participants are situated so that their engagement in their everyday activities and their self-interpretations are revealed. The researcher and participants share the public world of background familiarity and general social life. This is the basis of the common shared understandings upon which an interpretation of the experience in question rests. Three essential aspects of hermeneutic phenomenology as methodology guide the analysis. These are: forestructure of understanding, interpretation, and the hermeneutic circle.

Forestructure of Understanding

Everyone involved with an interpretation comes to the process from an existing position which has evolved over time in their life. It includes the three aspects of forestructure which are: (a) *a fore-having*, a practical familiarity in how we manage our lives; (b) *a fore-sight*, our point-of-view; and © *a fore-conception*, what we anticipate or expect (Packer, 1989). All three forestructures affect the interpretation and must be considered.

Interpretation

The forestructure links understanding with interpretation (Plager, 1994). Everyone continually interprets their experience in taken-for-granted ways. It is part of the invisible coping in daily life and remains in the background. It includes thoughts, feelings, and values that influence how a person responds. This is true for both the researcher and the participant. "First, as part of the credibility of the project, the investigator lays out preconceptions, biases, past experiences, and perhaps even hypotheses that make the project significant for the investigator and may affect how the interpretation takes shape. Second, the investigator may bring forth the forestructure of understanding for the participants. This may be part of the narrative that the investigator elicits in the study in order to make sense of the participants situation" (Plager, 1994).

The Hermeneutic Circle

People manage their lives based on what they understand and what makes sense to them, and this is constantly being revised as new information and understandings are acquired. It can be seen as a circular process of enlarging understanding. "In the circle we understand and interpret something as something because we have this background of shared human practices. Understanding allows us to be involved in our daily activities as meaningful events" (Plager, 1994). Everyone is in the circle because understanding is how we create meaning and without the familiarity of the shared background of our world, everything becomes meaningless and unintelligible. This personal and cultural life history is the basis for possibilities and potentialities in one's future life. This is the ontological circle within which everything in life takes place, including research.

Exploration of Sources of Commonality

Interpretive phenomenology is done to discover commonalities and differences in lived experience. The methodology does not support finding an ultimate understanding that allows for prediction, such as rational-empirical studies strive to do. Nor does it control for things that may affect the study results.

> The threats to validity listed in traditional rational-empirical texts, such as maturation, history, and learning, are all aspects of human agency, world, and temporality that form the interpretive phenomenological project, so controlling for them by excluding them makes it impossible to uncover transitions that occur over time. (Benner, 1994, p.104)

The commonalities and differences that are revealed in interpretive studies are found in the culturally grounded meanings participants have for their life experiences. Benner (1994) describes five sources of commonality explored in phenomenology.

Situation

This includes both a person's past and present circumstances. Questions concern how the situation is perceived. Is it normal, unique, or difficult. Knowing the life histories and current circumstances of the women in this study is essential to understanding their lived experience.

Embodiment

A person does not have a body, they are embodied. The physical experience of living in a body impacts on every aspect of how a person experiences their world. It includes their physical actions and emotional responses. The experience of HIV infection permeates every part of the lives of those who have it. The HIV also has an effect on the common ground of social understanding of the epidemic for everyone in society. That understanding is embodied in the behaviors of people that reveal the fears, stereotypes and judgements they have about the HIV. For the person living with HIV, the meanings in their lives become overwhelmed by the embodied experience of the epidemic for both themselves and others.

Temporality

Lifetime includes past, present, and expectation of the future. We understand who we are based on who we were and what happened to us in the past and how it relates to the present. "Temporality is more than a linear succession of moments. It includes the qualitative, lived experience of time or timelessness" (Benner, 1994). With HIV disease a person's sense of time may be altered and the value of a single day enlarged by the threat of losing future time.

Concerns

Concerns are what matter to people. Concerns determine what is salient about a situation, what needs attention (Benner & Wrubel, 1989). People respond to what is important to them; how much something means to them. This can be influenced by many things including cultural, socioeconomic, and political concerns. And concerns change as situations change. For the person with HIV infection, concerns change as the infection is revealed in their world and also with the progression of the disease physiologically.

Common Meanings

People agree and disagree about the meaning of many things. It is the common meanings that people share that often determine what is noticed. Common meanings usually exist in the background and are an assumed part of normal interaction. It is when a difference occurs that a common meaning is brought to the foreground for further discussion and a potentially revised understanding. The common meanings of HIV disease have evolved over time and are tied to common meanings people share about many other things including infectious disease, sexual preference, sexual activity, and drug use. Unfortunately the shared meaning includes negative judgement and is projected onto any infected person, regardless of their personal history.

The Process of Inquiry

The process of inquiry includes major considerations for the conduct of the study and describes the activities of the study. Van Manen (1990) described factors that should be considered during the process of conducting phenomenological research. These included a recognition that understanding comes through participation. The researcher immerses her/himself in the world of the participants in an effort to understand their lived experience as closely as possible. He directed the researcher to look to the background context in relationship to individual events, both current and past. And he encourages researchers to open a dialogue with their colleagues and associates throughout the research process to enlarge and challenge the approach, the emerging interpretation, and to provide personal support.

When the study is first conceptualized, the first consideration involves the researcher choosing a line of inquiry about the phenomenon of interest. This guides, but does not constrict, the interview with participants. The line of inquiry is later extended into the analysis of the text. At that time it is revised, challenged, and enters the hermeneutic circle of understanding concerning the emergent themes and essence of the interpretation.

The interaction between the researcher and participants is set up in a naturalistic way to allow a free flowing dialogue to occur. Participants are more comfortable revealing the meanings of experience in their lives when they feel secure. The researcher plans the interview experience taking into consideration where, at what time, and under what conditions the participants are most likely to relax and tell their stories in depth and detail.

The researcher encourages The researcher may return to participants for further clarification or added detail during the analysis.

The interviews are taped and transcribed thereby fixing the narrative into a text for analysis. This text is the data of the research study and is the foundation and core of the analysis. Repeated contact with participants is used to enlarge the understanding of the text. The text grounds the analysis in the details of the lived experience and can be returned to for specific instances which verify the essence of the experience as revealed by the analysis.

Application of the Methodology in this Study

This section will describe in detail how the methodological concerns that have been discussed were implemented in this study. The discussion will proceed in the order in which the process occurred; however, many aspects of the process were ongoing, interconnected, and found throughout the study.

Understanding Through Participation

I have been a participant in the HIV/AIDS epidemic since 1988 when I was asked to start an AIDS Clinic for my community. I was living in Santa Fe, New Mexico and the epidemic had arrived. Increasing numbers of HIV infected men were presenting themselves for care. I was director of the Northern New Mexico Visiting Nurse Service Hospice at the time. The reason I was asked to start a clinic was because no-one else in town wanted to do it. They feared alienating other patients and reasoned that since AIDS is a terminal disease, the Hospice could provide primary care for AIDS patients until they die. In starting the AIDS Wellness Clinic I learned first hand the meaning of stigma and prejudice directed at people living with AIDS, and in my case, those who try to care for them. The clinic endures and now has widespread support in the community.

At the time I started the clinic, I knew very little about HIV. I was immediately confronted with many aspects of the epidemic. They included the desperation and gratitude of HIV infected men (few women at that time) for having someplace to turn for medical care and personal support; the unwillingness of most physicians and health care providers to participate in the creation of a continuum of care for people living with HIV, the dedicated and loving care a few physicians and health care providers give, the pain and drama in families around issues of both homosexuality and HIV, the frustration inherent in trying to obtain funding and access to needed services for patients, the difficulty in educating staff to work directly with HIV infected people, and the challenge to inform the community at large about the facts of the epidemic.

Perhaps most pertinent to this study was my involvement with research. In 1988 there were few treatments available. Those that were available could only be accessed through participation in research studies. A proposal was developed around including rural, undeserved, minority populations in clinical trials (we also served Native Americans and Hispanics). The American Foundation for AIDS Research (AMFAR) gave the clinic a "special projects" award of $50,000 and clinic patients were allowed to enroll in AMFAR studies. I was invited to attend their national meetings where contacts were made regarding how to obtain other services for the clinic. I also met Dr. James Sampson through AMFAR. He is the executive director of The Research & Education Group (R&EG), the Oregon AMFAR site. In 1990 when I decided to leave New Mexico and move to Oregon, Dr. Sampson hired me as a nurse investigator. The R&EG had just been awarded a National

Institutes of Health Community Programs for Clinical Research on AIDS (CPCRA) 5-year grant.

I moved to Oregon and began working for the R&EG. At that time we served ten sites in the Portland metropolitan area including the Multnomah County HIV Clinic. I was responsible for HIV research at the county clinic. It was there that I began to see a change in the epidemic. There were increasing numbers of women. By 1992 the social worker and I became concerned that there were no services available for women living with HIV. What was available had been developed for homosexual men. The women we cared for often had small children. Their needs were very different from the needs of gay men. We decided to start a support group for women and called it Nurture Night. It was intended to be a time for women to gather with their children, share a meal, learn about issues concerning women with HIV, and support each other. Dinner, child care, and transportation are provided. The group continues to meet and a second Nurture Night was started in Salem in 1995. There are currently approximately 70 women on the active mailing list. It has been through my contact with these women that my interest in researching the lived experience of HIV for women grew. Most of the women in the study have attended Nurture Night in either Salem or Portland at some time.

My participation in the epidemic extends to my membership in the Association of Nurses in AIDS Care (ANAC). I am a past president and active member. The group is aware of my study, has provided input throughout the process, and several members have reviewed and responded to parts of this study. This community of nurses care for people living with HIV as their primary nursing practice and are a sounding board for each other regarding all aspects of caring for people living with HIV.

I teach HIV/AIDS educational programs. This includes my ongoing volunteer position as AIDS educator for the Washington County Hospice, being a guest instructor on HIV/AIDS in the School of Nursing at OHSU, and speaking at conferences and meetings. I continue to be discouraged about the level of misinformation people have about the epidemic. I am encouraged by the increasing number of people that show up to learn more.

Perhaps most important to my understanding through participation is my position as an identified person who supports women living with HIV. I receive phone calls from all kinds of people involved with HIV infected women. Nurses call for advice on how to safely do routine procedures. Family members call for advice about whether to, or how to, care for an infected relative, and women call to get information for themselves or a 'friend' that may be infected. These calls continue to inform the background context of the epidemic for me. The clinical care is challenging, and rewarding when it works, but it is on the edges of the epidemic that I think I get closest to the experience as it is lived by the women in this study.

Forestructure of Understanding

Discovering an appropriate workable perspective from which a study can be done includes the researcher's awareness of their personal perspective (Packer & Addison, 1989). The three aspects of forestructure were previously introduced in this report. The first is *a fore-having*. This is our practical familiarity with the area of concern. I have worked consistently for 8 years in HIV care and I have a very complete awareness of the practical tasks involved in caring for people living with HIV. This pre-understanding which I bring to this study is also something I am vigilant about controlling and managing. Because I have been close to many women living with HIV, I have preconceived attitudes and values about how they experience HIV disease in their lives. I recognize that I am personally involved and sympathetic in assisting women with the emotional challenges they face. I am in no way objective about their stories. I recognize that I must maintain a disciplined focus on the process of analysis from the content of the text and see clearly when my thinking is influenced by external or extraneous sources of information which are not relevant to a clear understanding of life with HIV disease from the women's perspectives.

The second aspect of forestructure is *a fore-sight.* This involves our point-of-view. I am a white, middle class, middle age woman. I have a graduate education and I work professionally as a nurse. My point-of-view is totally influenced by my demographics and the privileged position I have in society. I try to remember this when I interact with people from different circumstances, such as most of the women in this study. I understand that I live in a society that is racist, sexist, and ageist. Even if I reject those beliefs they contribute to the socially constructed judgmental attitudes people with HIV encounter in their communities. My point-of-view is also formed by influences that I choose. I am a feminist and believe in the empowerment of women. I am a spiritual being who believes in an ultimate beneficent source of all life. I am a nurse and consider caring to be the heart of my professional practice. And I am a teacher and believe in the power of knowledge.

As regards HIV/AIDS my point-of-view is as a nurse and a researcher. I believe we have the resources and skills in our communities to care for each other if we choose to. As a research nurse investigator I know that we will find a way to control HIV disease. I have confidence in science and promote participation in the search for a cure. I also believe that the lived experience of HIV disease is different for women than it is for men. It is also different for women living in white, rural, low incidence areas compared to the 76% of infected women who are African-American or Hispanic living mainly in large metropolitan areas. This was verified for me when I participated in the second national HIV in Women Conference in Washington, D.C., in 1995. The women in this study were not represented at that meeting.

The final aspect of forestructure is *a fore-sight*. This involves what we anticipate or expect. As already mentioned, I expect a cure for AIDS and control of HIV disease at a minimum. I expect that the trend of women being the fastest growing group becoming infected will continue. However, I expect that the epidemic among women will remain a silent one because the majority of women becoming infected have life circumstances and personalities that do not predispose them to becoming identified or outspoken regarding their situations. I believe this mainly has to do with their roles as mothers. I expect that HIV infection in women will remain essentially hidden. I believe we will see increasing HIV infection among women with lifestyles of multiple sexual partners, serial monogamy, or monogamy with sexual partners who either have other partners or use intravenous drugs. For these women the experience of becoming infected will probably involve significant guilt, shame, and denial; which may change depending on the kind of support available. This may or may not come from within traditional family relationships. I do expect that primary care in rural areas will improve as physicians become informed about the spread of the epidemic and realize that every woman must be considered at risk and appropriately assessed. Finally, I anticipate that women (both infected and affected) will enlarge the circles of informal support to provide access to any woman who becomes infected.

In summary, the forestructure or pre-understandings is the experiences, attitudes, beliefs and concepts that influence and orient a researcher during the interpretation phase of the study. For this study, the forestructure essentially comes from the researchers personal experience as an HIV/AIDS nurse and educator. The challenge for the researcher is to remain open to new and divergent understandings as the interpretation proceeds (Van Manen, 1990).

The Conversational Interview

The research interview is the time to be in a conversational experience with participants and hear their stories. Benner (1994) calls this the "communicative context." It is the place and time when a participant feels comfortable talking about their life and what it means. Van Manen (1990) sees it as serving the purpose of gathering and exploring the experiential narrative data. Participants were encouraged to tell their stories rather than comment on their experiences. A level of detail about all aspects of a situation was sought and included any concerns, memories, or understandings participants had or have about an event. The view is that no one story exists and every telling of a story may reveal an added aspect or understanding.

In this study the interviewing was done during visits to the women's homes, usually during the day when their children were at school. The time was chosen by the women as the one best for them. Interviews occurred on the couch, at the kitchen table, on the back porch and often included small children, pets, and interruptions by neighbors and friends. A small, highly sensitive tape recorder and microphone were used as unobtrusively as possible. The intention in each interview was to be informal and private. This did not always occur and several interviews were canceled or re-done because things happened. Once a woman was upset about how to pick up her car from a repair shop and the interview became a trip across town to get the car. When it was later rescheduled, I believe the level of self-revelation was enlarged because the participant felt I cared about her and could be trusted. The quality of the conversational interviews in this study is one of its strengths. The decision to create environments that personally supported the women in revealing the stories that give meaning to their lives was a good one. Interviews were done over the phone in two instances when the women lived too far away for a home visit. The calls were set up with the same attention to choosing the time and circumstances as the visits were.

Fixing the Narratives Into Text

The interviews were tape recorded and then transcribed into narrative text. The original tapes were secured in a locked, unmarked file. The narrative texts were then edited and all names and direct identifiers were changed to protect the confidentiality of the participants. An effort was made during the first reading of the typed text to add notations of nonverbal communication or emphasis. It is understood that a written page cannot convey the meaning that animated dialogue has. The intonations, inflections, gestures, pauses, and facial expressions are lost. The researcher must remember the difference between the original telling of the story and the flat nature of the written text as the analysis proceeds. Returning to the participants for further information or clarification was a valuable way to refresh the original nature of the telling of the stories in the text.

Discovering Essential Themes

The search for essential themes involves looking for the meaning of the story for the teller. It is about reflecting on what the sense of the story is and what is happening in the underlying experience that the person is describing. This is the point in the analysis when the researcher's biases, pre-understandings, and expectations can be challenged and changed (Benner & Wrubel, 1989). The task is to remain open-minded and not take anything for granted. All aspects of the experience must remain accessible to the interpretation. Even areas of inconsistency or disagreement may provide valuable insights (Benner, 1994). The process involves a hermeneutic circle of entering the world of the participants understanding through the whole text, and then drawing back and questioning the understanding, only to return again to the details or parts of the text (Packer & Addison, 1989). The process includes seeing the text as a whole and what the dominant meanings or main significance is. It then moves to looking for particular stories, phrases, or explanations that are especially revealing about the phenomenon. These are critiqued to determine which ones are most revealing of the essential theme that is being explored. A final aspect of thematic analysis involves considering difference within a theme and between themes as various aspects of the experience are expressed. Benner (1994) describes the researcher as engaged in cycles of understanding, interpretation and critique as the essential themes of the meaning of the experience are chosen. In this study the discovery of the essential themes included discussion of each aspect of the women's experience with members of the dissertation committee. Van Manen (1990) calls such discussions 'hermeneutic conversations."

Identifying Exemplars and Paradigm Cases

In the conduct of interviews about the lived experience of something as significant in a person's life as infection by the HIV, there are moments when the story being told captures the essence of an important core meaning of the experience. These stories reveal situations, feelings, and emotions that are found in other participants stories about similar concerns and meanings. This is a paradigm case. It reveals and enlightens the researcher concerning the true nature of some aspect of the experience. Once the researcher identifies the essential issue, exemplars are found in the text of the narratives that demonstrate similarity or shades of difference. The varieties of the essential experience are revealed in the theme which the exemplars illustrate. Benner (1994) refers to exemplars as the operational definitions of interpretive research because they reveal intents and concerns within the contexts and situations in which *objective* descriptions of the situations might be different. She emphasizes that the goal of the research report is to develop a range of exemplars that allow the reader to recognize the distinctions in meanings the interpretive researcher is making. Paradigm cases and exemplars uncover commonalities and differences that occur across situations, over time and within cultural contexts (Benner, 1994).

In this study paradigm cases and exemplars were chosen from the whole narratives that revealed the qualitative distinctions of major concerns and emerging themes. Comparisons between exemplars were made and they were critiqued for which provided the best insight into the meaning of the experience for the participant. Differences and commonalities were included in the decisions regarding which paradigm cases and exemplars would be included in the final interpretive report.

Hermeneutic Writing of the Interpretation

Van Manen (1990) considers reflexive writing as the very activity of doing phenomenology and says writing and rewriting is *the thing*. The process of discovering which paradigm cases and exemplars reveal the essential themes occurs as the text is considered and the meaning of the experience for the participants is written about. The participants' stories and understandings of their lived experience is fixed as data for the study when it is transcribed and turned into text for analysis. The analysis is fixed as it is written and tied to specific exemplars, paradigm cases and themes. The writing process is one of deepened understanding for the researcher and provides an opportunity for self-reflection and insight about preconceptions or superficial awareness of the issues discussed. Hermeneutic writing is an ongoing part of the analysis that begins with notes taken after each interview and continues through summaries of the issues each participant raises, descriptions of themes, highlights of discussions with others about the emerging themes, and ultimately the articulation of the final interpretation and preparation of the report. Copies of drafts of each section of the analysis were read by members of the dissertation committee, who offered corrections, made suggestions, and added valuable insights.

Sample

Recruitment of Participants

The women who participated in this study were recruited in two ways. The first was through community support groups for HIV positive women in Portland and Salem, Oregon. At regularly scheduled monthly meetings the study was discussed and women were invited to participate over a three month period in the Fall of 1995. Twelve women were recruited through the support groups. The second way women were recruited was through their HIV physicians who participate in the Oregon Community Programs for Clinical Research on AIDS (CPCRA) program. The researcher is responsible for a special CPCRA initiative to inform women of research studies available and assist them in participating. These are mainly phase three clinical drug trials. Six women in this study met the researcher over the past 5 years in her role as a research nurse investigator and agreed to participate in this study. All but two of these women also attend one of the women's support groups.

Those who indicated an interest in the study were contacted privately and informed of the process. When a woman agreed to participate a home visit was scheduled for the first interview.

Demographics

Eighteen women were recruited for participation in this study. Participants were women with a documented positive HIV antibody test and were all receiving primary care for their HIV disease at the time of this study. Women varied in which stage of their HIV disease they were currently in. The majority of the women were in the asymptomatic stage. One woman went into her terminal stage and died during the study. Women ranged in age from 22 to 49 years old. Thirteen of the women have children: six women have one child, six women have two children, and one woman has three children. One woman has four grandchildren. Eight of the women have had one marriage and six of the women have been married twice. Four women currently live with a husband. Six women live in the Portland, Oregon, metropolitan area. Four women live in Vancouver, Washington. Five women live in small communities in the Willamette Valley and three live in other communities in Oregon. The specific towns that they live in are not included because of concerns for their privacy and confidentiality. This is a major issue in this report because in several instances, the women in this study may be one of a few women with HIV in their community and although they volunteered to participate in this study, they do not choose to be public about their HIV infection in their home community. Specific information concerning women's risk behaviors is not included in these demographics for the same reason, although it is revealed by some women in the narrative text of this report. When it is revealed it is because they chose to share it. One woman is African-American and one woman is Asian.

Data

The interview was a semi-structured conversation (see Appendix C). Interview questions were open ended and included requesting participants to describe particular life experiences they believe were related to their becoming infected by the HIV. The women were asked about interpersonal relationships and issues or concerns which have meaning for them as they deal with their HIV disease. They were asked to describe how they care for themselves and what they believe are the influences in their lives that support them or make things more difficult. Finally, they were asked to describe their experiences with the health care system. They were specifically encouraged to describe the problems they encounter and how they attempt to manage or avoid them. The most natural way to start the conversation involved having a woman talk about her life before HIV, which usually started in childhood. The interviews naturally flowed chronologically through life before and then after HIV infection, ending with the present time.

The interviews were done in women's homes at a time of their choosing. Most preferred to meet during the day while they were alone. Two women were interviewed on the phone because of long distance travel; however, they also picked the time and circumstances for their interviews.

Data were collected in two phases. First, each infected woman had the in-depth interview which lasted between 2 and 3 hours. After the interviews were transcribed and the initial phase of analysis done, women were recontacted regarding specific concerns or issues that came up in the text. This was done both on the phone and in person. The researcher intended to only use the phone for follow-up contact because it assures the woman control over her privacy. However, because the researcher saw these woman in her clinical practice there were several instances when the women initiated conversation about the study with the researcher during other activities and a private conversation was held. Initially, plans included holding focus groups to discuss the emergent themes and essential meanings revealed in the analysis; however, this was not done due to the women's concerns for privacy. Even among themselves, the women carefully control who knows about their personal histories.

Data Management

The tape recorded interviews were transcribed and the original tapes secured in a locked unmarked file. Transcripts were immediately edited and all personal identifiers changed or removed (see letter in Appendix B). Women were later consulted regarding what pseudonym they preferred. No differentiation is made concerning which names are real and which are pseudonyms. Copies of all drafts of the transcripts were carefully monitored and none were given out for review that were not retrieved. Every effort was made to assure that the women's life stories were protected and not publicly available until the final text of the report was agreed upon by the researcher and the dissertation committee.

Data Analysis

The analysis of the text occurs concomitantly with the conduct of the interviews and may have an influence on the lines of inquiry. Benner (1994) describes the analysis and interpretation of narrative texts to include the use of thematic analysis, paradigm cases, and exemplars.

Thematic analysis involves the identification of concerns that are meaningful to the participants. This process includes careful consideration of each individual text followed by cross-comparison to concerns the emerge in other participants' texts. The text is read as a whole first and then sections, sentences, and words are considered as possible sources of meaning. The process moves back and forth from within the individual text to the whole text and between texts until the common emergent themes are identified.

Paradigm cases are identified as strong instances of concerns or ways of being in the world (Benner, 1994). Paradigm cases clearly reveal some aspect of the participant's life or concern and provide the reader with direct exposure to the lived experience under consideration. They stand out and may shift or enlarge the researcher's understanding of the concern being interpreted.

Exemplars provide additional aspects of the thematic concern. They may enlarge the understanding revealed by the paradigm case or show some additional aspect of it. They are used to show similarity and to provide contrasting examples of how participants respond to their concerns in the situation and context of their lives.

The Qualitative Solutions & Research (Q.S.R.) Qualitative data analysis computer software program NUD.IST (Nonnumerical, Unstructured, Data - Indexing, Searching, Theorizing) was used initially to analyze the narrative texts. The texts were read and descriptive codes used to identify the specific situations, issues, concerns, and meanings. The codes where then organized into categories of similar concern for further analysis and possible development into themes. (Appendix D). Due to problems with the software and delays in obtaining replacement and assistance in operating the program, the researcher did the major portion of the final analysis without the NUD-IST program. The computer program WordPerfect 6.1 was used to organize the categories and do the interpretive analysis. Paradigm cases and exemplars which had been chosen from the narrative texts were identified, retrieved from the text, and then included in the discussion of the emergent themes and common concerns.

The process of analysis involved continually confirming that the codes and categories reflected the shared experiences the women were having and what those experiences meant to them. Through comparing and contrasting these experiences and how the women dealt with them, the codes and categories formed a consistent pattern and the major themes were found and verified. As the themes emerged from the text, the common concerns women had around each theme became clear. Then the variations on the common experience were explored and those found to be shared by several women were included. The analysis is intended to both provide an understanding of the essential themes all women shared and also to show how women had differences in their lived experience of HIV based on differences in their personal histories, current life circumstances, and basic individuality.

Protection of Study Participants

Confidentiality and privacy is a major priority to those involved in HIVcare and research. A breach of confidentiality can have serious and far-reaching negative consequences for a person living with HIV. As previously mentioned, the original tapes and transcripts were seen only by the researcher and transcriptionist. All draft copies of the report were carefully monitored and retrieved.

A social worker specializing in HIV care agreed to provide mental health back up to the researcher as needed. At the beginning of each interview participants were given the social worker's phone number and told that she was available to talk to them if anything from the interview caused them to feel anxious or upset. To my knowledge she did not receive any calls from the participants in this study.

The women participating in the study were never revealed to other women in or outside the study by the researcher. The use of group interviews was omitted from the study when it was discovered that women are extremely discerning about what aspects of their personal histories they share with others. They want to control how things are known about them. There was concern that group discussion may not control for exactly what was revealed, or that unexpected, unwanted questions could be asked by members of the group. It was felt that the interpretation should remain private and confidential until the final report was completed. When the women revealed their participation in the study to each other, it was their personal choice to do so and they determined what they chose to share.

The study was reviewed and approved with revisions by the Institutional Review Board (IRB) at the Oregon Health Sciences University (Appendix A). Informed consent was obtained through the use of a letter of agreement to participate as stipulated by the IRB (Appendix B).

Validity and Reliability

Phenomenology provides a method to interpret and explain human thinking and behavior through understanding the everyday meaning of experience. It follows that an evaluation of the validity and reliability of an account includes subjective evaluation. This is antithetical to the reliability and validity standards used in empirical studies. The objectivity and control required in empirical studies to assure validity and reliability are not applicable to hermeneutic interpretive study (Holstein & Gubrium, 1994). Dreher (1993) maintains that validity and reliability are achieved in interpretive research through "an extended, trusting, and confidential relationship between investigator and informants, rather than through the establishment of the psychometric properties of research instruments" (p. 286).

Lincoln and Guba (1985) provide commonly accepted criteria for evaluating the validity or *trustworthiness* of qualitative studies in the naturalistic tradition. Their criteria apply to any naturalistic method, not just interpretive phenomenology. Establishing trustworthiness for Lincoln and Guba (1985) involves determining the credibility, transferability, dependability and confirmability of a research study.

Credibility

In naturalistic research multiple constructed realities are possible within one understanding of a phenomena. It is by using strategies to adequately represent those realities that a researcher increases the credibility of the interpretation (Lincoln & Guba, 1985). Specific activities such as prolonged engagement and persistent observation can increase the probability that credible findings are produced. Prolonged engagement is necessary to build rapport and trust with participants. It involves a commitment on the researchers part to remain engaged with the participants for a sufficient amount of time to build trust and become aware of distortions in the circumstances or situation that may affect the research. Prolonged engagement is also necessary to gain an understanding of the context and general background meanings of a phenomena. Persistent observation provides a process for remaining open to the life world of the participants. In this study there were participants that the researcher has known for years prior to the study. These women provided valuable insight to understanding the lived experience of HIV infection for women over time. When compared to women the researcher was just becoming personally acquainted with, the years of persistent observation of women with HIV disease helped the researcher in knowing how to build trust and rapport and create the circumstances for the interviews.

Transferability

Interpretive researchers provide thick descriptions of their findings and allow their readers to determine for themselves when and if an interpretation is applicable or generalizable to another situation (Lincoln & Guba, 1985). The naturalistic researcher presents their findings within the context of the time and circumstances in which they were found. Whether they are true in another context or at another time is not proposed. The researcher's responsibility is to provide a rich data base from which others can analyze whether the findings of the study are useful in another situation. In this study, women infected with HIV were not representative of women in the epidemic at large. They constitute a small proportion (24%) of the epidemic that is not African-American or Hispanic (one African-American woman participated). They are potentially representative of the cohort of women living in communities that do not consider themselves to be part of the epidemic. And they may provide insight to those working with women who are not considered to be at risk of HIV.

Dependability

Dependability concerns being able to establish the authenticity or consistency of an account. Ostensibly the purpose is to be able to replicate the results of a study; however, the transferability of an interpretative account has already been discussed. As an aspect of validity, dependability can be established through the keeping of careful records of the process of the research analysis. This was done consistently throughout this study through maintenance of a log of how the analysis proceeded. Each phase of the reading of the texts and determination of the codes and categories was recorded by interview (subject and page of text), date of analysis, and version number of the writing. This also provided a way for the researcher to go back and review or confirm prior thinking as the analysis proceeded. This log created an audit trail that can be followed to trace the thinking of the researcher throughout the analysis and back to the data in the original narratives. The process also included meeting with others to discuss the data and emerging analysis. The entire written record of the analysis can be saved for future reference and reflection, however in this study specific agreements were made with the IRB. The agreements were intended to support the privacy of the women and called for the destruction of the original tapes and named transcripts when the study was completed.

Confirmability

Confirmability includes the use of the audit trail to track the thinking of the researcher as well as to monitor the influence of the researcher's bias. It is important for a researcher to maintain an awareness of the role his/her forestructure plays in the analysis. The focus of the research is on the data and not on the investigator (Lincoln & Guba, 1985). Discussion of the data with the dissertation committee, and of the process with other nurses in HIV care, assisted the researcher in maintaining the confirmability of the report. The use of a personal journal also assisted the researcher in maintaining an awareness of the need for a separation between her personal experience in the study and the experiences of the participants.

CHAPTER IV

RESULTS AND DISCUSSION

This is an interpretive analysis of the text of individual interviews with 18 women infected with the Human Immunodeficiency Virus (HIV). The interpretation comes directly from the stories, issues and concerns these women shared. The content of the interview texts is the data of this research. This interpretation is enhanced and supported by the researcher's long-term relationships with many of the women and her clinical knowledge of their experience in the health and social service systems.

The data from the texts include a continuum of experiences reflecting the women's backgrounds as described in the discussion of the sample in the methodology chapter. Adjacent to the importance of their individual diversity is the awareness that these women also share living with HIV disease in the current sociopolitical environment of the Pacific Northwest, specifically Oregon and Southwest Washington. As Caucasian women, some of whom live in rural areas, they represent a small slice of the demographic pie of women infected with the HIV, 76% of whom are African-American or Hispanic and live in large Urban areas (CDC, 1995). As such they are truly part of the "Invisible Epidemic" (Correa, 1992). Any interpretation of their experience must include a recognition that their lived experience is rooted in essentially white middle class communities that do not perceive women as being at risk of HIV infection. Therefore, throughout the writing of this report efforts are being made to protect the confidentiality of the study participants. This includes not identifying the name of the community a women lives in; therefore, references to site, urban or rural, are used when necessary for the interpretation.

Every aspect of the experience originates in the fact that HIV is an infectious incurable agent. The primary sources of infection in 1996 are unprotected sex, the use of intravenous drug needles contaminated with infected blood and a mother's blood during the birth of a child (CDC, 1995). Prior to 1985 many people became infected when they received infected blood from transfusions, including hemophiliacs. People who became infected from transfusions, newborn babies and health care workers infected accidentally or "involuntarily" are often considered "innocent victims" compared to those infected by the socially unacceptable behaviors of unprotected sex or intravenous drug use (IVDU).

Part of the complexity in understanding what it is to live in the epidemic is the notion of "voluntary" infection. It is the basis for social judgment against infected people because they are perceived as having made bad choices, including the HIV risk behaviors. They may have had multiple sexual partners (including some of the same sex) or they may have used illegal drugs. Some believe HIV is a plague and a punishment on people who chose to practice socially unacceptable behaviors as was discussed in the background chapter. For those who do not place a moral value on HIV risk behaviors, there is still criticism of people with HIV. This can be seen in concern expressed in the literature about people who continue to practice risky behaviors even when they know there is a risk of infection. Those who criticise say people should be held accountable, and if they practice risky behaviors they must do them safely (Chu, Peterman, Doll, Buehler, & Curran, 1992). This assumes people have both physical and emotional control over what happens in their lives and what influences their behavior.

Two women in this study were infected by transfusions during surgery and one is a health care worker infected while caring for an accident victim. The life histories of these women which put them in harms way of the HIV are not that different from the life histories of women infected through unprotected sex or IVDU. One of them had a normal, non-abusive childhood as did two other women in the study. The life histories of these women became similar to the 15 others in this study when they found out they may be infected with the HIV.

Participants were consulted regarding their preference in using their name or a pseudonym. Some want their name used as an issue of pride and ownership of their story. Others preferred anonymity. No differentiation was made between the two in this report. In cases where extended quotations are used, participants were informed and permission to include the extended details was obtained. Occasionally the interviewer's questions are included if they enhance the flow of the information from the texts; however, the focus of the interpretation is to choose text in the women's own words that conveys an understanding of the issues being presented. The interview questions and any names or identifying information in the text are italicized.

This interpretive analysis shows how the naturally occurring world of each infected woman sheds light on others and leads to an explication of what the lived experience of HIV infection is for women living in the Pacific Northwest of the United States. By comparing and contrasting the women's stories of their life experiences, we gain a retrospective understanding of the similarities and differences in the interpersonal concerns and background meanings in their personal histories. We find meaning in why and how things are remembered and talked about. Developing an awareness of what has happened and what it means to women to be infected with the HIV informs us about ways to improve how we live in community with, and care for women living with this disease. Hopefully it may help prevent other women from becoming infected.

This analysis is organized to address the two aims of the study. The first section concerns the common histories of women with HIV which influenced their becoming infected. These include abusive experiences in childhood and not feeling valued as a person.

The second section concerns the lived experience of HIV infection as it unfolded in women's lives. The themes consistently found emerged from the narratives as coping patterns which changed as women responded to the progression of their disease experience. Women had one of four basic coping responses depending on the meaning of the experience to them.

In section two each stage of the lived experience will be discussed separately and the coping responses shared by all the women presented with specific examples of how women became caught in a particular stage. This section will also include times when women who had progressed on to other coping patterns returned to a prior pattern because of the intensity of an experience at a given time.

The analysis is guided by the three broad aspects of experience that appear to shape the background meaning HIV has for infected women. First is the importance of relationships to HIV infected women and how relationships both positively support and negatively undermine infected women's efforts to live with HIV disease. Second is the cultural context of the HIV epidemic and the socially constructed meanings and attitudes people have about those infected with the HIV, including the infected women themselves. Third is the ongoing difficulty of managing an incurable, unpredictable, complex illness. The goal of the analysis is to explicate the lived experience of HIV for women through understanding how background meanings and interpersonal concerns influence women's responses to the unfolding of the epidemic in their lives.

Section One:

Life Before HIV: Who Is Not an "Innocent Victim?"

Two consistent themes were found in the life histories of the women in this study: (a) home was not a safe place, and (b) not feeling valued as a person. The interpretation is guided by an understanding that behavior is influenced by prior experiences that shape and create the values and beliefs a person has about themselves, other people and the world they live in. This interpretive analysis intends to try to understand women's HIV risk behaviors including an exploration of the essential ways these women experienced their world during their formative years, when the influences which mold ones sexuality and self-protective or destructive skills and inclinations are strongest. These skills relate directly to the risk behaviors of HIV infection. The themes discussed in this section emerged from the interpretation and encompass the common experience found in the women's stories as revealed in the language of the texts. The themes began in childhood and continued through adolescence and young adulthood.

Home Was Not a Safe Place

Childhood is normally a time when children are valued and protected. Children's individuality and self-esteem develop in an environment where they feel safe and can trust that their parents and family will take care of them in every way as they explore their world. Unfortunately, not all children are treated this way. Negative, scary and hurtful experiences influence how children come to view themselves and their world and are an underlying influence for their future decision making and behavior (Pipher, 1994).

Children normally progress in their growth and development within the structure of relationships in a family. The mother is usually the main care giver and nurturer. Her relationship with the father is the model of adult love children learn. Mothers are expected to share family responsibilities with the father, however the father traditionally plays the dominant role of provider, protector, and family guide. Through girls' relationships with their fathers they learn about men and prepare to assume the roles of adult women. For many women living with HIV, their fathers played dominant family roles but often in ways that did not support them becoming well adjusted, healthy women. Quite the contrary, the behavior of many of the fathers in this study was destructive of the self-esteem these women were developing and created confusion about what a woman can or should expect from a man. In an epidemic which is sexually transmitted, a woman's childhood confusion about her self-worth and sexuality may cause her not to protect herself as she becomes an adult (Pipher, 1994; Cassese, 1993). The women in this study described the abuse within their families and with their fathers and shared their perceptions of the destructive role this abusive behavior had on their feelings of self-worth, their emerging sexuality, and their participation in high risk behaviors. Their experiences are consistent with what was discussed in the review of the literature concerning the abusive life histories common to HIV infected women (Pavone & Chavkin, 1993). In their own words the connections between abuse, reduced self-esteem and participation in risky behaviors is revealed.

Exemplar narratives will be used to demonstrate the theme of home not being a safe place and the connections these women made to participating in risk behaviors. Four exemplars are chosen to reveal the common experience the women participating in this study shared. Each is representative of a variation on the theme, however all four reveal the vulnerability women felt. They include: the effect of emotional and physical abuse on the development of young girls' self-esteem; accepted sexual abuse of young girls in extended families; long term damage of hidden incest, and girls having no one to turn to.

Exemplar: Emotional and physical abuse.

Sandy provides the exemplar of fathers' abusive behaviors toward their daughters. By all outward appearances this family was a model of success. The children lacked for nothing materially and the father was a respected professional person. He was present and powerful. What was not known was his growing cocaine habit and the hostility he brought home to his family. Men from all socioeconomic-economic levels bring their frustrations home to take out on their children.

> We went to really nice places . . . but to me there was still something missing. Taking us places wasn't enough. What was missing with my dad was we never got any tips on life. We weren't allowed to have an opinion or we got slapped. It was thought of as having a big mouth . . . Only what he has to say is what goes. So he was physically abusive and he was very emotionally abusive. He was always belittling us.
>
> Somehow I never know how to stay out of my dad's way. I always looked forward to him coming home. My mom would say, Stay out of his way, I'll make dinner, leave him alone. Because he would come home and he would be irritable and mean. . . . I'd want my daddy, and then I'd get smacked. My older brothers were smart enough to know to go to their bedrooms and leave dad alone. Well here I was this naive little girl just wanting the attention of father and always getting hit because of it.
>
> *So what happened as you grew up?*
>
> I had very low self-esteem. I just felt very bad about myself. I hardly had any friends because I didn't think I was very smart, very good, because my father told me I wasn't. In so many words he would tell me I'm not good. Because I was getting hit. Or you would get punished, but you wouldn't really get explained what you did wrong. So you don't really learn. All you learn is to be afraid of that person . . . and so right there, from getting hit and being put down you have low self-esteem. I felt that I did.

Sandy's parents divorced when she was 15. She turned to other men for the approval she never received from her father.

> "I wasn't getting attention from my Dad, so all of a sudden men looked right to me and I loved it . . . it was, kind of like a power. . . . I just went gung ho on sex."

Sandy links her early sexuality to the abuse and rejection she felt from her father.

> "I think probably because of my low self-esteem, I felt like I had to have sex with men . . . because I thought I would lose them if I didn't."

For other women the abuse was not just emotional and physical, it was sexual. Sexual harassment and abuse was part of their home environment. The behavior of men acting on their sexual urges with the female children in the family was part of the context of these women's lives.

Exemplar: Open, incestuous, sexual abuse.

Sharol provides an exemplar of how pervasive incestuous behavior was for some women and how devastating it was to their self-esteem. Sharol also draws a direct correlation between the chaotic sexuality of the men in her family and her behavior when she became an adolescent and sexual herself.

She was one of 11 children from two marriages. Like other young girls from abusive families, she watched her parents and learned that sex was not connected to safety or love.

> My mother and father came from [another state]. From what I remember they were married, but he was never around. He would just show up and want to be with my mother, get her pregnant, and leave, all during their marriage. They separated when I was four. I have some of my first memories from that time . . . [one was] being molested in the barn by a man I thought was a neighbor. Because there was never a face. My dress was over his face. So there was no face. And I remember my twin brother watching from the loft . . . [she found out later it was her father].
>
> I remember some of grade school. From when I was eight . . . it was my first . . . class picture. I remember I was molested the night before I got to school. And you can see it. If you look for the saddest girl in the whole picture, you'll pick me out. Ragged. Ragged. The next 2 years weren't too bad I guess. My brothers molested

> me. Wasn't my stepfather. He didn't make a pass at me till I was older. When my mom shut him off, he made his, but by then I was already man-wise.
>
> I went to school some, but I dropped out. I was very promiscuous. Very, very promiscuous. I would run away . . . or Mom would kick me out a lot. We could never get along. She never protected us. She was just very strict. Very strict. I don't know how she screwed up so bad with all us girls. Because there's only, out of six girls, there's only one has not been pregnant or had an illegitimate child. I just happen to have four [different fathers]. I've never been married, never will be.

Sharol is now dealing with alcoholism and depression. Her story includes the common adolescent behavior of escaping into promiscuity and substance abuse as part of surviving the emotional and sexual abuse of childhood (Paone & Chavkin, 1993, Fullilove, et al., 1993). Such children see no alternative to going into the streets in search of escape. Unfortunately, the abuse continues there, and includes ongoing self-abuse through drugs and alcohol. If a young woman had a child, the child had the potential to become a positive influence. Mothers with HIV disease see the healthy survival of their children through adolescence as a major personal priority. It provides a chance to have it be different than it was for them. Women spoke of "living for their kids." For women facing addiction, there is the additional worry that their natural inclinations not to take care of themselves will have more serious repercussions now that the HIV is involved. For Sharol, a recent depression and unsuccessful suicide attempt caused her to see that she is valued in her family and that she definitely wants to live to raise her daughter.

Having a reason to live is essential for women with experiences such as Sharol's. Brown and Rundel (1993) found in a prospective study of psychiatric aspects of early HIV disease in women that women do not have as much suicidal ideation as HIV positive men and attributed it to a lesser experience of stigma from homosexuality and to their maternal responsibilities. Throughout this analysis it became clear that the maternal role, being a mother, has the power to keep women's self-destructive inclinations in check.

Women were resentful and angry that their families were such unsafe places while they were children. They hated seeing their siblings and mothers mistreated and feeling helpless to intervene. If a family does not interrupt the abuse of children, the experience becomes buried as a "family secret" and emotional damage permeates the entire family (Pipher, 1992). It lingers into women's future relationships and has a destructive effect on adult relationships between siblings. This will be highlighted later in this discussion, in how women worked very hard to deal with their family histories when they wanted their families to know they were HIV positive and support them in their disease experience.

Abuse appeared consistently. The next narrative exemplar enlarges our understanding of the role hidden childhood abuse plays in the lived experience of HIV infected women. It also provides insight into the importance of relationships for women, even as young children, and how women put their own well being second to that of someone they care about. In Pam's case, her little sister.

Exemplar: Hidden sexual abuse.

Pam came from a typical, lower-middle-class, rural family common to approximately half the women in this study. This father was a farmer struggling to compete and survive socially and economically. He stood for strong Christian values. Respectability is important to such men and their children are considered prize assets over which they expect to have total power and control, especially their daughters. Unfortunately, a father's need for control may prevent a daughter from turning to him when she needs protection from others inside the family. Hidden family incest and sexual abuse, such as what happened in this family, are now considered major predictors of the risk behaviors associated with HIV infection (Paone & Chavkin, 1993).

> He was 70 when he died. So he came from the era where he ruled with an iron fist and the boys allowed to go out drinking and live with their girlfriends and the girls weren't allowed to be that way. And, of course, it happened anyway, obviously. But he was, he was definitely responsible. He took care of the family financially . . . he wasn't a loving kind of dad . . . but with the way he cares about his kids . . . I mean his boys would call him like if they were in jail, you know, DUI or . . . He'd help them out you know. . . . We were afraid of him more, the way he yelled. He yelled a lot . . . brothers were hard to control. . . . My dad was very angry.
>
> Dad was good to Mom in the fashion that he took care of her. But he was not good to her in that way that he took away a lot of her self-esteem by tearing at her. . . . And that's hard to live with, I couldn't stand him for the way he treated her. And, you know, I see that in the boys. They picked that up, they treat their wives the same way.
>
> *Did your dad pick on your self- esteem?*
>
> Yeah, he did pick on mine. As I was growing up he was so worried about . . . he'd say things like when we'd wear make-up. You look like Jezebel. . . . And it always made you feel kind of cheap And he didn't like you to wear red stuff, because in that era red was prostitutes. He was real particular about keeping us covered. You couldn't wear shorts to town, you know, things like that. I think he was just wanting us to be pure.
>
> There was some situations growing up that there was some abuse happening. Some sexual abuse that was real hard . . . it was going on from the time that I was in the third grade until about the eighth grade. And it was happening to my sister and I both, my youngest sister. And I think that kind of is what made us more close because we had this secret together. . . . It was my brother-in-law. It went on for 7 years . . . the thing is, when he first approached me I said, there's no way I'd do that type thing. And then when my little sister went there by herself without me, and she didn't have that kind of power . . . so he started sexually abusing her . . . and when I found out I felt like I had to be there for her in some way. It was kind of strange. I was upset about what was happening to her and was trying to protect her . . . I felt like since it happened to her I got to do it too. . . we couldn't tell Mom.
>
> *Your sister, did she know he was doing that to you?*
>
> Yeah, she did. And I have gone to counseling . . . they suggested I confront them. And I said, no way . . . it's just impossible. And then as time went on I found out about the HIV and I decided that was the time to tell and open members of my family up to it. I got a scenario going in my head that as I told them about this they would

> say that I deserved this because of the lifestyle that I lived. And I thought, well, how dare they. I felt like that as a result of the stuff that was going on with the abuse, I got promiscuous and infected as a result of my lifestyle. . . . I think that it's been proven that abuse and stuff like that, a lot of people act out promiscuously. . . . I don't want to blame the HIV on the sexual abuse, but they do have something . . . there's just got to be.
>
> I've grown a lot. And that kind of made me feel good. . . . I'm probably the healthiest [in my family], and yet I'm the one that has AIDS. I mean it's kind of strange that it takes something like this to really wake you up and make you think about life. I always think, well if I wasn't the one with this disease, and it was one of my friends, would I feel the same way about it as I do because it's me. You know, would I be the one judging, would I be the one saying, Wow, you know, you did sleep around. It's hard to say, I hope I wouldn't.

Ironically, the kinds of experiences fathers want to control never happening to their "pure" daughters may happen secretly within families and ultimately influence young women's' risk behaviors and HIV infection. A father's need for control may prevent the building of trust in a family, without which sensitive issues such as incest remain unspoken. The burden of the shame of the abuse then remains with the victims (Pipher, 1994). Kidman (1993) discusses the feelings of self-doubt and self-abuse that children feel following an abuse experience. Pam was strong enough to later seek counseling and feels she's healed herself. Her sadness remains for her family where the secret remains. In respect for her mother, Pam agreed not to tell her father about her HIV. He recently died of cancer never knowing that anything unfortunate had happened to his daughters.

Fathers' needs to exercise dominance and control in families may include the collusion of mothers. The people a child naturally turns to may not be there when needed and may actually perpetuate and support the abuse (Pipher, 1994). Not being able to turn to their mothers for protection was a major issue for many of the women in this study. Jako provides an exemplar of girls who tried to make home a safer place. She failed in her efforts. No one would protect her. She is an example of girls who are unwilling to accept home as being an unsafe place, who try to create change, who try to find help. These girls often become the women living with HIV who are unwilling to let the virus ruin their lives.

Exemplar: No one to turn to.

> I remember being conscious at the age of 9 or 10 that I wanted my mother to get a divorce, and that my father was wrong for beating us and for saying these derisive comments about us. But I had no power. And I think the powerlessness was debilitating, but I think that I had some kind of strength in knowing deep inside that I was right and that I was worth something. But it still didn't help me. I wasn't enough support for myself. I needed a lot more. But I didn't get a lot more. I am another one of the examples of people who asked for help many times but didn't get it. I reported my father's abuse five different times between the ages of 11 and 17, and nothing happened. On two of those occasions I had bruising, physical bruises. And I was not taken away. I mean, I would rather have ended up in a dysfunctional foster home and known that at least something had tried to be done.
>
> There were horrible words. I was degraded constantly, daily. I was never good enough. I was stupid, ugly, fat, a whore. Even at the age of eight and nine. Reworking those patterns is what my life is involved in right now. It's not HIV so much that is a difficulty for me. It's more my childhood abuse issues that I work on in therapy every week.

Jako had to go outside her family to protect herself. Unfortunately her perceptions of the unwillingness of social service and justice systems to interfere in families is generally correct. Other women simply gave up and ran away from home when situations of emotional and physical abuse became intolerable; often only to find themselves even more vulnerable and again in abusive situations. Women wanted their mothers to protect them, and felt betrayed when they didn't.

> I have very little respect for my mother because of her lack of, she has no sense of self. Very, a very weak mothering instinct because of her co-dependent love for my father. And she has enabled his abuse up to the present.

The importance of the role of mothers in the abuse within families emerged repeatedly. It included the experience of watching one's mother be abused, which reinforced women's feelings of helplessness. Additionally, women shared anger and pain at being abandoned by their mothers who were unwilling or unable to intervene on their behalf. Linda's Mother refused to believe her daughter when she told her she was being abused. "From that day on I felt I had no Mother, she was gone, dead to me."

The lack of strong female role models became problematic for many women as they entered adolescence and were faced with peer group pressure for sex and drugs. Watching their mothers endure ongoing abuse and continue to love, or at least stay with abusers, reinforced the notion that women trade sex and safety for some sense of love and belonging or safety. Women later endured criticism because they would not abandon the men who infected them; the love and belonging they thought they had was more important than the anger and betrayal. Ironically, some women replicated their mothers' loyalties to abusive men.

The unwillingness or inability of mothers to protect their daughters from abuse created negative wedges in their relationships. It was revealed when women first wanted to tell someone they were infected. The mothers who had betrayed their daughters were usually excluded. Weak mothers were occasionally forgiven because of a woman's need to support herself and her children economically. However, in instances where the mother knew and colluded in the silence of the childhood sexual abuse, the mother-daughter relationship was damaged permanently.

The fact that home was not a safe place and that as children these women were abused, set up the background meanings about having control over one's body. In these circumstances children learn they cannot control what happens to them physically. Abused children come to believe their bodies belong to whomever can overpower them, emotionally and / or physically. Such children do not develop the normal boundaries and limits that nonabused children learn (Pipher, 1992; Kidman, 1993). When adolescence arrives and sexual urges begin for both boys and girls, children without boundaries fall easily into promiscuous behavior because they have no experience with having physical/sexual limits on their bodies. The message not to use alcohol or drugs because they are bad for your body carries little weight for adolescents who are familiar with having bad things happen to their bodies. The numbing or stimulating effects of drugs and alcohol provide a chance to feel something for young people who had previously shut off physical feelings because of abuse (Fullilove, et al., 1993).

Not Being Valued as a Person

The next theme to be discussed involves not feeling valued as a person. It is about what it meant to be part of a family that did not meet a child's needs. In these families the adults did not seem to value or take care of the child. In these families being the daughter or sister often also meant not being as important as the sons or brothers.

Disruptive and insecure family life was common for this group of women. The background context often included situations of economic insecurity for the parents. Cycles of abuse and family violence were reported as being generations deep and women spoke of seeing their parents unable to cope with the circumstances of their lives.

Drugs and alcohol were part of what made home an unsafe place. What it meant for these women was that they did not have priority in their families. In the struggle to survive, parents did not focus on the developmental, emotional or even physical needs of their children. When parents did turn their focus to their children, it included seeing them as targets for venting accumulated frustration or anger.

Bobby provides a paradigm case because her story includes all the common concerns women expressed regarding what happened to them during their childhoods that later led to the behaviors of HIV infection. These include poverty, substance abuse and addiction, divorce and separation, violence and abuse, fear for siblings, lack of support, being relocated often, and social isolation. The social reality of such families was unstable, lower middle-class. To an external observer they would probably be seen as families with many problems. It is important to note that Bobby is not unique in that at no time did anyone attempt to intervene. Other family members, neighbors, or teachers never identified these children as being in any real danger. As was seen in Jako's story, the human services system does not readily become involved in troubled families. The outcome for children in these circumstances in not always immediately apparent; however, the damage is revealed in young people's behaviors at a later time, behaviors that put them in harms way of the HIV.

Paradigm case: Cascade of events to HIV infection.

> My mom got married when she was 15 and had me 14 months later. My father physically abused my mom. I remember watching him. I think that's a very big significant part of my life, because I was always very fearful. I had a lot of nightmares. And, even though I don't justify the fact that my father had any reason to do that to my mom, she was already an addict at that age . . . me and my little brother grew up watching my dad beat her up. And me screaming at the top of my lungs for him to stop. And I just remember the terror.
>
> He didn't hit us . . . we'd shut ourselves in our bedrooms. And my nightmares were horrible, horrid. To me they were real things happening . . . and mom would come home drunk or she'd be using, and dad would hit her . . . They finally ended up divorcing when I was four but my mom continued to come in and out of our lives, pop in, pop out . . . It was very hard . . . We moved a lot . . . Dad worked three jobs to support us . . . I never had any real close friends . . . I was the mom. I took that role of taking care of my little brother and my dad. . . . You know at six years old I wasn't very good at it.
>
> And then Dad all of a sudden took off and got married. I resented that. I was horribly mad. I resented her because all of a sudden she came into my life and it signified that my mom was not coming back. We started moving around quite a bit. I met one of

> my stepbrothers and at nine years old he started sexually abusing me. He was 16. And I didn't understand this, but this was how I was getting love from somebody so it was okay. I just didn't say anything. . . . It confused me . . . and I was watching my father physically abuse my stepmom . . . I remember trying to protect my father when he was having the cops called on him and being fearful of what was going to happen to me and my little brother. . . . I didn't like my stepmom. I wanted her out of our lives. And I wanted all these brothers and sisters out of my life. Then at 11 years old our house burned down. . . . It was around Christmas time and my dad didn't know what to do . . . he sent us to live with my mom who just had back surgery and was an alcoholic and a drug addict.
>
> Then all of a sudden my father came in and ripped us away and moved to [another state]. I was emotionally distraught. In 7th grade, got immediately involved with what you would call the sluts of the school. I got into smoking cigarettes . . . sexually experimenting . . . I had a lot of boyfriends . . . sneaking out at night . . . drinking heavily . . . ditching school . . . smoking lots of pot and having sex with whomever.
>
> My boyfriend was 18 . . . he was over one day . . . smoking pot and kissing . . . my dad caught us. . . . The very next day my dad sent me to [another city] to live with my mom. . . . As soon as I get off the airplane and got in the truck with my mom, she lights up a pipe and says: Here, do you want some? And it was pot. We lived in a motel.
>
> I tried to go to school. . . . I ended up losing my job . . . I met a guy . . . he kissed me and instantly I was in love. He ended up teaching me how to prostitute. I started shooting a lot of crank. He physically abused me. . . . I caught diseases from him.
>
> I'm an addict and I like to be as far away from reality as I could at that time. I think because I was trying not to feel any more. I had so much pain that I just didn't think I wanted to feel any more. So I wasn't. Everything was fine. It was okay that I was a prostitute. It was okay that I got beat up. It was okay that I was physically abused.
>
> *How old were you?*
>
> 16, barely 16.

Bobby went on to become the first woman discovered to be HIV positive in the Oregon State Penitentiary. She also successfully escaped from jail three times before turning her attention to her recovery, which changed her life. She went on to attend college, get married, have an administrative career, and have a healthy baby while she was infected. Bobby is an example of thirteen of the women in this study who survived traumatic childhoods and adolescence and broke through cycles of serious abuse and self-destruction only to find out later that they had become infected along the way. Her story also illustrates the fast fall young girls can take when support systems are not available to them. Pipher (1994) warns that we may be seriously failing young women in the United States today and putting them at significant risk.

The importance and effect of women's traditional roles is particularly apparent in rural areas where values are more conservative. This was significant in this study and reveals a concern that must be considered as the epidemic increasingly moves beyond urban areas. When fathers are absent or occasional mothers determine what everything means and how the world works for their children. Mothers use their experience and beliefs to create structure and order in family life. They may be unaware that they are perpetuating male-female relationships among their children that may be damaging to their daughters' abilities to later protect themselves as adults.

In families where education is not valued, career or personal advancement are not seen as important for female children. Maternal, passive, and care giving roles are what is valued and expected of women. This is a concern when discussing HIV infection because women's inability to assert themselves and demand that sex be protected is seen as a causal factor in the increasing incidence of HIV in women (Women Policy Studies, 1992). Women who cannot assert themselves in activities of daily living are unlikely to be sexually assertive. Norma provides a narrative exemplar of women feeling they are not valued and how that impacts their relationships with men.

Exemplar: Not feeling of value.

> Mom and dad got divorced when I was five. I was never around him. He left 13 kids. Mom never worked outside the home. All she ever did was stay home and take care of babies. I don't know if she could read and write.
>
> Education wasn't a priority of Mom's. I had plans of going to high school and on to college to become a home economics teacher . . . Mom could care less. If we didn't want to go to school that day, fine, stay home, I don't care . . . education was very low. It was more important to learn how to cook and sew and clean and take care of babies and take care of the men in the family.

Norma fits a profile of adolescent unwed mothers. She got pregnant at 16 and married at 17. Her mother was ashamed that she was pregnant and refused to allow her marriage in a church and made her go to another state to be married. The marriage did not last. She reflected on her loss of self-esteem and inability to protect herself from men.

> It wasn't until the last 2 years that we were together, and a friend pointed out to me that he was always putting me down and saying bad things to me, to my face in front of them and the family. I guess I grew up with it, being put down. From all my brothers.
>
> I think it all starts back with the way I was raised with mom telling us to cater to men's wants and wishes. If us girls were sitting down on the couch watching a TV program and boys came in, they would pick at us until we would, you know, yell Mom, make them leave us alone. And mom would say, well, you girls just get up and move. So we would get up and have to sit on the floor so they could have the couch. The boys did nothing around the house, it was ours to do. Help Mom chop wood, pack wood . . . did all the yard work, did all the garden raising. Took care of the chickens. The boys did nothing. They were just like kings in the family. If they wanted a drink of water — get up and get me a drink of water. And we would have to get up and do get it. We had to clean their room. They didn't have to do nothing.

Norma talked about what happened later in her marriage when her husband tried to help her.

> If he got in and helped me do housework, and then my brothers would tell him he was hen pecked. Men weren't supposed to do that. Why are you doing that. It's her place to do that. And they would tease him about it. And it would embarrass him and then he wouldn't do it.

The problem for women from families like Norma's is that the desire to please men is so great that there is no evaluation of the man's commitment, or the right to expect anything from men generally. Promiscuity and moving from relationship to relationship reveal women's unmet needs for safety, respect, and priority in someone's life. Norma's personal relationship history with men is typical of HIV infected women. It included many short relationships following her marriage, including one with a man who abused her daughter. She was able to escape that situation and did believe her daughter over the abuser. She wanted her daughters to see her as able to stand up to men, something her mother could not do. The man who ultimately infected her lied to her about his HIV status and knowingly had unprotected sex with her. Despite his betrayal, she remained loyal to him until his death, over the protestations of her daughters. She spoke of how he needed her and that she was not the kind of woman to walk away when someone was hurting. She managed his dying and became a support for his mother who came from afar. She even became responsible to put his tangled legal and personal affairs in order after his death. Norma both intellectually rejected and emotionally embraced the traditional subservient dutiful woman's role her mother taught her. To this day she remains proud of her care giving abilities and sees it as her greatest strength. She continues to be involved with men who abuse and take advantage of her. The women's roles learned in childhood can become significant obstacles for women who need to protect themselves from the heterosexual transmission of HIV.

A statement that Linda made partially summarizes the common concerns women have about their life histories that they believe put them in harms way of the HIV. Her childhood was also filled with abuse from her father, stepfather and men along the way. Her family moved, there were remarriages, and insecurity and disruption were the norm. She too succumbed to adolescent promiscuity and drug abuse leading to chronic addiction and the slow road through recovery and healing. One of her greatest accomplishments was graduating from college and recently celebrating ten years of sobriety. Like Sandy and others, she discovered she was HIV infected after her abusive years at a time when she thought she was in a monogamous relationship. She was not.

> There's something I need to say about all this . . . this happens to many little girls. This is in the histories of many women, and women especially with HIV disease. You know, I was a normal little kid, and I had no boundaries that were set for me. My parents violated personal boundaries, sexual boundaries, emotional boundaries, and I had no self-esteem, no sense of self, no sense of worth. And so boys come along and say I'll hug you and kiss you and give you drugs or give you booze or anything to spend time with me, and I would do it. The other women do it, and men do it. I mean, men are abused also. It's just really sad. You know I started out as a little baby, a little baby, and I wasn't socialized in how to be in the world. I wasn't told how to say no. So when you talk about HIV disease and why don't you just say no, why don't you use a condom, why don't you . . . whatever you need to do to take care of yourself. How is this little girl supposed to do that? You know, she couldn't say no or she couldn't do anything she wanted to do because people were abusing her.

The themes of home not being a safe place and not being valued as a person revolve around the experience women have as members of families and the primary relationships women have with their relatives, specifically their fathers and mothers. This is an important perspective to have in understanding the lived experience of women with HIV because the nature of the infection for the majority of these women is sexual. Children learn how people are sexual with each other mainly from watching their parents. How a woman builds her self-esteem and sees herself as a sexual being in the world has everything to do with whether or not a woman gets in harms way of the virus. It drives how women get involved with men, what kind of men, under what circumstances, and the nature of the relationship (Kidman, 1993; Pavone & Chavkin, 1993).

In hearing infected women's life stories, it is difficult to separate out what is most painful for some of the women. Many talk about struggling more with their abusive childhoods than with having HIV. Some deal with both the abuse itself and their mother's betrayal in not interrupting it. Pain often turns into anger as women try to heal themselves and discover that their self-destructive, promiscuous, substance abusing behavior was rooted in damaged self-concepts and a search for love and belonging that they did not feel as children from their parents.

The lack of personal boundaries, promiscuity and substance abuse are common experiences for HIV infected women. They are the risk behaviors talked about in the public media; however, as Linda implies, the discussion rarely includes why the risk behaviors were choices people made. The discussion needs to include what has happened to women that influenced their behavior and what the behaviors mean to women. Only by understanding how risky behaviors essentially meant escape or emotional survival, can effective risk reduction and health promotion interventions be created.

The stories of the childhoods and adolescent years of three women in this study were normal and uneventful. They comprise another small cohort of women in this epidemic, women who have no idea they are at risk of HIV. Their numbers are expected to increase as the epidemic moves more broadly into communities of heterosexual people. (Chu, et al., 1996).

Some AIDS researchers believe that the number of sexual partners at a given time may not be the major factor in male to female transmission. They view the problem as one of monogamous relationships women have with an increasingly large number of HIV infected men. Women may spend many years with several partners during their lives, never realizing the infection may remain undetected as people move from one relationship to another. (Carpenter, Mayer, Stein, Liebman, Fisher, & Fione, 1991). This was true for six women in this study.

It should also be noted that for some of these women, their timing in the history of the epidemic was unfortunate. The epidemic was truly not considered to be a women's problem at the time most of them were infected (Correa, 1992). We now know better and there are efforts to reach high risk women with information and support (Ehrhardt, Exner, Ortiz-Torrez, Yingling, & Rawadzki, 1995; Wyatt, 1995). Some of their risk behavior could be seen as the normal experimentation of youth. Certainly the rise of HIV infection currently in young people reinforces this idea (CDC, 1995).

It cannot be ignored, however, that there exists a predominant underlying experience of physical, sexual and emotional abuse in these women's lives. More importantly, they are the ones who identified it as a meaningful factor in why they got into the high risk situations in which they were infected.

Summary

This first section of the analysis of the text of the stories of this group of women's lived experience of HIV infection concerned their personal histories and common experiences prior to HIV infection. The experiences they discussed involved relationships with fathers, mothers, steparents and siblings; experiences of physical, emotional and sexual abuse; early sexuality and substance abuse; running and being sent away; and high risk lifestyles.

These common experiences grouped into two themes shared by the majority of the women. These were (a) home was not a safe place, and (b) not being valued as a person. Three women's experiences did not follow these themes. They had middle class, non-abusive families. As will be discussed in section two, their experiences of living with HIV became more closely linked to the other women in this study when they discovered they were infected.

Section Two:

Themes of the Lived Experience and Coping Patterns to Being Infected with the HIV

One way to understand what it means to live with a terminal illness is to look at how people cope with what happens to them. The thoughts and feelings women had and the behaviors and actions they took to cope with the difficult and changing situations of living with HIV revealed consistent patterns. These coping patterns help explain how the things that happen to a woman because she is infected by the HIV change the essential way she understands her world and the choices she thinks she has. The coping patterns provide a way to help explicate the lived experience of the disease which women have in common.

The analysis of the data, through interpreting the narrative texts, revealed that the 18 women in this study shared four basic coping patterns to being infected with the HIV. This process involved looking at their common responses to what was happening to them; and comparing the similarities and differences found among the women. The coping patterns encompassed the major themes of their shared experience of living with HIV and revealed what it was like for each of these women to live with HIV day by day. The coping patterns are connected to the women's life histories and are influenced by their personal experiences and the background meanings in their lives.

Responses varied with time and changing circumstances; however, the coping response patterns generally followed the progression of the disease in predictable ways. Women moved from one coping pattern to another depending on what was happening to them in the disease experience and how they felt about it. As the circumstances of their lives were affected by having HIV, how they responded changed and cycled. These coping responses formed the patterns that were consistent among the women.

The common concerns of the lived experience of HIV which the women shared generally led to one of the four coping patterns, usually when the concern was strongest and affected the women in the same way. They provide a way to see the commonalities and differences within the experience for these women.

The major themes of the study were the coping patterns women shared. These are:

1. Feeling overwhelmed at having HIV,
2. Avoiding HIV and disclosure as long as possible,
3. Feeling resigned about HIV,
4. Integrating HIV as part of life.

These coping patterns will be described and then discussed in detail in the following analysis. Specific examples and text are used to reveal the common concerns that emerged and how women used these patterns to cope. The circumstances when women unanimously all had the same coping response will be highlighted. The circumstances when women had different responses will also be discussed and the situations and meanings in their lives which influenced their choices will be considered.

First Coping Pattern: Feeling Overwhelmed at Having HIV

All women described their encounter with the HIV as beyond anything they had ever had to deal with before in their lives. Even in their most difficult times, there was the chance for change. HIV was permanent and they spoke of feeling out of control and unable to cope. The pattern of feelings and behaviors that emerged was one of being overwhelmed. They described life with HIV disease as being on unsafe, unsteady, unpredictable ground. Their lives felt totally affected, interrupted and controlled by the arrival and presence of the virus. It immediately affected every aspect of their lives from personal relationships to normal public life. As women learned to live with their HIV disease, the feelings of being overwhelmed occasionally returned. It happened when they felt trapped and complained of never being able to get away from it.

Part of the common experience of feeling overwhelmed is connected to the nature of the virus. Sometimes when women tried to manage their disease, they felt they were dealing with a moving target. The virus mutated and resistance developed, health care providers and treatments changed, there were new tests to take, and the options among alternatives proliferated. They did not know what would happen next and lived in a state of anxious anticipation about something, and they were not always sure what it was. They felt they should be on guard to protect themselves, against whatever it turned out to be. Feeling overwhelmed turned to frustration and coping patterns of resignation during these times. When women felt overwhelmed they became immobilized and were unable to take any meaningful action. They described uncontrolled feelings of self-blame and hopelessness which led to withdrawal and isolation.

For some women feeling overwhelmed was their primary coping response and they consistently returned to it as the disease progressed and their status as an infected person was revealed. They remained in a constant state of feeling overwhelmed about being HIV infected despite occasionally having other responses as events connected to being infected occurred in their lives. Overall, these women felt that their lives were essentially over and they were just marking time until they died.

For most women feeling overwhelmed was an occasional state of mind that came after particularly unsettling news of a change in the epidemic or in one's personal situation. For all women, it stands out as their first response to the shock of initially learning they were HIV positive.

The coping pattern of feeling overwhelmed will be considered first by looking at when it was primary and strongest. This was during the process of finding out one was infected. The circumstances surrounding how women found out they had the HIV are important to understand because they are connected to women's risk behavior histories. The emotions generated around the process of testing positive illuminate the painful socially constructed meanings attached to being HIV infected. This time also set the stage for how women moved into other coping patterns.

The process of moving out of the initial feeling of being overwhelmed and moving on to other responses is predictable. Time passes and the shock is replaced by the day to day adjustment to knowing oneself as an HIV infected person. Women did vary in how quickly they made their changes and what direction they chose to go. The factors which kept women from moving out of feeling overwhelmed and those that brought women back into feeling overwhelmed will be included in discussion of the common concerns.

Second Coping Pattern: Avoiding HIV and Disclosure as Long as Possible.

When women felt that as long as you could not tell by looking at them that they were infected with the HIV, they preferred not think about it and not to talk to anyone about it. Some call their mode of engagement denial. Others see value in women having as much normal quality of life as possible, for as long as possible. Women consistently avoided certain aspects of the experience for longer periods of time than others, especially telling people they were infected.

For some women avoidance was their primary coping response to living with HIV. They refused to let HIV define who they were to themselves or anyone else. They rarely attended support groups and preferred not to socialize too much with other HIV infected people. They did not feel hopeless or helpless about the virus, and did not feel it has come to persecute or punish them, they just preferred not to think or talk about it if they did not have to. Women in avoidance realized that the time would come when they would have to disclose their disease to others and become more involved in managing it. But until that time came, they were in no hurry to engage in the epidemic. Most maintained a reasonable relationship with their primary care providers and took the recommended medications. Beyond that, they quietly lived their shadow lives with their children.

Women with avoidance as their essential response will be most affected by the new directions in diagnostic testing and treatment that encourage HIV care physicians to be more aggressive about managing HIV disease earlier in its course. Previously these women's health care providers could respect their preference to move slowly since the research was inconclusive. The capability to monitor an infected person's viral load directly has changed the standard of care and avoidance may now be considered risky.

All women chose avoidance and delay of disclosure as meaningful responses to their HIV experience at one time or another. Avoidance provided a response that allowed for "time-out" from the daily vigilance of self-care or advocacy. Selective avoidance of disclosure was an effective short term strategy in managing difficult relationships and situations. It gave women time to decide how, when, or if they wanted to participate in the unfolding changes involved in life with the HIV.

Some women became frozen in their inability to confront knowing or having anyone else know they were HIV infected. The dilemma for them was that the movement to disclosure and out of avoidance remained impossible to accept, yet could not be avoided. For those unable to cope with HIV in their lives, avoidance was replaced by resignation as their predominant response when the growing presence of signs and symptoms made avoidance of disclosure impossible.

Third Coping Pattern: Feeling Resigned about HIV

For this group of women, part of feeling resigned about being infected with the HIV involved times when they believed it was stronger than they were. That was when it felt it was useless to fight back. Common coping patterns of resignation occurred when women realized that some things couldn't be avoided and just weren't going to change. Coming to terms with the physical signs and symptoms of the disease included resignation to the fact that the disease progresses and there is no cure.

The deepest coping pattern of resignation involved feeling that the experience was fated and that for some reason they deserved it. Once the reality of being infected sank in, women for whom resignation was their primary essential response began preparing to give in and die. Feelings of helplessness and suicide occurred. Feelings of resignation canceled thoughts of fighting the virus or actively advocating for themselves, emotionally, physically, or socially. What was most difficult for the women feeling essentially resigned to being infected was becoming isolated. They couldn't trust and were unable to allow others to help make their experience better.

All women experienced periods of resignation, usually immediately following a time of feeling overwhelmed by something or when coping patterns of avoidance no longer worked. Women for whom resignation was not their primary essential response were usually able to move through it, to other responses.

The time does come in a person's experience of living with HIV when the initial benchmarks of being infected have come and gone and the reality that one's life is never going to be the same fully sets in. That's when the coping patterns of resignation are strongest. The trauma of the HIV antibody test is a bad memory. Family, children, and friends know and basically adjust to having the epidemic more directly in their lives. As reported by the women in this study, most people preferred to relate to them in the same way they always had and this was the women's preference as well. Occasionally however, everyone had to deal with the realization that life really had changed for a woman they cared about because she was HIV infected. This happened when social judgment or prejudice occurred and the unfairness and injustice in the epidemic came close to home. It increasingly happened as people watched their loved one change physically and become vulnerable or frail from opportunistic infections, the side effects of treatments, or the general progression of the disease. It happened when casual conversation changed to include tracking CD4 cell counts and the latest HIV information on television. Friends and family also gradually became resigned to the fact that the epidemic is real, pervasive and now directly affected them.

What was not so outwardly apparent was the emotional experience infected women went through. These were the deeply private moments when women reflected on their relationships and confronted their fears and hopes. The quality of this inner experience is critical to the success or failure women have with their disease because these feelings inspire or inhibit the self-care behaviors necessary to surviving with the virus. They are crucial to whether women move through coping patterns of resignation to patterns of integrating the virus into their lives.

Fourth Coping Pattern: Integrating HIV as Part of Life

Coping patterns of integration did not usually happen immediately. Women went through the other patterns of coping first; however, moved through them and gradually became actively and openly involved with their disease. Their predominant attitude was that they decided they really wanted to live. And in order to survive, a woman had to take care of herself. The underlying source of their motivation was usually to stay alive to raise their children.

Another motivation was to not accept another assault on their self-esteem. They had survived brutal lives and were unwilling to give in gracefully to the HIV. These women, for whom integration became their essential response, became activists and advocates for other HIV infected and affected people. HIV may be in their bodies but these women remained in charge of their lives. They also appreciated each other and formed strong friendships to work together to fight AIDS. They worked closely with their physicians to plan their care management. These women intend to live as long as possible. They would like to be here for the cure.

For the women whose most comfortable, essential responses were feeling overwhelmed, resignation, or avoidance, moments of integration occurred around their most meaningful relationships, usually their children. It occurred when they felt compelled to rise above and beyond their disease to directly protect and educate people they cared about. The coping pattern of integration also included issues of spirituality and confronting death.

Coping Patterns as Revealed in Women's Lived Experiences

Discovery: Horror at Finding Out One is Infected.

The experience of having the HIV antibody test done is spoken of by women as shocking, fearful, and life changing. Men and women both talk about the moment they found out as a pivotal time in their life, one woman described it to be, "like a knife slicing through my life, separating it into two parts, before and after HIV." This is an epiphanic experience like Denzin (1992) describes. A life changing time when "routines are ruptured" and people experience "radical redefinitions of the self." The overarching meaning that pervades every social construction of HIV and AIDS is that when a person gets infected with the HIV their life will never be the same again. For the person it happens to the meanings are deeply personal and totally overwhelming.

In this section we will discuss the initial coping pattern of feeling overwhelmed during the arrival of the HIV within two concerns. The first part of the pattern involved the concern of discovering that something was wrong and the HIV antibody test needed to be done. Three examples will be used to illustrate how this occurred for these women: (a) systems that failed: infection by transfusion; (b) self-discovery: signs and symptoms without apparent cause; and (c) betrayal and anger over sexually transmitted HIV. The issues involved in betrayal and anger over sexually transmitted HIV apply to the most women and will be further differentiated by women who were infected in marriage, those practicing serial monogamy, and those infected by a past lover. This is a crucial part of understanding the feeling of being overwhelmed at discovering one is HIV positive because it involves a woman's most personal definition of self. It invades her most private life; her sexuality, past and present with implications for the future.

The second part of the pattern involved the concern of the trauma of being tested for HIV antibodies. Examples which will be used to understand the concern include: (a) living in denial: not wanting to test, (b) unrelenting belief that HIV means death, and (c) fearing the stigma of HIV.

The women in this study were infected between approximately 1984 and 1992. It is difficult to determine because some women are unsure when and by whom they were infected. The issue is that at the time they were probably infected HIV was considered to be a man's disease and women were not thought to be at risk. This is only recently changing as the CDC and other national HIV/AIDS education organizations are publicizing the rapid increase of HIV in women. Women initially infected in 1996 may not be as shocked to discover their positive status as this group of women were.

The socially constructed background meaning of HIV/AIDS has also changed. Long-term survivors appear on television and in the popular press. Celebrities and prominent people have revealed their positive status and provide social role models and discourage judgment against people living with HIV. Such revelations are now ongoing as more prominent people reveal their HIV status.

This is not to minimize that HIV infection still means an early death to most people. It's meaning for health care clinicians may have changed more than it has for the general public due to knowledge of new procedures and treatments. As an infected person establishes a relationship with a health care provider, the meaning may change for them as well.

The understanding of the lived experience of HIV for women described in this study began with difficult, often brutal childhoods which left them vulnerable to the risk behaviors of HIV infection. They were teenagers or young adults at the time of their infection. They were living on a margin of society, emotionally vulnerable, socioeconomically unskilled, and incompletely recovered from the trauma of their childhoods. These women had generally succeeded at hard fought recoveries from their high risk lifestyles. The trauma and feelings of overwhelm at the unexpected appearance of the virus was increased because it came at a time when a sense of future and hope seemed possible. And then something happened to change everything.

The lived experience of HIV infection started with the first information that something was wrong. The information came in various ways but it meant the same thing. It meant something terrible had happened. It meant that a test would have to be done and if it came out positive the woman's life would never be the same again. Women had the test done despite the fact that they feared the results. The very thought of testing was devastating.

Beyond the basic idea that HIV means death, the feelings that women had were influenced by the circumstances of how they found out they had been infected. The initial shock and feeling of being overwhelmed about having the HIV included variations, depending upon how a woman became infected. How the infection occurred and who was involved affected women's emotional experience beyond the shock of discovering they were infected by the HIV. The similarities and differences in women's emotional experiences all became part of the overall pattern of coping.

Systems that failed: Infection by transfusion. Until 1985 the blood supplied by the American Red Cross was not routinely tested for the HIV (Shiltes, 1988). Two women in this study were infected during surgical procedures. They share a common anger that it took so long for the Red Cross to believe that the blood needed to be tested. Like people facing terminal illness from exposure to toxins, there is a sense of betrayal that those who were supposed to be protecting the public failed to do so. In the predominant socially constructed understanding of the epidemic, people infected by transfusion are considered innocent victims of a public health system that failed to protect them, but victims none the less.

Marilyn's story exemplifies the totally unexpected shock people with no apparent risk factors experience when learning they are infected. Her story also reveals the awkward situation health care providers are in when they have to tell someone something terrible has happened. They may have to track a woman down through relationships or prior associations that are then difficult for the woman to integrate into the experience. This is part of the reason why state laws and federal guidelines provide training and protocols for health care workers involved in counseling and testing. Counseling and testing guidelines were not in place when Marilyn was told her HIV status.

Marilyn was a very successful executive in a corporate job, raising two teenage sons and recovering from a divorce, when the call came.

> But in 1990, in November, so it'll be 5 years, I got a call at work, out of the blue from the Red Cross basically saying that we suspect that some blood that you got back in 1984 was infected. You talk about a blow.
>
> They had tracked down my name from having received some blood from a donor who is suspected . . . a little boy had died. This donor had given blood which we received . . . I'm sure I went totally white. I was fairly numb to hear the words.
>
> When you get a phone call like that, out of the blue . . . having it gone to my ex-husband's house, . . . it was a shock. Okay, what's this going to be . . . just knowing what you know . . . He said . . . come in and get tested. . . .
>
> He took me into his office . . . they took the blood and he indicated that it would take a day or two to really get it, but within a few hours, they could give me an idea of what it was . . . what was going to happen. He would call me that night and let me know what the preliminary results were. That was about it.
>
> When I left . . . my son had a water polo game, so I went there trying to concentrate on that . . . just sat there really numb. . . . Just feeling like all of a sudden, I'm just not knowing . . . but knowing that it was probably pretty certain that I was.

> *And so you got home after the game . . .*
>
> And then there's dinner . . . my kids were there . . . he called and I went into the bedroom . . . really attempted to just have it be normal.
>
> *What did he say?*
>
> Just that I was positive.

Marilyn moved through feeling overwhelmed directly to coping patterns of avoiding disclosure. She led people to believe she had cancer. She kept her HIV infection totally to herself for years until her health failed and she finally had to take time off from work. Women in avoidance move reluctantly into resignation as their disease progresses and they have to tell their friends and family what has happened to them. Everyone's expectations for the woman's future then changes. Learning she was HIV antibody positive meant that instead of starting a new phase of her life following a divorce and getting her sons through high school, she was now going to die prematurely.

Becoming infected during a transfusion meant systems one trusted failed. It meant that years ago a life saving surgery had actually created the circumstances of HIV infection and now a probable early death. For women infected by transfusion, the background meaning people share about going to a hospital to be cared for in a safe, professional environment, was an illusion. Their feelings of overwhelm at finding out they were HIV positive included having no lifestyle risk factors and now being associated with people who do.

Lois provides another example through her story which reveals the thinking women go through as the possibility of a potential exposure comes more slowly. The feeling of overwhelm builds with the realization of what has happened. Lois initiated having the test done after her experience of emergency surgery in a rural hospital which included multiple transfusions.

> There was a thing on the news back in 1990, 1991, about different hospitals that had received bad blood. And there was like 12 other cases in that hospital [where she had surgery]. So I thought, Oh I'll go, I know I don't have it. And within the 2 weeks it took to get the test, I didn't have it , then I did have, it, you know, trying to make it easier for when it came back. And by the time the test came back I had already convinced myself that I had it.
>
> I went into the health district . . . and when the results came back , there's a guy there, he's a case manager . . . really nice guy. He was waiting there to talk to me.
>
> It was really hard, I think I went through every emotion just in a 10 to 20 minute time. I mean the anger to no, not me denial. I went through them all. And he sat there and said . . . you can cry. And I just looked at him and I said: No I can't. I mean I could not have shed a tear that day if I'd wanted to. Totally in shock.

Women describe the shock of finding out about something that they know will totally change their lives. Similar descriptions are heard about people learning of a cancer diagnosis and the first awareness of life threatening illness. (Kleinman, 1988). It is a time when the world momentarily stops. Past and future become one with the experience and the present feels overwhelmingly out of one's control. Women went numb. Other women described their initial shock and horror as well; however, it was women infected by transfusions for whom the total unexpectedness was most pronounced. Another commonality women infected by transfusion have with some cancer patients is the knowledge that the cause of their infection may include the unwillingness of people who knew there was a risk to protect them.

<u>Self-Discovery: Signs and symptoms without apparent cause</u>. Coping patterns of feeling overwhelmed include growing anxiety over signs and symptoms that will not go away. One way women discover they are HIV infected is by figuring it out through a process of elimination. These women have signs and symptoms of disease that do not resolve with normal treatment. Over a period of time they discover that the reason they are not well is HIV infection. The diagnosis of the reason for the symptoms does not mean that treatment can be started and a woman can look forward to getting well as it does with many other

conditions. Quite the contrary, it means that something much worse is coming. It means that the symptoms probably will not go away and that they will probably ultimately get worse. It also means that an infectious disease may have been passed on in your family and others may be sick as well. A sense of foreboding builds as the reality of what is happening becomes clear. The feeling of being overwhelmed sinks in as the awareness slowly grows.

It is important to note the context of the time during which these women became infected. There were no gynecological guidelines for primary care providers concerning HIV. There were no recommendations for the treatment of HIV infection in pregnancy. They would come later (NIH, 1995). It was not until 1993 that the definition of AIDS was amended by the CDC to include conditions unique to women, such as invasive cervical cancer. HIV infection was not considered or ruled out in assessing a woman who appeared to have no risk factors.

The difficult process a woman goes through to discover HIV through her signs and symptoms is exemplified by Cathy. She is a model of the factors that can work for or against women in discovering their HIV status, including living in a rural area and being cared for by physicians unaccustomed to seeing HIV in women. She is a woman who could be living in any small community in America, going to work, caring for her family, receiving perinatal care.

Cathy was enjoying her new role as a mother and living with her husband in a rural community but she knew something was very wrong with her health. She worked in an administrative position which gave her access to specific diagnoses for various signs and symptoms which were reported in the paperwork she processed. Her experience of feeling overwhelmed gradually emerged as she did her personal research.

> For years I fought and I couldn't get below 170 pounds. I was always really athletic . . . then all of a sudden . . . a couple of years ago I started gradually losing weight and I wasn't dieting and I wasn't trying . . . I was down to 147 when I got pregnant. I just didn't gain anything at all my whole pregnancy. When I had the baby I only weighed two pounds more than when I got pregnant. And yet she was a normal size. But I got much thinner. . . . And then she was an emergency C-section because I had an infection in my uterus and after I had her I never got better. My obstetrician did all kinds of tests, everything except that one . . . They tried everything and couldn't figure out why I wasn't getting better. And it just got progressively worse.
>
> Then I started looking things up and saying . . . well, why would I have fevers for all these months? What about this red rash . . . bleeding gums that I'd had for years and thought was stress from the job. And the white spots in my mouth . . . and I'm having a sore throat and difficulty swallowing and fatigue. So I started looking things up symptom by symptom and making a list. And then when I made the list I started cross-referencing and the one thing that kept coming up under my list of symptoms was AIDS.
>
> And I told my mother that. . . . She was so glad when I tested negative for Lupus. . . . And I said, Mom, you know, I'm thinking of something a thousand times worse than Lupus. And I told her and she said, Oh, no that's not possible. And I said, It is possible. I have had unprotected sex with other people. .
>
> [Baby daughter] was only 3 months old and I was breast feeding. That's the worst part of it for me because I know I quit breast feeding before I got tested . . . I just had a feeling. . . . There will never be a time when I don't cry over this because . . . it just kills me to know that I may be killing her and I thought I was being such a good mother breast feeding and doing the right thing. And I would never have had her if I had known, I would never have had a baby. But I wanted a baby so badly. And we tried for 4 years for me to get pregnant. And we really, really were happy when we found out. . . . It was just like God really dumped on me. And I still wonder why. . . . I still don't know if she's positive.

Cathy's baby has been tested for antibodies three times and has been positive the last two times. Her husband refuses to be tested. Understanding unresolving symptoms was the reason Cathy found out she was positive. Now she is constantly coping with feeling overwhelmed at the possibility that her entire family may be infected and die from HIV.

Other woman experienced similar trajectories of events that led to finally knowing they were infected. This part of the coping pattern of dealing with feeling overwhelmed at finding out involves women being worn down by the suspicion of being positive. Having multiple HIV tests was common for women with histories of risk behaviors.

For Rose the process took many years and involved multiple HIV tests in two states. Some were positive, some were negative. Unrelenting fatigue was the symptom that finally motivated her to insist her primary care provider, who was resistant, test her for HIV again. She described the results as a mix of "dread and relief." Dread to know what her future would be and relief to finally have her failing health diagnosed and have the possibility of treatment start. She immediately went into avoidance to protect her adolescent daughter.

Here again, the context of the times in primary care affected these women. In 1994, the National Institutes of Health Division of AIDS (DAIDS) in the Institute of Allergy and Infectious Diseases issued specific guidelines to researchers receiving federal funds. The guidelines prioritized the inclusion of women and minorities in clinical trials for HIV/AIDS and specifically acknowledged that we do not have enough information on HIV in women because women have not been adequately included in HIV/AIDS research. The intention was to enlarge the discussion of women with HIV/AIDS in the professional literature and ultimately influence the standard of basic primary care. Additionally, training in the clinical manifestation of HIV/AIDS in women is now easily available through the CDC and through mini-residencies at regional DAIDS training centers. These recent initiatives on behalf of women were not yet in place when the women in this study were struggling with their unresolving symptoms and being seen by physicians unaccustomed to caring for women infected with the HIV.

Betrayal and anger over sexually transmitted HIV. Betrayal and anger over sexually transmitted HIV is the predominant reason why women think they are infected and go for testing. It happens when a woman discovers she may be HIV infected because of a current or past sexual partner. It can be said for some of the women in this study that the possibility of infection by IVDU is also present. The CDC (1995) reports 38% of infected women cite an IVDU sexual partner as their primary risk factor and 53% of women had sex with a man with documented HIV infection. Nine women in this report had an IVDU partner and two were infected by men who knew they were positive and did not use protection during sexual intercourse.

The feeling of being overwhelmed which women who were infected by a lover share included anger and betrayal. This was true both for women who were infected by their current lover as well as for women infected by a past lover. There were also variations as the following examples reveal.

The coping pattern of feeling overwhelmed was affected not only by how women found out they were infected, but also by who did it. Women currently living with the man who infected them faced not only an emotional change in the relationship they considered their primary support, but also had to decide whether or not to stay in the relationship. This involved concerns for security, children, family, and friends. It meant a possible total disruption of everything women had worked to create for themselves. It meant possibly taking everything apart right when a support system would be needed the most. It also meant that the men who infected them were probably further along in the progression of their disease than the women were. If they stayed together women knew they would have to care for their partners until death. Then the question became, who would care for them while they died? Women infected by their current lover coped by managing their feelings of overwhelm as this litany of common concerns unfolded.

Mary exemplifies the experience of women discovering a current lover, a husband, had infected them. Like women infected by transfusion, the information of becoming positive was a total shock. The difference in meaning concerns the presence of the man who infected her. Mary's story also helps enlarge understanding about how violated a woman feels, how immediate and concrete the association of being dirty or bad is.

Heartache of Infection in marriage.

> And so everybody said because you want more than $75,000 insurance you have to take this blood test. Well we went, What's the blood test for? . . . We laughed about it.
>
> And so the insurance company had a nurse come out and take blood and we signed papers and everything. And she came back and said, We need to take another sample. This is like a week later. And so . . . okay, fine. He did it again. And they sent me a letter telling me I was not able to increase my insurance because the results of my husband's blood test. And then they came out here and told . . . that it was positive for HIV.
>
> And it just devastated us right there . . . and then they sent me this letter saying they couldn't insure me for any more either, and that I needed to go get tested. So I did.
>
> The nurse called me. At the time she called me I was getting [daughter] ready for school . . . first grade. I just started hitting the walls. I was hitting [husband]. Anything in sight, I was just hitting. I couldn't believe it. I wouldn't let him touch me. I didn't want to touch him. I felt filthy.
>
> And because [daughter] was still at home I didn't want to get her upset . . . she was in her room getting ready. I just sort of clammed up on everything and said, I can't deal with this right now. I got to get [daughter] ready for school and then I'll handle it after that . . . and when she left we just sat and cried.
>
> I didn't want anybody to see me. I felt, I went in and I took a shower and I just kept scrubbing and scrubbing and scrubbing. I just didn't, I didn't feel clean. I felt like I had been raped. Everything that I had accomplished in life had been taken away from me.

Mary went quickly through the cascade of emotions women have when feeling overwhelmed by the information of being HIV positive. These include anger, loss of control, sadness, isolation, repulsion, and grief. Like most infected women, Mary stayed with her husband and cared for him through his death which came approximately one year before hers. Her feelings of anger and betrayal at her husband were deflected because she blamed their infection on a woman her husband rejected to marry her. It helped her keep from confronting the possibility that the infection meant he had prior life experiences he had not shared with her (another betrayal). Denial and avoidance appeared to be useful responses for women who choose to accept and not question things they feared and could not change.

Being in a marriage provides social structure and family support that helps women cope. Infection by a lover has a different meaning for women who are not married to the man who infected them and who they are currently in relationship with.

The meaning for unmarried women was more self-directed. Women said things like, "How could I be so stupid?" or "I must not care very much about myself." Learning they were infected meant their judgment had failed them and someone they trusted had betrayed them. Women also fell back on their established ways of being as they tried to emotionally survive receiving the information about their infection.

Norma's experience enlarges our understanding of how women discover they have been betrayed. It again reveals a health care system that did not yet consider women at risk of HIV. It also shows that women's basic, learned, childhood way of being has a stronger influence on their behavior than current influences from society or family.

Norma exemplifies the heartache of betrayal for women who thought the painful years of abuse were behind them and were enjoying jobs and children. She is an example of the women who practiced serial monogamy. This is considered to be the fastest growing group becoming infected in the epidemic currently (CDC, 1995). Norma heard on television about a man in jail for deliberately infecting three women and questioned her new boyfriend directly. He denied any possibility of having AIDS.

Long term risks of serial monogamy.

> Have you ever been tested for AIDS? And he said, Oh yeah, I get tested for AIDS all the time. . . . I go and get it every 3 months. . . . And, I don't know if I ignored the fact that I thought he had been lying to me. I don't even think I cared. Because my world had just shattered many times and I didn't care any more. . . . He didn't have it, he told me so.
>
> When [friend] gave me a box of condoms . . . we didn't use them . . . we started having regular sex in January . . . by the end of February I was dragging . . . I was barely able to get up and go to work. . . The last week my fever got up to 104.5 . . . I ended up in the hospital. . . . And they'd keep poking me and poking me, doing all these blood tests. And I says, Have you tested me for absolutely everything you could test me for? She says, Yeah. . . . . And again, the thought of AIDS came to my mind . . . I didn't know you had to sign something special to be tested for AIDS . . . I had no idea. So I thought they tested me.

After her hospitalization, she returned home to a slow recovery. Her boyfriend moved in with all his belongings. While straightening up their bedroom a couple of bottles of medicine fell out of his clothing. She did not know he was taking prescription drugs or what they were. She wondered.

> What could he have that he wouldn't tell me about? And of course AIDS hit me. So I went to the phone and called the AIDS hot line, and I asked them what the drugs were for. And she says, . . . if he's taking that medication he's got it, he's infected. Chances are you are too. Well, the other medication is for herpes. And he had never mentioned he had herpes. I mean I talked to him.

Once again someone a woman trusted had betrayed her, and this time she thought she was going to die, and die soon. The feelings of overwhelm become mixed with resignation and self doubt when women feel betrayed.

In Norma's text the feelings of overwhelm are mixed with a sense of exhaustion and hopelessness at endless bad luck. Yet she, like most women in similar circumstances, stood by her man through his painful, difficult death and orchestrated his funeral and family to the end. She explained that having him infect her did not mean as much to her as his asking for forgiveness and begging her not to abandon him. HIV meant a lot, but not more than women's deeply held roles as care givers. Women's resignation at their responsibility to see a lover through to death is common. This is consistently seen in infected women and in the roles women have played throughout the epidemic (Simpson & Williams, 1993).

Other women became enraged and could not tolerate the knowledge that their lovers infected them. They were totally and immediately furious about the betrayal. Their feelings of overwhelm and shock moved quickly into anger. These women spoke of a major shift from loving someone to never wanting to see him again. It was a complete, total, emotional change and occurred the moment they discovered they had been infected. These women were younger than those who refused to reject the men who infected them.

Linda exemplifies these young women who include anger at betrayal as part of their coping pattern of feeling overwhelmed. When she found out her lover, the man she planned to spend the rest of her life with, had infected her because of his bisexual secret, she went into a rage that lasted for weeks.

> "I just went into a rage, I went nuts, and I was more in a rage because he had lied to me, not because I was infected. Because, one more time I trusted somebody and that person was not worthy of my trust."

She found support in her Alcoholics Anonymous (AA) group that "stuck to me like glue until I could stand up again." Even her ex-husband supported her until he died of a drug overdose. Her rage at betrayal returned because he was to have been the one to take care of their young daughter if something happened to her. Like Norma, she fights depression from feelings of hopelessness at the pain she has had in her life. Unlike Norma, she became celibate because she felt she could not have healthy relationships. "Always the same conclusion. A person is a liar, dishonest, and I get abandoned and betrayed." She is one of the women who has spent years in therapy working on childhood abuse issues, actively trying to rebuild her self-esteem and confidence. Women who include anger at betrayal in their experience had intense emotions and energy that helped them push through feelings of overwhelm, avoidance and resignation to coping patterns of integration. They were determined to reclaim their lives for themselves and their children, even with HIV.

No escape: Infection from the past. It is important to compare the coping patterns and meaning of being infected by a current lover to knowledge that someone from the past did it. This is particularly true for this group of women who have life histories that included painful, difficult years as children and young adults. Having the HIV come into their lives meant that they had not escaped the past. It meant their current life was not safe from former influences. Perhaps most important, it meant that their recovery from substance abuse, or the end of their promiscuity, did not matter. They would not have the future they hoped was possible. HIV meant they got caught just when they thought they had escaped. Within the immediate feelings of overwhelm was a sense of hopelessness and helplessness and led to resignation for some women. For others the coping pattern included anger that fueled a move to integration.

These women were not having symptoms, did not discover their current love had betrayed them, they did not get a phone call after a transfusion or voluntarily have the test done. They are women who were moving along in their lives apparently unencumbered.

Robbie exemplifies women who have recovered from brutal lives on the street and had their addictions behind them. The women in this study she exemplifies were grateful for surviving their past and proud of their recoveries and renewed lives. She and her boyfriend appeared to be a solid middle class couple planning to marry and have children. Like thousands before them they went for routine HIV tests at a County Health Department. They were doing precisely what every HIV/AIDS care provider recommends.

> [Boyfriend] always wanted kids. And I kept putting it off. Because I was going through incest therapy and all . . . and I just wasn't ready. So finally I got ready and we went and got tested. I knew I needed to test. So his came back negative and mine came back positive. . . . I was devastated.

Finding out an HIV antibody test is positive means life immediately and completely changes. Instead of planning a life, such as a wedding and a pregnancy, women faced months of terror and emotional pain as they struggled with their lovers about how to go on. This included whether they would even continue to have relationships. This can now happen to any woman. For Jako, a young single woman, having a routine HIV test was just part of getting ready to have a relationship.

> I didn't ask for an HIV test. I just got checked for SDS. And pretty much as a last minute thing the nurse asked me if I wanted to have an HIV test. . . . I thought at least I'll have this piece of paper that says I'm negative. . . . I'll be able to show this to any future partner . . . they can respect me in turn by getting themselves tested and telling me what's up with them. . . . . I came back for the results and the doctor told me that my pap smear was normal but that my HIV test was positive....the counselor talked to me for 2 hours . . . I don't remember a word she said.

Jako went into the classic period of feeling overwhelmed and then used her youthful energy to make sure what happened to her didn't happen to other teenagers. She went public and became an HIV/AIDS educator for young people living on the streets. She made f film about "HIV and Youth". She did not have a long period of avoidance.

This aspect of coping with the feelings of overwhelm at discovering someone from the past had infected them involved women who got mad and refused to let the information intimidate them. Like Jako, Sue exemplified that part of the coping response which includes self-defense, and wanting to protect others. This will be discussed further in the section on coping patterns of integration, however it is important to note that it commonly first appeared at the beginning of the HIV experience, during the time of initial feelings of overwhelm.

> I was mad as hell. . . . He called me at work . . . it was pretty awful. . . . He called me at work and said he was going to go kill himself. And he just told me that I wasn't ever going to go have the kids that I wanted. And when [current boyfriend] found out that I had AIDS that nobody would want me.
>
> I called the channel 4 news and I told them. And I called the newspapers and did interviews with them and went public. . . . I moved out of town up into the mountains with [boyfriend] . . . because I got discriminated against a lot . . . it was a homo disease . . . women didn't get this shit . . . we left . . . [they moved to Oregon].

This is an example of the women, married and single, who pushed through their feelings of overwhelm to integrated coping responses of not letting HIV stand in their way of having a life. These women's lived experience of HIV is not despairing, but rather rapidly integrated and kindled by their fighting spirits. Throughout brutally abusive childhoods these women knew they would grow up and get away. Such children are sometimes called resilient (Herman, 1981). Their confidence in themselves allows them to move through their coping patterns of feeling overwhelmed, avoidance and resignation and become advocates for other women. They reject the negative socially constructed meanings and attitudes some people have about HIV.

Living in denial: Not wanting to test. Some women do not want to know they may be infected. HIV means so many terrible things they reason the best way to cope with their HIV is to avoid having anything to do with it. This happened for women who both didn't want to test and for women who tested and didn't go back for their results. The following two examples reveal the insidious feelings of being overwhelmed which women felt at the very thought of testing positive for HIV.

Sandy is an example of a woman who had such a response when her mother called with news about an ex-boyfriend who had died.

> And 2 years into our marriage, in 1986, I get a phone call. And my Mom said, You know who has AIDS? Not remembering that I had gone out with him. . . . I was in shock. And I said, Mom, I used to go out with him and I have slept with him. Oh my God . . . so [husband] convinced me to go get tested. I didn't want to go get tested. I said, why get tested? There's no cure. I'm just going to go get upset if I'm positive. They can't do anything. And somehow he finally convinced me and I went . . . and sure enough I turned out to have it.

Sandy is sad about having HIV; however, she blames no one except herself. She exemplifies women who are resigned to thinking their infection is their own fault because of years of promiscuity..

Women's coping patterns between feelings of overwhelm and resignation occurred consistently in this area of self-blame. Women who had behaviors they regretted not only feared getting tested, they had multiple tests, not always going back for the results.

This behavior creates concern among HIV care providers and educators. They know high risk women often respond to the information that they may be positive by avoiding getting tested or getting the results. The social stigma and fear of judgment mean more than the possibility of an improved disease experience through good care. This includes women who have had many ex-lovers who could have infected them. For these women discovering they are positive means HIV has probably been part of their world for a long time. It means there was probably no way to escape being infected.

Ann's story is an example of the women who have been in the epidemic for many years. She also shows how women can change in their willingness to confront the possibility of being infected and get tested. She shows how women may need time to integrate the presence of the virus in their lives before moving into coping with testing positive.

Ann had a long-term relationship with a man who rescued her from her abusive father. He appeared to genuinely care for her over many years and an international move. His abuse of her could only be considered part of the IV drug use they shared. They ultimately parted and went their separate ways; however, she always remembered and kept track of him because he had played such an important part in her teen years. She first learned of his AIDS from his brother.

> I was still in contact with [boyfriend]. That's when I got a letter from his brother stating that I should just forget him. . . . They knew already he was dying of AIDS.
>
> Well, I knew he was sick from his brother saying that he wasn't well. But he never told me why he wasn't well . . . no one told me . . . like maybe 6 months after he was dead someone said, did you know [boyfriend] died of AIDS. 1986 was the first time I got tested for the HIV .
>
> The first time I got tested I didn't go back for the results. I was scared. Then for awhile I didn't see anybody . . . and I ran into this person . . . and he was bisexual . . . I had a relationship with him and he was having relationships with men. He died in 1992 due to complications from AIDS. I hadn't been tested since 1986, so in 1990 . . . it turned up positive.

The world that women such as Ann lived in included the fact that HIV was part of knowing men. Who infected who became a moot point. The period of time women felt overwhelmed at testing positive was usually short because it was expected. Then the periods of avoidance and resignation began. Few of these women were able to fully integrate HIV into their lives.

Believing HIV means death. Believing that HIV infection means death is part of the cultural context of the epidemic in which these women live. People remember the early years when men infected with the unknown disease got sick and died in a short period of time. Despite scientific advances in the treatment and management of the opportunistic infections that come with AIDS, it is common belief that HIV is rapidly fatal. For some women, it was the first thought in their minds when they found out they were positive. Having HIV meant they were going to die soon.

Rose felt the immediacy of death when finding out she was positive. She was having a battery of test done to find the cause of her unrelenting fatigue.

> It started with my pap test is how I found out everything else. At first, when I found out . . . I was shocked. I thought, Jesus, I'm going to die. You hear people . . . when you say you have AIDS . . . that it is the end of your life.

It meant the same thing to Sandy. She was one of the women who had a support person to turn to. She received a call from her doctor while she was at work and immediately called her husband.

> I got my results. And he said, I know, I know. He said, Let's go home, I'll meet you at home. So I went home. And I didn't even cry yet. I was just shocked and scared to death. Too scared to cry.
>
> We laid on the bed and we were just holding each other like that. And I told him how scared I was. And I said, I want to die. I want to kill myself. I don't want to go through this . . . I thought I would die tomorrow or a week from now. I didn't know. And I said, I want to die, I want to kill myself.

The desire to have it over quickly comes in part from a sensational public media that has graphically portrayed people dying painful, difficult deaths from AIDS. The disease progression is one that sometimes includes multiple, often physically deforming infections. It is not uncommon to hear people say that they do not fear being dead as much as they fear the dying process.

Women may find out they are infected at the same time their lover finds out. They share the feelings of overwhelm and shock. Women then not only have to manage the reality that having HIV means they will die, they also have to integrate their lover's probably death. It is often difficult to separate the two realities. Kim is an example of women who suddenly deal with it all. Her experience included her lover's possible death, her own probable dying from HIV, and her children and mother finding out all at the same time.

Kim's lover of 5 years had been moved to a larger hospital outside the rural community where they lived because no one could diagnose the cause of his serious signs and symptoms. An infectious disease physician readily had an HIV test done and Kim described the experience of finding out the results.

> We'd been together for almost 5 years. No way it could be HIV . . . [doctor] asked everyone to leave the room except for us . . . [boyfriend] was just devastated . . . he was rolling on the bed. . . . Don't touch me, don't touch me. If you touch me you'll die. He thought for sure he was going to die. Absolutely horrible.
>
> *How did you find out?*
>
> I just remember kind of sitting in the chair in shock. As [boyfriend] would say, One day it was Hiroshima, the next day it was Nagasaki. It was two bombs coming down on your life. . . . I felt like everybody was existing around me but I was there by myself. And just hearing people talking in voices . . . basically going through me, not into me. I didn't feel like myself. I felt like . . . I wasn't there. I was just so numb . . . I think I froze . . . in some kind of shock. . . . I thought a lot about my kids. And my parents.

Kim had little time to manage her own experience because she was totally involved in caring for her sick, possibly dying boyfriend. For five women in this study the care giving role for another infected person seemed to predominate, as it does for many infected women (Simpson & Williams, 1993).

Fearing the stigma of HIV. Following the experience of testing positive, women immediately had to face the social stigma and judgment people had toward HIV infected people. These negative emotions coming from others became part of their coping pattern of feeling overwhelmed. From that point on women felt they had to either live in secret of be prepared for the prejudice. Women revealed that the hardest part was needing to protect their children. This became a major factor for women who were able to move out of feeling overwhelmed into coping patterns of integration.

Lois provides an example of the way negative emotions can take over when people find out HIV is close to them. It is an example of how quickly a community can turn against a woman and what women are willing to do to protect their children. Her case particularly highlights the problems women face in rural communities.

Lois voluntarily went for testing after learning about 12 people infected at her local rural hospital from transfusions they received at about the same time she had many transfusions there. Her experience is especially important because despite its dramatic and rapid outcome, it introduces a part of becoming infected that leads to the next section in this analysis. And that is the response of other people to finding out a woman is infected. When one begins to see the depth and intensity in the negative socially constructed meanings around HIV, it becomes easy to understand why women move to coping patterns of avoiding disclosure.

Lois described earlier in this report going to her local health department and being told she was HIV positive. She did not cry. She was in shock. She talks about what happened later that day.

> And then, I told one person because I thought I could confide in her. And by the end of the day I had people coming up to me giving me hugs. Oh, I'm so sorry. I'm like, What are you talking about? And then I had rocks thrown through my windows. I had my child picked on, the whole bit. And so we left.
>
> *You left town because of it.*
>
> Yeah, we were basically run out of town.
>
> *How long did that take?*
>
> A couple of weeks. They've run a couple of other people out of there since then.

When that fateful day was over and the feeling of being overwhelmed from being infected sets in, women described days, weeks, months and years of playing the experience over and over in their memory. As with any important event in a person's life, the details become enlarged, the feelings permanent and from that day forward life is changed.

Disclosure: Fear of Becoming Known as an Infected Person.

This section explicates the experience of becoming known as an infected person to others. Telling others meant disclosing a terribly private part of their lives, becoming vulnerable and exposed. It meant possibly being rejected and judged. It also had the potential to mean one would be supported and cared for. For this group of women it meant figuring out how they felt about specific individuals or groups of people and deciding whether it was safe for others to know about the HIV infection.

The normal progression of HIV disease includes an asymptomatic period of time following the original infection during which it appears the person does not have a disease. The infected person can stay in complete control of who knows. This asymptomatic period usually lasts 5 to 7 years. The recent approval of protease inhibitor drugs and plasma RNA testing may extend this period even longer. For some HIV infected people called long-term-survivors or slow progressers, it is not uncommon to have up to ten years or more before the onset of opportunistic infections and the progression of HIV disease to AIDS. Despite outward appearances, the lived experience of being infected with the HIV continues throughout this asymptomatic period of time, albeit often secretly.

In 1994, it was thought that women did not live as long with HIV disease as men lived. A closer analysis of the data revealed that what was really different was that women were diagnosed later than men and often did not receive the same care, specifically anti-retroviral drugs and aggressive treatment for opportunistic infections (El-Sadr, Brosgart, Wentworth, & Neaton, 1995). This difference may also have been due in part to the expressed wishes of women, like some in this study, who were resistant or reluctant to start aggressive care. Taking medicines that have side effects and having frequent medical visits was a constant reminder of an infection that some women preferred not to think about.

A further evaluation of other reasons why this was happening verified that women did not voluntarily get tested as soon or as often as gay men. Therefore, when they did they were at a later stage in their disease. At the time these women were becoming infected the common belief was that this was a disease of gay men and drug users. As mentioned in the background section, women do not have the extensive subculture gay men have and therefore do not have the informal networks which include other HIV infected people at all stages of the disease. For all of the women in this study, they were the only woman they knew with HIV disease at the time they found out they were infected. Why this information is discussed here is because it has a direct bearing on when, how and to who these women revealed their HIV status. They had no successful models to emulate for how to tell people about being infected. Additionally, all but five of the women in this report found out they were positive late into the asymptomatic stage of their disease. They did not have long periods of time to adjust to their secret before they started having signs or symptoms of the progression of their disease, and had to deal with it publicly.

HIV disease is a very private matter that women usually shared with very few people until things started to change, such as needing to quit work. The natural response was to maintain control over who knew and avoid disclosure to others as long as possible. Avoidance of disclosure arose from feelings of being overwhelmed. The coping pattern of avoiding disclosure was helpful in the beginning as women took the time they needed to adjust themselves and prepare how they chose to tell others. There are exceptions, which tended to be women who chose to become spokespersons and HIV/AIDS activists. These women displayed an integrated coping pattern and were open about their infection, occasionally from the very beginning.

When a woman began to disclose to people that she was infected, she began an often painful period of not only dealing with her own feelings but also feeling responsible for the feelings of others. For her children, family and loved ones the feelings remained intensely personal and private. As word of a woman's infection spread to friends, acquaintances, and strangers it became more difficult because it was no longer private, and women become targets of both the fear and the reality of the judgment, stigma, and prejudice that HIV infected men have experienced for years.

The following discussion of the women in this study becoming known as infected persons will follow the natural way in which it happened for them. Disclosure was a long term process of making the HIV real in their lives. First came consideration of who would help? This came directly from feelings of not wanting to face the crisis alone. The urge to involve one's family at a challenging time arises from a universal human concern people have about who they can turn to for support and comfort in a crisis. When, whether to, and how to tell one's family (husband/lover, mother, father, siblings and relatives) was a concern for every woman. Depending upon what had happened in the past and the interpersonal relationships within the family, women felt varying degrees of safety telling their relatives they were HIV positive. How and when to tell one's children was a major concern. Telling friends was both positive and negative. The work site was usually the major public disclosure; however, it did not always happen.

The concerns involved in revealing one's HIV infection that were common among the women in this report included two major fears women expressed. The first was: who will help?, who to turn to? It involved dealing with expectations of becoming sick and dying and included the core relationships in women's lives. Depending upon a women's basic coping pattern, communication about becoming infected happened immediately or over a period of time. Women revealed common meanings around telling their husbands or lovers, parents, and siblings. They unfortunately shared consistently negative experiences becoming known as an infected person to their in-laws.

The second concern was: something has happened, who should know? The concern was not for basic survival and assurance of a support system when one gets sick or dies, but rather for continuing to have a social life and be a participant in one's community. The meaning of determining who should know involved women being protective of both themselves and their children. Shadow lives were created and maintained and women described balancing the risks of becoming known against the effort required to maintain the secret. Telling one's children concerned women the most and was often avoided until the situation and timing were right. As the disease progressed, women's coping patterns often shifted and the meaning of being known as an infected person changed as women's' priorities changed.

The women in this report were all living independently of their families of origin when they found out they were infected. Many described themselves as estranged from their families, or certain members of their families. Yet without exception, the issue of telling their parents and siblings was a primary part of coming to terms with being infected. It was second only to telling their lover or spouse and children.

Who will help? Who to turn to?. At the time these women found out they were HIV infected, having HIV meant dying and women immediately wanted to know who would be there for them, who they could turn to. Telling their lover or spouse was the first major disclosure for the women in the study who were not infected by that person. The concern that emerged involved a woman's fear that she may have infected the person she loves the most and now may lose him. Or worse, he will despise and reject her. We have already discussed the experience of those who were infected by a lover (past or current). As was revealed in the getting tested section, how a woman's uninfected partner responded to her news of being infected had a major effect on how she dealt with the experience.

Sandy provided the example of women whose husbands' responses made the difference between wanting to commit suicide or wanting to go on. For married women who shared their infection experience openly with their husbands from the start, the experience was difficult but whatever the outcome, they reached it together. They consistently credited "doing it together" as the basis for what they felt to be strong, supportive relationships. These women often shared the integrated coping pattern as they responded to other aspects of their HIV disease. Once the initial feelings of being overwhelmed by HIV infection passed, they actively asked for the participation of their spouses in their HIV experience. Men could be both supportive of their wives and in denial about themselves.

This contradiction revolved around women's fears that they had infected their husbands. They felt frustrated because they were unable to resolve their fears, because their husbands refused to be tested. During these times women's coping patterns went from feeling overwhelmed at yet another uncontrollable aspect of the experience to being integrated in their HIV advocate personas while resigning themselves to avoidance when dealing with their families. At home women worried but preferred to "keep things as normal as possible" which did not include the HIV. This behavior was also seen in a reversed way when women were integrated and open at home and avoided public disclosure.

The husbands of infected women who choose avoidance as their primary coping pattern were able to remain in denial of both the serious reality of their wives infections and the possibility of their own. The thought of losing their wives and how their lives would change appeared overwhelming and more than they could cope with. Cathy spoke of the burden she feels she's put on her husband because of her infection.

> I feel like it's so much that I've put onto [husband]. I worry about him all the time and . . . what will happen to him if something happens to me. He won't be able to take it. That's the only time I've ever seen him cry. He is a big, tough man. And I've never, only once, seen him cry and that's when I told him my test was positive. And he told me he can't live without me. He cried.

Cathy continues to feel overwhelmed about the emotional pain she feels she's causing her husband and her helplessness to change anything.

Women who were not living with a husband or lover had a choice to make in telling their lovers they were infected. Marilyn is the example of women who had lovers at the time they found out they had received infected blood. She was feeling so overwhelmed she could not tell her kids. She needed someone's support so she told her lover.

> If I had not been dating . . . it would have been really hard . . . he did tell me that he was just absolutely scared when I told him. He knew something was wrong. I met him downtown . . . he called [the Red Cross doctor] and talked to him. But if he had just said bye, or just left me, I would have . . . stayed home until I got ill. Kind of like, never go out again type feeling. He was extremely supportive . . . helped me get through it . . . although I know he was scared.

Her words reveal the vulnerability and need for reassurance women felt during the initial time of finding out about their HIV infection. Marilyn would later have less supportive experiences with men she dated who immediately rejected her when they found out she was positive. Once women's initial time of feeling overwhelmed passed they tested how open it was safe to be and usually decided they preferred to create shadow lives where people thought they had cancer and avoid the judgment.

The support of women's husbands or lovers after finding out they were positive was a crucial part of women being able to see that they still had a life to live. This was true for women of all ages. For adolescent or young women the fear was that they were now unlovable because they were infected. They felt shut out of love before they had a chance to experience it. At age 20, Jako was an example of women who felt their HIV infection would prevent them from ever having "pure true" love. However, after a period of time feeling overwhelmed and avoiding disclosure, she rediscovered her sexuality and began hoping for someone to share it with. When she met her current lover, she was afraid to tell him, yet knew she had to. She is a woman who integrated HIV quickly. Yet her fear of telling a special person revealed the vulnerability women have around issues of intimate relationships.

> That first time we talked the whole night, till 11:30. That night I didn't tell him I was positive because for all I knew I'd never see him again. It just didn't seem like I needed to. And maybe I was a little scared. Not maybe, I'm sure I was a little scared of telling him I was positive and ruining the moment. But I was in love with him. I was completely gone . . . I told him the second time we went out.
>
> I told him the truth. I'm infected with HIV, something like that. And I started crying. I really thought he'd just hate me, or be mad at me, or run away, or something . . . I really expected awfulness. I didn't expect any acceptance or anything. And he just, probably did the perfect thing. He turned toward me and asked me if he could hold me. And he hugged me while I cried.

Jako went on to become a crusader for kids on the streets of Portland. She credits much of her courage in speaking out to having the support of her lover. She talks about how the relationship made her feel whole. Infected women's need to feel loved and have closeness in their lives was a concern beyond revealing their infection status and will be discussed in detail later.

After telling their lovers, women talked about how important and difficult it was to tell their children, and most elected to delay it. It was their mothers who were often immediately involved as soon as a women found out they were positive. In many cases it was the same mothers that the women felt had not protected them as children. Just as estranged mothers often show up for their gay sons at the time of death from HIV, they appeared to be the first choice of many women when faced with where to turn when they found out HIV had infected them.

Support or rejection within the family. Decisions about disclosing their HIV status to their families meant revisiting primary relationships which varied from functional to painful. The underlying meaning of telling their parents and relatives concerned who would be there for them, and their children, if they got sick or died from AIDS. Disclosure to family either softened the blow of HIV or reaffirmed that there was little support in this world. This initial decision about disclosing to people who "had to love you because you were related" set the tone for future disclosure in non-blood relationships. Fear of disclosing to family usually meant greater fear of public disclosure. Women with strong family support felt they had less to lose when they went public.

The family concern women shared first was about disclosing their HIV status to their mothers. It involved turning instinctively toward or away from the person that had originally given them life, at a time when they faced the possibility of dying. When women asked who could help me, they thought of their mothers; some with relief, some with sadness and anger. This group of women were either in close contact, or no contact, with their mothers. Those who did not tell their mothers did so deliberately and with strong conviction. Those who did felt their mothers needed to know they would die from the HIV infection, and maybe soon. Once told, mothers were usually immediately integrated into the experience and offset the panic and feelings of overwhelm women felt about who would help them. Women had very strong feelings, both positive and negative, toward their mothers knowing about their infection. This was consistent with the strength of their own maternal feelings and the mother child bond. Women were often concerned about who would care for them because they worried about who would care for their children.

Women are often in close relationships with their mothers as adults. Mothers are family historians and keep track of everyone. For Sandy it was her mother that told her about the death and infection of the man who infected her. This mother was immediately and totally involved and continues to call constantly with the latest bit of new information she's heard on television. She exemplifies the mothers that integrate HIV infection into their love for their daughters and never hesitate to help. The meaning HIV has for women is profoundly affected by the responses of core loved ones, such as mothers. Cathy provides another example of such a mother. Her mother is an active relationship in her life and it was in conversation with her mother about her unraveling symptoms and suspicion of HIV that the decision to get tested was made. This mother was in denial that her daughter could be at risk and protested the possibility, but she still went with Cathy when she had the test done and was with her when she found out. Another example is Pam's mother who was also in denial that her daughter could be infected, even as she was present when the results were revealed.

> She was there when I found out the results . . . and she cried and stuff. And she went back to giving birth to me and thinking that she had a blood transfusion, . . . wondering if she gave me the HIV. Because there is just no way that I could be sexually promiscuous. Even though I was pregnant . . . I had led them to believe that, at that time that, you know, it was a one time thing.

This mother remained in the denial that had characterized Pam's family life throughout her abusive, incestuous childhood. This mother also protected her husband from ever knowing about his daughter's infection. She knew her daughter may be dying and kept the information to herself. It was their secret from him. Like many mother-daughter relationships, they shared avoiding any disclosure about the HIV as their response to the rest of the world.

> My Dad never did know. By the time I had nerve to tell him he was dying of cancer. And Mom thought: Why drop something like that on him? . . . That was a stressful time and I felt like maybe I didn't do the right thing by not telling him . . . it's something I can't do anything about now.

Part of the coping pattern of resignation includes missed opportunities to reveal oneself, and then the self-doubt that follows. Pam's family remains inconsistent when it comes to who knows and who does not know about her infection. The secretive behavior and mistrust among siblings and siblings in-law which started in childhood continues to this day. Pam exemplifies women who chose the avoidance response in all their core relationships and essentially just want to keep everything as normal as possible as long as possible. She does not pressure her husband to get tested and she does not tell anyone in his or her family about her infection if she can avoid it. Her mother knows and that is enough.

Women are fortunate who have emotionally healthy, intact families who are in communication with each other at the time the infection is revealed. These might be called integrated families.

Mary's family exemplified these integrated families. She provides a good example because she was the most advanced in her disease among this group of women. Other women's families appeared similarly integrated, however had not been fully challenged yet. Mary's family is the type that have always been openly and actively involved in every part of each others' lives. The HIV infection was no exception. Mary and her husband called their parents and siblings as soon as they found out they were HIV positive. They had laughed with them just weeks before about the absurdity of their being tested by the insurance company just because they had a new mortgage. Then they shared their horror and feelings of overwhelm. Their families supported them totally throughout their difficult disease progressions and both of their deaths. For them there was never any question who they would turn to or who would help them.

Women with supportive families knew that if they became sick they would not have to die alone. For the 13 women with children, having someone care about them soon became eclipsed by issues of who would care for their children if anything happened to them.

It should be noted that four women had resigned themselves to rejecting their mothers and did not tell them about the HIV infection. For example, one woman sees her mother as too difficult and critical to deal with. She does not tell her because she does not want to have to handle her mother's inability to cope or keep a secret. Others remain angry about their mother's abuse of them or her inability or unwillingness to protect them from the abuse of others. The topic is difficult and the dialogue is charged with emotion. None of them seems interested in changing their feelings toward their mothers at this time. They have no expectation that their mothers would care for them if they became sick. The coping pattern used with their mothers is one of resignation and is irreconcilable.

Telling their fathers meant very different things than telling their mothers. Half of the women in this study do not have contact with their fathers at all. It was not a matter of avoiding disclosure, they have simply resigned themselves to the fact that their fathers are simply gone and having HIV changes nothing. Six women do not even know if their fathers are alive, and several say they do not care. These are the fathers who came and went throughout their daughters' childhoods and their presence was often more painful than their absence. The fathers role in most of these women's lives was noticeably minimal or missing once their childhoods were over. At the time these women found out about their HIV infection, they were resigned to not having their fathers in their lives at all. The women in this group who still interacted with their fathers, did disclose their HIV status to him; and continued to try cope with what he had done to them in the past, in order to relate to him in the present.

This has particular meaning because disclosing their HIV infection to their fathers is connected to the fact that many women who were seriously abused by their fathers resolved their anger over the abuse after they discovered they were positive. The HIV infection forced them to confront the sources of the behavior that led to their becoming infected. This included not blaming themselves for their risky behavior once they understood it's relationship to their childhood abuse. It was part of long-term counseling and therapy that now included putting anger and resentment behind them as they moved forward to integrate HIV disease in their lives. Trying to bring healing into their lives included healing the abuses from the past. For the fathers, several of whom had their lives unravel and had to go through their own recovery, this was now a time for supporting their daughters. The relationships are now controlled by the daughters who determined how their fathers may know them. For the most part these women appeared to accept their fathers in their lives and guardedly accepted some support. Several women have gone even farther and have become peacemakers in their families. They are attempting to get their siblings to also address the issues of abuse in their past and find a healing. In one instance this has been successful. The others are still in process. The importance of this to understanding the lived experience of HIV disease for women is that the experience of infection appears to give women the possibility, if not the opportunity, to not only change their own relationships with their parents, but also influence others in their families to do the same. As women confronted how they felt about themselves and their lives, they caused others to revisit and re-evaluate long term relationships within their families.

As women integrated their HIV disease into their lives, they wanted to integrate other aspects of their lives as well. When the length of life is threatened the quality of life becomes more important and this included dealing with lingering pain from the past. Unfortunately women discovered that confronting and managing their pain from the past did not always change it for others in their families. Women shared patterns of resignation in not being able to bring integration to their families as a whole. The awareness of their own threatened mortality also heightened their awareness that time was limited for their families to heal and come together.

The relationships with mothers and fathers for this group of women covered the full continuum from one extreme to the other, from total love and support to complete rejection and distrust. It highlights the primacy of these relationship in people's lives, both positively and negatively. Women's patterns of disclosure in their families were usually determined by the quality of these core relationships prior to their infection.

Disclosure of HIV infection within women's families was definitely by gender and sisters were usually as close or closer than mothers. In some families where the mother was deceased or absent, it was sisters that became the focus for overcoming the avoidance and the initial disclosure of the secret. Despite the trauma or drama in families, blood relatives remained the predominant people infected women turned to when the time came to reveal themselves as HIV infected. Sisters often knew their history of risky behavior, some had shared it, and were not as judgmental as others for whom a woman's past was unknown. Women wanted to know they were still loved for who they were and that their family would continue to be there for them whenever they needed help.

For example, that time came for Chris when she was caring for the dying lover who had infected her and needed her sister's help with her children. The sister came without hesitation and became a family advocate.

> It helped me but it didn't help [lover]. He was jealous of the time I spent with my sister. He'd say: She's supposed to be watching the kids. But it helped me to know that I had somebody. She says that if I get sick she'll be there for me. So I feel very fortunate . . . hopefully nothing happens to her.

Women traditionally assume care giving roles for each other and for each other's children. In families without a living mother this care giving role among sisters becomes more pronounced. When women rejected their mothers, their sisters became the next possible core familial relationship they turned to. Sisters were usually assumed to be the ones who would take a woman's children when she dies.

Cathy's infection became a family affair for all her siblings. Hers is a paradigm case of supportive families with dysfunctional histories. It reveals how siblings who shared abuse as children can join together for protecting each other as adults. Just as they had tried to protect each other from their father's beatings, they banded together as adults to support

Cathy. She remains in a state of feeling essentially overwhelmed at having HIV. Her story provides insight about a family that has more completely integrated a woman's infection than the woman has herself.

> *How did your family take it?*
>
> Well, different ways. My [sister S] is a nurse. And so she was very matter of fact about it. . . . She's been very helpful. She immediately started gathering information. I knew nothing at the time I was diagnosed. And so she started sending me all kinds of material to read.
>
> My [brother D], he's a lawyer, he took it very well. He's very supportive. They're all very much behind me.
>
> My [brother J] took it the hardest because [sister S] told him and he yelled at her: That's not true. . . He's the smartest one in our family. Once he got it in his head that this was true and it was happening, he just immediately started trying to learn it. . . . He started absorbing everything he could about this disease and now he calls me every weekend. . . . We talk for an hour and a half every Sunday. And he tells me everything he's heard on the news, and new treatments, and what he's read. And he goes to the library and looks things up.
>
> *Sounds like you've become a family project.*
>
> Well, kind of. And they all say if there's anything they can do at all to help me, they will. And I know that's true. . . . We all, we've had a lot of problems. Every one of us. But we're here for each other. Because we love each other a lot.

Cathy's level of support from her siblings shows some of the best that happened when HIV entered the families of these women. Their support helped her accept feeling overwhelmed. Cathy will probably have the same level of total caring that Sue and her husband had throughout their illnesses. She will definitely not have to experience her HIV disease alone.

Other woman do not expect any support from their families. For example, Lois's brother's rejection of her started when he found out she was sick and she believes it came from his fear of seeing her die. The boys and girls were often treated differently in these women's families and the differences were now reflected in the adult relationships among the siblings. Men who did no care-giving or who were expected to always be strong in every situation had a harder time accepting their sisters had HIV. They had no skills to help them find a workable response to the situation. Men in these families were not raised to support women emotionally.

> *Do you feel you have good support?*
>
> I have my support through [boyfriend].
>
> I wouldn't necessarily say my family, no. My family's the kind of people that'll be going through my stuff before my body's cold.
>
> A couple of years ago at Nurture Night we had that thing where we brought something that was important. And I said; You have your family and then you have your chosen family. Because, in my opinion, I don't have a family. But I have my chosen family that give me a whole lot more support.
>
> I mean, I was in the hospital for 3 days and my family never came.
>
> *Did they know?*
>
> Yeah . . . I really don't expect them to . . . even to this day, my brother won't come to my house now.
>
> *How come?*
>
> Because I scared him so bad. He thought I was dying and it freaked him out. I went and stayed at my aunt's for a couple of days when I got out of the hospital and he came over and I was lying on the couch really sick, and he left in tears. He thought that was it . . . I don't know how he's going to handle it, you know. He's the only relative, brothers or sisters, that I . . .

Her pain in telling the story was obvious. Talking about the experiences of rejection and pain in communication with siblings was extremely difficult. These women expressed feelings of resignation, frustration, and hopelessness at ever being at peace in their families. Yet they really wanted it before they died. Women who were able to integrate many complex aspects of HIV disease in other parts of their lives were deeply saddened about having unsupportive families. They were able to deny, avoid or deflect the judgment of others but could not easily accept rejection from their families. As mentioned earlier, when women had been supported in their own healing, there were instances where they became peacemakers and took the initiative to solve problems in their families. However, for many of the women, the hurts were so deep and old that it was easier to just let the relationships with family go. It may not be until their dying time that these women find out if their families really do care. That is when many gay men discover that their family's love is greater than their fear or rejection. Unfortunately it often comes very late.

The one exception was for women who are essentially resigned to their lives generally. The lack of energy and involvement they exhibited regarding their HIV disease was also seen in their not expending any energy to disclose their HIV infection in their core relationships. It was as if the energy to sustain and maintain (and resolve if necessary) core relationships did not exist and has not existed for some time. These women expressed feeling alone and were uncertain about who would be there to care for them when the time comes. They expected to find out when the time came and not before.

Telling one's in-laws was difficult in ways that were different from telling one's blood family. They are important players in the unfolding understanding of the lived experience because they bridge the gap between disclosure within the tight inner family circle, where secrets can live forever, and disclosure to the outside world. In-laws were often the first ones to bring the shame and blame associated with the judgments of society about being an infected person. The revelation of HIV status got all tangled up with women's needs for the love and support of their husbands or lovers and feeling bad for the position they have put these men in, or the position infected men put them in. The concern that emerged came out of feelings that in-laws think the infected woman is going to kill their son. Finding out their son's wife or lover was infected was a shock many parents never thought would happen to them. It was especially hard for mothers whose sons were not infected and who had been looking forward to becoming grandmothers and now had to replace their positive hopefulness with fear for their sons' lives and hostility toward their sons' lovers or wives. It became complicated when sons felt they had to choose between the women they loved and their families. It became even harder considering men don't know how long the women they loved would live. The fear is that a man may be alienated from his family when she dies and he needs them the most.

For the women in this study disclosure to in-laws meant confronting and disappointing people important to their husbands, lovers and children. The worst cases involves in-laws who rejected both their daughter-in-laws and their grandchildren. A woman's pain of personal rejection was compounded by the knowledge that a core family relationship will not be there for her children, especially in her absence. Relationships with in-laws when grandchildren are desired include another set of difficult common meanings for everyone concerned. Foremost was the well being of the son. Often unspoken, but known to everyone, was the concern about whether there would ever be grandchildren. Sue is an example of such a situation.

> *Does his family know?*
>
> Yeah, they know. . . . Well, until I got sick. They were pretty cool about it. When I got sick, it upset them. And I'm sure it was because they do care about me, and, of course, they were threatened . . . and, they're terrified for him. And I can certainly understand why. They really want grandchildren.

Jako's experience involved the subtlety and innuendo so often present and reveals the sensitivity women had to being judged. Her lover's mother appeared to be caught between wanting to have a positive relationship with her son's girlfriend (potential wife), and wishing he had never met her. Jako describes a time when she stopped to see her lover's mother.

> His mother's a psychologist and when he told her . . . meeting me . . . what a great person I was . . . but HIV positive. . . She said: Well, she'll be a great friend. It's still a real barrier for her to deal with the fact that her son is dating someone who has a life-threatening disease that is communicable. Her only son is dating this woman who has a life-threatening disease.
>
> *Has she ever said anything?*
>
> She did once say some indirect things that were very painful to me. . . . She started talking with me about her life. And she . . . made it clear that she wished her son was going out with someone who was healthy. And she didn't understand why her son was disrespecting her and going out with someone who endangered his life.

For Jako, her mother-in-law appeared to be focused on her relationship with her son and his future in a way that excluded any caring about Jako or her situation. Jako became resigned to knowing that this woman would try to undermine her relationship and would definitely not be there for her.

The hurts that came from being rejected by relatives or in-laws often could not be repaired. Painful things were said and done during that difficult time when women first found out they were positive. Later, when people adjusted, looked back, and wanted to change what they had said or done, it was too late for women who had been hurt. In-laws reside outside the blood-family circle and as such are connected to the general socially constructed attitudes people hold about HIV. The immediate response of rejection at finding out a daughter-in-law (or potential daughter-in-law) was HIV positive had the effect of triggering bad feelings about both social stigma and personal self-esteem for women. Judgmental words re-stimulated women's own negative feelings toward themselves about their risk behaviors. This was very difficult to forget later. Women withdrew from relationships and become resigned and unwilling to invest any further in what seemed to be situations of rejection.

Robbie provides a clear example of such a situation. Her story also contains the positive potential of relationships with in-laws. She tells of how her lover went to visit his family to tell them he probably was not getting married and having kids right away because something had happened. Robbie was HIV infected. She knew this disclosure meant rejection of her and a challenge for him.

> And that was really difficult because that was during that first 6-month period. . . they at first thought he should leave me.
>
> Me and his stepmother don't even speak really. She has been so mean over the years, I could care what she thinks. She has never accepted me . . . and his dad didn't accept me for years, but he finally realized that it's not his decision. And now he's nice to me, but you know, we don't have a lot going because there was just too many years that I wasn't accepted by him.
>
> His stepmother is in the medical profession . . . She tried to tell him all these things that should be happening. He shouldn't kiss me because I'll have sores. And that I should be dead by now. That I'm some rare case and should be in a study. You know, she didn't know shit about HIV. She told him all these horrifying things. And told him he shouldn't be with me, he's going to catch HIV.

Robbie and her lover survived the emotional battering from his parents. They integrated her HIV infection into their relationship and decided to go forward with their lives together. In the fall of 1995 they decided to get married. Robbie sees the struggle her lover went through with his family as something that strengthened him as a person as well as helped them redefine their love. It also meant she had to confront feeling overwhelmed as how she was coping with her HIV disease and it forced her to take a more integrated attitude if she hoped to maintain her relationship. She now avoids contact with his father and stepmother if at all possible. She hopes they now understand that she is not going to kill him.

<u>Difficulty in managing who should know and when.</u> Once the personal pain of telling lovers and family was over, the meaning of being HIV positive moved into all the other relationships in womens lives. Outside the privacy of family business, having people know

their HIV status meant things started changing in even the most unexpected parts of women's lives. The time came when the need to reveal one's HIV status became an issue for these women in all their relationships.

The issue varied depending on women's primary coping response to their disease. All women had to decide how secret they wanted their HIV infection to be. Women who integrated HIV in their lives quickly became instant advocates for others. This was the rare response. Most women went through a period of feeling overwhelmed and disclosed only to people in key and core relationships until they had time to adjust to having HIV in their lives and then chose their level of avoidance or integration. Women who felt completely overwhelmed became resigned, withdrew and felt little need to share their situation with others. The meaning that emerged for women who were not resigned involved wanting someone to know that something important had happened to them. Women wanted their friends to know that things were different in their lives now because HIV was part of it. They did not want to have to keep the HIV a secret from everyone. Keeping the secret meant being alone.

Initially women spoke of avoiding disclosure to their closest friends. They worried about what HIV meant to their friends and how they would react. They feared their friends would become overwhelmed just as they initially had been. They feared their judgment or rejection. Yet the need to disclose usually overcame the fear and the effort to keep things secret was more than women wanted to invest. Cathy provides an example of the mental process women went through of both telling friends themselves and having friends find out from someone else.

Has [having HIV] affected your relationships with other people?

> Oh God yes, because I can't well, I can't tell anybody. I told two friends. One in Florida, my best friend. I just had to tell her. She called me the day I found out just by coincidence. And I was crying so hard I couldn't talk to her. And I just told her that something really, really bad had happened and that I would tell her later. And then she called me over the next several weeks, I just couldn't even function. And she kept calling and leaving messages and I never called her back. And finally I just said, I had to tell it to somebody outside the family. I was just going crazy. And I felt so mean lying to her and not telling her. And so I told her. And she cried, but she took it very well and she's very optimistic about it. And we still stay in touch and everything. She doesn't know a lot about it either, but I guess she's probably learning more as we go. And then I have a very, very good friend here in town and my sister told her. She's a real good friend to both of us. And I was upset that my sister told her. But I would have told her eventually myself because I was thinking of telling her. So I was mad at my sister for going ahead and telling her without asking me first.

This story displays several things common to the experience of women telling their close friends about their infection. Relationships and friendships were very important to these women and they both feared telling their friends and yet really wanted them to know about the HIV. Her friends' persistence in calling to find out what was wrong was important to Cathy. The role of Cathy's sister in telling another friend is also a common occurrence. It shows the difficulty people experience in close knit circles of relationships with having information that they know everyone wants and needs; and still respecting the right of the affected person to decide when, where and how people find it out. Unfortunately, sisters were some of the worst offenders. Perhaps because they saw the sharing of the information as supportive, even protective, and were not personally avoiding the potential judgment and rejection.

The risk of telling one's friends usually turned out to be supportive when women took the chance. The response of close friends meant women could take the truth of their HIV status outside family boundaries and test how the world would treat them.

The following is an example of couples as friends. Pam and her husband were playing volleyball when it came up that the reason they were not having another child was because they had to "deal with something you don't have to." Their friends' response was that "it could have been them."

Another example is of a friend of many years. Marilyn's best friend found out she was having a hysterectomy (within weeks of finding out her HIV status) and came from another state for a week to care for her. Marilyn initially avoided any talk of HIV.

> I just, you know, at that point, because I'd just found out, I didn't tell her. . . . I went down later that spring . . . to visit. And I finally told her.
>
> *How did she react?*
>
> Really supportive, upset that I hadn't told her before. She and I had been best friends since 7th grade. We were closer than she and her sister were. . . . We told her husband. We all had met at the same time when we were in college. And there's just been a group of us that has stayed real close together. And they've been real supportive.

Marilyn is an only child and both her parents are deceased. She expects little support from her ex-husband or her sons. This group of long time college friends have become her primary source of support. They have individually come for visits from many states and she was comforted in thinking they will be there for her no matter what happens. She even considers moving to live closer to a small group of them. It is in extended groups of friends such as this one that the reality of the fact that anyone can get HIV comes home to professional, upper middle class people who do not see themselves at risk in the epidemic. They also exemplify the power and importance of relationships and friendships in people's lives. In this regard women share one of the best things the HIV epidemic has revealed, and that is the power of the caring and love that people who are not blood relatives can have for each other. It is the power of long-term friendships that grow out of communities of shared interest. For many infected men it is the gay community. For Marilyn it was her college friends. For Mary it was her church community. Leah believes the Bahai community will be her support system. Support groups such as Nurture Night are designed to build the possibility of community for infected women.

The women also experienced support in unexpected ways. Robbie talked about a friend she expected to lose.

> I have this friend that has been so sheltered her whole life that I thought for sure she would not be able to handle it. And I told her while we were walking one day and it was like, no big deal. I said: You know, I really expected to get some kind of reaction from you. And she adds; Well, you know, If I were sick I would want you to support me. And that's it. But at the same time, when I talk about HIV stuff, I can say whatever I want and she'll listen.

Sandy summed it up after sharing stories about her friends.

> The one I expected the least to be good about it, and not mind, or the one I didn't think would want to be with me, or be my friend any more is the one who stayed with me as my friend. Whereas the one I thought would be okay about it, never heard from her again. Still don't hear from her even after I made a phone call.

The risk of disclosure to strangers was higher than the risk of disclosure to friends. Shared history was not part of the situation of disclosure. If anything, the shared background meanings were the socially constructed stigma and judgment toward HIV/AIDS. This was why avoidance was the response of choice for women, and even occasionally for women who otherwise predominantly integrated HIV disease concerns in their lives. To tell someone outside the family also meant women lost control of the information and how and to who it may be conveyed.

Sandy provides the example of situations with both positive and negative outcomes for disclosing oneself as an infected person. She was extremely reluctant to share her HIV status for a long time. She then decided to take piano lessons and was surprised by a teacher's reaction.

> I wanted to take piano lessons. And somebody gave me a list of names to call and one of them was an elderly woman. [She was concerned about her having time to practice so Sandy told her she was on disability.] She said: Disability? I didn't expect her to probe . . . What's wrong with you? Is it your back? And I said No.
>
> I finally, for some reason, at that point in time I thought, well maybe the world is ready for this, and I was kind of calm about it., and I said: Well, I'm HIV positive. Mistake. Total pause on the phone . . . she didn't say anything . . . I asked her: do you have a problem with that? She said: Yes I do. I'm an old woman and I'm healthy and I don't want to take any chances. And I said: You can't catch it like that. And she said: I know, I took a class, but you never know. It's still kind of a new disease. It's only been around 10 or 15 years. You never know.

Sandy went on to find another teacher.

> I didn't tell her about the HIV, and I planned I would never, ever tell her about my HIV. Not after that last experience. I didn't want to get hurt again. And, I really liked her [but she worried about keeping her secret].
>
> So I thought I got to tell her because I may go downhill and she's going to want to know what's going on. [The impetus came when Sandy was planning a trip to Hawaii with her husband and her teacher shared the loss of her husband and how important it is to grab special moments together.]
>
> So when she said that about her husband I was bursting to tell her. I said; I don't have cancer, but I do have something and it's very bad . . . .It's one of those things, one of those red flag diseases. And she said, Boy oh boy, She said HIV? And I said Yes.
>
> And she grabbed my leg, which meant so much to me, the fact that she wasn't afraid to touch me. And she said: I'm so sorry. I wish you had told me before. Because, you know, if I had a cold I could call you and let you know that I have a cold and warn you beforehand. Or if one of my students before you was not well, had a cold, I'd know to clean up the keys real well. And it just meant so much to me that she was understanding.
>
> And I decided that wasn't enough for me to be confident in her unless I came back a few times more and she treated me normal. And she did . . . she's as good as can be . . . sits right up next to me. . . . And that was a relief. And it's nice knowing I'm not keeping a secret. It's so awful to feel like you are keeping a secret. Especially to someone you really like and you just don't want to hide things from them.

In her experience with the piano teachers Sandy went through a common cascade of experiences infected women relate. It started with wanting to tell someone in their lives about the HIV. This was followed by rejection, hurt, and discouragement. After a time there was a recovery and a second more cautious attempt to create a relationship. The second attempt was usually not as open about the HIV, and even when positively received, was not readily believed. Once it was, a sense of relief was felt.

Keeping the secret took effort and a lot of vigilance. Women spoke of getting weary of being on guard and just wanting people to know that something had happened but that they were still who they were before they got infected. Women who had integrated the HIV into their lives wanted everyone else to do the same. They did not want to invest their energy in keeping the secret. They preferred to use it to take care of themselves. Women who were resigned or avoiding becoming known talked about all the ways they had to be careful to assure no one found out. The vigilance became another feeling of emotional overwhelm that drove women to just stay home and not interact socially. Some women in this study spent entire days alone because they feared someone might discover their secret if they socialized. They became resigned to feeling exposure meant rejection.

Living in rural areas was a final aspect of avoiding disclosure of their HIV status that affected many of these women. The HIV has been documented in every county in the state of Oregon. Every community, no matter how small, is affected. The concern of importance for women living in rural areas is the lag time in the knowledge base of the socially shared understandings of the disease. In rural areas the stereotype of out of control, high risk or morally unacceptable lifestyles of people with HIV prevail. Avoidance of disclosure of one's

HIV status was probably a smart thing. Cathy described what women living in rural areas expected from their neighbors.

> I have no idea. I think it would be awful. Because this is a very rural, red-neck kind of area. There can't be more than a few hundred people out here.
>
> *So you think they wouldn't be supportive if they found out you have AIDS?*
>
> I know, not at all. Not at all. Because just from what I've seen of the people around here, they're just red-neck kind of country people. And some of them aren't real well educated and not very open minded. I think, in general, the more intelligent a person is, the more likely they are to accept something different or something new, something they don't know about.
>
> I just think there's a lot of people who don't want to understand or learn about this, and I would be scared to tell them.

For Cathy, like the other women living in rural areas, remaining safe meant she had to maintain a shadow life to her neighbors. They did not really know why she has lost weight. Women from rural areas spoke of working very hard to overcome feeling overwhelmed and about how they would like to become advocates for others with HIV. However, they were quick to include that this would not be in their own neighborhoods. Women with integrated responses to life with HIV consistently drew the line when it came to having their immediate neighbors know about their HIV infection. The concern mainly involved their children and how they would be treated if people knew.

Women preferred to avoid their neighbors through maintenance of their shadow lives. Having a shadow life required hyper vigilance to assure information was not available that could lead to rejection. Marilyn provides an example through her experience in what she calls "a conservative town" and her shadow "retired" life.

> They know that I was sick in June and they kind of looked at me . . . and they'd ask when I was going back to work. And I told them, I'm retired.

Her fear in having people find out was not for herself.

> I don't want it to affect my son. . . . Just, you know, kids and things like that. . . . I just think he doesn't need the pressures of having people knowing. Who knows what people would say. I'm sure there's some speculation out there. . . . I've lost weight . . . people think I have cancer. . . . I'd rather have them just keep thinking that.

Rarely, but occasionally a more positive side of life in small, rural communities was seen, especially among health care providers with some understanding of how HIV is spread. Sue tells of her husband's surprise at the support of the pharmacist in their town's small drug store. She is one of the most public of all the women in this study, so everyone knew her HIV status. The pharmacist knew her HIV status from the medications she took and regularly told her husband how well he thought she was doing. This expression of understanding was very important to Sue and her husband, especially after having to leave another community because of prejudice against them. Likewise, in the small community Pam lives in, I once had to request a blood specimen be drawn unexpectedly at the local hospital and the phlebotomist arranging the procedure said no problem, no charge, everyone there knew and liked Pam a lot and wanted to help her. Like the illness itself, the responses of people can be unpredictable. Within the medical communities of rural areas, when the level of education about HIV is increased, people become more accepting and are able to manifest the friendliness often associated with smaller communities. They often assist HIV infected women in perpetuating the shadow life in the larger community.

The experience of being a person infected with the HIV happened over a period of time for this group of women. They were tested and diagnosed early enough in their disease to permit them some control over the transitions that inevitably happened. Two of the most important events in becoming known as an infected person occurred when the secret became too hard to keep. Ironically they concerned people at opposite ends of women's continuum of relationships. One involved telling their closest relationship, their child or children; and the other happened with acquaintances or strangers when they decided to stop working. In both instances women weighed the pros and cons and carefully decided how and when the revelation would occur.

Pain of telling one's children The women in this study unanimously agreed that the hardest person to disclose their HIV status to was their child. Regardless of their pattern of coping with HIV, the time came for every woman when the secret was too hard to keep and they could no longer avoid telling their children. The period of avoidance was replaced by resignation to the fact that a woman may not live to see her children grow up, that someone else may have to replace her role as their support and protection. The feelings were overwhelming. In this study seven women have more than one child. Six women have one child. Five women are childless and openly wish they had children. This discussion concerns women's inability to continue avoiding their children. It involves the meaning of the experience of telling one's children that their mother has a fatal, socially unacceptable, incurable disease. Moving through avoidance around children's issues was the major factor influencing the change in coping patterns through resignation to integration. Essentially women said, Okay, I'm going to die of AIDS, but not just yet. I have a child (children) to raise. The narratives revealed how deeply women care about their children. Women hesitated and carefully crafted how and when they told their children to make sure the child knew that their mother intended to stay around and protect them from anything bad the virus might bring. The message was not to be afraid. Unfortunately, the majority of the children in this study were of school age and are exposed to fearful public messages about HIV and AIDS. The important understanding is that mothers remain determined to live, give children correct information about HIV, and see them grow up. This was the essence of the message when women told their children they were HIV positive.

Mothers wanted to be in control of the circumstances when their children found out about the HIV. This was part of integrating the virus into normal family life. Unfortunately that was not always possible. Occasionally children got caught in situations beyond their mothers' control.

Lois is an example of the women who integrated the HIV into all aspects of their lives. She tries to control the effect the virus has on her quality of life as much as possible. Her story is valuable because it exemplifies the process women and their children may have to go through together to avoid the judgment of others.

Lois had no control over how her daughter found out. Starting the day she discovered she was positive, Lois immediately had to begin protecting her daughter from other people's fear of HIV. She experienced a rural community in which a few people's enormous fear of HIV dominated the situation for everyone. Her daughter was taunted by neighbor children and was present when rocks were thrown through their window. There was something wrong with Mama and it meant they were going to have to move away. She was 7 years old.

> I just don't understand the hatred. You know, I mean, I just don't understand it. Why pick on my kid. She doesn't have nothing to do with it. And I think that's the hardest part, I probably would have stayed and fought if it had been just me. Not everybody in the town was like them. But I mean, I confided in one person. And now I'm real leery of even telling anybody because of it.

She resigned herself to their judgment and moved from the small rural community to a larger metropolitan area. Unfortunately her daughter once again became the target for neighbor kids whose parents had "inadvertently" seen her mother's mail and found out she was HIV infected.

> They just started in on her. You mom has AIDS and she's going to die. And she'd say: She does not! And they're like: . . . Well you know people that get AIDS, they burn in hell forever.
>
> She defended as much as she could. But once she was in the house and it was all done, it really, really upset her. She was about 9 or 10.

Women often talk with pride about their children's knowledge of HIV. Lois's daughter apparently knew more than the teacher when her 7th grade class recently went through the required lessons on HIV disease. The lessons reminded Lois of her earlier experience.

> Oh, she's more educated than most of the teachers in her class, you know. They did AIDS class and 40 some percent of the kids were not allowed to attend because their parents wouldn't sign a permission slip. And [daughter] she whizzed right through it. And the teachers are like: How come she knows? And it's like, she lives it day to day.

The children of the women in this study have often integrated HIV into their lives better than their mothers have. Unfortunately what they have integrated is not always positive. Lois is now very protective of her daughter after their earlier experience and says that is the reason she does not speak out more freely as an AIDS advocate in her community. Mothers have to deal with not only their children's fears of their dying prematurely, they also have to deal with the effect everyone else's fear of HIV has on their child. They try to help their children cope with the socially constructed meanings of HIV which include stigma, bigotry and fear of HIV

Finding out their mother has HIV can happen in many ways mothers cannot control. However, the mothers in this study tried to create environments of trust within their families to offset the stigma. An example is Kim. Her son and daughter were in the car in the hospital parking lot and saw their grandmother collapse screaming on the ground when their mother told her why their mom's boyfriend was so sick. Kim's handling of the experience for her children shows how some women dealt with their infection head on, integrating it quickly, openly and as powerfully as they could.

> And the kids were right there. And they heard then too.
>
> *Did they say anything to you later, the kids?*
>
> I told the kids anytime they had . . . yes, they've asked me lots of questions about it. I've gotten [son] several videotapes about it. [Daughter] has read several books about it. You know I said: Anytime you have questions, just go ahead, no matter how stupid you think the question is, ask me. I said: If you don't feel comfortable asking me a question, make a phone call.
>
> Yeah, ask somebody. And they do have some organizations out there now that I've learned about for kids. Kids writing kids. And I haven't talked to my daughter about it yet, but she, I think she might like that [She's 13 years old]. . . . I'll give her that option to do that. Because I think it would be good for her. And then, if she had some questions that she didn't think she could ask an adult, she can ask a kid.

The importance of empowering one's children came up again and again for mothers. It first emerged as women talked about how they did not want their daughters to have the same abusive experiences they had. It moved to talk of telling their daughters not to be like them or do what they did as young women. It returned to the present with words about not letting people make children feel bad because their mother has HIV or AIDS. It evolved with the disease to preparing to say goodbye and wanting to be well remembered.

In other families circumstances were different and women waited and avoided telling their children. Waiting to tell one's children was a time for women to manage their own feelings of being overwhelmed and plan how to share the information. It could take a long time. Some women delayed the time until they got sick and a tangible reason existed for the child to know something had happened to his/her mother. The women in this study who did not have symptoms wanted to be in control of how their children were told.

Mary is an example of the women who felt totally overwhelmed by the news of their infection. Her's came via an insurance exam. She was unable to control her older daughter finding out but wanted to be in charge of the news for her younger daughter. It started for her the day she found out.

For Mary, her protective instincts were immediate when the phone call came right as she was getting her youngest daughter off to school. She stifled her horror until she got the child out the door and then she totally lost control. She decided not to tell her daughters until after the Christmas holidays. Her concern for a happy holiday for her children was greater than her need to include them in her trauma. It also meant she had a little more time to manage her own overwhelming feelings. To her chagrin, her ex-husband told her older daughter (age 15). The girl was depressed because her mother had become distant toward her, and she thought she had done something wrong. The distancing was part of her mother's pain and avoidance at having to tell her. The longer she waited the harder it became. She had no way to know that her mother's anxiety and withdrawal was due to the HIV. Mary described how hard it was telling her younger daughter.

> I didn't know how I was going to tell her because she was so much younger [7 years old]. It was on a weekend . . . I wanted her to try to comprehend what was being said. She was too young to understand what AIDS was or HIV, and so I just said a blood infection that would make you get really sick and that you could die.
>
> She started crying. And I said: Well, I'm going to try to be around as long as I can. And I intend to live a long, long life. And we'll just have to be together and we'll just have to be strong for each other. So, she cried. She didn't want to tell anybody. She wanted to keep it real quiet. She did eventually tell a few friends of hers, that she was really close to, that she trusted. Of course, you still have those kids out there that you can't trust.

When Mary died the girls went to live with their father. The dying time was very difficult for Mary because part of how her family chose to support her was to remove her children completely from her house and restrict the amount of time she was allowed to be with them. It was her greatest loss. They feared she was becoming demented. What they didn't understand was that she posed no risk to her daughters.

The overarching meaning for women like Mary of telling their children they were infected was resignation to the fact that the experience was now out of their control. There were now neighbor kids, and relatives, and grandparents to deal with. Mary talked about that last Christmas before everyone knew as the end of her "real" life before HIV.

Women delayed telling their children until they felt they had no other choice. There were many examples in this study. Marilyn waited almost a year and was prompted by a hospitalization for Pneumocystis Carinii Pneumonia, a disease only HIV infected people get. Linda felt her daughter was too young to know why Mommy cried all the time. She finally took her camping and told her when she was six years old. They became a team and decided to move to the Pacific Northwest and leave the painful memories behind.

Women planed exactly how they wanted the experience of disclosure to be. They realized it would be an epiphanic event for their children. Telling their children meant that the HIV had fully permeated all aspects of their lives including their childrens' future. Chris provides an example of how women tried to make the information as positive as possible. She continues to carefully avoid telling anyone else about her disease but she wanted her children to know after her lover died.

Chris used an article on long-term AIDS survivors in the *Parade* magazine to initiate a discussion with her two children. She wondered if they suspected because her lover had died in their house and his AIDS was no secret. She chose her birthday as the time to tell them. She set it all up carefully, even enlisted a counselor to support her.

> They went to spend the weekend with their father. I said, I have something to tell you and I want you home early on Sunday . . . I didn't know how to [tell them]. So my counselor helped me. And she gave me her number. She was so nice. Just to get enough courage up and stuff. And so I had that already to go [the magazine article about AIDS survivors] . . . and was very positive about what I was going to tell them.
>
> They thought we were moving or something. And so it wasn't as bad as I thought. My daughter [age 14], I think she was more concerned. I told them that I had never been ill and that I felt that I was going to be here for a long time.
>
> She keeps her eye on me now. But we don't talk about it all the time because it's, I don't want it to be the first focus of everything. . . . I think they're handling it okay as long as I'm not sick. They have seen two people die in the past year.

Chris felt good about her situation with her children. Her sister has agreed to help if she gets sick, so she feels her bases are covered. She appreciates the good care she thinks she gets from her doctor and she was not planning for any changes. Being positive meant she had a big secret that she shared with her kids. She was a woman who was working hard to support her family and thought about HIV as little as possible. Some would say she was in denial and others that she was making good choices to maintain the quality of her life.

Another choice women made to avoid telling their children was the use of deceit. Some women who felt overwhelmed needed to deceive their children until they were able to talk about it. The deceit was often part of a shadow life of having something else wrong, something easier to accept. The most difficult age appeared to be pre-teens, age 11-13. These women's children ultimately found out anyway. Sharol denied her HIV test was positive when her daughter asked her directly about it. It was not until the girl found medicine in her purse and again confronted her that she admitted it and began the process of sharing her secret. She was resigned to her disease and her daughter now shares her resignation.

Rose and Marilyn told their children they had cancer. For Rose the deceit carried another fear, that her daughter might be infected. She had her secretly tested for HIV under the guise of a hepatitis test. She was struggling with the severe fatigue that had sent her in for the test. She was completely distraught at her deceit and finally told her daughter. Like Chris, she used something from the media to help her broach the subject. She used a television show, *Oprah*, about a health care worker with AIDS to start the talking. Her agony in telling her daughter highlights how difficult becoming known as an infected person can be for mothers. She remembers their conversation.

> What's wrong with you Mom? Why is that AIDS show so important to you? You already watched the show. You don't need to see it again. And I say: But I want to send it to someone, to my older daughter. And so the next day I couldn't get up, depressed.
>
> She came home from school and she said to me. You know Mom, . . . I go to school . . . you sit home all day and do nothing but watch that stupid television. And you can do things around the house. And that hurt me. Because all my life I always worked. I never sat around doing nothing. And here my kid, she doesn't understand . . . so I get upset and go to my room and stayed there all day. I don't want to come out, I cried and cried. And she came to me and she said: Why are you so depressed? Normally I say things like that and it doesn't bother you. Why does it bother you today? How come you don't want to see me? So I told her.
>
> You know what. You sit down, I want to talk to you. I started to cry and tell her. I said you never knew that I have AIDS and it scares me to death that I'm going to die and leave you behind and I don't know how to start it, to tell you. And she hugged me and said: Mom, I'm sorry, I didn't know. I said . . . it is very hard for me to tell you because I don't want to scare you. . . . She said: No, you don't have to. You should have told me earlier and I can help you deal with it.
>
> And I tell myself: Okay now I have the disease but I'm not going to die right away. Some days I may feel good, one day I may not feel real well. But I'm not going to die on you. So don't get too scary . . . She tried to comfort me, but I know she's scared.

Rose and her daughter became a team. Their agreement was that the HIV was their secret. Rose's daughter decided she wanted her friends and their rural community to think, as she did, that her mother had cancer. They were both coping by avoiding HIV as much as possible, disclosing to no one and worked together to maintain the shadow life of cancer.

It is ironic that the daughters of infected women become protectors of their mothers in the same way the mothers were once protectors of their siblings. In the past it was protection from family abuse. Today it is protection from the stigma of HIV. In both instances, children felt they had to be responsible to protect someone they loved and keep a family secret from being discovered. The shadow life was created to avoid the stigma and persecution. It was an illusion that is projected outward to veil the real experience and make it easier for people to accept. It also has the effect of masking the full extent of the epidemic and perpetuating the myth that HIV is not a disease of women.

Losing control: Becoming known at work. The final area of concern in avoiding the disclosure of HIV as long as possible involved becoming known at work. It occurred for women when the secret became too hard to keep and women's energy needed to be directed elsewhere. It was usually the major public disclosure women made, short of public speaking as activists. For women who had been in avoidance coping patterns it was a difficult time and women often worked very hard to leave work with their secret intact. Women who were resigned may or may not have cared who knew. Leaving work was the end of the major time of avoiding disclosure. Life then became more private.

Having a job and working meant many different things to the women in this study. Four women were not working and had not worked for some time when they found out they were HIV positive. The other 14 women included having to cope with HIV and keep working as one of their greatest challenges. The goal of avoiding discovery of their HIV by their co-workers was something women finally could not control. By the time women stopped working they had avoided telling family, children, friends and acquaintances as long as possible.

Having a job was important. It was a symbol of being a normal member of society. It meant that the everyday life a woman had was the same as other regular, normal working class women. Coming to the point when the decision was made to quit work meant the woman was different in a negative way. How a woman chose to respond to having to leave her job did not really matter, because regardless of how secretive or open she was, the unspoken message was that she was having health problems and would not be able to work much longer. To her it meant she was going home to prepare to die, perhaps not right away, but sooner rather than later.

Work was a symbol of healing from brutal childhoods. It meant independence and self-esteem for most of these women. Those who had recovered from abusive childhoods and destructive young adulthoods were very proud of themselves and derived a great deal of self-worth from being able to hold a steady job. They talked about working in the following ways:

> Bobby: My job was like having a real life.
>
> Robbie: It was my first "clean job" and then I became a manager, responsible.
>
> Norma: I was finally independent of my husband. I supported my children .
>
> Marilyn: I was an executive, a prominent professional person.
>
> Mary: I loved my job. I was good at it and getting ahead.
>
> Rose: It was an honest job working for a friend.
>
> Pam: I love teaching aerobics.
>
> Chris: Nursing is my life work.
>
> Cathy: I was important to the company, I kept things running.
>
> Leah: My job is all I have.

The progression of HIV disease can happen slowly and be an insidious process of quietly just getting terribly fatigued; or it can be a sudden, life threatening opportunistic infection. However it happened, the process could not be avoided and was ultimately one that led to the decision to first work part-time if possible, and then quit altogether and go on disability.

For every woman, quitting work was both a physical and an emotional struggle. They avoided it as long as possible until they became resigned to the fact that they were exhausted and just couldn't do as much any more. Working was connected to feelings of self-worth, to self-images that had changed for the better, and to feelings of self-esteem. For women from abusive backgrounds these feelings had not come easily and only after years of recovery, therapy and hard work. So the realization that work would have to end was especially difficult. It was also a relief. The reasons women worked as long as possible were often economic, but were also driven by not wanting to disrupt family life for their children, and live the shadow life of normalcy as long as possible.

The initial experience of telling people at work about their HIV infection was not that different than it had been telling families, friends, and children. Women's thinking includes whether to tell, and then when, and how to tell. Women discovered hidden pockets of support. What was different was that if they were rejected they could just walk away and not look back.

The two women who are still working made different decisions about telling their coworkers about their HIV. They both work in health care. One is avoiding disclosure of her HIV disease and one is resigned to it. They share common concerns about disclosing their

HIV status at work. Chris is an example of the women who struggled with telling people about their HIV at their work site.

> Well, the reason I haven't told anybody at work is because working with women, . . . they can be so vindictive and back-stabbing about everything. . . . If you tell people what's going on in your personal life, they make all these little judgments and everybody knows everything.

Leah has not kept her HIV a secret. She did not really care who knew, although she now wishes she had kept it secret.

> Most everyone knows that I'm positive.
>
> *How do they treat you?*
>
> Well some of them, . . . and you can tell that they have a big problem with it. . . . Just little comments. I mean real little discrete things . . . under their breath type things.
>
> *When they do that, how does it make you feel?*
>
> I try to ignore them. Meanwhile, I'm looking for a new job. . . . I can feel that it's there. And other people have, people that are nice to me at work, have said to me that they have noticed people making comments that were inappropriate. Employees . . . and so, I don't walk around with one of those sandwich boards saying that I have HIV or I have AIDS on it. But I mean, I don't mind talking to people about it if they want to talk about it, that's fine. But I don't bring it up. So I thought I was using some discretion. I'm not hiding what's wrong, but not going out of my way to let everyone know. And I guess it's just proven to me that it's not what I should be doing. That I should keep it a secret at work.

Sandy's story is a paradigm case because it clearly highlights the daily emotional distress in the long-term process many of these women went through while they tried to continue working and avoid having anyone find out their secret. It began the day she found out she was HIV positive, because she found out at work. She immediately felt overwhelmed. She struggled to have some control of the HIV in her life. It started for her at work where she received the call about her HIV test.

> And I called [Doctor] and he said: You're positive. And I was totally in shock. And I didn't get along real well with the women I worked with. So I didn't want to share with them what happened. One woman said: Oh tell me what's wrong? I said: I got a blood test. I never did tell her what it was. She kept pressuring and pressuring. And I said: I don't want to talk about it.
>
> I'm so happy I never told her because later on I found out she is scared to death of HIV. We got a piece of mail that came to the wrong address, and she opened it . . . and it said HIV on it and she asked me: What's that? And I told her that it's associated with AIDS. And she dropped it on the floor. Like a piece of mail is going to contaminate her. And then the other girl that I worked with said she would not go to her hairdresser anymore because he is gay and she's afraid that since he's gay he might have AIDS. So I kept my mouth shut for fear I would lose my job or something, like I'd be shunned at work. So for 4 years, I only told one person at work. And I didn't hear too much from her afterwards either.
>
> I became very isolated, because I felt like I was keeping a secret and I was nervous. If I do tell them I'll lose my job or be shunned, so I was living with the fear for years.

Sandy was relieved when she was finally able to go on disability after an opportunistic infection. She was one of the women who successfully avoided having to tell their co-workers about their HIV. She had been successful in maintaining her shadow life at work, however this meant that she had to endure the constant fear and isolation.

Not all women left their work sites in a controlled way. The end of work also came as a surprise and was part of social rejection from people women knew and expected to be trustworthy. Several of the women found out that the fear Sandy had of losing her job was real. Sharol told her boss about her HIV and was never again listed on the schedule to work. For Rose it was a more painful firing because she was working for her best friend from childhood. The friendship did not matter.

> And I told her, I said: I think I have AIDS. And she said: What are you going to do about it? Because the club, we serve drinks, we serve food. She said: Do you think you could quit, because I don't want you to give it to somebody else. Now I knew her from when I was a little kid. I'm just like a sister to her and she was saying that. And that's why I married the second guy. I didn't love him at all, but I just wanted to get out to where I didn't have to work.

In each of these situations, the judgment and stigma came from ignorance of how HIV is transmitted. People believed they could die from just being near the infected woman or touching something she had handled. Like so many aspects of these women's stories, we can only hope that their painful experience was due in part to the timing of when they were infected and the lack of public education about HIV and the epidemic at that time.

Two final examples will be used to reveal another important aspect of losing control of who knows in work situations. This involved women also being positively surprised by the support that can be found in a work site. It is unfortunate that the positive experiences are not a bigger part of the socially constructed meaning of HIV that is communicated in the popular press. One woman had lived in a state of feeling overwhelmed for years as she cared for her husband and managed her children. The second example is of a woman who also felt overwhelmed but had been able to avoid confronting her HIV disease until her health began to fail.

Mary was exhausted at having to carry the secret of why her husband was sick so much and why she consistently missed work. She finally resigned herself to stop avoiding her co-workers and decided to accept whatever response they had.

> Well, [husband] was going in and out of the hospital. You know, what's going on with [husband], how come he's in the hospital. And I just came out and said it. It's like at work too, you know. I knew that more and more people were finding out.
>
> *What was it like that day?*
>
> Well, I was on a network. I wrote a letter to the company, the managers and the staff and all the other employees stating that [husband] and I were both HIV positive and the husband has AIDS. Because, see I was leaving work a lot to take him to the doctor and stuff and I knew that people were getting suspicious. And just for my own self-worth I wanted to let everybody know. And I said, you can continue to be my friend, or if you aren't able to deal with this, then walk the other way. And I'll understand. I gave each department a letter and they read it to their staff.

> *What was it like when you came back to work?*
>
> I was really nervous. There were a lot of people that came up and gave me hugs. And until this day, they still send me little cards. And then on my birthday they sent me a chime . . . and they keep saying come in and see us . . . we miss you and how are things going.
>
> *Was anybody negative?*
>
> Not that I know of.

Other women in this study who knew Mary from Nurture Night used to joke about how they were all recovering from a hard street life and Mary gave them "nice" lessons. Over and over at her funeral people talked about how her smile could light up a room. Her personality may be partially why her co-workers were so supportive. Even though she left her work site to go home to prepare to die, her co-workers bridged the gap and continued to care about her and communicate with her. Issues around being known at work tended to be one extreme or the other. Some women discovered they had strong support from their co-workers at the time they left their work site. Some expressed regret that they did not reveal themselves sooner. The risk of rejection was simply too great.

The second example is one of women who were not as forthright about announcing their infection. They preferred to tell selected people and were surprised when they received unexpected support. Robbie was such a woman and described the sweet awkwardness she felt when her supervisor's boss, the manager, came around after he found out she was positive. She worked for the City of Portland.

> I was afraid for my manager at work to know.
>
> *What was your fear?*
>
> That I would be judged. Because he's so high up there. . . . Probably never exposed to anybody that's had my risk behaviors. Although none of them know anything about my life. Everybody thinks I'm just normal.

> *How did he find out?*
>
> Well, when I was filing for my disability, we pretty much needed to tell him that there were going to be changes happening. They were going to have to hire a new employee. I had my supervisor tell him . . . he came down. I had been off with shingles, so when I came back to work he came down to my work space to talk to me. And it was very awkward. You could tell we were both very nervous. He's like, how are you doing? I'm glad you're back. . . . and I'm like, you know when you're nervous. It was hard and nice. And then he was like coming down every day.
>
> *So was he telling you something he wasn't saying out loud?*
>
> Yeah. And then he would bring me flowers and stuff. And he brought me across the street to tea one day and we sat and talked. And he gave me different forms to fill out. The family medical leave, to get 90 days. . . . He's been extremely supportive.

The caring of this important man meant a lot to Robbie. She was a woman whose father had abused her and she had spent years being abused by men during her time of addiction. She elected not to tell her fellow employees until she left her job, but she spoke fondly of it and said she missed work a lot. Working made her feel she was of value to the people she helped and she was proud to be a civil servant. The support she received at work helped her move past her resignation and integrate the HIV more publicly and positively in her life.

The meaning of becoming public and disclosing one's HIV status at work includes both the pain of prejudice on the job and the unexpected comfort of support. Telling people at work about one's HIV infection ultimately always came down to the time when women quit their jobs to take care of themselves and turn all their attention to managing their HIV disease. Leaving work meant many things. For Marilyn it meant "getting out of the rat race." She learned how to sleep late, play golf in the middle of the week, and spend a whole day with her dog. Her disability income is generous and she is enjoying her retirement and planning an international trip. The hardest part is loneliness. She says, "I don't know that many people who don't work."

For women who have pulled themselves up off the street and out of addiction, leaving their jobs was not as easy. Work meant more than a job. Bobby is the example of women who felt leaving their work meant they were now actively preparing to die.

> In February my doctor told me I had to quit working . . . it was very hard for me. I didn't want to quit working. I wanted to continue working. But what was happening, my job was also killing me. And I had to accept that. I had to see that. And it took a while for me because I've always worked. Ever since I got clean. And I've been a hard worker. And that was one of my accomplishments. It was something I had worked so hard to get to, that I didn't want to give it up. But, what the thing was, is if I quit my job, I was admitting that I was dying. Or I was admitting I couldn't do it any more because of my disease. And that's what was so hard for me. I didn't want to admit to that.

Unfortunately Bobby was right and has battled one opportunistic infection after another since leaving her job.

Summary. The interpersonal concerns and background meanings that emerged as women talked about avoiding disclosure as an infected person to their families, children, friends, acquaintances, and co-workers are probably where the most universal issues of the epidemic in women's lives are revealed. It is in the acknowledgment of being infected that women came face to face with the people from their personal histories who were involved in the experiences that set up their risk behaviors and the circumstances of their becoming infected. These are also the people that will probably be involved in caring for them when they die. When women told their children they faced the socio-cultural fears and attitudes about HIV that are still prevalent in U.S. society and which they are helpless to protect their children from. And when they revealed themselves to their friends, acquaintances, and co-workers they confronted the socially constructed meanings people have about people infected with the HIV and they discovered the power relationships have to both hurt and help. Disclosing their HIV status took these women through many coping patterns. The primary one was avoidance of disclosure, which they all shared initially. Most moved on to varying levels of integration of the disease into their lives and relationships. A few remained resigned or recycled back through feeling overwhelmed when being known was more than they could cope with.

Managing the Illness: Day by Day Life with HIV Disease

There appeared to be a relationship among these women between the interest and attention they paid to self-care and the quality of their physical experience. This included compliance with standard medical recommendations, the use of alternative and complimentary treatments, and participation in research studies. On the negative side, it included ongoing substance abuse and continuing participation in abusive relationships. These are not only risk factors for becoming infected, they are factors affecting women's ongoing wellness and well- being living with the disease because the immune system is susceptible to both physical and mental stressors.

Women's coping patterns also contributed to stressing or depressing their immune systems, especially feelings of helpless resignation. When women felt resigned they had a sense of futility and hopelessness about caring for themselves. They neglected normal activities of daily living and personal care, such as rest, exercise, and nutrition that have added importance for anyone with an immune disease. Some turned to drugs or alcohol to help them cope. Every day they made choices that affected their health. Linda lamented, "I take better care of myself now that I have HIV than I did when I wasn't infected. It's a bummer to think how good I could have felt then if I hadn't been so out of control." Sharol shared, "I've never been someone to do a lot of healthy things and having HIV hasn't changed that. I know I should, I just don't have the energy."

The new science of psychoneuroimmunology is devoted to understanding the mind-body relationship and reinforces that a persons mental and physical experience can either contribute to enhanced wellness or further stress a compromised immune system. The quality of life for an HIV infected person includes a balance between emotional and physical health. Living with the HIV involves being prepared for bodily changes and being able to manage all the other changes that happen because one's body is changing. Linda adds, "Having this disease is a full time job. Between taking all my pills and getting all the treatments and not getting freaked out in my head, there isn't time to have a life." Periods of frustration and resignation occurred for all the women when HIV signs and symptoms interrupted their lives.

The discussion will now look at the underlying concerns women shared about living with HIV disease throughout the changing progression of the illness. The concerns which emerge from the narrative texts revealed how life with HIV is an ongoing process that builds in intensity as the virus slowly destroys the immune system. This discussion will include how women's coping patterns to living with HIV directly affected the quality of their experience. It is important to note at the outset that the nature of HIV disease is such that women felt they were not always in control of determining their coping pattern; such as when fatigue was overwhelming or when depression led to feeling hopeless and resigned. On the positive side, seeing their families integrate their signs and symptoms provided a boost to women's efforts to integrate the HIV in their lives. A positive interaction with health care providers encouraged more participation in their care and discouraged isolation and coping patterns of avoidance and resignation.

The concerns which will be discussed include: (a) not feeling sick and not wanting to live as a sick person; (b) fearing the results of diagnostic tests; © importance of mental health;

(d) dealing with physicians; (e) longing for intimacy and closeness; and (f) staying alive for children. These are the concerns and common meanings women shared about the ongoing, daily experiences of living with the HIV.

Not feeling sick and not wanting to live as a sick person. The process by which the HIV invades and destroys the human immune system includes a period of time during which the damage being done is not directly felt. The human body conducts its inner battle against the virus without the immediate outward signs that other viruses such as measles or chicken pox create. The difference is that when the measles rash or the chicken pox sores heal, the body has defeated these viruses and is now strengthened and immune to the disease. Antibodies were created, fought the virus, and won. With HIV the first appearance of the battle happens approximately 6 weeks after initial exposure and looks like the flu. The person experiences fever, malaise, headache, and body ache. These are the classic symptoms of an activated immune system battling a virus such as the flu. The difference is, the HIV wins and the body's immune system retreats. Then begins the long battle Saag (1995) describes.

> Infection with HIV-1 causes a slow yet relentless destruction of immune system function over a period of years. The precise mechanism by which this immune system dysfunction is caused remain unclear. However significant insights have been gained recently through basic science investigations of the virus and its interaction with specific cells of the immune system.
>
> The picture that emerges is one of a titanic struggle between the immune system and the virus that begins on day one and continues through the terminal stages of the disease. The immune system creates a hostile environment for the virus, which the virus attempts to nullify with sheer numbers. The immune system demonstrates a remarkable ability to replenish itself (1 billion new CD4 cells/day), although over time the immune system apparently fatigues and viral replication/burden increases. Eventually, the immune system response wanes, leading to the development of opportunistic diseases. The goal of therapy thus becomes straightforward: to keep the viral burden as low as possible for as long as possible through whatever means available. (Saag, 1995)

The inner war can last for many years. At the 1993 International Conference on AIDS it was suggested that it can last 20 years with good care and treatment. New tests and treatments continue to enlarge the possibility of longer life with HIV and some go so far as it propose it may become a chronic disease.

The first period of time is called the asymptomatic period. It currently lasts 5 to 8 years and is the time when the HIV is slowly but surely overwhelming and destroying the body's T-helper cells. These cells are also called CD-4 cells after the receptor site they use on the T-cell. What is important to understand is that during this time the quality of the daily, lived experience of the infected person is influenced by their underlying basic health and vitality and how they choose to emotionally and physically take care of themselves. Meanwhile, the virus is insidiously doing its damage. However, until the number of T-cells is reduced to a level that makes the body unable to defend itself against other pathogens, the infected person can do things to enhance their body's ability to fight the virus and enlarge other aspects of their body's ability to feel good. HIV infected people who use integrated coping patterns have set a new standard for how actively a patient can become informed and involved in their disease management.

The goal of medical therapy in the treatment of HIV disease is very clear, keep the viral burden low, preserve CD4 cells, and protect the body from opportunistic microorganisms and neoplasms. The state of the science is very sophisticated and with the recent addition of plasma RNA testing and the promise of protease inhibitor drugs, researchers and health care providers dare to talk about a significant move forward in managing HIV disease as a chronic illness (Saag, 1995).

Just as the disease itself is a slow progression from HIV infection to full blown AIDS, scientific and medical knowledge about HIV and how to manage it has also been a slow progressive effort over the past 15 years. The pace has been affected by a myriad of social, political, economic, and psychological influences that not all infectious disease research efforts have had to deal with. The reason for mentioning it at this point in the discussion of the lived experience of HIV for women is that two experiences are going on at once for women. One is their own subjective daily life as an infected person. The other is their life as part of a population cohort in the most pervasive pandemic in history. A woman must constantly balance protecting her own private life with being part of the ongoing public and scientific grappling with the deadly microorganism. The battle is recounted in the press and on television, health care providers talk about promising changes, and people living with HIV share new information about the risks and benefits of each treatment or procedure.

Women have different levels of interest in all the details. Women who have significantly integrated the HIV into their lives (such as Sandy, Kim, and Linda) are interested active participants in the epidemic. Women who are resigned or avoiding the epidemic (such as Sharol, Chris, and Leah) prefer to think about it as little as possible. The other women in this report spread out over a continuum of interest in the science and treatment of HIV depending on their basic or current response to being infected. Women who essentially felt overwhelmed had a difficult time with the complexity of the treatment and management choices. They wanted to keep up and be well informed, but could not cope with the quantity or pace of new information. Those who did not try to keep up were at constant risk of slipping from feeling overwhelmed to feeling hopelessly resigned that they would never be able to fully understand and manage having HIV. At the other end of the continuum were the women whose interest in promising treatments was heightened as signs and symptoms of disease progression began to appear. These were the women who have integrated the disease into their lives and try to do everything possible to fight the HIV, and still focus on living fully.

In this study, women are evenly spread in the progression of their disease. Four were diagnosed with AIDS at the time they tested positive for HIV. Eight have progressed to AIDS since they tested positive. And five do not have AIDS yet. One is deceased. Those in the more advanced stages of their disease are the ones having the most physical problems. Interestingly, they are not necessarily the ones who have been infected the longest.

What mattered most to the women changed as their CD4 cell counts dropped and the disease became more apparent. The CD4 cell count has been the marker for watching the progression of the disease as it gradually destroys the immune system. Women lived with endless waiting and hoping that the unseen decline would be slow. The benchmark numbers are 500 and 200. When the CD4 count drops below 500 decisions about anti-HIV drugs begin. When the CD4 count reaches 200 health care providers get nervous about opportunistic infections and recommend drugs for the prevention of PCP, Cytomegalovirus (CMV), Mycobacterium Avium Complex (MAC) and Herpes.

Women and their health care providers had to agree on an approach. Some elected to move proactively and used the arsenal of drugs and treatments early and aggressively. Others were more conservative because of concerns about side effects and long-term consequences, such as resistance. Some women decided to develop their own treatment plans from the huge selection of alternative and complimentary options available. And women moved back and forth in their approaches to treatment, each had unique experiences with their disease and the treatment options currently available. As a group these women exhibited the full variety of possible responses to managing their disease. What they shared was the unending complexity of HIV treatment.

For example, Chris was early in her disease and asymptomatic. Her coping pattern of avoidance worked well and she focused on the non-HIV parts of her life. "You just sort of have to live life. Because you don't know what's going to happen." Once she told her children she was infected with the HIV, she decided to just not think about it too much. So far she does not really need to. She likes her doctor a lot and feels she receives good care. Her menopausal symptoms were more bothersome than the HIV.

Women like Chris still have to manage their disease. During the asymptomatic time their HIV care is similar to other chronic diseases that require more frequent doctor visits, monitoring tests, and a focus on self-care and wellness behavior.

As the disease progresses, the chronic disease care changes to include the addition of medications that may make a woman feel worse than the disease makes them feel (like hypertension medications). Compliance with recommended care then becomes a concern because women want to feel good as long as possible. They have to be reminded that the value of treatment during the asymptomatic period is in preventing the progression of the disease. Avoiding the preventive care hastens having to care for the disease more aggressively. There really is no escape. Women unanimously disliked having to take so much medication all the time. Sharol bemoaned her inability to remember to take her medicines. She's "tired of taking pills." Many women mentioned wanting to take drug holidays just to have a day that felt more normal. Ann said, "All I do all day is take pills." Unfortunately going on and off medications can have serious repercussions when dealing with microorganisms that have the capability to become drug resistant and rebound in the absence of controlling drugs. The new protease inhibitor drugs require vigilant, consistent compliance to be effective. Overall, for all the women the need for medications during the asymptomatic period was a constant unwanted reminder of the disease.

There were moments when HIV was not all negative. One of the positive things having HIV meant to these women was having the time to do things they enjoyed, after they stopped working. For example, the asymptomatic period meant there was time for Sandy to learn to play the piano. Linda said she enjoys working full time as an unpaid AIDS advocate. She is sad that she never got to use her hard earned college degree because the HIV arrived during her last year. Yet, she is proud of her contribution and sometimes feels good enough to flirt with giving up her disability and getting paid for her work. Pam teaches aerobic classes at a local health club and thinks she is "the healthiest person in my family." Marilyn is planning her first international trip with a friend.

These women may be able to remain active and involved in their lives, but still had days when their compromised immunity failed them and they were ill, or terribly fatigued from the constant inner battle. Side effects from medications and treatments are also unpredictable and can cancel any activity precipitously. Women's coping patterns are directly linked to their signs and symptoms of disease. Feeling good encouraged avoidance. Feeling bad led to resignation and recurring feelings of overwhelm.

The asymptomatic period provided time. Time to develop relationships with physicians and other health care providers that become primary as the illness progresses and requires complex care management. Children, families, and friends have time to get used to knowing the woman is infected before they have to deal with watching her get sick and die.

Those who do not find out about the HIV until women get sick have a more difficult time. (Perhaps for some of the same reasons involved in why women do not tell them sooner.) The comparison to cancer emerges again here in the way that both cancer and HIV disease give people time to prepare for their dying, unlike a sudden heart attack or death by trauma.

Fearing the results of diagnostic tests. The very recent development of a new test to measure the amount of HIV in the blood has a direct effect on this discussion of the coping patterns and meanings of the physical experience of HIV for women. Physicians can now carefully monitor viral replication in a person's body with plasma RNA (and bDNA) testing and design combination drug therapies that can be changed whenever it appears the virus has mutated or become resistant. This has happened within the past year and is considered the first major breakthrough in HIV care in many years. It has permanently changed the standard of HIV/AIDS care. It comes at a time when the menu of options to choose from has expanded to include a growing range of possible drugs. These include nucleoside anti-retrovirals (AZT, ddI, ddC, d4T, 3TC), non-nucleoside anti-retrovirals (Nevirapine, Delaviradine), protease inhibitors (Indinavir, Ritonavir, Saquinavir, Nelfinavir) and immune modulators (Il-2). The Salk vaccine is now available through a research protocol and researchers are openly hopeful that it will add one more way to help the body beat the virus. This is very new. As recently as 1993 reluctance to start anti-HIV treatment existed because it was feared once a person became resistant to the few (AZT, ddI and ddC) drugs available, there was little to turn to. This has all changed and now monotherapy is not recommended at all and some physicians believe multiple drug treatment started early has significant value.

What this means to women living with HIV disease is that the option to be reluctant, resistant, or hesitant to start drug therapy while in the asymptomatic stage of the disease is now not the option it once was. In the past providers may have felt okay allowing a woman to delay treatment because she was not sure she was ready. Now the standard of care has changed.

Robbie is an example of women whose physicians have advocated anti-retroviral treatment for years and accepted their resistance to taking it. Her attitude has been, "I just don't trust those drugs. I know they're strong and hard on your body and I just don't feel good about taking them. I prefer the natural treatments, you know, the herbs and vitamins and stuff." With the pRNA test and protease inhibitor drugs, physicians now may not be as able to support women's reluctance. This means the dialogue between women and their providers is changing to include these new options and women may not be able to avoid taking the drugs and remain under the care of HIV physicians who follow standard of care recommendations.

At the same time the dialogue continues in the patient literature about fears of cross resistance, cost, and side-effects. There were many examples of how this community of women are integrating this new information. Linda and a group of AIDS activists in her community planned a community wide seminar in April of 1996 to discuss the pros and cons of the new drugs and treatments. The physicians who care for the women in this study hold seminars for their patients to go over the new information. As with any new scientific discovery only time will provide the assurances of value that people want now. The meaning for these women is that with this disease there are no easy answers or clear-cut choices. The problem is that a decision has possible life or death consequences with no going back. Even when the disease appears to be quiet and non-intrusive in women's daily lives, the context of the evolving standard of medical care for HIV disease presses in and demands attention and decisions. It makes it hard to stay in denial and still have a relationship with a health care provider. Avoidance and resistance become coping patterns with increasing consequences as the disease progresses. Women who cope by feeling overwhelmed are usually able to continue their engagement with the epidemic, it just is uncomfortable and anxiety producing.

Sores that do not heal (Navajo name for cancer). The promise of managing HIV as a long-term chronic disease is here; however, the reality for this group of women is that their disease is progressing and the asymptomatic period ends and the signs and symptoms of immune deficiency arrive. In this group only three women remain symptom free, Kim, Jako, and Chris. They are also the most recently infected. For all the others, the asymptomatic period is over and the meaning of life with HIV now includes becoming resigned or accepting of specific body problems that do not completely ever go away. In the Navajo Native American language cancer is called "the sore that does not heal." From their narratives it appears that HIV feels the same way for infected women who are no longer asymptomatic.

Moving from the asymptomatic to the symptomatic stage of HIV disease often begins with diffuse symptoms that indicate the infection is spreading, such as fevers, weight loss, and fatigue. Clinicians watch for these symptoms in an HIV infected person as signals to initiate more aggressive care. For women who do not know they are at risk for HIV the symptoms are harder to understand. This is in part why the Center for Women's Policy Study cited unresolving symptoms as one of the reasons why gynecological problems needed to be included in the CDC listing of infections indicating AIDS. Unfortunately it was not until 1993 that gynecological problems (dysplasias) were accepted as AIDS defining. Many clinicians, especially in rural areas, may still not know to check for HIV when these symptoms appear or when gynecological infections will not resolve with normal treatment. Health care professionals have been criticized for overlooking gynecological conditions associated with HIV (Benson & Maier, 1990, cited in Pizzi, 1992). Even when clinicians are aware of the relationship between gynecological symptoms and HIV women reported having to beg for attention. Women in this group who receive their care in large health maintenance organizations (HMOs) complained that their doctors would not take their endless menstrual cycles seriously. They believed they needed more comprehensive care to stop the debilitating bleeding and that their capitated HMOs did not want to pay for it. Whether this is true or not, it is an example of a part of women's physical care that was not part of the epidemic when it mainly concerned gay men and that now requires attention and public discourse.

Cathy has already provided an example of women who had to figure out for themselves that they were HIV infected. She also provided insights into the problems associated with pregnancy in infected women. Cathy was frustrated after she had her baby because she was sick all the time. She had not gained any weight during the pregnancy.

> And then she was an emergency cesarian section because I had an infection in my uterus, and after I had her I never got better. I never snapped back. And everybody said: Oh, It'll take a long time and you'll be weak for 6 weeks. And then 6 weeks came and went and it's like: Well, why do I still feel like this. I can hardly walk I can barely move. It was fevers and night sweats. And that just keeps going on. And my obstetrician did all kinds of blood tests and everything except that one. They tried everything and couldn't figure out why I wasn't getting better. And it just got progressively worse and I started looking things up, at my job.

She made a list and cross referenced her symptoms and it was AIDS that came up again and again. She told her mother and went for the test which confirmed her worst fears. She could not stand not knowing what the symptoms were. Even though it was painful to find out they meant she had HIV, the mystery was a least solved. Unfortunately, knowing the cause did not change the experience. It just changed what the symptoms meant. Now they meant she was permanently sick. She was also angry that her rural doctors had not figured it out.

Symptoms mean disease. We are taught that they are messages from the body that a disease is present. In the best of circumstances, treatment is started and the symptoms and the disease go away. With terminal incurable illnesses, symptoms mean more than that. They mean that the disease may be here, may be getting worse, may never go away, or may kill you. For many women this is information they would rather not have and preferred to ignore their symptoms as long as possible. Women who feel breast lumps and put off having a mammogram may be similar to women who delay having an HIV test or making an clinic appointment to evaluate a symptom. HIV clinicians and care providers become frustrated when high risk or symptomatic women will not get tested or treated. For some the fear of knowing they have a terminal illness and will have to face the stigma and judgment associated with HIV is greater than fear of the disease itself.

Cathy is our example of the other end of the denial continuum. She launched a self-directed investigation to discover the cause of her symptoms. Since she figured out her diagnosis she struggles with incorporating HIV disease into her life. She reveals the experience of women who may be resigned and feeling overwhelmed, but are not in retreat. HIV is a blow to their self-esteem and self-confidence.

> What bothers me the most about all this, is I feel helpless. And I have always been strong and able to deal with these physical things and never had any kind of illness or broken bones or anything. And now all of a sudden, all these weird little things are happening to me. And I'll have to be on medication. And I just feel like some kind of invalid. And I don't like that because I know I'm stronger than that. That's just not who I am.

The symptoms such as Cathy described varied among the women. Sometimes symptoms were directly related to an opportunistic infection. For each woman the symptoms, the opportunistic infection, the change in her body's health also meant other things happened. The women in this study had the full variety of typical experiences. Marilyn experienced weight loss and weakness from a serious bout with PCP which precipitated her leaving work and beginning her disability. Bobby also had to finally give up her job and focus her attention on herself and her son after being hospitalized for life-threatening Acyclovir resistant herpes. Leah recovered from Tuberculosis to come home to an empty house; her daughter had been unexpectedly adopted. Mary began a fast downward spiral to death when Lymphoma struck shortly after her husband died. The specific opportunistic infection may be different for each woman, and the uncertainty of which one it might be is part of the emotional burden of living with HIV. Pam reflected, "You just feel like you're waiting for something and you don't know what it is or when its coming or how it will show up. So I just don't worry. What good does it do anyway?" This was the basic attitude of women who turned resignation into integration and getting on with their lives.

The change from being asymptomatic to having active disease does not always come with the onset of an opportunistic infection. It can show up in subtle insidious ways as well. Fatigue is a serious symptom that arrives inevitably, gradually, often by itself, and limits and restricts infected women's lives significantly. Physiologically it takes tremendous energy to combat the disease. The symptom of night sweats is a graphic reminder of how hard the body is working to fight the virus.

Fatigue was the symptom women mentioned most. It was the primary reason Linda maintains her volunteer status as an AIDS activist. Working with women like her means accepting their limitations. They never know when they won't be able to get out of bed and have to take a day off. They learn to tell people that they intend to do things but there is always the possibility that they will have to cancel. For Linda, this was one of the ways the disease has helped her value herself and her well being. She gave herself permission to take care of herself (so she can stay healthy and watch her daughter grow up). For her, fatigue means the virus is active and she needs to lay down and focus all her energy on fighting back. She is one of the women with long-term infection who remains free of opportunistic disease and intends to stay that way. Her coping pattern is the mix of resignation and integration seen during this time in the lived experience of the disease.

> I just know I have to watch how tired I get. If I get uptight or overdo my activities I pay for it. And then I have to go to bed and just be quiet and wait to get my energy back. It's scary because I never know how much I can do. This disease is just so predictable and unpredictable all at once.

Fatigue is also often the first sign that disease is progressing. Rose is an example of the women for whom this was true. She reported constant fatigue that frequently devastated her and was the reason for her final request for a HIV test. As someone who usually had two jobs and unlimited energy, the unbearable fatigue was a major change. Like Cathy, she wanted to know what was wrong. She is a woman in total avoidance of other people concerning her disease, but she is working hard to become more integrated in her efforts to access care and take care of herself. It is difficult because women living in rural areas have to be aggressive in asking for the care they think they need.

> I worked so hard, I thought my body cannot take any more stress. And so I got sick. I felt tired all the time. I didn't eat right. I didn't sleep right. And so I went to the county health department to get tested. Because I said: Why do I get tired all the time?
>
> First, my pap smear test came out abnormal. And I said: Okay, I wanted to run that test, but I want to check something else. Why do I feel so tired? I saw a sign with the symptoms of Hepatitis B. . . . I felt like that's how I feel. I said, I want that test. And I got the test. . . . And Hepatitis B, yes I have that, but I still felt tired. . . . I felt funny. Not normal. Like before, when I worked two jobs, even three, I still had energy to go. But now, even though some days I have off, I don't have any energy at

> all. So I talked to my doctor and she finally said, Maybe we should run an HIV test . . . it came out positive.

Women reported being able to ignore their signs and symptoms until they interrupted their relationships with others, especially their children. The fatigue proved most painful for Rose when it became an issue between her and her daughter. Her daughter was accustomed to having an energetic lively mother. While Rose was struggling with how to tell her young daughter about the HIV, her daughter was getting impatient with her mother's fatigue. She complained.

> She came to me and she said: You know Mom . . . I go to school . . . you sit home all day and do nothing but watch the stupid TV. And you can do things around the house. And yet, when I come home you want me to do it.
>
> And that hurt me. Because all my life, I always worked. I never sat around doing nothing. And here my kid, She doesn't understand that, and she tells me I'm doing nothing. Sitting home watching TV. So I got upset and went to my room, stayed there all day. I mean I didn't want to come out. I didn't want to see her. I stayed in there and cried and cried.

That was the day Rose finally told her daughter about the HIV. Once again the importance of the primary relationship between women and their children was the factor that influenced a pivotal decision to be made. As other mothers and children did, they agreed that they would continue their shadow life of a mother with cancer to mask the fatigue and symptoms Rose exhibited. What changed was that now the progression of increasingly more serious symptoms meant that the time to find a new home for Rose's daughter could no longer be avoided. It also meant that it was okay to do nothing all day. The pressure to hide the reason for the symptoms was gone. Since that time Rose and her daughter have become active participants in support groups and programs for women and their children living with HIV. Rose reports it is easier to feel bad from HIV knowing she's not the only one. Recently several other positive women aggressively intervened in Rose's care to assure her access to the new tests and drugs. It is not possible to ever say its okay to have symptoms from HIV disease or opportunistic infections. It is possible to say that having them alone and in secret isolation is horrible.

I've become a hypochondriac. Once the symptoms arrived the resignation and the vigilance began. Linda exemplifies women's concerns when she complained that, "I've become a hypochondriac. Every bump, twinge or ache could be the beginning of whatever's going to kill me. I hate it." The vigilance happens in all the private moments in life such as when we look at our bodies after bathing or feel it as we fall asleep. For people with HIV disease, the vigilance also revolves around the CD4 count. Until early in 1996 and the arrival of the pRNA and the bDNA tests the way clinicians tracked the activity of the virus in the body was by monitoring the decline in the CD4 count. It informed decisions to begin or change anti-HIV drugs, reflected the impact of other stressors, and was the overall measure of where a person was in their disease progression.

Women reported mixed feelings about their CD4 cell counts. Pam has no measurable CD4 cells and is still able to maintain a relatively normal life free of signs or symptoms. Her CD4 count does not mean a whole lot to her. She talked about it.

> In our first year, when we got married, Mom knew we were going to die . . . get sick together. And we survived that first year and things weren't so bad. The only thing that was bad was that my T-cells were continuing to drop. And they never have gone back up. No matter what medicine I had been on, they had always gone down. But at that point my doctor says, well, maybe they're not all they're cracked up to be. And, so he was real encouraging the first year, or two, or three even. I'd come home crying, Oh, I'm dying, you know, this and that. And you know, it's not yet.

Pam lives in a rural area and is cared for by a primary care physician. She is his only female HIV patient. When she found out about the new pRNA test and protease inhibitor drugs, she wanted to have the test. She went to a nearby larger town, saw an infectious disease specialist and enrolled in a research study which provided the test to two arms of the study. When she did not get randomized to the part of the study providing the test, she found someone to pay for her having the test done privately because she really wanted to know her viral load. She wanted to know whether to start taking protease inhibitor combination therapy. She may not think her CD4 cell count means much but she still wants to know how fast her disease is progressing. She has a baby daughter to raise. She has definitely integrated the importance of managing her disease. Her self-confidence, take charge attitude, and positive outlook are considered part of why she does so well by everyone who knows her, including other women with HIV.

On the other end of the continuum were women who were afraid of their CD4 cell count number and did not want to know what it was. It was the ultimate symbol of how the HIV virus was slowly killing them. Sandy is the example of these women. She has an agreement with her husband that he knows the numbers and can only tell her if they are really bad or good.

> I don't know my numbers and I know they're bad. And [husband] lets me know they're bad, because I told him to let me know if they're bad or good.
>
> *[Husband was present and replied]: I didn't say they were bad.*
>
> Well, you didn't use that word. You said: They're low.
>
> *Husband: Well, lower.*
>
> They're down. I had to know so we could decide what to do treatment wise. This blood test thing is going to determine whether I change or I don't change. So I have to know, yet I don't want to know. I get scared to death every time if it comes to the numbers, my heart starts beating.
>
> *Husband: And I have to pretend nothing's wrong.*
>
> [Husband] wants to know the numbers, so he has to kind of play nonchalant and casual about it. Sometimes he doesn't even tell me he received them yet because he

> doesn't want to scare me. I almost faint when I'm about to get those numbers. I get that panicky.

Linda does not want to know her CD4 cell count either. Her doctor just tells her if there's been any big changes up or down. Women had love hate relationships with their T-cell counts. Cathy found out her CD4 count had risen to almost 600 and was very happy about it.

> But then I tell myself, see old pessimist Cathy creeps back in and says: But like my friend said, her's went up and down by leaps of 300 over some legal battles she was having. She'd lost like 300 T-cells in one 3-month period and they came back. So I'm not going to get too worked up over the number even though it's a nice number compared to what it was. I know by now that the number is not necessarily the important thing. I know people with one T-cell who are going strong and working full time and I know people with 500 who are sick a lot. I can't rely on the number, but I personally feel so much better than I did. And no more fevers and no more night sweats. And so much has changed for the better physically that I feel like if I could get over this emotional crap, I'd be sitting pretty right now.

She is right about the number not being the disease. It will be important to see how having a definitive test like the pRNA will affect people living with HIV disease compared to the second hand nature of the CD4 test. The CD4 number reflects how much damage the HIV has already done to the immune system. The pRNA tells precisely how much virus is in the plasma at the moment the specimen is drawn. It is a specific count, not a damage estimate. More viral particles means the virus is active and growing. It is highly unlikely that we will see people with high viral loads who do not show signs of disease progression like we have seen in people with low CD4 counts. Some people's immune systems seem to adjust to the loss of CD4 cells (such as Pam), and continue to protect the body from opportunistic infections. We do not know yet how specifically viral load will predict demise. But we do know that having the test definitely changes what we can know about the virus's activity in the body at any given time.

The CD4 number also had an effect on women's relationships with their children. Kids knew what concerned their mothers, especially when it came to living with a terminal illness. Chris was an example of women on the edge between avoiding and integrating their HIV disease. Tracking one's CD4 count was a tangible way women engaged minimally with their disease. Chris said that she enjoyed sharing her good CD4 count with her doctor and her kids.

> And then he *(her physician)* was really happy about my tests the last time. So I felt really good. I didn't have anybody to tell. Except I did call my kids.

Having a shadow life meant not getting to share the good news of a CD4 count with her coworkers and friends who did not know she was positive. Some women also hid their T-cell count from their children. Lois talked about not letting her daughter know that her counts had dropped because she did not want her to worry. She planned to have the test repeated because she thought it was low due to her recent hospitalization and might come back up.

The CD4 cell count is a reflection of the day by day health of the immune system that responds to stressors of many kinds including such routine life influences as alcohol, exhaustion, menstruation, tension, or stress. If Lois had a pRNA test, repeating it probably would not change it. She would not have this period of time to think that the number is incorrectly reflecting her HIV disease status and prepare to tell her daughter. The use of the PRNA test eliminates the uncertainty of just what the virus is doing in a person's body. As the scientific management of HIV disease improves, the gray areas of whether or not to do something disappear and women are increasingly faced with having to make irreversible treatment decisions sooner.

Something should be said about alternative and complimentary care and its role for women who actively integrate their disease into their lives. The women in this study live in the Pacific Northwest. The only two Naturopathic colleges in the United States are located in Portland and Seattle. Naturopathic medical care is used commonly and often as an adjunct to regular western medicine. As a Pacific Rim area there is a large Asian influence and Chinese medicine is readily available, both acupuncture and herbal treatment. In Portland there are several Chinese medicine clinics including a large Immune Enhancement Program affiliated with programs in San Francisco that conduct HIV research. The county health department subsidizes acupuncture for recovery from addiction. And there is a lively and large "holistic health" community of programs promoting wellness and healthy living available to people living with HIV. The interest and commitment required to learn about, arrange for, and attend or acquire these treatments varied among the women. One-third of the women in this study were fully committed and integrated to doing anything possible to stop the HIV. They are ready and willing to try whatever they thought would help. The others were managing their responses to the disease and picked what appealed to them, depending on their ability to organize and motivate themselves. It takes time, energy, and money to use treatments not provided by mainstream clinics or covered by normal third party payers. Women did want to know about all the possible approaches and wanted to be able to make informed choices. It is important to mention that not one woman indicated that her use of anything alternative was a problem for her primary western medicine provider. There did exist a time when patients were caught between paradigms of care and had to choose one over the other. Knowledge has now been shared sufficiently to at least allow for a level of tolerance among providers from different philosophies of care. There are even instances where providers from both ends of the paradigmatic spectrum participate in the same research protocols. The CPCRA is investigating acupuncture versus Amitriptyline for the treatment of peripheral neuropathy.

Having an environment of open communication about alternative and complimentary treatments meant a lot to these women. Alternative treatments are usually less aggressive and provide a time of adjustment for women. Then when the time arrives that the softer natural treatments were no longer sufficient, the move to stronger pharmaceutical interventions was an easier one.

Dealing with depression and dementia. As the lived experience of HIV progressed women began to think about the inner unseen damage the virus was doing. They especially feared for their minds. HIV disease is systemic and invades the entire body. It accumulates in specific cells and organs such as the T-cell and the lymphatic system; however, it is found in many others parts of the body, including the brain. Opportunistic infections also affect the brain, such as Toxoplasmosis and Cytomegalovirus. The thought of having parasitic Toxoplasma gondii in one's brain is revolting to women and men alike. It exemplifies a total violation of the person. It created feelings of terror, helplessness, and hopelessness.

The most feared symptom of HIV progression was dementia. It was also probably the hardest thing to accept in caring for a loved one dying of AIDS. It steals the familiar persona and leaves a diseased body behind to be cared for until it dies. For women with children, the fear was not just for themselves and their inability to care for themselves, it was for their children. The fear was that their children might have to care for them and would see them in a disgusting and unrecognizable state. Women also feared losing control over their children when others decide they cannot mentally manage themselves. Mary provides an example. She knew part of why her father and ex-husband removed her daughter from her household was because they thought she was "changing." She worried that she did not always know where she was, and frequently could not remember her train of thought. She hoped she physically went before she "lost her senses." Considering the advanced stage of her disease and her immense viral load, it is reasonable to conclude that the HIV had entered her central nervous system and was causing mental changes. Her confusion, resignation and helplessness were probably influenced by HIV in her brain.

Women worried about their mental health long before they entered the terminal stage of their disease. Dementia was the fear. Sue said: "My mental capacities have been affected. And without them, I just can't hack life. I couldn't hack life with Alzheimer's." Her doctor assures her that she is not demented. For anyone living with HIV disease, the fear is there. It is there because it is real and because anyone who is part of the HIV/AIDS care community has seen people change completely as the virus invades their minds. It is the one symptom that was most often mentioned when women talked about assisted suicide or living wills. It was especially important to women that their children remember them as whole, in body and mind. The fear plunges women into feeling overwhelmed when they think they are having symptoms.

Managing depression and maintaining mental health are considered part of the standard of care for people living with HIV disease. The use of anti-depressants and other psycho-active drugs is common because people living with HIV disease are both understandably anxious about their life circumstances and may be physiologically challenged mentally by the HIV. Health care providers working in HIV disease recognize the importance of monitoring mental health and the women consistently reported taking anti-depressants when needed and having other medications available to help them fight their anxiety, lethargy, or sleeplessness. Women spoke of being "eternally grateful" to Prozac (Fluoxetine) for lifting a heavy dark veil that often seemed to hang over each day. Linda knew her disability was based on clinical depression and was very careful to monitor her medications and emotional condition. The women supported each other constantly regarding taking care of "feelings" and not getting "emotionally constipated." The natural tendency of women to be nurturing and care giving contributed to their supporting each other emotionally. From their personal life experience they had developed an appreciation for genuine caring and it was mentioned many times as being something they rarely felt but deeply desired.

The concern of wanting to be mentally healthy was not just about the major fear of brain illness or dementia, but was also about being able to be happy and enjoy life. Women spoke of the progression of their disease as including a growing sense that all there is to life is HIV. This was the underlying basis of the coping pattern of resignation. As the disease progresses, the goal is to keep pulling oneself up out of its potential darkness.

Even women who were well integrated in their coping with HIV talked of needing an emotional break from the virus. Women who were feeling overwhelmed did not see that as a possibility. Jako shared a common scenario when she told of the time she tried to escape to the beach with her partner and they promised each other not to mention HIV the whole time away. It was wonderful. Then on the way home they made the mistake of turning on the radio and there it was on the hourly news. She bemoaned, "this illness just overwhelms everything, it takes over your life."

The women worried about things everyone worries about, such as housing, transportation, and health insurance; except for them having HIV disease changed everything. Everyday decisions and interactions became a potential source of stress related to being HIV infected. Giving up employment and going on disability meant a permanent drop in income which also meant the car did not get fixed, or if it did it was not driven much because there was no money for gas or insurance. The decision to tell a landlord about their illness was troublesome. Ann did her laundry late at night because she feared her neighbors complaining she might infect their dirty clothes and she did not want to be evicted. One of the greatest ongoing fears was losing their health insurance. For example, Cathy lives with her husband just above the eligibility cutoff for the Oregon Health Plan. She wants to stop worrying because she knows the stress is not good for her health but she feels furious and helpless to affect the things that threaten her. It contributes to her feelings of being essentially overwhelmed. Women worried about what the stress of it all was doing to them.

Dealing with physicians. Life with HIV disease includes a mandatory relationship with a health care provider. Women struggled with how to relate to their physicians because they were afraid of making him/her mad and thereby possibly negatively affecting their care. The women in this study reported the best and worst of times in these relationships. Women living in rural areas had the most difficulty and felt they had the most to lose. Cathy provides the example for the complexity non-HIV specialists face in caring for HIV infected women.

> My primary care physician, I've always felt that she doesn't really care a lot about me as a person. . . . And she was very unfeeling toward me in the beginning. Like she felt that I had lied to her. And [other doctor] said the same thing. That he thought that I had withheld something when they asked me had I had any high-risk partners. But they asked me had I had any high risk partners in the last 5 years was the exact question that both of those doctors asked me. And so of course I answered them honestly. And then they came back later and acted like I did something to them when I tested positive.
>
> And I don't know why [other doctor] didn't just automatically test me when I was pregnant anyway. I would think they would just test pregnant women. I assumed that was one of the tests they were doing when I was pregnant. And I just, I don't know. It's just such confusion. But I've never felt that [lady doctor] was a friendly warm doctor. And lately that's changed somewhat. I mean she does actually care a little more and inquire about me and, you know, call sometimes to see how I'm doing if she hasn't seen me for a while. You know, I like that.

> But just when I was in there last week she said something about: Well, before you got AIDS. And I didn't even bother to correct her. But that's the way she is. . . . . I don't have AIDS and I don't like people saying that I do. I don't know, I have been real sensitive about that. I don't want people saying I have AIDS if I don't. I'm HIV positive. I do not have AIDS. . . . It just bothers me that here's my primary care physician and she says stuff like that. It's like she doesn't really want to understand this. And she freely admits that she knows nothing about it.

People living with HIV often choose to see a specialist for their HIV care and remain with their primary care provider for everything else. This was commonly seen among the women in this study. They decide to get their specialized HIV care in Portland and continued to see their primary care providers because they wanted a physician that lived in their local community. As Cathy said, they "did not want to be running in to Portland for every little thing." They will ultimately face the challenge of the distance when some bigger thing happens and their local doctor cannot manage it. The thought of starting over with a new doctor was more than women wanted to cope with. For Cathy, she felt she's finally getting this one to come around and care for her the way she likes. For most women, the relationship meant more than the physicians knowledge of HIV.

Leah articulated the experience of women whose primary care physicians may not be AIDS experts; however, do provide the specialty referrals and desired emotional support.

> I'd just as soon stick with her
>
> The only drawback with her is that she's a family practice doctor and I'm her only patient with HIV, or a least diagnosed with HIV. So I've been seeing her for the last 3½ years . . . When she left for her maternity leave she called me. And her office is real good about calling back with lab results and things.
>
> *So you feel well cared for?*
>
> Yeah. I don't like it, that if anything strange happens physically I'm referred to someone else . . . I've gotten to know her and I really like her. I'd just as soon stick with her. So, then if I have to see a specialist . . . I hate going to the doctor. I just dread it. So, I mean I want to stick with her just because I feel comfortable that she's

> compassionate and she's good at following up, and she doesn't just kind of brush me off.

Leah related that whenever she went to see her physician she just cried and cried and its okay. This physician was providing the individualized care and personal relationship women wanted. This was especially important because Leah was one of the women who was essentially resigned to her disease. These women need significant encouragement and assistance. What is not resolved is what will happen for women living in rural areas, or those seeing physicians who are not AIDS specialists when their disease becomes full-blown with complex and often multiple opportunistic infections going on at once. Managing the later stages of the disease is difficult enough when one has a long standing relationship with a physician and it is a quick trip to the office or hospital. For women living in rural areas, maintaining their relationships with their local primary care providers may meet their immediate needs for acceptance and a sense of local belonging; however it may not serve them well as their disease progresses. There are no easy solutions for these women. Likewise, their physicians also face personal and professional challenges as participants in the ongoing disease experience of their HIV positive women patients.

The concern of wanting to be seen as a regular woman, and even be physically touched by a health care provider, came up many times. Chris provided the example. She works in a hospital.

> Well, you know, he gives me a little pat and squeezes my hand.
> It's something like, if I had a lump in my breast I could tell people at work and I'd have all this sympathy and concern. Now I have this and I have to sort of keep it to myself. I suppose because I'm not sick it's like something that's not there. I don't feel it.
>
> What I feel is my menopause. And my doctor was really sweet the other day. He was in the hospital and he tells me: Did you get my message? And I'm going: Well, I got the prescription but I didn't get any message. So he came back and said: Well, I

> talked to your GYN doctor and we put you on the lowest dose of the Premarin. I was having terrible hot flashes. [She was scared.] And he goes: Oh, its just menopause, and that's treatable. And he laughed.
>
> And I was reading this book [Bernie Siegel, *Love Medicine and Miracles*] about being able to hug your doctor again, you know, pat him. And he's doing that. So I feel really good.
>
> *He's hugging you?*
>
> Well, you know, he gives me a little pat and squeezes my hand. And he sees me in the hall . . . he says, Hi . . . How you feeling? Like that. And then he was really happy when my tests came that last time so I felt really good.

He cared about her and showed it. He treated her like a normal woman with regular middle age women's problems and he laughed about it with her. And he touched her, probably the most important personal caring he does. This elderly physician is well known in the community and has a huge practice. He exemplifies the kind of direct yet casual personal caring that women wanted. Women said that going to see the doctor felt best when it also felt like being with a friend, someone who was glad to see you and shared a moment of their day by day.

In a disease with the significant social stigmatization and judgment that AIDS has, being treated with friendliness, respect and caring become all the more important. Chris is confident that whatever happens he will be there for her. This is another common concern of women who are unsure who in their families will be there for them. It cannot be overstated how important this is to women. Having someone who they know will be there means there is one less relationship that will change or have to be negotiated as the disease does whatever it is going to do. Such physicians play pivotal roles in women's abilities to successfully integrate HIV into their lives. They provide assurance that it is possible to have a reasonably normal life and be HIV infected, at least for awhile.

On the downside, other women talked about having very difficult times with physicians and health care providers. Robbie is an example of women who are not ready for the pressure they receive about their care. This happened to her when she received the results of her HIV test from a nurse.

> It was scary. It was very, very scary. And I really feel that the nurse, this man that gave it to me really made it scarier for me because he kept trying to drill into me how serious it was and that I needed to get to a doctor, and I needed to do this, and that. And I was going: Wait. I'm not ready. This has just happened. I'm not ready to go to a doctor. I'm not ready to start AZT. I'm not ready to do all that. And he was like going on: But you don't understand how serious this is. I think that just made it worse for me. Because he was emphasizing how serious it was. Instead of going: Well, you look fine, just do it when you're ready. You know, this is just the facts. And so it was really hard.

The nurse was following a prescribed protocol for informing someone of everything they needed to know to get started with their new life as an HIV infected person. What he did not include was understanding what this women was feeling and he obviously did not stop to ask her.

Other women talked about their testing experience in much more positive terms as we have already discussed. However it happens, it is a devastating experience to find out one is positive and all responsibility for sensitivity rests on the person giving the results. In the current climate of political conversation about expanding mandatory testing, the importance of recognizing what this experience means to people becomes even more critical. It sets the stage for a cascade of events that can ultimately influence how or if an HIV infected person accesses care. Health care personnel are well served to include in each encounter with an infected women (or man) a brief assessment of the client's current feelings or cultural understandings. If this man had stopped a moment to listen to Robbie she would have told him to back off and give her a minute to cope.

Some experiences were more serious and damaging. Sharol shared two instances of abuse by physicians. Once involved sexual abuse and happened when she and her sister were hospitalized as children. She deferred the details but said the abuse happened more than once during the hospitalization and that no one but she and her sister ever knew about it. She did say that after it occurred, she would only allow female doctors to examine her and sees a woman physician at the present time. Her experience is included here because it points up the pervasiveness of the vulnerability of young girls to abuse, or their perceptions of abuse. In the first section of this report it was revealed that the abusers came from both within and outside the families of these women. One could hope that a hospital would be a safe place for little girls. Her other experience came during an evaluation for social security disability.

> When I was applying for social security disability they sent me to a man doctor to be evaluated . . . And it was the worst experience I've ever had. I came out of there mortified. [Friend] had taken me and waited for me. When I came out she said: What is wrong? I said: I don't want to talk about it. You know, then I went and got drunk immediately.
>
> *Was he mean to you?*
>
> He wasn't mean. It was just what he asked. What he did. How he portrayed the whole thing. I was put off immediately, because I don't like men doctors. I was put into a room. He closed the door. I put my chair up against the door. His desk was clear across. There was an examination table in there. He made me feel like I was filth. Come to find out . . . they denied me on his evaluation of me. And I had to go back into therapy after I had seen him. And come to find our he was a chiropractor that had evaluated me mentally. It was a Saturday. I felt like I was interrupting his golf game.

Sharol felt this man did not value her as a woman or as a person. Whether she qualified for social security disability or not is not the issue. What an experience like this meant to women with Sharol's background was that once again she was not valued and felt she had been abused. She responded in the only way she knew how, she turned to alcohol. He may never have been trained in working with vulnerable populations let alone women who have traumatic personal histories. The situation is also an indictment of health care programs that provide off hours (weekend) services without adequately oriented or trained personnel. The need to expand testing and basic services will grow as the epidemic increasingly moves into heterosexual populations and cohorts of young people. If experiences such as what happened to Robbie and Sharol are to be avoided, a priority needs to be placed on the training and preparation of program staff.

Overall, the reports of successful and satisfying relationships with health care providers far outweighed the negative. As Ann said, "I get damn good care." Throughout the health care system women reported supportive experiences. Marilyn was very happy with the home care nurse that made her transition from hospital to home after PCP easier. She recounted how much it meant that the nurse stayed and talked during the visits. This visiting nurse prepared her for not going back to work and helped her think positively about making her self-care a top priority. Pam has an advocate at the local health department who is helping her create easy situations where her husband might agree to be tested. They failed when he went in for a flu shot but she speaks warmly of the friendship and support the nurse provides. Linda wants to adopt her case worker and considers her part of her family. Sandy and Robbie attend the patient seminars their doctor occasionally gives for his HIV patients and value his open-mindedness toward the many alternative and unconventional things they like to try. Bobby brings snapshots to her physicians assistant to add to his collection. He has pictures of her little boy on his wall from the day the child was born. In every instance the defining factor in these positive relationships is its personal quality. Specialized knowledge about HIV is not the most highly valued part of health care for these women. The quality of the experience in which the care is given is what means the most and is what helps them integrate their disease as successfully as possible into their lives.

Longing for intimacy and closeness. The next concern in understanding life with HIV for women was their longing for intimacy and closeness. It was probably the area where women were most resigned to the effect HIV has had on their lives. Women were close to their children; however, a child's love does not fill the physical and emotional needs of adult women. For infected women, partners who care for them offset all the ways no-one else wants to be near them. The isolation infected women experience happened in many ways including personal, physical, economic, socio-cultural, political, and spiritual. They talked of feeling separate and different from normal people. They have reluctantly integrated the socially constructed perception of people with HIV as being people who have given up their rights to expect much from society because of their unacceptable risk behaviors. They may be willing to accept society's unwillingness to care for them more readily than they are willing to give up hoping there is some single someone who will love and care for them. Women in all four coping patterns talked about their feelings of loss and loneliness if they did not have a current partner. No matter how they felt, they wanted someone to share it with.

The women who became advocates and educators try to raise community awareness about the pain of being rejected and the need for the community to accept, include, assist and embrace people caught in the epidemic. Linda questions how successful advocates really are in changing public perceptions but she remains committed to keep asking to be included and supported; if not for herself, for her daughter. She talked about how she sustains her dedication to public speaking by convincing herself that people change one at a time and maybe hearing her will open one more persons heart. She is also one of the women who grieves that she is not the center of any one person's heart besides her daughter's.

The experience and fear of rejection also caused women to avoid initiating friendships or relationships. They often initially distrusted people who were genuinely trying to know and support them. This made existing, trusted and dependable relationships and friendships all the more valuable. It also places huge responsibility on social service and health care workers who build relationships with infected people. They must never underestimate the importance of the trust they have been given by their clients, both men and women. It is in this context of social vulnerability that women long for intimacy and closeness.

The desire for intimacy and closeness will be explored looking first at the fortunate few women who are in supportive marriages. Next will be a discussion of women who live with a male partner. The analysis will finish by looking at women living alone or with their children and their struggle to resolve a need for adult closeness.

Sue provides the example of women in supportive marriages. She and her husband had just started their marriage when her ex-lover called to taunt her with his HIV status. They subsequently weathered the social judgment of a small Rocky Mountain town and moved to Oregon where they now live in a rural area.

> I love my husband, more than, sometimes life.
>
> We've had a lot of stress and pressures, that we shouldn't have. And I speak now in terms of we, instead of just I, because I have not done this all by myself. . . . .I've had a lot of support. My husband has been like my doctor as well. He's a ski patroller, a rescue worker.
>
> He's also my best friend. . . . He's my only friend sometimes. Because you really find out who really loves you when you've got HIV. And I'm very rich because I do have my husband.

Husbands in this study became publicly identified with HIV because of their wives' infections. Sharing their wives' illness changed other relationships in men's lives. Men typically preferred avoidance to telling their friends or co-workers. When they did tell, they were sometimes surprised at the support they received. Sandy's husband is an example of a stereotypical working class man. He talked of his struggle to tell his best hunting buddy and the tears of joy they shared when they made a pact to do whatever they could for Sandy. He also told his co-workers in a health care facility, who now support him. He even talked of overcoming his Marine Corp homophobia after meeting the gay men in Sandy's support group.

Women also worried about their husbands. They assumed typical, normal, care giving roles. With HIV there is a significant difference however, because fear always lingered regarding him being strong enough to carry the load if the woman ever got sick. Women knew how hard it was to continue supporting them. Sue validated that the experience has not just been hers to bear. She and her husband are a team.

> My husband's just wore out and he needs a rest . . . He says he's fine but he's not. And that's alright. But, I guess the thing I'm the most worried about besides the virus is him.
>
> I just think that this disease. I mean everybody says support, support, support. Well, what people don't realize is that support is needed for others besides just the person with the disease. I know you're doing this study on women, but it's pretty amazing what he's lived through. Been there for me, every step of the way.

The importance of supportive marriages to women with HIV was enormous. A husband's presence and help significantly affected many aspects of women's self-care from picking up prescriptions, to caring for children, to being there when the judgment hit. On the other end of the spectrum were marriages where men had not yet integrated their wives HIV. These men were usually using coping patterns of feeling overwhelmed and avoidance. Cathy provides the example. Her marriage was a source of both support and great pain because her husband was unwilling to share or acknowledge any aspect of living with the disease (including being tested himself). This put her in the hard place of having to keep it all to herself. She was resigned to his feeling overwhelmed and his withdrawal and still cannot imagine doing it without him.

The women with partners to whom they were not married had a similar range of involvement and support from the men they loved, but with a critical difference. The strength of the love and closeness in these relationships was enhanced by the fact that there was no marriage bond, and the choice to stay had to be made continuously. The variety of experiences among this group of women predominantly revealed supportive men. Lois refers to her man as "her rock." Jako saw her life begin anew the night her love held her in his arms and said it did not matter that she had HIV. His rejection of his stepmother's judgment further cemented their emotional commitment. It is in Robbie's relationship that a paradigm case emerges. Here was a relationship that went through the entire continuum of the jagged journey that begins the moment HIV arrives. Robbie has already shared the devastation women feel in finding out their HIV test was positive and their partner's test was not. The insights to be gained from Robbie's experience are both how deeply important women's relationships with the men they love are, and the importance of community support (in this case a retreat) to help couples realize normal adult love, even marriage, is possible for people with HIV.

> He was afraid to kiss me. We didn't know whether he should stay in the relationship. One of his family things that was hardest for him was having to take care of his Mom being ill when he was a child. His Dad left when he was real young. . . . So he has a lot of stuff around having to take care of somebody. And that's terrifying. . . . It was very hard during that time . Not only was I having to deal with the fact that I tested positive for HIV, but I already had AIDS.

Robbie and her partner went through a difficult 6 months that included her flirtation with suicide and his decision to reject his family's judgment of Robbie and stay with her.

> Things changed with (partner) actually when I went on the HIV Women's Retreat. That's when they changed. I was gone. It gave him some space where I wasn't constantly there in this cripple mode, you know, trying to ask him to decide whether he was going to stay. I knew he was going to leave me. It gave him some time to get centered and it gave me time to get centered. . . . I came back a completely different person. I left as a basket case and I came back feeling great. So when I came back, [partner] was different. He had some time. I also came back knowing about other couples where the women were positive and the men weren't. So . . . things just fell into place after that. I mean it wasn't immediately better. It got better and better. . . . . We knew we weren't the only ones dealing with this shit. Now, there's no question about whether we're going to stay together or not. Now, we don't take our relationship for granted at all. We love each other, in fact we love each other more.

Being with other women facing the same challenges with lovers and husbands was always mentioned as being very important to women. They sorted out their feelings in these groups and moved from coping patterns of avoidance and resignation to feeling able to integrate having HIV with a primary relationship. The power in Robbie's experience of love with her partner culminated in the Fall of 1995 when he proposed marriage and a wedding was planned for the summer of 1996. Their story points up something that is missing in talk of the epidemic. And that is the experience of male partners in relationships with infected women. Like the children, the depth of the life experience with HIV for these men is lost in the epidemic drama. Robbie's story illuminates that men also have trauma from their childhoods that impact on their abilities and willingness to engage in adult relationships. Men go through the same coping patterns of feeling overwhelmed, avoidance, resignation, and integration. And they too can integrate their past and overcome their personal challenges to be with the women they love.

It would be remiss not to be reminded of the women whose lovers were infected and for whom they became care givers. Some would judge the sanity of women who put their all into caring for the men who infected them. Especially, as was true in both cases in this study, when the men knew they were infected and did not protect the women they were having sex with. Perhaps what these relationships depict is the importance of the intimacy and closeness to women. That even in the dying the value of the connection remained. It was that important. Women realized that it could be the last intimate relationship they would ever have. This leads directly to the final area for discussion, women who are resigned to being alone and wish it was different.

When women talked about not being *normal*, they were often referring to their sexuality. One of the hardest parts of being different because of HIV infection was feeling that the normal adult urge to be sexual was unacceptable, not smart, dirty, or somehow wrong. These are women in the prime of their lives when normal women enjoy their sexuality either in or outside marriage, but certainly as part of acceptable adult life. Women's sexuality is a central part of public media. It sells cars, groceries, and insurance. The all American couple is seen constantly in situations dripping with sexual innuendo. Women talked of being jealous of HIV positive gay men because they appeared to have incorporated safe sex into their social lives and then went on to enjoy their intimate interactions with each other.

The women in this study shared the confusion they felt in trying to balance their persistent physical and emotional needs with what they knew about HIV infection and the social context of dating and meeting men. Marilyn provides the example of how things changed for women once they became infected. She was a professional, successful, desirable divorcee who tried to continue dating after she found out she was positive. She talked about one man's reaction.

> You know, I think of it just as this reaction. . . . I've dated during this time. And that's a real gut wrenching experience. I've had some weird reactions. This one guy, . . . We had worked together. . . . His wife died and my friend asked if I would go out with him. . . . And I ended up telling him. And he was just livid that I would even go out with him. It was really very strange because when you looked at the situation, he could have been an ideal person. . . . I haven't been out with anybody for a year and a half.

She has chosen to avoid the risk of rejection in dating and meets her need for love and belonging through the friendship of college roommates who have come forward as her primary support system.

Sharol provides the example of women who are still trying to socialize and enjoy men. They find it can be very difficult to meet one's need for intimacy in the context of an HIV secret. She is one of the women resigned to having HIV and wants to at least have some fun in life before she dies.

> There's people I meet every day that I wouldn't trust with my information. I don't want it known. I just don't want to have to live it down. I want, I think it's still that intimacy thing. I don't care if the women know. Except that they'll tell the men. I don't want men afraid of speaking to me or asking me to dance. Or thinking I'm unattractive because of the disease. It's hard when everybody knows. It just is. You're judged immediately.

She talked about her history with alcohol and promiscuity and her desire for closeness.

> Even before I knew I was an alcoholic, I'd go out and drink a lot. Very promiscuous. And if it wasn't for this disease, I'd still feel like being promiscuous. It's not that I have many chances. I just still feel it. I don't want to live with men. I don't want a relationship with anybody, but, that would be nice . . . The thought is always there. . . . I don't think it's a sexual thing, I think it's the closeness.
>
> *You mentioned intimacy a while ago.*
>
> Yeah, just knowing someone really cares for you. And desires you. To even know you are desirable.

Sharol worried that she may have been responsible for her own private epidemic before she knew she was positive. Other women in the group shared the frustration that came from wanting intimacy and fearing that they may infect someone. Women were completely unwilling to take even the slightest risk that they might give HIV to someone else. Rose talked about it. After ending a relationship with a man who did not like her daughter she evaluated her need to be with men.

> So I chose my daughter and I dumped him. And after that I'm not interested in men anymore. You know, like I do like to date them, but I don't want to have a relationship with them because I don't want to have something go wrong and get hurt . . . I hardly dated anyone . . . Because if I did, since I have the disease, I might spread it to a lot of people.
>
> I look at men differently than before. Like before, I didn't have HIV . . . if I date someone or I see someone, you know, they look sexy . . . and I want to get to know him and sooner or later I'll go to bed with him. Now I don't have that feeling any more. Because I feel like I am dynamite. If somebody gets involved with me I'll hurt them somehow by this disease. . . . So, like I said, sometimes I feel very lonely. You know, you need companionship.

Women sought out closeness in other ways, with family, friends, and through their spiritual faith. Rose became involved with a Buddhist teacher and community that provided her with spiritual support. They did not accept her HIV status and she can no longer help in the kitchen, but she still seeks companionship from them.

> But like I say, it's my problem, it's not them. If they accept me, it would be wonderful. But if they don't, it's okay. And yes, I do, now and then I feel lonely. I just want, I'm not trying to find a partner to have sex with, but I would like somebody to understand me, just not be afraid of me.

Women faced potential rejection in all the situations of their lives. Therefore the search for acceptance and closeness was always at risk when they interacted with other people. They did not much mention having non-sexual friendships with men. For women from abusive childhoods, the trade off they learned was sex for intimacy. Now that HIV has made sex dangerous, their ability to find intimacy seemed to have been taken away. These women found closeness through old friends and spirituality. They are resigned that HIV has taken away their chance for love, but they still talked longingly of being held in the ways that mean so much to women who have husbands or partners.

It is not possible to articulate all the ways the isolation, aloneness and sense of loss around emotional intimacy and closeness came up as these women described what the day by day life with HIV means to them. Children helped offset the emptiness of a household, but brought with them other burdens that women had to bear as single parents. And a child does not hold you like a lover. Chris summarized the loss of emotional closeness women felt.

> I feel like I'll probably be single the rest of my life . . . and I don't know if I'd ever have the courage. . . . . I don't want to go through the stressful thing of telling them about my disease.
>
> *How does that feel?*
>
> Its depressing to me sometimes. That's what depresses me the most.
>
> *The thought of not having another relationship?*
>
> Well, yeah. Not having one, not even having the possibility. I just don't feel there's a possibility. Because it's hard enough for me to meet people to begin with. And that this makes it even harder.
>
> *You think that's the most depressing thing about having HIV?*
>
> Yeah, I think so. Because I won't have a partner if I got sick or something. You don't have that relationship . . . I don't dwell on it. I could just sit here and cry.

Her voice was soft and trembled around the edges as she said this. She had watched and cared for the man who infected her through his death. She knew what was involved in dying from AIDS. Her words bring back the discussion of self-esteem and lack of self-confidence which started for most of these women in childhood. Among this group of women the risk of hoping and trying was too great.

Motherhood: The Final Hope: Staying Alive for my Child.

Motherhood is a major concern in this analysis because it came up as an issue for every woman, regardless of whether or not they had living children. The decision to have children is one of life's primary choices for women. For infected women decisions concerning children took on additional complexities because they included all the ways the mothers' experience of HIV affected her children's lives. Women felt guilty and grieved if their child was infected because of them. Telling children and reassuring them that they will be safe was difficult, especially in circumstances where it is not yet determined who will care for the children. Children became women's reasons for living and women wanted to make sure their children are never abused or neglected. Mothers talked of empowering their children to be knowledgeable about HIV and to have a healthy future. This was a lot for women to incorporate into everything else involved in surviving with HIV infection. It sets women's lived experience apart from that of HIV infected men, which is not to diminish the issues that fathers face. However, even in families where there are two parents present (which is rare), it is usually the woman who manages the children and arranges for their needs, physically and emotionally. Motherhood continues to be women's first priority ahead of their concerns for their own health (Simpson & Williams, 1993; Baals et al., 1993). Every coping pattern that women had in dealing with their disease was directly linked to their relationship with their child (children).

Five common concerns that relate to motherhood will be considered. They are: valuing children, living for children, protecting children, arranging for care, and children as hope for the future. Lois's feelings exemplify those of all the mothers in this study. From the day she almost died during the surgery in which she was infected, Lois credits her relationship with her daughter for keeping her alive. It gave her a will to live. Her daughter is the most valuable part of her life. She is a single parent and there is no contact with the father.

> I went through almost 9 hours of surgery.
>
> *So you must have thought it was some kind of miracle that you didn't die?*
>
> I think so. But [daughter] was only like a year and a half old. I couldn't die. And I really believe that.
>
> *So she's kind of like a reason for living?*
>
> Right.
>
> *Do you still feel that way?*
>
> Definitely. Especially right now . . . Well, when I ended up in the hospital and my count was 26, and I hadn't been feeling very well. And I'm just not ready to go. And you know, I don't think she's ready. . . . I really think she gives me the strength. Even through the poisoning and all that. To keep going. I don't think she's ready to be without a mom. So that keeps me holding on.

Women spoke of getting through similar times of serious physical illness buoyed up by knowing that they could not die yet because they had a child to care for. For women who had experienced very little success in their lives, being a mother made them feel worthwhile. Raising a healthy child is their contribution to the world. Despite their own difficult lives, their children provide hope and possibility for something better. The children literally and consistently prevented their mothers from succumbing to debilitating coping patterns of avoidance and resignation. Women spoke of discovering the depth of their priority for their children during difficult times when they had to make choices. Bobby provides the example. She vividly remembers the time in the hospital when her primary care provider told her she was going to die soon if she did not take better care of herself. She remembers thinking what a relief it would be to die and then recalls that she decided then and there that her little boy could not be without her yet and she would just have to make some changes and live. He survived her infected pregnancy so she felt it was the least she could do for him. Pam is very clear that her will to live is tied to being there for her small children. For the women in this study with children, being a mother was the positive, basic core of their identities. Focusing on the hope they have for their children's future helped balance women's feelings that they had been robbed of their own future.

If the children were old enough, often they became partners with their mothers in confronting the epidemic and responding to the challenges as a team. This group of women with HIV mainly came from vulnerable socioeconomic backgrounds and most are single parents or living with men who are not their children's biological parent. Mothers and children have often had to endure difficult times together and see themselves as co-survivors in life. HIV adds one more obstacle to overcome together. The closeness varied from sharing things seen on television or in the paper to full partnerships where every subtlety from a strangers remark to their mother's recent lab values was shared. One of the hardest things to share was the emotional pain of prejudice and judgment. Lois's experience of being run out of town within weeks of finding out she was positive has already been discussed. What's important to note here is that the leaving was because of the abuse to her child. Women consistently drew the line on judgment when it affected their children. They were willing to endure it themselves, but would not tolerate their children being targeted. Lois would have stayed and fought if she had not had her child to consider. Another example is Linda who has struggled for several years with becoming public as an advocate for HIV/AIDS services. She had a fully integrated coping pattern and yet falters into avoidance when her child is involved. Her greatest fear has not been the reaction of the larger community, it has been what would happen to her daughter in their neighborhood and at her junior high school. It was only when her daughter decided to speak up from the "kids' perspective" at a televised AIDS Day rally that the concern was resolved. Their shadow life continues in their neighborhood and they have agreed to confront any rejection or criticism head on. This mother and daughter are an integrated duo.

Women take pride in their children and feel hopeful that if their children are well informed and empowered they will make a difference in the epidemic in the future. In conversation with women, their demeanor changes when they talk about this. They brighten and speak with conviction. Women need to believe this for their own well being. Lois provides the example when she talked about her confidence in her daughter's ability to deal with AIDS in an incident where 40% of her daughter's class missed an AIDS education session because their parents would not sign permission slips. It was noticed that her daughter knew more than the teacher. Because as Lois said, "She lives with it every day." She spoke of women's hopes for the future being tied to their children.

> Enjoy the children, that's what's important. And I think its going to be [daughter] and [Linda's daughter] that will change things. You know, they're the ones who are going to stop this. . . . [Daughter] has a memory box full of everybody that has been close to us that has died. And I really think her seeing all these people dying, she's going to be one of the ones that stops it . . . I would certainly like to see it stop before [daughter] grows up.

The hope is for something beyond one's own survival, and extends to having there be an end to the epidemic. Hope that there may be a cure in time for them to see their children mature was almost too much to consider. Women talked of their concerns about the future in terms of their children entering adolescence. They remembered their own troubled teens. Over and over women talked of not wanting their daughters to be like they were. This was the driving force for Sharol as she battles with the depression that drove her to attempt suicide. She spoke of what keeps her going as being a desire to see her youngest daughter graduate from high school. She would be the first one to make it.

One of the major ways women integrated the HIV was as activists to inform children and young adults about HIV. Linda has spoken tirelessly to groups of school children about her story and the need for children to protect themselves. Kim ordered every educational program for kids she heard about. Pam regularly drove 30 miles to talk to college freshmen about safe sex and abuse. The desire to educate and protect children and young people provided these women with pride in themselves as parents and citizens. They may not have succeeded as children or as young adults themselves; however, through their commitment to children they finally see themselves as worthwhile and valuable. Lois articulated their satisfaction in parenting.

> *So what do you look forward to?*
>
> Just to hold on as long as I can and stay around as long as I can for [daughter]. Watch her grow. She's only 12. I got a long ways to go parenting.
>
> *Sounds like it's an important issue in your life.*
>
> I think that's more important now than a cure.
>
> *Being a parent.*
>
> Yeah. The most satisfaction.
>
> *What does it mean to you to be a parent?*
>
> Probably, like I said the satisfaction. The knowing I'm raising my daughter totally different than I was raised. Nobody's going to hurt her. And it gives me strength to protect her.

Within the seriousness there was humor as well.

> She's at that age where she's no longer my child either. . . . Aliens came down and took my kid and left this one with me. This one can't be mine.

> *Sounds like teenage hormones.*
>
> Definitely. But you know what, that's part of it I don't want to miss out on. I mean, everybody goes: Oh those are the worst years when my kids went through that. But they don't want to miss out on it either.

Women talked about protecting their children and it gave them a sense of purpose and power they felt their mothers never had. Women spoke of breaking cycles of abuse and powerlessness. It had to change and be different for their daughters. Pipher (1992) emphasizes the critical role mothers play in breaking through abusive cycles and modeling to their daughters that women can protect themselves. There were many examples in this study which revealed the ways women tried to prevent what happened to them from happening to their children. Norma considers when she left her partner because he abused her daughter as one of her proudest moments. She believes part of the reason her daughters are now devoted to her is because she never abandoned or betrayed them. Ann has no children of her own but shares her home with her 16-year-old nephew who is estranged from his mother. She experiences her maternal, protective instincts when she worries about him. He symbolizes vulnerable teenagers and she cares deeply for him. Knowing she is his last hope for support in her family, being there for him inspires her to do the things necessary to stay well.

> I do, I rag on him. And I know he gets tired of it. He says to me: You keep talking about safe sex over and over and over. And I say: You know, because I don't think it sinks in. I've got to make him understand. And if it means taking him over to Our House [AIDS Hospice] to help people that have it, to nurture them, then that's what it going to have to be. It's going to take something drastic to open people's eyes.

The final concern women expressed about motherhood was the most difficult. It involved who would care for their children if they became sick or died. The possibility of dying before one's child was grown forced women to confront issues in their families many preferred to avoid. Even the women who were resigned to their HIV disease actively engaged in thinking about the future care of their children.

Lois exemplifies women determined to stay healthy for their children. If anything should happen to her she has no confidence her family would help. She is resigned that "they'll be going through my stuff before my body is cold." It is her current partner who she feels will be there for [daughter] if necessary. She does worry about the "legal stuff." This is a valid concern.

Unfortunately, families often show up saying they will care for a child after the mother dies, when they were conspicuously absent during the mother's life. Gay men have suffered through the pain of a family showing up at the last minute for their son and then discounting the tireless devotion and caregiving his partner has shown, often for years. This is enraging to health care workers who have shared the months during the dying time with the loving partner. Health care workers' rage extends to distant families that have not provided support to the mothers, and then converge to scoop up the children when their mothers die.

This fear of what will happen to their children if they die seems to permeate these women's lives. It can put an edge on any experience, especially if it is thought it could be the last. It adds bittersweet poignancy to each childhood benchmark that is shared, from the loss of baby teeth, to first dates, to sitting in the bleachers watching baseball games. Mary spoke of longing to be a grandmother even during her final days.

Arranging and negotiating who will care for the child or children consumes women's attention until it is resolved. If it is not resolved it becomes an open wound of emotional pain and uncertainty that literally may have a depressive impact on a woman's health.

For African-American and Hispanic women this is not the same issue it is for white women because they usually live in communities of culture where extended family places a high priority on caring for any child in the family. In Hispanic and Native American communities the pressure may even be on a women to have a child to leave behind as her legacy, so her mother can be a grandmother. This pressure is an even greater possibility with the new AZT treatment protocol that reduces the risk of an infected woman having an infected child to 8%.

All but two of the women in this study are white and the process of arranging for their children's care was not yet complete. Arrangements started years in advance of when they may be needed with the hope that they never will be needed. It is a tentative process of testing someone to be sure they are trustworthy.

Not all women were successful. Sometimes situations turned sour and women discovered the trust cannot be assured and they have to start over. Rose provides the example. She thought she had found someone after her ex-husband's parents rejected their granddaughter. Unfortunately the arrangement deteriorated and she is now anxiously renewing her search for support. The process is extremely difficult for her 12 year old daughter. They are a team. However, the task of searching for a replacement mother is compelling and awful.

Then there are women who have large, local, supportive families. Kim is the example of the positive side of a stereotypical rural community. The good part is that everyone still lives there. Kim is fortunate in that her challenge is balancing four grandparents who all want their grandchildren if anything happens. In the same community, Pam just does not know who will take her children. The difference can be traced to problems between siblings rooted in childhood secrets. She still prays her husband is not HIV positive. Marilyn celebrates that soon her youngest son will graduate from high school. She exemplifies older women who are almost finished with the responsibilities of minor children. Every woman with children struggled with this concern in some ongoing way.

Each women had her unique experience and feelings to add to the emotional understanding of the role of motherhood in living with HIV disease. Yet motherhood is rarely included in the public perceptions of who HIV infected women are. It mainly comes up when women are considered vectors of disease to their unborn children. However, the media and public debate about HIV rarely includes the children who are not infected but who are affected. Their lives are forever changed by the virus as well.

Becoming Part of the Epidemic.

When women had dealt with the relationships closest to them, (friends, family and children) they enlarged their thinking about being an infected person. A question women kept coming back to was how involved in the epidemic they wanted to get. They questioned how much time, energy, and general preoccupation a person should give to living with this disease? A reasonable commitment had to be made to ongoing medical management and clinical care to prevent as many problems as possible, but beyond that women differed in their comfort levels regarding their willingness to get involved in the epidemic. The issue of being involved in the epidemic included both involvement in the science and search for the cure, as well as doing things to help others.

Becoming involved in research was one way women empowered themselves around their physical care and became part of the greater HIV community. Research also stimulated women to integrate the worldwide pandemic and search for the cure with their individual

HIV experiences. And, it was a way to obtain costly medications and tests for free; often before they were publicly available. The plus was that it made their doctors happy. Women also reported feelings of generativity toward others and wanting to make a contribution. Rose is the example of women who felt that way. After finding out she was positive and starting a treatment plan Rose told her doctor she wanted to help.

> And I told her that I would volunteer. I anything needed to be tested for the cure, take me. Because, I told her, Maybe I'll stay alive long enough to help, because they can't take the disease away from me, but at least we can do something so the next people who come along don't have to go through what I'm having to go through. Any kind of test . . . that's what I'd like to do.

More than half of the women in this report have participated in research studies. Several currently serve on the Community Advisory Group of the National Institutes of Health Community Programs for Clinical Research on AIDS Program in Oregon (CPCRA). It is probably important to note that some of these women may have agreed to participate in this study because they have had good experiences in other research efforts. Unfortunately, this has not been true for everyone.

Participation in research has also been a negative experience for some women. The following incident is included in detail because it further highlights a consistent pattern women experienced of impersonal care from providers who did not have ongoing relationships with them and were uninformed about issues of vulnerability and abuse common among women with HIV disease. The situation began when Linda agreed to participate in a complex study which included removing one of her lymph nodes for testing. The removal was to take place at the National Institutes of Health in Washington, D.C. Linda traveled to Washington and then had a terrible experience. It seems the physicians who were conducting the study were so intent on acquiring Linda's lymph node that they forgot about her. She thought she had agreed to have an axillary node removed from under her arm. When she arrived the physician in charge insisted that he had to have a node from her groin. Linda tried to negotiate but he was insistent. This was very difficult for Linda because she was alone, in a strange place, and a strange man was going to be between her legs. Linda was deeply involved in her incest therapy at the time and became extraordinarily anxious about the procedure. When the time came to do the procedure the physician came into the room with four other men and a nurse and spread her legs. Linda became hysterical and began to cry uncontrollably. The doctors fled leaving the nurse to find out what was wrong. Some time later, after a long process of forcibly holding herself together, Linda recovered. She wanted to leave immediately. The nurse convinced her to reconsider and provided her with a sanitary napkin to wear during the removal of the node. Linda recalls she was emotionally and physically exhausted and agreed to the procedure in order to "just get out of there." They took their node, sent her back to her hotel, and she never heard from them regarding the event. She returned home emotionally reduced and disheartened.

After time with her therapist she decided to send them a letter informing them about the prevalence of sexual trauma in the lives of HIV infected women and the importance of sensitivity regarding anything with sexual associations. She sent several published articles documenting her concern. She offered to help them understand. She sent six packets to all the physicians and the nurse involved. She never heard from anyone. It is unfortunate that these HIV researchers may have missed a valuable opportunity to be educated about a very important issue by a well- informed, well-intentioned woman. Instead, they maintained their silence and can only be criticized for their treatment of her. They should also be criticized because they did not tell her she had the legal right to withdraw her consent to participate in the study at any time. Some health care providers, in this instance HIV specialists, appear to be unaware of the vulnerability of their female patients and exhibit destructive insensitivity in their actions.

Unfortunately Linda is not the only woman who reported having negative experiences with physicians because of their desire to conduct research. For some women a negative experience with a physician was enough to influence major life change. Sue is an example of a woman who considers her bad experience in a research study to be part of why she decided to move to another town and find another doctor. The treatment she was given left permanent scars on her inner thigh. In another instance Robbie was put off when her doctor brightened at the thought of her being anti-retroviral naive. He was looking for research subjects for a study that needed naive patients. She declined to participate and worried he was mad at her.

As with almost everything else about living with HIV disease, participating in research meant a full range of things. It meant being included and even honored as community representatives, it brought good feelings of contributing to finding a cure, it helped in accessing hard to get expensive drugs and procedures. And it also meant getting emotionally and physically hurt if researchers did not honor the mandates of informed consent and ethical treatment.

Women living with HIV disease have the same love-hate relationships to their bodies that all women have. They enjoy having their hair cut, smelling fresh, and having someone notice when they look good. They do not much like gaining weight, menopause, or menstrual cramps. Having the HIV along in every experience, both positive and negative became a routine part of life as well as a constant subtle tension that never went away. Life now included the progression of HIV disease, the slow arrival of signs and symptoms that indicated time was passing and the viral load inside was increasing. While other women considered taking vitamins, or hormones, or using expensive skin care products, women with HIV also grappled with anti-retroviral combination therapies and multiple drug regimens for the prophylaxis of opportunistic infections. Routine lab tests included the requisite calcium and lipid levels every woman should watch and had an added immune panel for a CD4 absolute count and CD4 CD8 percentages. Now a couple of extra pages are being added for the viral load report.

Living with HIV meant that every day of feeling well and symptom free was a time to celebrate with friends, family, children and even the doctor. Because when "the weird things start happening to me" women knew that the symptomless days may become few and far between. Nobody knows what symptom or opportunistic infection would come first. Fatigue was awful but it does not compare to the fear of dementia. The goal was to stay as healthy as possible in any way one could and be prepared with one's physician and supporters close by. Women know scientists are searching for a cure and new treatments to stop the HIV, yet they still see people dying and fear for their own deaths.

Preparation for the expected unknown bodily demise took many forms. Ann was adamant that her funeral be paid for and all arranged before she gets sick. Others were not focused quite so far out into their disease process. They want to live as long as possible yet prepare themselves with medical power of attorneys and living wills. They want to assure that their opinions are respected about how they wanted their bodies treated, should the time come when they can no longer be their own advocates.

The experience of life in an HIV infected body includes how one's health care providers treat it. This discussion has already covered the importance of closeness and intimacy for these women. Is there any more physically close relationship that a woman has than the one she has with the people who look in every warm dark orifice she possesses and question the well being of every organ, tissue and part of her body? Hopefully these are the people that care what the HIV is doing. These people possesses knowledge about what causes the HIV to be active or quiet and have access to the tests and medicines that carry hope for managing the virus and living longer. These people also share the secret and hopefully can tolerate the tears and sadness that cannot be treated with drugs. Sometimes the best therapy is "when he gives me a little pat and squeezes my hand."

In understanding the full meaning of the coping pattern of integration, the last part of this analysis will look at the essential and final meanings and concerns women have about life with HIV disease, including their dying. The spiritual meanings HIV has for women involve all the ways women connect with their largest experience.

Meaning of life in the face of having AIDS

> In facing AIDS (or any other terminal disease), one must finally come to terms with issues regarding the *value* as well as the meaning of life. Because there is a vast array of diseases that can inflict untold suffering on the person with AIDS and that make living itself a punishment, it is simply not enough to cling to life at all costs. In fact, with this disease, the prospect of clinging to life may be more oppressive than letting go. However, when the conversation regards the comparative merits of death and life, a larger discussion of soul matters will invariably be present. Questions about God and life, sin and death, reward and redemption are very likely to be raised: 'What is my meaning and purpose in the larger scheme of things?" "What is my ultimate destiny?" "How can a loving God do something like this to me?" and "Am I being punished . . . ?"
>
> Rev. Ted Karpf, 1988

The time came toward the end of each interview with the women in this study when the interpersonal concerns and background meanings of daily life with HIV had been explored. This included pain from the past laid out for perusal and reflection, family secrets shared, and the reality of life with the virus revealed. Women talked about how having HIV caused them to reconfigure how they thought about themselves and about their lives. Women came to recognize their coping patterns individually and generically with other HIV infected women.

Then came the question. So what does it all mean anyway? What is the meaning of life in the face of having HIV? Is there a bigger picture, a moral or spiritual aspect to living with this virus? Does it all come together in any common way? Women's thoughts connected back to many things that had already been said and it is impossible to separate the prior sections of this analysis from any discussion of the overall meaning of HIV in these women's lives. Everything appeared to contribute to the dialogue.

The meaning the experience had for women organized around seven areas of concern where the common coping patterns emerged. These were the areas that most clearly distinguished how women were or were not able to integrate HIV into their lives. They were: (1) the uncertainty of HIV, (2) how HIV makes one look at life, (3) wanting to beat HIV, (4) becoming an AIDS activist, (5) a protective or punishing God, (6) the comfort of spiritual practice, and (7) death seems so close.

The uncertainty of HIV. Once the initial feelings of overwhelm at being infected passed and women told who they needed to, they had to come to terms with having this microorganism inside their body forever. This meant HIV from now on. Women could not run away from the abuse the virus was going to do like they had run away from abuse in the past. Living with the uncertainty of HIV called for a whole new range of emotional skills that women wondered and worried if they had.

The women talked about how disorienting the arrival of the HIV was. One blood test, a phone call, or a clinic visit and everything changed, or so it felt. Yet in the day by day world very little actually changed immediately because these women were in the early stages of the disease. What changed was their emotional experience and what life meant now that HIV was part of it. They would soon have to integrate the physical experience of HIV disease as well. What every woman knew immediately was that it meant death was in some way nearer, and that no one knew how to cure this disease.

Women had different responses to living with the uncertainty. Women who were emotionally fragile had the most difficult time. They either remained feeling overwhelmed and it became their ongoing predominant coping response, or they succumbed to helpless resignation. Everyone went into feelings of overwhelm for a period of time; however, after the initial shock wore off, women went on to other coping patterns, usually based on their personality and support systems. There were women who moved very quickly into integrating the virus and getting whatever information they needed to offset the uncertainty. Women who integrated the HIV sometimes were very matter of fact about how they did it. Linda said, "Everybody's going to die of something sometime. I know what mine is, it's HIV. What I don't know is when sometime is going to catch up with me. That's why each day of feeling good means so much."

Some women felt good about themselves when they were able to avoid being preoccupied with the HIV. One was Chris.

> I don't want to think about it all the time. I know there's people that have been, that probably, they get depressed about it and they're on anti-depressants and stuff like that. And I understand that part. But I don't honestly think about it all the time. I think its just my personality.

Ultimately it is the uncertainty, the waiting for HIV to change and progress that is hard on women. When little things indicate that the virus is growing, some women lose their patience. Robbie provides the example of women who had a hard time managing the uncertainty.

> Right now, I'm not in one of my spiritual places. Right now I'm in one of these places like, it really sucks. I've been in that place the last few days where I wish I'd just die and get it over with. Because of the fear and the anticipation, and the not knowing from day to day what's going to happen, and the fatigue, and all that stuff just sometimes wears me down. And I just think: Screw it. I wish I'd just get sick and die and it would be over with. . . . But then at other times I am like really grateful for the lessons that I've learned with it. You know, the lessons of love, patience, friendship. And I wish that I could say that I could always stay in that place. But I don't.

Robbie was teetering on the end of the asymptomatic stage of her illness. She was fearful because she knows her CD4 count was under 100 when she first tested positive for the virus. She wanted to be well for her wedding and she was afraid her growing fatigue and mental confusion meant the disease was progressing and she would not have her happy time. She treasured the intimacy and closeness in her relationship and feeling bad meant HIV may be growing and threatens to ruin everything. It was a race against time. She hates the pressure of feeling forced to take AZT before she is ready, but worries it may already be too late. The medicine means feeling bad but maybe living a little longer. She hates thinking about it all the time. Especially since the thinking and worrying does not lead to any answers.

The end of the asymptomatic stage in the progression of HIV disease is a critical emotional benchmark for women. Everything begins to change more rapidly and the illness increasingly dominates life. Women felt angry and helpless when it started to happen. They had seen it occur in other peoples lives and feared what was coming. This was a time of recycling waves of feeling overwhelmed as T-cell counts dropped, opportunistic infections were diagnosed, and it became impossible to avoid having everyone know. Women who reached coping patterns of integration before they become symptomatic had more success in not becoming resigned and remaining engaged and active in their lives.

More than half of the women in this study are approaching the predicted end of their asymptomatic time of 8 to 10 years of infection. The meaning of symptoms and the unpredictable nature of the disease becomes more personally ominous as future plans and pending activities are immanently affected by unresolving physical signs that the disease is progressing. There were many examples of women doing things sooner rather than later because they did not know what might prevent them from doing something in the future. For example, Sandy and her husband went to Hawaii and Marilyn is planning a trip abroad.

Not only pleasurable activities were the focus of women's attention. Linda and Rose were actively arranging for the care of their children and Pam was worrying about it. The emotional task was to keep ones perspective and not become intimidated by the virus. It was more difficult for some women than it was for others. Staying involved and ahead of the virus takes a lot of energy. Sometimes the respite of resignation seemed appealing.

Within this group of women there was also hopefulness and acceptance in the face of the uncertainty. Women wanted quality in their lives. One of the issues in having HIV in ones life is the notion of enjoying whatever life is left. Even women who ranted and raged against the uncontrollable virus spoke of wanting and needing to enjoy their lives. Pam reflected on how she would respond when asked what life with HIV was like.

> Oh, some people might think I'm crazy, but, nobody knows when their number is up. But you know your number is coming.
>
> And I just feel like, I want people to know that life is still worth living. And enjoy it. Whether it's 6 months or 6 years, or 6 decades. . . . It's still going to have its disappointments. And it's still going to be, have its hurts. But it doesn't mean that it isn't worth it.

Pam is an example of women who make every day count in their lives. Having HIV may mean there will not be as many days, but these women intend to enjoy every one. She recently took on two toddlers as a foster parent and her friends (and physician) thought she had lost her mind. She had no problem with it. She loves being a mother, she defines herself as a mother, and these two needed an immediate home and a loving woman to care for them. Pam has created quality in her life. She uses patterns of integration when she feels she can, avoids HIV totally within her family, and deliberately goes out and gets what she knows makes her happy.

This is clearly not true of all the women living with HIV in this study. The defeats and disappointments from the past limited and constrained other women's abilities to even discover what made them happy or believe they deserved to be happy. Becoming infected with the HIV simply confirmed in their minds that they were probably never intended to be happy women.

As long as women such as Pam remain asymptomatic their aggressive focus on creating quality in their lives will work. After that, some of their energy will need to be redirected away from their children and toward their disease. It must be emphasized however, that people living with HIV disease can create quality throughout the entire progression of the disease, it just becomes more difficult. Chris captured this idea when she said:

> You just sort of have to live life. Because you don't know what's going to happen. It could be, like my friend's leukemia. She was my age and she's gone. And I've got this virus and I could be here another 10 years. I got to see her grandbaby and she didn't. So I don't feel sorry for myself.

When women reach this place of accepting the uncertainty of HIV infection into their daily lives, they no longer feel battered and off balance by the experience. Rose adds, "I am not dying with AIDS. I am living with AIDS."

How HIV makes one look at life. When women integrated that the virus and the uncertainty were permanent, they also discovered that they were not dead yet. They could resume their lives, however, with a new perspective. And the new perspective included, as Jako called it, a passenger.

> I was feeling better, definitely. I was getting strong again. And I was realizing I was the same person, just with something inside me.

Ann is an example of the women who anthropomorphized the virus. It allowed them to look at their life a little differently, in a way that let them include the virus, however ironically.

> [Having HIV] means I have to learn how to live a different way and accept this as part of me. Like a lifelong partner. Someone that's going to be with me until the day I leap up out of here. But see, I don't think I'm going to go up out of here. Because if I go up out of here, so does the HIV. And he wants to live more. Doesn't want to die. I look at it from that point of view. I'm keeping it alive while it's keeping me alive. Sort of like a partnership with one another.
>
> *Why do you call it the gift?*
>
> It was a gift. Maybe not one we wanted, but it was given to us. We're blessed, we have the gift. So everybody now that I know, even Lois, she calls it the gift. Because there's a lot of people that don't know she has it. She was run out of town for it. So when we talk, we say the gift, and people just look at us. They don't know what we're talking about.

Women could not control being given the HIV, but they could control how they chose to think about it. Anthropomorphizing the virus helped Ann keep a sense of humor about what the virus was really doing to her. The reality of one's biological vulnerability in the path of this mutable virus is that after over fifteen years of scientific research we have no vaccine or cure yet. The pandemic is not under control. The HIV has no opinion whether it lives or dies. It exists to replicate, overwhelm, and reinfect. Calling it the opposite of what the public perception of HIV is, a blessing as opposed to a curse, feels empowering in some way to these women. They can look at their lives in a playful way. They have their ironic secret word and can openly talk about "the gift" in public and share their shadow lives with each other. It provides a way to ban together and hold the virus at bay. Like other disabled people, those living with HIV may joke with each other about their situation in ways that would be disrespectful coming from an able bodied or healthy person. Only an HIV infected person could look at their life and call having HIV a blessing. Ironic language takes the focus away from what HIV means to most people, and that is death. It provides a way to be resigned to being infected and yet not be debilitated or withdrawn.

When women had a chance to step back and look at their lives, they mainly rejected that HIV means death. This didn't happen immediately, it came with time. For example, when asked what she would say to a newly infected woman Lois went straight to this notion.

> *What would you tell her?*
>
> Not to take it as a death sentence. There's so much new research and so much everything. And if you convince yourself that it's a death sentence, I believe you can actually cause yourself to become ill. That's what I think. It's not a death sentence.

Women rejected that HIV equals death at this stage in their disease because it did not mean that currently. Yet everyone knew how unexpectedly currently could change in life with HIV. And when things changed women looked at their lives in ways healthy people rarely have to do.

When women looked more closely at their lives because of HIV infection, some were critical of themselves. For example, Sharol wondered how she cared so little about herself that she let it happen. Her feelings are an example of the other end of the continuum and of how some women were resigned to the idea that they deserved to be infected.

> It's not that I didn't know about it being out there. It's not like I used protection. I slept around a lot. It's like I must not have cared. I mean, yeah, I don't want this disease. I don't think I intentionally went out to get this disease. But I did everything I did. I don't know how to explain it. Nobody deserves it. But if anybody does, I guess it was me.

The issue of whether a woman thinks she deserved to be infected came up as they looked back at their lives after becoming infected. Women included it here as part of thinking they just weren't good enough to have been spared. Having HIV meant something must have been wrong with them.

Chris reveals how women tried to make sense of why they got involved with the men who infected them. She shows how women blamed themselves and thought they deserved it because they were needy, dumb, and vulnerable.

> I've had a hard time dealing with it, I felt really stupid because I felt like I shouldn't have gotten it because I was supposed to be smarter than that. But I was probably in a different frame of mind because I was newly divorced, pretty vulnerable, and I don't think that many people, probably men, would find me attractive.
>
> I never had this feeling of like, if somebody had something, a disease or something, I never have ever turned them away or been judgmental about that. So it was like, I got sucked in.

Chris was resigned to thinking that if she had been smarter it could have been different. Leah enlarged the understanding. Hers was an instance of how abused women's self-esteem may be so damaged that they connect the reason they deserved to be infected to other painful experiences. For Leah , her accidental infection was connected to the pain of her mother's abuse during her childhood.

> Well there must be a reason. I mean, I don't necessarily believe in coincidences. I think that everything happens for a reason and that I just don't know what it is.

> I kind of have a gut feeling that, you know . . . I said that when we were growing up my mother made me feel, you know, about two inches tall. And I kind of feel like maybe I do need to be punished for something.
>
> *But what have you done, you're innocent*
>
> Well I don't know. But there must be something.

Feeling unworthy contributed to these women's ongoing struggles against giving up and giving in to feelings of isolation and resignation. Their patterns of coping with the issues that come up in life with HIV infection were influenced by their low self-esteem and feelings of self-doubt. They each lived carefully crafted shadow lives in public. Their shadow lives were a way to escape the blame and judgment from others that they felt toward themselves. The self-reflection that having HIV brought to these women has not been a positive experience. The isolation they are creating during their asymptomatic period will not serve them well as their disease progresses and they need help.

Women's self-doubt and criticism can affect their physical care. It is difficult to motivate any woman to do all that is required to successfully live with HIV and prevent lurking opportunistic infections. If women feel they aren't worth protecting, such motivation becomes even more difficult.

There was also another possible outcome for women who suffered from diminished self-esteem originating in childhood. These were the women who refused to accept feeling unworthy and had struggled to get themselves into counseling and learned to advocate for themselves. In the stories of their abusive lives something happened to stop the negativity from continuing. It was usually therapy. Then when the HIV arrived these women were challenged and questioned the progress they had made. They became fatalistic about ever having their misfortune end.

Some women have had to empower themselves over and over in their lives. HIV was only their latest challenge. Their empowerment came through lives of constant struggle. Kim thought her life was over when her abusive young husband committed suicide and she discovered he had another life, including huge credit card debt.

> So after he committed suicide . . . I needed some counseling. I needed some help. I had a lot of issues to face. Being widowed with two kids. Not sure of who I was because I was beat down so bad. You know, no self-esteem. Didn't know where I was going, what I was going to do.

Kim had survived a broken family and life with an alcoholic father. She felt her teachers in high school had betrayed her and prevented her graduation. Her marriage became a painful illusion ending in suicide. Her daughter has a chronic, potentially fatal genetic disorder. And when she found out she needed to be tested for HIV she became fatalistic. She looked at her life and all she saw was struggle.

> [Doctor] was in the room when I went in there and [partner] was hysterical. He goes: Well, you probably need to be tested. He goes, I'll tell you what. There's a 60% chance that you possibly don't have it. And I thought, after 5½ years, yeah, right.
>
> You know, I thought to myself: With my luck and what I've been through in my life, I got to have it . . . Well, of course, the next day the test came back positive. Just like I thought it would.

She responded with action and not resignation. Her energy to become informed and active in the management of her illness is also connected to being a mother. She is just one of the many women in this study who looked at their lives and wondered if it was worth going on. And then they remembered their children. The children are their legacy. As they look at their lives, the best thing they see that will endure, after they are gone, is their children.

The process of looking at one's life through the lens of HIV infection continues for women throughout the course of their illness. If women survive the self-scrutiny and are able to construct lives with the HIV that are in some manner acceptable, they usually decide to fight back. They know the disease is filled with uncertainty. They realize that what they have discovered about living with HIV may be important or of value to other people. Often the primary motivator is once again, the children and their future. If nothing else, they don't want others to have to go through what they have gone through.

Wanting to beat HIV. Women who have coping patterns that allow them to integrate the virus into their lives want to survive HIV and be here for the cure. Part of what differentiates them is their energy and motivation to do everything required to potentially assure that. Their energy to fight the HIV and engage actively in their care and in the epidemic is also a function of where they are in the progression of their disease. As women's disease became more advanced, they also became resigned to the fact that they may not be here for the cure, but they could hope. Mary provided a graphic illustration of how women can still want to conquer HIV, even during their final days. Her image was of scraping at the inside of the container of HIV that traps her. She was asked what she would say to someone who asked, "What does it mean to have HIV?"

> You feel like you are in a bottle and the neck of the bottle is so tight you can't get out of it. And that no matter what you do, it's still going to be there. But I'll keep scraping and praying and hoping that one of theses days in the near future there's going to be something out there that will open that bottle up and see me bloom again.

Unfortunately, she did not live to see that time.

Other women who are not as advanced in their disease plan to beat it. They refuse to accept that it is going to kill them and they physically and psychologically do everything they can to stay ahead and on top of it.

For women who do not plan to give in to death from AIDS their will to live extends into every part of their lives and includes an awareness that their drive to survive is linked to the brutality they endured in their childhood. Sue talked about this.

> I do beat this disease. Like, I've continued to win for 9 years . . . I'm just trying to stay alive. I mean, I just don't care [about what people think]. And I'm telling you when I write my book, called convicted upon conception, you'll know why. It's not just for people with HIV, but also for abused children. That's where my interest lies.
>
> *Do you think there's a connection between abuse and HIV?*
>
> Totally.
>
> *What do you think it is?*
>
> Well, I think when you're conceived that if you're conceived in a bad environment, such as a rape, or a force, that it has an impact on the fetus. And then when you are exposed to a very verbally and physically abusive father and stepfather, that has an impact. And you grow up trying to just stay alive.
>
> *So you think that had something to do with the choices you made?*
>
> I think it had to do with survival.

She joined the ranks of women who married as teenagers to get out of their fathers' houses and then became involved with abusive men. One of them infected her.

Sue personified an integrated coping pattern to living with HIV disease. She used Chinese herbs, has participated in research studies, reads and uses everything she can access to combat her HIV disease. And she does this from a rural community.

> Like, I started taking Acyclovir a year before anybody knew it was worth a shit as an AIDS drug. And I don't take it every day. Every other day, but lately I've been taking, I've been taking too much shit, too many drugs. Because I try so hard to live. But I'm afraid if I lay down my swords, it'll [the HIV] think I'm willing to get outta here.
>
> What I need to do is differentiate between living and surviving. The reason I have a problem with it is because of child abuse.
>
> *You think that's connected?*
>
> Oh, hell yeah. I know in my heart.

She speaks for women who have taken all the abuse they're willing to tolerate in this life and have convinced themselves that they can beat the HIV.

> People die every day of diabetes and heart disease, normal deaths. I'm telling you, I'm not going to die of AIDS. . . . It has been a very long time. . . . I'm convinced that there's a cure just around the corner. I'm trying my best, to keep my faith and not get sidetracked.

Becoming an AIDS advocate. A final area in the discussion of integrating HIV in women's lives involves generativity and advocacy. People with HIV want to defeat the virus and they want to be involved in the political decisions about how the epidemic is managed. The AIDS epidemic has permanently changed the role patients with life threatening illnesses play in creating the socially and medically constructed meanings of their care. They have set a new standard for being involved that cancer patients and others now emulate. People living with AIDS have picketed the NIH, testified at congressional hearings, learned the intricacies of pharmaceutical drug trial regulations, and have become leaders in disseminating the knowledge base of HIV/AIDS to people living with the disease. AIDS advocacy is a cause celebre. Women whose lived experience of HIV was fully integrated felt the need to speak out about HIV, especially to young people. Mothers' needs to protect their children from what harmed them has already been discussed. The advocacy discussed here is larger, it involves defeating the virus and protecting everyone's kids. It also includes replacing judgment with understanding, and contributing something to society at large.

Throughout this study the activities of women on behalf of other people has been mentioned. There are many examples of how these women combat the virus through giving of their time and energy. Telephone support is a well recognized tool in the epidemic and Kim is a woman who volunteers on a rural hotline. She stays home close to her kitchen phone several times a week just in case another HIV infected person needs to talk to someone. Pam is one of the women who talks to college students. Other women served on advisory boards and attended community HIV Ryan White funding meetings. Women participated more or less depending on how empowered they felt at any given time. And this was always dependent on how they were responding to what was happening in their personal illness experience.

Then there are the women who have made battling the fear and ignorance in the epidemic an avocation, such as Linda and Jako. They stand out in the group because of their ongoing, indefatigable work as AIDS advocates and spokespersons in their communities. Linda exemplifies woman who will educate anyone who will listen and has spoken to business groups, school children, churches and nurses. Other women are more focused in their interest. Jako's advocacy is directed at young people. This is extremely meaningful for her and her words probably mean a lot to isolated infected teens. She described her efforts.

> As young people we are dealing with the same issues that someone, anyone with a life-threatening disease, or a life threatening anything experiences. You know, cancer or . . .
>
> *But is it different?*
>
> It is because there's a sense of: I could have done something different. Or a sense of: If only I used that condom. Or: if only I hadn't shot up with that needle. There's the if only and there's the ostracism that a lot of times results from this disease. If you go out and tell the whole world you have cancer, it's perfectly acceptable because you didn't do anything wrong to get cancer. But if you go out and tell all of your peers that you're HIV positive, there's no avoiding those few people who look at you as dirty and look at you as someone who deserved this because of something wrong. Having it means something you did that was wrong. And we're seeing a commonality of experiences . . . every single youth we've talked to has felt alone. Every single youth we've talked to has felt dirty and horrible at first. And we just want to show them, especially those people testing positive the first time, that we're out there, and that there's a lot of us that are really being strong. We're coping with this and loving with this.
>
> *When you talk with young people, what do you think it means to them to have gotten this illness? Does it mean anything specific?*
>
> There are certain youth who feel like they have been chosen by God to be infected, and that it has happened to them for a reason and because of that they are going to take it and do the best with it they possibly can. There are other people that feel like

> they slept with so many people that they deserve it. There are other people who struggle with a reason. They want one. And there are other youth, I think like me, that don't really look for a reason. Maybe look at some of the causes. I'm just talking about myself right now. I don't think that as a young person I've ever felt like this was something that I was chosen for or fated to have. I think it was just chance, whatever you want to call it. I ended up infected and there's no reason for that. Oh, there's definitely the what ifs, but there's no going back and I need to do the best with what I have, the best I can.

In an understated, matter-of-fact way Jako reveals the isolation and emotional pain of teenagers living with HIV. Grave concern exists among epidemiologist and HIV social services providers about a trend in incidence rates which shows rapid growth of the HIV among young people, both homosexual and heterosexual (CDC, 1995). The knowledge needed to protect oneself is available, what is missing is the motivation and skill to manage one's behavior and exposure to the virus. Jako is doing her part to help.

> I definitely believe that our doings affect others in such an exponential way. . . . I consider myself valuable. I figure the most important thing for me to have done while I'm alive and in my community is to have helped that community and to have helped my fellow human beings. And I think I've already done that. And that's really important to me, that I know that, I feel happy with my life.

Being an advocate provides women with a sense of well being and purpose. Other women aspired to become advocates. They instinctively knew it would be important and beneficial for them. Cathy talked about this.

> That's what I need to get over [breaking into tears every time she talks about the HIV]. I started taking Prozac, so when that kicks in . . . I will get to the point where this doesn't break me down. Because I would like to go out and talk to groups of young people and stuff. I love public speaking and I would love to get to the point where I could go talk to young people about this and how serious it really is. And how it can happen to somebody like me who's just a normal wife and mother. And has a nice normal life. Nice house and nice job. Nice things. And I'm not some derelict living on the street and I'm not a drug addict and I'm not a hooker and I'm not, you know. I didn't do anything wrong, I'm just a regular person. All messed up.
>
> *That may be an important message for young people to get.*

> Well that's why I wish I could talk to a group of people about this without getting all choked up. I'd go on a talk show and blab to the whole nation if I had the guts. I can't talk about it without crying, so if I'm going to talk about it, you have to put up with me crying because that's just the way it has to be. I just can't seem to get through it without the tears.
>
> But I wish I could get to the point where I could quit choking up and go back to where I could get in public and tell people about this because I think young people are still not taking it seriously. And it's not a joke and it's not very damn funny when it happens to you. I just can't even express how horrifying that feeling is when they tell you. It's just, somebody just drops a big ton of bricks right on top of your head and you can't get up for several weeks. You can't even move.

Many HIV infected women had similar passion in their words and made powerful impressions on anyone they were able to speak to. Cathy's message is especially pertinent to young women contemplating pregnancy because her baby is positive and her husband may be as well. Being able to do public speaking is a hope for the future for women such as Cathy. It means they may be able to use their misfortune to help protect someone else.

Another thing that happened was that the experience of having HIV provided an impetus for women to do things they had never done before. For instance, Sandy overcame her long standing fear of public speaking and being an advocate is now part of her new self.

> I've become a more daring person. I don't know if I would have done some of the things I've done if I wasn't HIV positive. Like the scuba diving. I don't think I would have had the guts to do that. Or jump off the 25 foot cliff like I jumped off a couple of months ago. And I went white water rafting. And I think public speaking. Wow, that's a huge thing. Because when I was in high school I would take an F as opposed to getting up in front of a class. I was scared to death of getting up in front of the class. And now I will get up. It's still scary, but not what it was before. And I share my HIV and what's happened. That's been a big plus for me. So I think I have been more daring. Maybe it has to do with thinking maybe life is short and I got to get these things in now. Or I could say I accomplished this. I feel like I better do it because who knows if I'll be here tomorrow.

The desire to speak out to protect others was prevalent among women who had been through all the coping patterns many times and had essentially integrated HIV into their daily lives most of the time. This allowed them to extend their concern beyond themselves. One of the primary concerns women had was for the female partners of men they know were infected. It may come from a wish that someone had protected and warned them. Kim was one of these women and worried about other women that her partner slept with before their relationship. He resists telling them and it bothers Kim.

> I think it's only proper and fair to inform other people. Because I think if you got it from someone who knew they had it . . . they didn't notify us so that [partner] could have been on treatment. He might not have even gotten sick from this last thing. It's only fair, only the human thing to do. But I can't make him do it. Tell those people, it's out of my hands. But boy I sure do nag about it. It doesn't do me any good though. It's nothing but a waste of breath.
>
> If there's other women out there that . . . he had a relationship with a woman for 9 months that I know of, at least notify her. Because he doesn't want to call them because it would be too hard. And I said: Honey, you don't have to call them. You just have to write down their names, their phone number, their address, or their parents address. I said: The state will do the rest for us. I said: They won't tell them [partner] infected them. They don't do that. They're trying to curb this.
>
> *Why do you suppose men don't want to tell the women they sleep with?*
>
> I think they're embarrassed. They feel dirty. They're sad. They're ashamed. I know if I had this and slept with other people and possibly gave it to somebody else, I'd feel guilty. I know [partner] did.
>
> *For giving it to you?*
>
> Yeah.

Women also worried about other single woman in the dating scene. For Pam it was her sisters.

> There's still risky behaviors that everyone will have. I just see that going on these days and it's like . . . I just want to say: Hey you're ruining your life, with, you know, not being educated about your choices. Because if I had even thought, I don't know, it would have been different. I really can't say. You always think it's not going to happen to me. But, I have sisters who are back in the dating scene. And I think, look at this, this is part of your family. This happened to your sister, It can happen to you.

She speaks to college students at a nearby state university and worries about them as well.

> I go and talk to the class and tell my story and stuff like that. It's kind of a therapy and kind of to me, my way of saying, you know, I look normal and, I've got this disease. And you can't tell by looking who does and who doesn't. And I was talking there and after class this woman came up to me and was telling me about how she was a Christian too, and she was sexually abused and she, just doesn't know how to deal with it. . . . Her family doesn't know, and all this kind of stuff. And it was, I felt . . . definitely felt like I might have been in over my head. . . . I'm not a counselor, I don't know how to tell her what to do or things like that. But I just told her about my experiences of going to counseling and the healing process and stuff that goes on there . . . people come up to me privately after class. . . . Sometimes its just about HIV and a lot of times it includes the abuse.

Once again the connection between HIV and abuse is made. The connection is there because any non-consensual sexual act potentially includes HIV. This is true even in the way that childhood sexual abuse sets the stage for unhealthy sexuality later. Pam's story of her advocacy also highlights that as these women reveal their stories publicly, they fight not just HIV but the socially constructed shadow life of denial everyone shares around sexual abuse.

Spiritual Concerns and Practices

A protective or punishing God. In any discussion that involves an illness experience that includes an incurable, inevitable, fatal outcome, people's beliefs about God emerge. This is especially true in the HIV/AIDS epidemic, because those who are predominantly affected are young people who would otherwise have long lives ahead of them. The HIV disease experience is about premature death and the struggle to survive. The language of the epidemic includes "people being cut down in the prime of their lives."

It is interesting to note that a difference can be seen between how women articulated their direct personal opinions about God and how they described their spiritual practices. Generally speaking, they were mad at God and grateful to have spiritual practices that nourished and comforted them. Women often wanted to avoid God, or were resigned to being punished by God while still integrating HIV into their spiritual practices. Spiritual practice supported their living even if they were unsure about where God would be for them when they died. Women had one of two basic feelings about God. They were either confused and angry or comforted and inspired. Their individual experiences usually determined which common meaning they held.

Cathy speaks for other women when she summed up the essentially negative feelings many women have toward God when she spoke of her infected child. "It was just like God really dumped on me. And I still just wonder why." Even for the women who were active Christians and involved in their churches, the anger was there. Mary was one of these women. She was buried in a church with standing room only. The choir she sang in was there. She described herself as a good Christian and getting HIV just didn't fit.

> What did I do? We both did, both of us, we blamed God. Why are you punishing us? What did we do for you to do this to us? I know that there are things in the Bible that if you get an illness you maybe are being called to be a teacher for somebody else. Find someone else . . .

Other women who believed God was just and fair and got mad at God when they found out they were positive. They felt betrayed. Norma was one of these women.

> I felt like I was going to die next week. I thought, what about my kids? I've got my grandchildren to enjoy. I'd planned on this long life. Great-great-grandchildren. And I felt like everything I had been working for was ripped away. And I got angry at God. Why did you put me on this earth to suffer through the childhood that I suffered through. . . . Why am I being punished? Why me? What have I done my whole entire life other than taking care of everybody. . . . I tried to make everybody's world happy but my own. I could care less about myself. I was always taking care of everybody else. So why should I suffer?

Women who were not mad at God usually considered the arrival of God in their lives as being a positive turning point for them. This was true for women who had been through recovery in the Alcoholics Anonymous (AA) model. Bobby provides the example of women who found God in therapy groups. She was in prison and it happened soon after she tested positive for the HIV. She's is now a believer and God has been part of each step she's taken in her recovery, including her pregnancy.

> I wanted to live. I finally saw that I had not been living. I had been killing myself. That's what I had been doing. And when I did find out that I was HIV positive I realized that I needed to change something here. I wanted to have a life. So that's, I think that's what helped me in my recovery. Something changed. I don't know what it is. God came into my life.

Bobby met her husband at an AA support group, he was also HIV positive. They fell in love and after her release, lived together, married and she got pregnant.

> It was devastating because I didn't know if I should keep the baby because both of us were HIV positive. And it was real scary. Because he could have been born HIV positive. And we would have to take that risk. We didn't know if we were willing to take that risk. To take care of a baby that was going to die. And we both agreed that we would. That we were strong enough together. . . . And that God would take care of us and God would take care of the baby.

The child has been tested for HIV antibodies repeatedly, and at 24 months remains negative.

> [Son] means the most to me right now, and my recovery. God is in my life. And I pray. And [son] asks who's God? Where's God? So I'm trying to teach [son] those values.

The issue of whether God is punishing or protective appeared to involve how long God has been in their lives and whose side women felt God was on.

For other women, their conception of a supreme presence in their lives was not a Christian male God. Women talked of other beliefs that supported them spiritually. Linda is the example of women who rejected their religious upbringing and embraced other forms of divinity. She called her spiritual support her higher power, which was female. The walls in her bedroom are covered with positive images of women and sayings of empowerment and spiritual encouragement. Her bathroom mirror tells her daughter how much higher power loves her.

> Higher power is with me all the time. She directs my life. I believe the reason I have this virus is because I can handle it. Higher power helps me all the time. I must have the protection of a higher power to have survived my life. All the abuse, the drugs and men, getting sober, losing two husbands, and I just keep going and I'm not suicidal. I certainly couldn't have done it by myself.
>
> It does make me angry when I hear people talk about "embracing their illness." All I see is the terror in my daughters eyes every time she thinks I'm getting sick. I don't embrace that. The only time I ever embarrassed myself publicly was when I was on a panel and some lady was embracing her illness and being thankful for it and I leaned over and stuck my finger down my throat in front of everybody. I was sorry I did that because it was rude, but I really meant it. Higher power loves us and helps us but I'm sure she doesn't like that we have this wretched disease.

Whatever form God took for women, there were strong feelings about how a spiritual presence felt in women's lives. For women who were angry at God, the descent into the terminal stage of their illness carries more fear than it did for women who believe there is comfort for them beyond death.

<u>The comfort of spiritual practice</u>. The women shared the many ways that they spiritually nourished and comforted themselves. No one mentioned anything negative about spiritual practice. Not everyone actively does spiritual things; however, the majority of the women did and appeared to derive significant positive value from their efforts. The patterns of women's coping did not appear to matter when spiritual practices were involved. Women who are resigned to their illness were as involved as women who had integrated their experience. Perhaps this was due in part to the very private experience of spiritual practice. Concomitantly, women also talked about being in groups as a part of their spiritual practice. When women talked about spiritual practice they didn't necessarily talk about god.

Meditation consistently came up as something women used to help themselves. They liked it because it was free and could happen anywhere. There also is support for meditation in the popular press as a recognized stress reduction technique. Women could enjoy its benefits even when they didn't want a lot of religious overtones. Sue is an example of women who practiced meditation regularly as part of how they planned to beat HIV. Other women read and reflected on inspirational AA, new age, and feminist spiritual literature.

Thinking positively and saying affirmations was a way to provide positive input and feel integrated and whole. The power of positive thinking and having a good attitude have long been associated in the epidemic with long-term survivors or slow disease progressors. Cathy is a woman who exemplifies this and credits the rise in her CD4 count to her dedication to saying her affirmations every day.

> I say my affirmations 30 times every day. Thirty times every day I say: I am strong and immune. My T-cell count goes up every day. My hair grows strong and funny from a healthy, relaxed scalp. And I say that crap 30 times a day, whether I feel stupid doing it or not, every single day, and its working.
>
> *So you believe there's a spiritual side to helping yourself?*
>
> Yeah. What's why I wish emotionally I could get myself on an even keel. Because I firmly believe that your body hears what you're saying and if you're negative, you're going to have a negative response, and if you believe you're getting better, you're going to get better. I've always believed that. Because I used to be a body builder. And I was very serious about my body and listening to it and getting in tune with it and doing right by myself. I wish I had never let that go. But at least now I haven't smoked for 3 years and I will eventually get my body back to the way it ought to be, but I really don't want to let something as stupid as a little virus come up and kick me in the butt. That's what bothers me the most about all this, is I feel helpless.

Saying she is healing and remembering when her body was strong and powerful gave Cathy hope and made her feel involved in getting better. Having a relationship with one's body, talking to it and making deals with it came up for all of the women. It is an area of real challenge for women because they also talked about their personal histories of abandoning their bodies to abuse, and how hard it has been to reclaim feeling good about anything physical. This mind body relationship is the basis of the science of psychoneuroimmunology which gives credibility to women's beliefs about thoughts influencing health. Even women who would previously never consider their thoughts as affecting their bodies talked about changing their minds. Ann was one of the women that changed her mind. She had heard that HIV means death. Then she learned about having a positive attitude.

> The things I heard about it, was that I was going to die tomorrow. But that's because I didn't know anything. I didn't know that my having a positive outlook and thinking positive, how that goes into my life, and that my body will do it for me . . . get better

Women reflected on how they had treated their bodies in the past and wanted to do things differently now that they were infected. They specifically began to set limits on others regarding the treatment of their bodies that they never learned to set as children. Ann vowed that there would never be another relationship with anyone who did not respect and value her body. She had a new relationship and commitment to her infected body that she never made to her body before HIV. Now she believes it really makes a difference.

Women wanted to feel good about their bodies and in most cases, they were doing it alone with the help of their spiritual practices. The negative social messages about bodies infected with HIV were not acceptable to these women. Women with spiritual beliefs spoke of how it helped them maintain feelings of appreciation and love for their bodies. The words are positive and they possibly do make a difference.

The final area of spiritual practice which emerged from this group of women was spiritual practice from non-Christian organized traditions. This is especially important for women who have had negative experiences with organized religion, particularly more conservative Christian churches that are extremely judgmental about HIV infected people. Fortunately women have many religious traditions to choose from in Oregon. There were several examples in this study.

Leah may be estranged from her family and prefer not to socialize, but she found companionship and security among a group of people practicing the Bahai faith. She attends their meetings and is slowly revealing her HIV status to selected people. She was happy to have their non-judgmental response. She was even told of another member of their community who they cared for during his AIDS death. She mentioned it several times in the interview. She expects that if there is to be any support for her at all, it will probably come from these people. She is very tentative in her expectation.

Another example is Rose who embraces a Buddhist faith. She wears her teacher's picture on a necklace and displays her picture prominently in her home. The meditations she attends were her only non-HIV related social outlet and she never missed, despite a long drive. When she told her teacher about her HIV, the teacher's acceptance was not immediate; however, after consultation with higher authorities in the faith, she is permitted to continue her participation. She misses working in the kitchen and helping prepare meals for the poor, but she understands their fears and is grateful to not be shunned. She has not experienced the warmth that Leah has in her Bahai group.

Both of these women, had a need for belonging to an organized faith. They choose the ritual and structure of a faith with a history and traditions. They are fortunate to have also found a place to have social contact and feel part of a community because both of these women are in avoidance and prefer to remain extremely private in the rest of their lives. They point up the diversity and variety in the ways women find to provide for themselves spiritually.

Death seems so close. The final area to be considered is death. It is always difficult to talk about even as it stands on the edges of talking about anything else concerning this disease. Women who have had near death or potentially fatal experiences are relatively resigned to death. It is not being dead that women feared, it is what it will be like to die that is hard to think about.

In this study women had been close to death from HIV in many ways. Three women cared for the men who infected them and saw first hand what death from HIV looked like. When it was all over, Chris said, "It was almost a relief." People who have not been involved in a death from AIDS may not realize how challenging it can be to manage multiple complex opportunistic infections at once, and ultimately fail, only to watch them overwhelm and kill someone. Other women participated in decisions to turn off life support systems in intensive care units. One woman stuck by her man despite the disapproval of her daughters and another cursed the doctors and nurses that made her husband’s death seem like a hospital nightmare. Sometimes it just is.

It is very difficult when women lose loved ones to AIDS, but it is devastating when the women lose each other. Mary died in the same room her husband died in less than a year before. The same nursing team turned off her life support while her friends and children waited outside. The children of other women in this study knew this was happening. Her death had an effect on everyone in this study. Women struggled with saying goodbye because for them it was like looking in the mirror. Sandy says she has quit the funeral scene; "it’s just too hard to see friends die."

Nobody wants to die. Feelings and patterns of coping around dying vary like everything else in the lived experience of HIV. And like other concerns, it ultimately came back to the reality of still being alive and dealing with the details of day by day life.

Interestingly, it was in making preparations for their funerals that women talked about dying with some sense of control. Ann provides a final example.

> The only thing I worry about, well I can't say I'm really worried about it, but it's crossed my mind, is when I depart this earth. My burial. I don't want to be buried. My cremation. You know, I want to maybe talk to Friends of People with AIDS.
>
> *Make some arrangements?*
>
> See if I can start paying maybe $20 every month or something where I'll have the cremation covered, and my little box that they're going to put me in, or whatever. Because I don't want to, I don't know, I don't want my family to do it.
>
> *You want to take care of it?*
>
> But then I know I'm not going anywhere anytime soon. I was reading in one of these newsletters, this guy said he was waiting for 8 years to die. Shit, he says, he's tired of waiting, he wants to live. It's changed my life having this. I've always been a sensitive person anyway. But I think I'm more sensitive than I was before.

Living with the virus spiritually involved many things such as the uncertainty of HIV, how HIV makes one look at life, wanting to beat HIV and becoming an advocate. It includes deciding whether God is protective or punishing, the comfort of spiritual practice, and ultimately dealing with dying. The concern of having death so close is one of searching for reasons behind HIV infection and wondering whose side God was on. God and living and motherhood became one conversation for women. Whatever form God took, the relationship included the women's children and allowing women to live as long as possible to be with them. Women had a full range of spiritual practices from affirmations and meditations to formal Christianity and eastern religions. The form varied but the feelings expressed were essentially positive, empowering, and supportive. Dying is not acceptable. Yet life with the pandemic provides many opportunities to brush close to someone else's dying. The fear and sadness became part of the daily understanding that death has to be planned for no matter how you die.

CHAPTER V

SUMMARY AND CONCLUSIONS

AIDS is now a worldwide pandemic and the United States is seeing a change in the epidemic which makes it look more like the rest of the world, where there are more women infected with HIV than men (Hamblin & Reid, 1994). This study contributes to efforts being made to understand what the common concerns of women are and how best to promote, arrange, and manage their care.

Purpose and Aims

The purpose of this study was to describe and understand the lived experience of HIV for women. The two aims were : 1) to describe the specific life experiences women believe had an influence on their decisions to participate in the risk behaviors that led to their HIV infection, and 2) to explicate the interpersonal concerns and background meanings HIV has for infected women, as they are revealed in women's efforts to live with and manage their disease.

Methods

The methodology was interpretive phenomenology. This study looked in depth at the experience for 18 women between the ages of 22 and 49 who live in seven communities in the Willamette Valley of Oregon, including the Portland metropolitan area. The sample included one African-American woman and one woman of Asian descent, consistent with the demographics of the epidemic in Oregon. Women were interviewed at least twice in a semi-structured format in a private site of their choosing. Open ended questions were used to ask participants about: 1) particular life experiences they believed were related to their becoming

HIV infected, 2) interpersonal relationships and concerns that have meaning for them as they deal with their HIV disease, 3) how they care for themselves and where they get support, and 4) their experiences and challenges with the health care system. Interviews were tape recorded and transcribed in a confidential process.

Data analysis included thematic analysis of the narrated texts and identification of common concerns and patterns as seen in exemplars and paradigm cases. The analysis was guided by three aspects of the experience that shaped the background meaning HIV had for these women. First was the importance of relationships and how relationships both positively supported and negatively undermined women's efforts to live with their HIV disease. Second was the cultural context of the HIV epidemic and the negative socially constructed meanings and attitudes people have about HIV. The third was the ongoing difficulty in living with an incurable, unpredictable, constantly changing illness.

Findings

Common histories, concerns, and coping patterns emerged from the stories of the women in this study. Experiences in childhood appeared to have a direct influence on women's later risk behaviors. The women represent a diversity of life experiences and socioeconomic backgrounds and the similarities and differences among them were revealed in their common coping patterns. There were concerns that emerged for all the women at specific points in the experience, such as becoming known to one's family, and other concerns that emerged over and over throughout their experience, such as issues of motherhood.

Common Histories that led to High Risk Behaviors. Home was not a safe place. Childhood physical, emotional and sexual abuse was seen as a direct influence on women having the high risk behaviors which led to their HIV infection for all but three of the women in this study. The abuse was both openly known in some families and hidden in other families, however the common experience was that it was long term and there was no-one to turn to for help. This led to damaged self-esteem and caused women to feel that they were not valued in their families. They turned to multiple sexual partners and substance abuse for escape and comfort.

When describing their personal histories, women's feelings ranged from resignation, to sadness, to anger to resolution. Women's coping patterns to other aspects of the illness often coincided with their response to their childhood abuse experiences. Ultimately women shared a common understanding that their promiscuity or substance abuse as adolescents was directly related to having their self-esteem damaged as children. They did not know how to protect themselves and often they came to not even care. Unfortunately, this group of women were infected before the CDC and other public health organizations began providing HIV information and support for sexually active young people.

Common Coping Patterns for Living with HIV. The analysis of the common concerns and ways women responded to living with HIV led to the identification of four common patterns of coping. These coping patterns became the major themes of the study. They were: 1) Feeling overwhelmed at having HIV, 2) Avoiding HIV and disclosure as long as possible, 3) Feeling resigned about HIV, and 4) Integrating HIV as part of life.

Discovery. The first coping pattern of feeling overwhelmed emerged during the period of discovery and included horror at finding out one is infected. The arrival of the virus was an epiphanic event for every woman and their first response was always shock and feeling overwhelmed. It meant their lives would never be the same and that they would die prematurely, maybe soon. Women felt immobilized and numb. The meaning becoming infected had for women varied depending on the circumstances of how they were infected. It involved a cascade of feelings including self-blame, shame and terror. The essential meaning of feeling overwhelmed was that a woman's life was no longer in her control and that it was permanently and negatively changed.

For women infected by transfusions, it included feeling betrayed by institutionalized systems they trusted such as hospitals and the American Red Cross. For women who figured out they were infected themselves, having HIV meant that the troubling signs and symptoms were not going away, and in fact would get worse. Testing positive toward the end of the asymptomatic stage also meant that there was not much time left. These women had an AIDS diagnosis at the time they first found out they were HIV positive. They are the women like those in the study which revealed women die 30% faster than men (Melnick & Sherer, 1994).

Being infected by a lover, past or current, was the most common experience of becoming infected for this group of women. The common meanings revealed feeling guilty, angry, and betrayed. For a woman currently living with the man who infected her it included watching someone she cared for die. This person would also not be around to care for her. For women infected by a past lover, testing positive meant they may have infected their current partner, or their child.

Feeling overwhelmed lasted varying lengths of time; however, it regularly returned when events and circumstances associated with being HIV positive occurred and women had trouble coping. And because HIV is an unpredictable disease, the threat of feeling overwhelmed was always on the periphery of the women's lives.

Denial helped some women cope with thinking they would die soon and gave them time to consider how to manage the secret of their infection and when to tell who. The importance of creating shadow lives and avoiding involvement with the epidemic came from fear of being judged, stigmatized and rejected. Only when women became willing to confront the stigma and rejection were they able to make coping decisions that integrated the virus into the rest of their lives. This usually came when women were willing to risk having their HIV status publicly known.

Disclosure. If possible women avoided HIV and revealing they were infected for as long as possible. Women first disclosed their HIV infection in core family relationships because the need to tell someone was driven by the need to know if someone would be there to care for them and take their children if they became sick.

Who will help? Relationships with mothers re-emerged in women's lives both positively and negatively. Mothers who had not protected them as children from family abuse were not expected to be helpful now. Disclosure to in-laws was especially punishing. Concerns for who would care for their children usually involved sisters, many of whom had shared their childhood abuse and were especially supportive now.

Women's coping patterns and the circumstances of their testing experience often determined who and how quickly others, especially extended family, found out. For example, women who consistently felt overwhelmed became resigned to having HIV and made little if any effort to access their families for support. They believed support would not be there, and didn't want to risk asking for it and being disappointed. Other women shared their initial feelings of overwhelm with their families and went through the difficult process of disclosure to get the support they needed.

The critical role of family support for infected women has not been a major focus of the epidemic, beyond the need for care giving during the final stages of the illness and legal responsibility for children left behind. Families are often unprepared for the initial devastating experience of discovering someone is HIV positive, yet play a crucial role in determining how a woman ultimately copes with her life as an infected person.

Once families were dealt with or dismissed, women had to manage who should know they were infected and when to tell them. The reconstruction of a woman's image of herself as HIV infected happened first just for herself and the people she was closest to. The move to going outside the family involved a critical revelation of self that some women were unable or unwilling to do. Women lived in fear someone would do it for them, and when it happened they felt violated and betrayed. Avoiding and controlling who knew they were infected was how women protected themselves from judgement, stigma and rejection.

Going Public. Women began telling friends when it was too hard to keep the secret. Confiding in friends meant women had to evaluate who was trustworthy. It meant potentially being judged and losing control of how far the information would go. Women were surprised at who was or was not supportive.

Becoming known at their work site was a benchmark in the progression of their disease. Telling co-workers meant publicly acknowledging that their world was not as it appeared to be. The reconceptualization of self as an infected person became public. For women without symptoms it meant that there may be time to do some of the things they would not be able to do later if they became sick. Mainly it meant dealing with unpredictable responses from people women didn't know very well but had to interact with. It meant coming to terms with considering oneself a disabled person.

Women who had struggled to escape dysfunctional and brutal childhoods and adolescence saw working as symbolic of their finally being able to take care of themselves. Not working reminded them of past times when they were not part of the working class. The meaning of avoiding disclosure at work helps us understand why women don't want to relieve their stress by working part-time or leaving work, even when it would benefit their health.

Managing the Illness. Women grappled with patterns of avoidance, resignation and integration as they faced the challenges of the long term management of their unpredictable HIV disease. These challenges included both physical and mental health. Essentially, living with HIV meant constant vigilance over their bodies because signs and symptoms mean the disease is progressing and something has to be done. Vigilance takes many forms from managing one's activities due to debilitating fatigue, to monitoring dropping CD4 counts, to staying adherent with difficult medication regimes. Mental health includes battling depression, alcohol and drug use and fearing dementia. Women wanted to be able to get away from disease management, take time off, and pretend life was normal.

Relationships with health care providers included wondering if they were skilled in HIV care and trustworthy. These were problems for women in rural areas. Ultimately women valued a doctor's acceptance of her personally as more important than his/her HIV knowledge. Participation in research played a key role in HIV care during this period of time. Women's experiences covered a full continuum of feeling they were making a difference in finding useful treatments to feeling abused and devalued by impersonal researchers.

Intimacy and Closeness. Longing for intimacy and closeness was an issue for women without partners, and especially for women without children. The unmet need to be loved, valued, accepted and appreciated originated in childhood. Because sexuality was seen as the means of receiving intimacy and closeness, the sexual transmission of the virus seemed to end women's willingness to risk relationships with men. Women coped with resignation and grieved this loss and it made the non-judgmental support of family, friends and health care providers even more important. Women with partners or spouses were deeply grateful for their support.

Motherhood. Without exception the most difficult emotional concern for women was for their children and what it meant in a child's life that their mother had HIV/AIDS. The thought of not seeing their children grow up was considered worse than dying itself. It meant that someone else would have to be found to care for the children and that one's children may see their mother sick, debilitated, or lose her mind. In unsupportive families this meant counting on the charity of strangers.

At their most vulnerable time, when women felt overwhelmed at finding out they were infected, they struggled with how and when to tell their children. Once they did, children unanimously became women's greatest sources of strength and support. The finding was that even among the most depressed, resigned, hopeless women; having children present motivated them to push through their resignation, integrate the HIV into their lives, access care and take their treatments and medications. Children were connected to both the most painful and the most hopeful parts of women's lives. They provided a reason to live and when they were taken from them, women's coping patterns reverted to feeling overwhelmed, resigned and hopeless.

Becoming Part of the Epidemic. The meaning of life shifted in the face of having HIV/AIDS. Women looked at the meaning of their shortened lives and reflected on what had happened to them. Women's coping patterns determined who felt life was a curse or a failure and who saw a purpose in their experience. For women who made it to integrating HIV as a coping pattern, they wanted to beat the HIV, reclaim their lives, and they usually joined the epidemic as activists. Having HIV provided an impetus for them to do things they never felt possible, such as public speaking. This empowered them as they communicated hopeful messages to women who shared their brutal past experiences and who were in earlier stages of infection. Many wanted to make the world safer for their daughters.

Spiritual Concerns and Practices. Initially women were angry at God and felt spiritually betrayed because after finally getting their lives healed, they learned they were infected. These women had a variety of spiritual practices which were important to them and which they continued to practice, including Christian, Buddhist, Bahai, and New Age. Unfortunately not all faiths were accepting of their infected members.

Women wanted to believe in something greater because death seemed so close. Women did not fear death as much as what it would be like to die. This especially concerned what their death would be like for their children.

Implications for Practice

Public Mandates to Protect Children. In order to fully understand women's HIV infection, people must look at the precursors of HIV risk behaviors such as damaged self-esteem from physical, emotional, and sexual abuse which occurs in childhood. This includes supporting public policy aimed at intervening in situations of family abuse or child neglect and enlarging sexuality and HIV/AIDS education in schools.

Integration of Emotional and Psychosocial Factors in Hiv Care. Women may have multiple diagnoses including mental health and substance use problems. These affect their ability to maintain complex treatment and medication regimens and providers must include assessment, referral and follow-up for these problems if HIV disease treatment is to be managed effectively. Patience, reassurance and personal support from health care providers are key factors in women's willingness to confront underlying mental health concerns and practice self-care.

Trauma of Testing. Women said the discovery of HIV infection meant the end of their "real lives". To be HIV positive was a death sentence. The shock and horror of finding out one is HIV positive must occur in an environment of total support and understanding. HIV test results cannot be handled casually such as being conveyed over the telephone or in the presence of others. Anyone involved in testing must complete recommended training and follow disclosure guidelines.

Importance of Privacy. Feelings of being overwhelmed included fear of judgment, stigma and rejection for themselves and their children. Women's need for protection of their privacy and secrecy concerning their infection is critical. Absolute care must be taken to assure records, visits, and treatments remain confidential. This involves everyone and all systems within the health care environment. Electronic records, fax machines and e-mail must be carefully used. Betrayal of trust can mean cessation of care from that provider. When information must be shared (such as for case management) women should be informed and included. This is especially true when individuals outside health care systems become involved, such as children's teachers, lawyers, or social service providers.

Create Family Centered Care. Women value the care of their families above their own care, especially the care of their children. Every possibility of integrating family primary care with HIV care should be done. In rural areas this is essential and what women want to have. HIV specialists are often unprepared to manage the multiple concerns of these women, many of which are non-HIV related but definitely associated with women's self-care abilities. Specialists need to communicate closely with primary care providers to assure changes in treatment, new diagnoses, and access to research are shared.

Support Positive Reconceptualizations of Self. Health care providers should include validation of women's participation in the HIV epidemic as part of their care. This includes invitations to seminars, conferences and talks for knowledge building. It includes encouraging and actively facilitating women's access to social and support programs designed to offset isolation and withdrawal. It includes attending to and affirming the small steps women make to take responsibility for their care. And it includes knowing when and how to positively support transitions to unemployment, disability, and assisted living.

Importance of Inter-disciplinary Care Teams. Many HIV infected women struggle with managing the activities of daily living for themselves and their children and need extra help especially as their disease progresses. The timely intervention of trained volunteers, social workers, case managers, nutritionists, pharmacists, research nurses and others can significantly help women make the necessary transitions as their needs and priorities change. Usually the primary care provider initiates the referral process for needed services. He/she needs to know what and who is available, accessible, and affordable.

Willingness to Be Reflective with Women. Struggling with the meaning of life in the face of having HIV and AIDS is a constant issue for women. Health care providers need to make time in their routine care for women to discuss their underlying anxieties and fears. They want to share this with the person responsible for their diagnosis and treatment, the person who knows the most about how close to their death they may be. The unexpected and unpredictable nature of AIDS and the opportunistic infections that suddenly appear can create a sense of urgency and foreboding among women. Women felt safer and more secure if they felt they could confide in their health care providers. This is especially true for women estranged from their families. It becomes most important as treatments fail and women see their disease progressing.

Limitations

A limitation of this study was that the women who volunteered to participate were already part of a group of women involved in support services for people living with HIV disease. This involvement was occasional and minimal for several women; however, everyone found out about the study through someone being in a supportive relationship to them and telling them about it.

The effect this may have had on this study is that this group of women do not represent women with HIV who are not involved in the health and social service system or who are completely isolated or living in denial. The coping patterns of resignation, feeling overwhelmed, and avoidance of disclosure may capture some of what women who are totally isolated feel; however, there is no way to discern from the data in this study the coping patterns of other HIV infected women. One can only surmise that with increased isolation and denial, the intensity of a coping pattern may increase. In future research, efforts to reach women through other kinds of referrals would increase the variety of women included in a study. This might include the criminal justice system, religious organizations, or treatment facilities. Including women who are new to their disease or to the epidemic may always be a problem due to the incredibly private nature of HIV disease, especially during the initial asymptomatic stage when women typically deal with feelings of overwhelm and denial by avoiding anything to do with the epidemic.

Another limitation of this study is the fact that almost all of the women are in approximately the same stage of their HIV disease. They are all approaching the end of their asymptomatic period and beginning to experience the progression of their disease. This emerged in their common concerns; however, a fuller explication of the lived experience of HIV disease should include women who have just found out they are infected as well as more representation of the experience as it becomes more acute. Only one woman provided insight into the terminal stage of the disease. This happened as a function of how the study sample was recruited. This limitation could be addressed in two ways. One would be to continue to follow this group of women as they progress through their disease. Another would be to deliberately recruit women who are sicker. Perhaps women who live in assisted living or hospice environments. Arrangements would have to be made to assure privacy. Additionally, the interview would probably have to be done in several smaller segments.

Recommendations for Further Study

This research points to three areas of further study. First, research is needed which includes the lived experience of the advanced and terminal stage of the disease in women. Second, the complex relationships within the families of HIV infected women needs to be further researched because of the important role families play in both supporting or not supporting infected women. Of particular concern are discovering ways to assist women and families deal with the role family violence and abuse has on the circumstances of how and why women become infected. This is a recognized area of HIV research and this study confirms the importance of continuing these efforts.

A third area for further research is the lived experience of children whose mothers have HIV disease. These children are not infected, they are affected. There currently exists a recognition of the importance of assisting infected women in having healthy babies and the needs of infected babies; however, this study revealed a concern for older children. Very little information is available about how these children deal with the social judgment and stigma about HIV/AIDS that they fear and are forced to live with. These children watch as their fathers, parents' friends, and ultimately their mothers die. The assumption is that relatives or human services agencies will do what is required. Longitudinal study of the impact of losing one's mother to AIDS would be valuable.

Interpretive phenomenological research aims at generating interpretive accounts that are understandable and useful. Benner (1994) indicates that accounts must be plausible, offer increased understanding of the world being interpreted, and must explicate the practices, meanings, concerns, and practical knowledge of the participants who live in that world. This study has addressed the lived experience of HIV infection for women. The two aims of the study have been achieved. The first aim was to explicate the specific life experiences women believe had an influence on their decisions to participate in the risk behaviors that led to their HIV infection. The second aim was to describe and explicate the interpersonal concerns and background meanings HIV has for women, as they are revealed in women's efforts to live with and manage their disease. The narratives provided themes and common meanings in women's practical experience of having HIV. The understandings that were found regarding this group of women's experience of HIV disease can be used to assist health care providers and others who care about these women to be more sensitive, knowledgeable, and helpful.

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APPENDICES

APPENDIX A

Protection of Human Subjects Initial Review Authorization

OREGON
HEALTH SCIENCES UNIVERSITY
3181 S.W. Sam Jackson Park Road, Portland, OR 97201-3098
Mail Code L106, (503) 494-7784, FAX (503) 494-7787
Office of Research Services

November 1, 1994

NRCC
Special Review Committee
Dr. John C. Chah, SRA
NINR
Westwood Building, Room 740
5333 Westbard Avenue
Bethesda, MD 20892

RE: CERTIFICATION FOR HUMAN SUBJECTS EXEMPTION

P.I.: Catherine Salveson
Title: HIV Infection: The Lived Experience of Women

Agency#: 1F31 NR06988-01A1

Approv.
Date: October 28, 1994

Subject application falls under Category #2 of the federal regulations (45 CFR Part 46.101 (b) and is considered to be exempt from review by the Committee on Human Research. The institutional DHHS Assurance No. for human subjects is M1359-01.

Please feel free to call me at (503) 494-4854 if you have any questions.

Sincerely,

Lisa M. Nguyen

Lisa M. Nguyen
Grant Application Specialist
Office of Research Services

LMN:ors

cc: Catherine Salveson, SN-ADM

APPENDIX B

Invitation Letter to Participants

You are Invited to Participate in a Study Concerning the Lived Experience of Women with HIV

Hello, my name is Catherine Salveson and I am a nurse in graduate school at Oregon Health Sciences University in the School of Nursing. I also work as a nurse doing research on HIV and AIDS. In that role, I have seen an increasing number of women with HIV and I am aware that we know a lot about the lives of men with HIV but really very little about the lives of infected women.

Therefore, I decided to do my dissertation research at OHSU on the lived experience of women with HIV. I plan to do this by transcribing tape recorded interviews with approximately 15 women to identify the issues from their perspective. The goal is to truly reflect what women experience.

I would like to invite you to participate in this study. If you choose to participate you would be interviewed twice during a six month period and invited to a group meeting.

I would first meet with you to discuss the study and answer any questions you may have. We would then arrange a convenient time for the interviews. They will take approximately one to two hours. If child care is needed I will provide the funds necessary. After the first interview I will contact you for a second interview to follow up on issues and concerns that emerged and make sure I fully understand your perspective correctly. After all the women participating have been interviewed, a group meeting will be planned to go over what was discovered and give participants a chance to discuss it and give further input. Any woman who does not wish to come to this group meeting is welcome to work with me privately to assure her critique and input is included.

I realize that these are very personal issues and I can assure you that the interviews will be kept strictly confidential and no one except me will know who the women are that participate. The transcripts will be typed to exclude any names and identifiers and the tapes will be destroyed after they are transcribed. Anyone who assists in the evaluation of the data will only be given coded names. All records will be kept locked and secured. Neither your name nor your identity will be used for publication or publicity purposes.

I also realize that talking about HIV can be an emotional experience and may cause strong feelings or memories to emerge. A clinical social worker who is experienced in HIV counseling will be available to you for support following each interview if you would like to talk to her. She will be available as long as the study is being conducted and can be easily reached if necessary.

I am available at 795-6630 to answer any questions or concerns you may have at any time. This study is voluntary and you may stop your participation at any time you choose. Your participation will not affect the health care you receive in any way.

I look forward to sharing this research study with you if you feel it is something which would be of value for you to participate in.

APPENDIX C

Interview Guidelines

INTERVIEW GUIDELINES

Understanding the Lived Experience of Women Infected with the HIV

1. The purpose of the study and the protection of the data and the participant's confidentiality is explained.

2. The availability of a clinical social worker for emotional support is discussed and arrangements for telephone contact made.

3. The participant is invited to tell the story of how she became infected with the HIV in her own words. (Not to be interrupted if at all possible.)

4. The participant is asked to describe her thoughts and feelings at key times in the process of learning that she is HIV infected and beginning to live with the disease. Possibly including:

   - When she first heard about HIV.
   - When she first knew someone who is infected.
   - What her friends, family, and children thought about HIV and AIDS.
   - What she felt were her major risk factors.
   - What she first thought about being tested.
   - What happened when she was tested.
   - What she did when she found out she was positive.
   - How people first reacted to her infection.
   - How her life changed as a result of being infected.

5. Finish with time for the participant to talk about it feels to tell her story.

APPENDIX D

Summary of Analysis Codes

Analysis Codes and Categories

SECTION I: LIFE BEFORE HIV: WHO IS NOT AN "INNOCENT VICTIM"

A. Home was not a safe place.
    1. Normal childhoods / supportive families
    2. Disabled families
        A. Persistent emotional abuse
            1. Living in fear
            2. Isolation / no support
            3. Protecting siblings
            4. Parental conflict
            5. Unwanted step-children
        B. Physical and sexual abuse
            1. Abusive Fathers
            2. Abusive mothers
                a. Abused mothers
                b. Mothers not protect
            3. Brothers / relatives
                a. Abusive siblings
                b. Siblings abused
            4. Abusive strangers
            5. Protecting siblings

B. Not being valued as a person
    1. Damaged self-esteem
    2. Abandonment
    3 . Early sexuality / multiple partners
    4. Drugs & alcohol / addiction
    5 Prostitution
    6. Incarceration
    7. Recovery

SECTION II. THEMES OF THE LIVED EXPERIENCE: COPING PATTERNS

A. Feeling Overwhelmed at having HIV
    1. Suspicion of infection / getting sick
        A. Suspicious symptoms
        B. Chronic fatigue
        C. Confusing tests
    2. Betrayal by a beloved
        A. Bisexual lover
        B. Lover lied
        C. Husband's past

- 3. Discovery: Lover or Ex has HIV/AIDS
  - 1. Lover - Hemophiliac
  - 2. Lover - Hospitalized
  - 3. Lover - Dead
  - 4. Lover - ex-partners sick
- 4. Unexpected phone call
  - A. Medical exposure
  - B. Accidental exposure
- 5. Getting tested
  - A. Total shock
  - B. Numb / out of body
  - C. Positive = death
  - D. Kids = orphaned
  - E. Unlucky
  - F. Informant / personal
  - G. Informant / phone
  - H. Rage
  - I Suicidal
  - J. Unfair
  - K. Fear for lover
  - L. Expected positive test
    - 1. Addiction
    - 2. Prostitution
    - 3. Fated
    - 4. Cursed
  - M. Fearing stigma
    - 1. Stigma / kids
    - 2. Stigma / self
    - 3. Rural stigma

B. <u>Avoiding disclosure as long as possible</u>

- 1. Fear disclosure.
- 2. Who help?
  - A. Tell Mother first
  - B. Never tell Mother
  - C. Sisters care
  - D. Family support
  - E. Being outed
  - F. Reject father
  - G. Reject family
- 3. Judging in-laws
- 4. Tell children
  - A. Afraid to hurt child
  - B. Too young to tell
  - C. Delay tell child

        - D. Create shadow life
        - E. Prepare for stigma
    - 5. Tell friends
        - A. Friend reject
        - B. Friend support
        - C. Christian rejection
        - D. HIV friends support
        - E. Fear make new friends
        - F. Fear neighbors
        - G. Past friends
        - H. Hero to friends
        - I. Friend far away
        - J. Rural friends
        - K. Unexpected support
    - 6. Going public
        - A. Tell co-workers
        - B. Losing control
        - C. Unexpected support
        - F. Hide at work
        - G. Sad / lose work
        - H. Sick leave from work
        - I. Co-worker prejudice
        - J. Too tired to hide

- C. <u>Feeling resigned to living with HIV</u>
    - 1. Being infected - feeling well
    - 2. Managing medications
    - 3. Medical care / positive
        - A. Helpful doctors
        - B. Being encouraged
    - 4. Medical care/ negative
        - A. Hurtful doctors
        - B. Monstrous medical system
        - C. Hospitalization
        - D. Fearing diagnostic tests
        - E. Hypochrondiac
        - F. Research participation
        - G. Hate taking pills
        - H. Side effects of meds.
    - 5. Mental health fears
        - A. Fear dementia
        - B. Depression descends
        - C. Disgusting to children

6. Disease progressing
    A. Frightening fatigue
        1. Escape into sleep
        2. Tired - Can't be Mom
    B. Fear my body
        1. Hyper vigilant
        2. Grieve lost beauty
    C. See lover die
    D. OB / Gyn problems
        1. Endless bleeding
        2. No more kids
        3. Never a Mother
    E. Alternative treatments
    F. Search for cure
    G. Self-care
    H. Personal health promotion
    I. Losing weight
    J. Expense of care
    K. Becoming disabled
    L. Opportunistic infections
7. Loss of personal life
    A. Feeling lonely
    B. Grieving lost sexuality
    C. Longing for closeness
    D. Risking relationship
8. Staying alive for children
    A. Fear abandoning child
    B. Protect child from stigma
    C. Protect all children from HIV
    D. Feel hope through children
    E. Value in life = mothering
    F. Find support for child
    G. Arrangements if die

D. <u>Integrating HIV as part of life</u>
1. Becoming an Advocate
    A. Speak out = feel strong
    B. Prevent HIV from spread
    C. Protect other women
    D. Speaking = overcome fear
    E. Protect young people
    F. Organizing against HIV
    G. Educate in schools
    H. Involved in epidemic
2. Revisit life's meaning

A. Uncertainty of HIV
B. Forced to confront past
C. Becoming a fighter
D. Punishing God
E. Protective God
F. Spiritual comfort
G. Dealing with death
    1. Fear of funerals
    2. Making death arrangements