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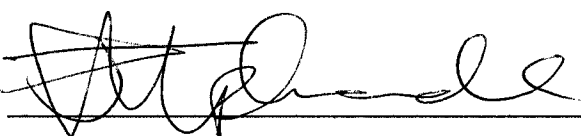
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A STUDY OF WOMEN'S EXPERIENCES OF LIVING
WITH HIV/AIDS IN RURAL AREAS

by

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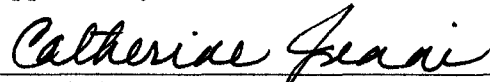
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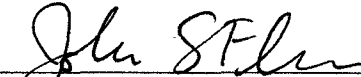
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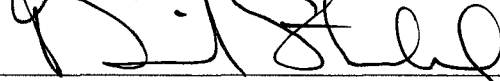
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DISSERTATION ABSTRACT

Mphande, Joyce Tinanani Ed.D, May 2004 Counselor Education

Women's Experiences of Living with HIV/AIDS in Rural Areas

Co-chairs: Cathy Jenni, Ph.D., John Sommers-Flanagan, Ph.D.

The purpose of this study was to gain an understanding of the experiences of women living with HIV/AIDS in rural areas, addressing the question: *What is your Experience of Living with HIV/AIDS in a rural area?* Using qualitative methods, data were collected through the use of personal one-on-one interviews of seven women living with HIV/AIDS in rural areas. These interviews yielded participants' descriptions of their experiences, relationships, and day-to-day situations. Current and prominent literature on HIV/AIDS was reviewed. The data was analyzed using the constant comparative method (Strauss & Corbin, 1990) as the framework. Findings are discussed through the prevalent themes that emerge, contributing to our understanding of women's phenomenon of living with HIV/AIDS in rural areas.

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Prologue

I have been involved in the HIV prevention work since 1983, when I worked for the World Health organization, teaching both youth and adults in the villages of Malawi about safe sexual practices. When I came to the United States in the early 1990s I got involved in volunteer work on HIV/AIDS issues. Since I relocated to Montana, I have been involved with the Missoula AIDS Council as a volunteer, Missoula Indian center and the Partnership Health as an HIV counselor. I have worked for the Health Department as a Community Health Specialist working mainly on the HIV Prevention grant. I continue to be involved in HIV work by volunteering with the HIV Prevention and Treatment Planning Groups in Montana, both at local and state levels. It was in this capacity that last October, 2002, I attended a 'Woman Power' retreat organized by the Lewis & Clark AIDS Project in Helena, Montana.

The retreat drew thirty women living with HIV/AIDS from different rural Northwestern United States. The retreat is held every year for the purpose of providing an environment in which participants come together and feel safe to share unique experiences of living with HIV/AIDS. In order for the Lewis & Clark AIDS Project to better understand the experiences of the participants' lives living with HIV/AIDS, as well as for planning and evaluation of the retreat intervention, some women volunteered to participate in an interview process at the end of the retreat. I conducted interviews of nine women.

A couple of years ago I lost a cousin and have lost many friends to HIV/AIDS. Attending the retreat in October 2002 brought back the sense of loss,

and it made me realize how much I wanted to contribute to the issue of women and HIV/AIDS. When I conducted the interviews of the lived experiences of some of the participants at the retreat, I knew this was the data I would want to analyze for my dissertation due to my interest in women and HIV/AIDS issues. The process provided an opportunity to collect data that I believed was very important for the women's needs and improvement of future retreats, but also provided a voice for the women because not much literature has been written about women and HIV/AIDS. The participants liked the prospect of having their stories shared.

CHAPTER ONE

Introduction

When I think of all the friends I've lost to this damned disease, I try not to be bitter or depressed – and that's hard. But I believe their lives had meaning and glory, no matter how short. And their thwarted desire to live fires me up with an almost ferocious desire to beat this thing. That's why I believe we each must put ourselves to work to find the best treatments available from all medical traditions and push for unflinching public support in pursuit of a cure.

(Gregory, 42, Artist, Diagnosed in 1986)

The AIDS epidemic was first acknowledged publicly on June 5, 1981, with the publication of a notice in the *Morbidity and Mortality Weekly Report* alerting physicians to the occurrence of rare opportunistic infections in several gay men who had previously been otherwise healthy (Centers for Disease Control, 1981). Affecting first gay and bisexual men, and later injection drug users, their sexual partners and their children, scientists concluded that the cause of this new malady was some blood-borne pathogen (CDC, 1991). In more recent years this disease, once thought as an illness of gay men and intravenous drug users, was also recognized as a threat to the health and life of women. Gorna (1996) reports that at local, national and global levels the absolute numbers, percentages and rates of increase of women with HIV and AIDS have grown steeply since AIDS was first identified. Between June 1993 and June 1994 alone, while there was a 10 percent increase in the number of cases in males of AIDS, the rate of infection for females increased by 37 percent. The number of women with HIV infection and AIDS has been increasing steadily worldwide. The National Institutes of Health (May, 2001) reported that as of

December 2000, 16.4 million women were living with HIV/AIDS worldwide, accounting for 47 percent of the 34.7 million adults living with HIV/AIDS.

Increasingly, officials at state and federal health agencies, and researchers studying HIV/AIDS are taking notice of the women affected by this epidemic, something that activists argue is long overdue (Pennisi, 1995). The rapid growth of HIV infection among women calls for emphasis on understanding and learning how best to treat those women whose infections develop into AIDS. The National Institutes of Health (May, 2001) reports that HIV/AIDS is now the third leading cause of death among women ages 25 to 44 in the United States, and the leading cause of death among African-American women in this age group. HIV-positive women are from diverse social classes, age groups, ethnic backgrounds and lifestyles. AIDS has become the third leading major cause of death for women of reproductive age in major cities in the Americas, Western Europe and Sub-Saharan Africa (Berer & Ray, 1993).

Sexually active women who live ordinary lives, and women of all social classes are increasingly at risk. Women are vulnerable to acquiring HIV through sex with men, as well as through sharing drug-injecting equipment (Gorna, 1996). Women are more vulnerable than men to acquiring HIV from sexual intercourse. To understand the real needs of women living with HIV and AIDS, the National Institutes of Health (May, 2001) has made research on women an important component of the Institute's AIDS agenda. Investigators are studying the unique features of HIV/AIDS in women and developing treatment regimens especially for them. For example, findings of cohort studies in the United States

have associated the increased risk of heterosexual HIV transmission with alcohol use, a history of childhood sexual abuse, current domestic abuse, and use of crack-cocaine (NIAD, 2001).

AIDS researchers seeking to prevent HIV transmission are aware of the physical, psychological, and social obstacles to stopping the spread of HIV infection, no matter what policies public health agencies recommend (Pennisi, 1995). To learn how best to treat AIDS has precipitated studies designed to address a wide range of biological and psychosocial questions pertaining specifically to women affected by this disease.

Need for the Study / Statement of Problem

Even if prevention efforts succeed in reducing the rates of new HIV infections, there are already numerous seropositive women who will develop AIDS (Gardner & Preator, 1996). Many of these women are impoverished and unemployed. Thus there is an obligation to those who are exposed to significant risk and have great difficulty providing for themselves. There is evidence that an HIV client's physical and mental health is adversely affected by lack of access to care, which affects her ability to provide good self-care (Gardner & Preator, 1996). The quality of life of positive women bears directly on their quality of life for their own physical and mental health. The services important for women affected with HIV/AIDS may include substance abuse treatment and case management services to help with the many challenges posed by the illness and its long-term care (Gardner & Preator, 1996). In addition, little specific research has been done to shed light on the experience of HIV-positive women

in rural settings, who may have needs that differ from HIV-positive women in urban areas.

The purpose of this study was to describe the experiences of women living with Human Immunodeficiency Virus (HIV) or Acquired Immunodeficiency Syndrome (AIDS) in rural Northwest America. The researcher looked at those aspects of HIV-positive women's lived experiences that impact how various services were delivered in a rural context including overall quality of life, access to services and social support. As drugs extend the lives of people dealing with this epidemic, the challenges women face in coping with this illness continue to grow. Not the least of these challenges is managing the psychological stress that accompanies the diagnosis of a stigmatizing life-threatening disease and the emotional difficulties associated with adhering to a complex regimen of anti-retroviral drug therapy (Cohen & Doner, 1998). This study sought to explore the experience from the perspective of HIV-positive women in order to increase understanding of the phenomenon of living with HIV/AIDS. This group is a mostly invisible one in North America and deserves improved understanding.

Significance of the Study

Many professionals in the field of health education are confronted at some time with individuals who are HIV-positive. A better understanding of the impact of HIV/AIDS on individuals offers great potential for improved work with HIV/AIDS as a health issue. This understanding can be beneficial in that it assists providers to recognize and deal with important emotional and social

factors involved in living with HIV/AIDS. Providers who work with women living with HIV/AIDS must work with all aspects of the women's lives. AIDS is a disease that afflicts people of all ages, including infants and young adults and especially the families of women who are HIV/AIDS positive. The significance of this study is to provide a better understanding of the personal experiences of women living with HIV/AIDS in rural America, and to identify those factors related to the way in which they cope with the emotional and social aspects of this disease.

Research Design

In an attempt to gain insight into experiences and personal perspectives of women living with HIV/AIDS in rural areas, this researcher approached this investigation by using a qualitative methodology, focusing on the emergent themes in each participant's story. This inquiry provided a methodological framework within which participants could express their own understandings in their own terms, regarding their experiences from their own unique perspectives. With emphasis on procedures that allowed subjects to speak for themselves, this type of methodological inquiry seemed best suited to look into the experience of living with HIV/AIDS from the perspective of the women living with the HIV/AIDS. The method for collecting data was open-ended in order to find out what the participants' experiences and interactions meant to them. The data collected in this study consisted descriptions of situations, people, and interactions. Also included are quotes of the participants'

experiences, their attitudes and beliefs and thoughts about living with HIV/AIDS.

Research Question

The following research question was addressed:

WHAT IS YOUR EXPERIENCE OF LIVING WITH HIV/AIDS IN A RURAL AREA?

Data Collection

The data for this study were collected through in-depth interviews, and the informal conversational interview technique. Probing for increasing depth and awareness in the interviewee was used as the major tool in the data collection. All interview data were tape-recorded. Each interview was later transcribed and analyzed to identify relevant dimensions of living with HIV/AIDS. These dimensions emerged as the common themes in several interviews. This researcher recorded the eight themes that emerged.

Selection of Participants

Participants in this study consisted of seven women living with HIV/AIDS in rural areas. These women were part of a group of thirty HIV-positive women attending a retreat for positive women held in October 2002 in Montana. They volunteered to participate in the interviews, which were conducted initially to provide data for the Lewis & Clark Yellowstone AIDS Project, for the purpose of assisting in the planning and evaluation of the retreat intervention. The number of women who came forward determined the total number of participants that were interviewed for this study. In fact, initially nine

women came forward to be interviewed, but this researcher used only seven participants. One unused interview was from a minor and the other did not provide enough data to be used in the study. Qualitative studies conducted via a depth interview must triangulate; that is, there must be at least three and preferably six useable interviews to provide both diversity and potentially unifying themes. The number of participants in the current study meets this criterion.

Data Analysis

The data were organized in different ways to facilitate analysis. Tapes; verbatim transcripts; summaries; and themes were used to tap into different dimensions of the data. Themes were identified by physically sorting the examples into piles of similar meaning. The data was organized and presented in the form of a multi-subject case report.

Assumptions

For the purposes of this study, the following assumptions were made:

1. Interviewees were honest and accurate as to their own experiences in providing information during the interviews.
2. Interviewees were capable of expressing in words their own understanding of their experiences in living with HIV/AIDS.
3. Interviewees fully understood the questions by the interviewer.
4. The participants' interviews may or may not represent truth in an external, objective sense. Rather, the interviews represent each participant's personal, subjective experience.

Delimitations

For the purpose of this study, the following delimitations were considered:

1. The participants were delimited to women living with HIV/AIDS in the rural North-west America when data was collected.
2. Data was collected by means of in-depth personal interviews.
3. This investigator was responsible for all data collection.
4. The results of the study were analyzed through careful theme analysis within each participant's narrative and ultimately across each participant.

Limitations

For the purpose of this study, it was reasonable to acknowledge that limits existed. The following limitations existed:

1. The study is limited to geographical region of the United States.
2. The study is limited to women who attended a retreat and thus may have been more open about their HIV/AIDS status.
3. The study was limited to the data collected in personal depth interviews.
4. Analysis and interpretation of data is value-laden. Thus, the data collection and analysis may have been influenced by personal attitudes, beliefs, and perceptions of the investigator.
5. The quality and depth of data would have to have varied due to the interviewer and interviewee relationship when data was collected.

Definition of Terms Used in this Study

In order to present the general concepts of this study, terms are defined below which provide definitions, as will be used in the study.

- AIDS – Acquired Immunodeficiency Syndrome. A lethal infectious disease caused by the Human Immunodeficiency Virus (HIV) (Purtilo and Purtilo, 1989).
- Antiretroviral drugs - anti-HIV drugs or HIV antiviral drugs (Uretsky & Odle, 2004).
- HIV – Human Immunodeficiency Virus. The virus attributed to causing Acquired Immunodeficiency Syndrome (AIDS) (Purtilo & Purtilo, 1989).
- Epidemic – Prevalent and spreading rapidly among many individuals in a community (Latham, 1992).
- CDC – Centers for Disease Control (1981).
- Health risk behavior – Any personal activity that places an individual at risk for poor health and contributes to a higher probability of morbidity and mortality (Centers for Disease Control, 1995).
- NIAID – National Institute of Allergy and Infectious Diseases (May, 2001).
- NIH – National Institutes of Health (2001).
- Seropositive – Showing a positive reaction to a test on blood serum for disease (Kalichman, 1996).
- WHO – World Health Organization (Gilks, 1991).

CHAPTER TWO

Literature Review

Introduction

The twenty-first century perspective on women's health focuses on the fact that what differentiates women from men is not their reproductive role per se or the assumption that all else is similar in men and women, but that the ability to reproduce has biological, psychological, and sociological impacts on women's health and illness. Learning to live in the long-term with an epidemic like HIV/AIDS, rather than as a sudden crisis, makes it essential that diversities are addressed. Women with HIV/AIDS face their own challenges, because they must contend with vulnerability related to reproductive issues and domestic violence, social, psychological, and care access problems. Although HIV appears to take the same course in women as it does in men, immune-compromised women are susceptible to a number of gynecological infections and cancers that have only recently been recognized (Kalichman, 1995). They suffer from stigma and are more vulnerable in some ways than men to violence, abandonment, and to neglect of their own care, because they are basically caretakers for others (Kalichman, 1995). Until recently, however, women with HIV/AIDS have been largely invisible in the epidemic. This chapter will provide an overview of current literature pertinent to issues of HIV/AIDS.

Public Health Threat

HIV is considered the world's greatest threat to public health because it is transmitted from one person to the next person, without the affected person knowing he or she is infected (Kalichman, 1996). One of the most remarkable features of HIV infection is its unparalleled ability to infect the host for prolonged periods of time without symptoms. The host symptom-free while the virus causes a progressive disease with the development of a large mass of virus material in the body (Schoub, 1994). This HIV infection eventually leads to AIDS and death in the majority of infected people. There is no cure for HIV/AIDS at this point. HIV has spread across the world and fifty-eight million people worldwide have been infected with HIV, the virus that causes AIDS, according to the Joint United Nations Program on HIV/AIDS (Christiansen-Buller, 2001). Twenty-two million have died after the virus rendered their immune system ultimately defenseless, leaving them open to some types of cancer, nerve degeneration and opportunistic infections such as tuberculosis and pneumonia that physicians once thought were under control (Christiansen-Buller, 2001). Over the past 20 years, AIDS has become a part of life everywhere on the planet. People are living for years with HIV infection while unknowingly spreading the virus to others (Schoub, 1994).

Response to AIDS Epidemic

Early in the AIDS epidemic, people who were infected with HIV had few places to turn to for help. Kalichman (1996) indicates that the communities most affected by AIDS began to respond to the epidemic by establishing

grassroots organizations to meet the needs of people with HIV infection. Today, almost every U.S. city and surrounding areas have service providers who specialize in helping people with HIV and AIDS. The increased political momentum and the prospect of significant increase in available resources make the need for clarity about the best methods in tackling the HIV epidemic more crucial than ever (Piot & Coll-Seck, 2001).

Twenty years of public discussion about AIDS has yielded slow progress in the ongoing debate about how to fight the disease and care for those who have it. Today, the financial, political and social issues that stem from AIDS are discussed as much as its symptoms, and these issues grow more complex each year (Christiansen-Bullers, 2001). AIDS is a devastating disease. The toll that HIV takes goes well beyond bodily functions. Kalichman (1996) states that unlike other life-threatening diseases such as cancer, HIV infection lasts for years with multiple symptoms. Much public response has been fearful and rejecting, and there is no hope for a complete cure. People living with HIV infection, therefore, require a great deal of medical and emotional care and support, as do their families and loved ones.

In the 1980s it was common to think about AIDS as a disease for certain types of people who came to be called "risk groups." Berer & Ray (1993), reported that the belief that HIV and AIDS was restricted to particular, apparently well defined, and often marginalized groups. This reinforces stereotypical views and prejudices about sexual identity and immoral sex, rather than emphasizing an illness that can be the result of sexual behavior in anyone.

But as the epidemic has expanded and we have learnt more about specific behaviors that place people at risk, the notion of risk groups has become less meaningful (Kalichman, 1996). It is the things that people do that lead to HIV infection, not who they are.

Women and HIV/AIDS

Although AIDS was first documented among homosexual men in this country in 1981, according to the U.S. Centers for Disease Control, the total AIDS cases attributable to women in the U.S. increased from 7 percent in 1985 to 20 percent in 1996 (Goldman, 2002). The CDC reports that in 2001, there were 48,360 women and adolescent girls aged 15-44 years reported to be living with AIDS in the United States. These women and adolescent girls are of childbearing age and in the years of highest fertility. An additional 37,309 women and adolescent girls in this age group were also reported living with HIV infection in regions that conduct name-based, confidential, HIV surveillance in adults and adolescents. The CDC states that the numbers presented here are an underestimate of women and adolescent girls living with HIV or AIDS, since many reside in states without integrated HIV/AIDS surveillance. In addition, they report, there may be many infected women and adolescent girls who have not been tested or not reported in areas with relatively new infection surveillance systems. Together these numbers indicate the burden of HIV and the number of persons in need of HIV-related medical and social services for themselves and to prevent the transmission of HIV to their children and others.

The number of women with human immunodeficiency virus (HIV) infection and AIDS has increased steadily worldwide. As of December 2000, according to the World Health Organization (WHO), 33.6 million people living with HIV/AIDS, 16.4 million women were living with HIV/AIDS worldwide, accounting for 47 percent of the 34.7 million adults living with HIV/AIDS (NIAID, 2001). The facts and figures according to WHO (2000) show that of five million adults newly infected in 1999,

- 2.3 million were women;
- Of the 2.1 million people that died of AIDS in 1999, 1.1 million were women;
- 12-13 African women currently infected for every 10 African men;
- There are half a million infections in children (under 15), most of which have been transmitted from mother to child; and
- 55 percent of adult infections in sub-Saharan Africa are in women, 30 percent in South East Asia, and 20 percent in Europe and USA.

HIV/AIDS was only officially acknowledged by concerned international agencies to be a major women's health issue after a meeting in Paris in November 1989. It was given adequate public recognition with World AIDS Day on December 1, 1990 (Berer & Ray, 1993). Professional attention to women with HIV/AIDS began at the Eighth International Conference on AIDS in Amsterdam in 1992 (Berer & Ray, 1993).

By the late 1980s, the demographics of HIV infection began to change as more women became infected, and by the 1990s, women's needs, with women's voices articulating those needs, and women's activities to meet those

needs were much more in the forefront of HIV/AIDS work (Berer & Ray, 1993). The World Health Organization (WHO), in the year 2000, reports that the AIDS epidemic in women is transmitted overwhelmingly heterosexually. This is almost entirely so in Africa and South and South East Asia. In other areas, a proportion of women are infected through: sex with a bisexual or drug injecting partner, their own injecting drug use, heterosexual sex without these factors like drug use, and blood transfusions (in developing countries where blood is not routinely screened). In the recent years though, the role of women in the AIDS pandemic has changed. Early on they were perceived only as care providers to the ill. Many women actually learn they are HIV-positive through prenatal screening, a nearly routine test in most urban hospitals (Anderson, 1993). If testing occurs early in pregnancy, women have to go through the struggle of having to decide whether to terminate in light of potential perinatal HIV transmission. Pregnant women must also consider the use of antiretroviral mediations that may help protect the fetus against infection but with risk of unknown teratogenic effects (Kalichman, 1995). The incidence of women with HIV has been rising at an alarming rate and thus, more women-specific services need to be provided (Rosen & Blank, 1992). It may also be the father of their fetus who infected and likely betrayed them, contributing to additional confusion and emotional distress.

As of 1999 women makeup 17 percent of all people with AIDS and 27 percent of HIV-positive individuals in the United States (CDC and Prevention, 1999a). AIDS is now the fourth leading cause of death among U.S. women ages

25-44 (CDC, 1999b). Although women's experience of HIV disease was largely ignored during the early days of the epidemic (Stevens, in Kalichman, 1995), much has been learned about the psychosocial effect of HIV disease on women in recent years (Katz, 1997; Moneyham et al., 1997; Nannis, Petterson & Semple, 1997; Sowell et al., 1997; Weiner, 1991).

The CDC reported significant increases in AIDS among women of childbearing age, many of whom had young children, and among heterosexual substance abusers and people of color, especially African Americans and Hispanics (Jue, 1992). These women, with limited access to health care, have lower overall quality of life, experience less energy, more pain, a lower sense of well-being, reduced cognitive function, more loneliness, less hope, and a reduced ability to fulfill their social roles (Gardner & Preator, 1996). There is significant evidence that the physical and mental health of women with HIV/AIDS is adversely affected by lack of access to care, which affects their ability to provide good self-care (Gardner & Preator, 1996) as compared to men. In the past, the focus of care has been on the physical health in HIV-positive women, but more recently the mental health factors have become a key concern in quality of life and in survival itself (Gardner & Preator, 1996). One issue that women have to deal with is finding social support that can be available without disclosing their HIV status. What support is available for all people with HIV/AIDS is available if they must disclose their status. Kalichman (1995) states that difficulties associated with HIV status self-disclosure include fears of rejection and social isolation that can occur at times when needs for social

support are greatest. The difficulty in disclosing HIV status is common, even to sexual partners, where there is moral obligation to do so (Marks, Richardson, & Maldonado 1991). Disclosures of HIV infection by parents to children are inhibited by fears of rejection and by the desire to protect the children. The potential costs of self-disclosure are therefore pitted against the benefits of gaining support (Turner, Hays, Coates, 1993). In dealing with disclosure issues and family affairs and what an HIV infected person has to experience, Kalichman (1995) summarizes the whole thing in the following way:

Relationships with committed partners, friends, peers, family members, and professional helpers form a structure and context of social support. Ethnic, cultural, and gender differences in social networks, and social stigmas in HIV infection, create barriers to support, increasing isolation among people who need support. To gain support and opportunities to reciprocate, HIV-positive individuals must overcome barriers and selectively disclose. Although numbers and frequencies of social contacts are related to the availability of support, the content of relationships and the actions of others determine the support that a person receives. (p. 246).

In the recent years, Remien and Rabkin (2001) have reported that most patients with serious, progressive illness confront a range of psychological challenges, including the prospect of real and anticipated losses, worsening quality of life, the fear of physical decline and death, and coping with uncertainty. HIV infection and/or AIDS bring additional challenges due to the rapidly changing treatment developments and outlook.

Appropriate therapy and preventive drugs can forestall the development of AIDS-related symptoms and prolong life in HIV-infected men and women (National Institutes of Health, 2001). However, other factors, including alcohol use, history of childhood sexual abuse, current domestic abuse, and other

psychological and social obstacles also need to be considered in the treatment of HIV/AIDS (NIH, 2001). In the recent years, government agencies have been working together to step up prevention efforts, to improve diagnostic and treatment services, and establish community-based health education and risk-reduction programs for diverse populations (Segal, 1993). These populations include gay and bisexual men, prostitutes, injection drug users, heterosexuals with multiple sex partners, women at risk because of infected partners, homeless people, and youth in high-risk situations, such as runaways and youngsters in shelters or detention centers (Segal, 1993).

The early HIV epidemic in the United States was concentrated among gay men in urban areas such as San Francisco and New York City. However, Shilts (1987) reports that heterosexual women and women who used intravenous drugs were among the first to be diagnosed with the immune-suppressed condition that would eventually come to be known as AIDS. The confluence of psychosocial factors such as motherhood, poverty, and lack of social support, low status and subsequent lack of sexual autonomy have resulted in women obtaining treatment later in their development of HIV/AIDS than men, and thus have received less aggressive treatment (Amaro, Raj, & Reed, 2001).

In light of HIV-positive women's increased susceptibility to breast and cervical cancer, cervical and anal dysplasia, and menstrual problems related to hormone fluctuations, it is especially important that women have access to and are encouraged to use all HIV-related health facilities and programs in their

communities (Cohen & Doner, 1998). Changing health-compromising habits and adopting health-promoting behaviors can improve both general wellness and enhance a sense of personal control. The benefits of health-behavior changes are many, but it is important that clients are not misled to believe that such changes reverse the course of HIV infection (Kalichman, 1996).

HIV/AIDS Process and Treatment

People living with HIV infection in industrialized countries are surviving longer today than at any other time in the history of AIDS, nearly a doubling of life expectancy in the past decade (Kalichman, 1996). Rapid advances in the medical management of HIV disease have improved both the quantity and quality of life for countless people who have access to care. Equally important are social and psychological support, easy access to health care, resources and the availability of essential drugs (Kalichman, 1996). The health of HIV-infected people has substantially improved as a result of recent advances in drug therapies (Johnson & Gerber, 2000).

HIV/AIDS

HIV is a virus, essentially a submicroscopic parasite consisting of a core of RNA wrapped in a protein coat that cannot replicate without invading living cells (Christiansen-Buller, 2001). Like all viruses at its most basic, the virus takes over the cell's mission control center to make the cell do HIV's bidding instead of functioning normally. HIV directly attacks the cells of the immune system. HIV invades a type of immune cell called the CD4 lymphocytes, which play a crucial role in the immune system because they coordinate the attack by

white blood cells and antibodies on viruses and other body invaders (Christiansen-Bullers, 2001). These unique abilities of HIV have made the medical fight against the virus extremely challenging.

AIDS Drugs

There are many variables that cause despair for people living with HIV/AIDS, but there are also many variables that foster hope and resiliency (Kalichman, Ramachandran, & Ostrow, 1998). The medical treatments for HIV infection are one important source of such hope as they offer a chance to live longer with a higher quality life. AIDS is a serious, difficult-to-treat and ultimately fatal disease, though the outlook for those living with it has steadily improved in the United States as new drugs have gained approval from the Food and Drug Administration (Christiansen-Bullers, 2001). Following long periods of asymptomatic infection, any number of general and nonspecific early symptoms may develop for a person living with HIV, and later stages may be characterized by severe depletion of CD4 lymphocytes and the onset of specific illnesses (Kalichman, 1995). Scientists and physicians have not seen anything like this virus before, and in the early 1980s there were no drugs to treat it (Christiansen-Bullers, 2001). However, in the late 1980s and in the 1990s, public hysteria as well as prevention and lobbying campaigns matured, and medical research began bearing fruit in the form of new drugs (Christiansen-Bullers, 2001). Despite their complex workings and complicated names, the AIDS drugs stop or retard the duplication of HIV inside the body's cell. The virus is prevented from overwhelming the immune system, which it normally

does when left unchecked, according to the research findings. The researchers creating early HIV medicines followed this concept, and current medications have built on this approach (Christiansen-Bullers, 2001).

AZT (Zidovudine) and a group of AIDS drugs known as *nucleoside reverse transcriptase inhibitors* (NRTIs) were the first group of drugs developed to fight the virus approved by the FDA in the United States in 1987 (Christiansen-Bullers, 2001). However, AZT and the other NRTIs were no cure. In 1995, the National Institute of Allergy and Infection Diseases (NIAID) showed that combining AZT and other NRTIs and another group of drugs called *protease inhibitors* slowed the high rate of mutation, a characteristic of HIV. The drug combinations became known as cocktails, a breezy name for a major advance in the battle against HIV. A new treatment era was born, accompanied by previously unknown levels of optimism (Christiansen-Bullers, 2001). According to the Kaiser Family Foundation, between 1996 and 1997 the number of AIDS-related deaths dropped 42 percent and another decline of 20 percent followed between 1997 and 1998. There is evidence, however, that these highly active antiretroviral therapies (HAART) do not work well for everyone and that HIV can evade these potent drugs. Nevertheless, the positive findings from clinical trials evaluating HAART have revolutionized AIDS care and have given hope to many people living with HIV infection (Kalichman et al., 1998).

Although these current HIV treatments are extremely effective at reducing viral load for many, a host of aversive side effects, including nausea,

diarrhea, headache, rash, vomiting, and sleep disturbance, may accompany such highly active antiretroviral therapy (HAART) (Remien, Hirky, Johnson, Weinhardt, Whittier, & Minh Le, 2003). Whereas some side effects may subside with time, others persist as long as the medication is continued. These side effects may interfere with medication adherence because they can interfere with daily routines, obligations, and quality of life. This problem of poor adherence cuts across health conditions, treatment modalities, age, gender, and ethnic and socioeconomic groups (Remien et al., 2003). Some experts have grouped the range of factors associated with adherence into four main groups:

1. Patient factors, such as alcohol and other substance use, age, attitudes toward treatment, and personality characteristics;
2. Medication characteristics, such as dosing complexity, number of pills, or food requirements;
3. Interpersonal characteristics, such as the doctor – patient relationship, and other social supports; and
4. The general system within which care is administered (Chesney, 2000).

Thus, health care providers need to be aware that there are typically multiple emotional, cognitive, and behavioral factors that influence people's medication-taking behavior. Adherence is not static, one-dimensional behavior, but rather is dynamic and influenced by changing internal and external variables (Remien et al., 2003).

Current Treatment Needs

Antiretroviral treatment using combination drug therapies, including *protease inhibitors*, can produce sustained suppression of viral replication and decrease viral load to undetectable levels (Deeks, Smith, Holodniy, & Kahn, 1997). These developments in new antiretroviral medications have revitalized hopes that HIV will one day be a controllable disease. However, the changing horizon of HIV treatments is accompanied by new psychological and social challenges (Kalichman et al., 1998). Recent research has demonstrated that HIV-infected women are living with their illness longer than ever, due, in part, to the benefits of these newer, more effective antiviral medications (Moore & Chaisson, 1999).

It is important to note that these treatments have both indirect and direct implications for the mental health care of people living with HIV/AIDS as well as for many individuals at risk for HIV infection (Kalichman, 1998). History shows that news about advances and setbacks in HIV treatments influences the psychological adjustment of people with HIV/AIDS (Schroder & Barton, 1994). For HIV infected persons, services need to be focused on early problem solving including educating those who are HIV-positive about how to stay healthy and asymptomatic (Land, 1992). The treatment of those who have developed AIDS symptoms must center on containing the illness and on enhancing quality of life. The approach to the medical care and monitoring of people living with human immunodeficiency virus (HIV) infection has changed rapidly as health professionals have become more proficient and knowledgeable about this

disease (Scofield, 1995). The psychological implications of protease inhibitors and combination therapies include issues of adherence to treatment regimens, treatment decisions, potential drug interactions with psychoactive medications, economic barriers to accessing care, renewed hope and optimism, coping with treatment failures, and prevention implications (Kalichman et al., 1998).

Land (1992) reports that HIV/AIDS has become more than a calamity heard or read about in the media. It is an intrusive and unwanted guest demanding change in every aspect of life. It is a crisis in which the individual anticipates the disease state; copes with the innumerable vicissitudes of the disease; undergone the physical, social economic, psychological, and spiritual changes that the disease brings; and lives with the devastating consequences of its aftermath (Land, 1992).

Infection with HIV is no longer an early death sentence, and certainly not an immediate one. For women living with HIV, it is a time of uncertainty and hesitation, of coming to terms with who they are and what they want as women and as HIV-positive persons (Berer & Ray, 1993). As the number of people needing medical services increases, HIV infection will place even greater demands on an already burdened health care system, again exacerbating negative attitudes toward HIV/AIDS (Herek, 1990). As medical treatments for HIV infection continue to advance, therapists and counselors must make an effort to keep up with their rapid pace. And to remain optimally effective, Kalichman et al. (1998) suggest psychotherapists and counselors must be informed about the progression of HIV infection and the progress of medical

science in battling AIDS as well as the most recent of what is hoped will be many new treatments for persons living with HIV/AIDS.

Women's Psychosocial Needs

Although the rate of men diagnosed with AIDS each year has slowly decreased, the rates of women diagnosed each year in the United States has grown in recent years (CDC, 2001). Women comprised 20 percent of newly reported AIDS cases in 1996, but by 2001 this figure rose to 26 percent (CDC, 1996, 2001). The number of new HIV infections has also continued to increase among women, from 3983 (29%) new infections reported in 1996 to 11,133 (32%) new infections in 2001 (CDC, 1996, 2001). Extended survival and increased rates of infection have resulted in a substantial increase in the number of women confronting the psychological challenges of living with HIV/AIDS as a chronic illness (Schrimshaw, 2002). Multiple factors interact in HIV-related distress, including perceived responsibility for having contracted HIV, the potential for having unknowingly placed others at risk, and changes in physical appearance that may occur in later stage (Nichols, 1985).

Psychological distress among people with HIV infection is as diverse as the epidemic itself. Reactions to HIV infection may include feelings of sadness, worry, despair, and confusion, as well as other affective, cognitive, and behavioral responses (Kalichman, 1995). Several medical events occur over the course of HIV infection that serve as markers for vulnerability to psychological distress. People suffering from human immunodeficiency virus (HIV) infection have vast psychosocial needs that begin with diagnosis and evolve over the

course of the illness (Scofield, 1995). HIV infected women may experience significant difficulty adjusting to their illness. A recent epidemiological study of HIV infected women identified 77 percent with chronic or intermittent symptoms of clinical depression (Schrimshaw, 2003). Schrimshaw suggests that the high rates of depressive symptoms among women living with HIV/AIDS demand an urgent need to identify factors associated with their adjustment, so that effective interventions can be designed and implemented. It is important that a system's framework is used to describe the chronic illness stressors and strategies to promote health among HIV-positive women. Thus, it is necessary that a psychosocial history is used to evaluate a woman's mental status, including appearance, behavior and attitude, mood affect, thought process and content (Sternberg, 1992).

In recent years, the majority of researchers and clinicians have moved away from a strictly biological model, acknowledging in addition the role of psychosocial factors. These are social and environmental factors associated with increased or different needs than those associated with women who are not HIV-positive and report mental health problems. These differing needs include the following:

1. Caring roles,
2. Employment status,
3. Gender role socialization,
4. Representation of femininity,
5. Multiple role strain and conflict,

6. Sexual violence or abuse in adulthood (Ussher, 2002)

Research is furthering an understanding of how women living with HIV and AIDS deal with their mental health (Corea, 1992). Other issues that must be evaluated during psychosocial assessment, according to Christ & Weiner (1985), should include:

- How medical treatment will be paid for,

- How clients will support themselves if they are unable to work,

How clients will disclose their diagnosis (and perhaps life-style) to family and friends.

Clinical and psychosocial interventions that are related to HIV will vary and change over time due to the unpredictability of the manifestations of the conditions that are caused by the virus, since the course of the infection is impossible to predict (Christ & Weiner, 1985), as well as the infection's impact on each person's unique life situation.

HIV/AIDS and Mental Health

Extensive literature has demonstrated that there is influence of social interactions on psychological adjustment to chronic illness (Willis & Fegan, 2001). People living with HIV/AIDS must deal with the physical impact of the disease as well with emotional reactions, changes in their role performance, and changes in their relationships with others (Furstenberg & Olson, 1984).

Veilleux (2004) reports that many people living with HIV, and at times their partners, families and friends, will engage a course of psychotherapy in order to address issues or difficulties that arise directly or indirectly in relation to HIV infection. Common themes that clients bring to psychotherapy include issues

related to disclosure, anger, loss, abandonment, betrayal, dependency, shame, guilt, uncertainty, dependency, suicide, loneliness, anxiety and fear Veilleux (2004). It is essential for the psychotherapist to conduct a thorough assessment of all issues that may affect psychological functioning. For many people living with HIV and experiencing psychological distress, psychotherapy with a strong therapeutic alliance is an important facet of working toward a healthy adaptation to life with HIV (Veilleux, 2004).

Various aspects of the disease and its treatment cause the feeling of lack of control and the sense of powerlessness over one's life. Bereavement over AIDS-related deaths appears most pronounced among people who are themselves HIV-positive. Given that HIV is principally spread through sexual behavior and needle sharing, people with HIV infection experience multiple losses because of the prevalence of HIV in their social networks (J.L. Martin & Dean, 1993b). Witnessing the degenerative effects of HIV infection, the onset of AIDS, and the eventual death of a friend or relationship partner provides vivid images that prompt thoughts one's own impending illness (Kalichman, 1995). Studies show that people bereaved over an AIDS-related death may seek mental health services to adjust to their own AIDS-related concerns. Literature indicates that when providers focus on information sharing, emotional support, problem solving, and enhancement of coping skills, they empower people living with HIV/AIDS to manage their lives (Schrimshaw, 2002).

Useful group modalities include cognitive behavioral therapy and self-help, for example group work or reading (Macks, 1989). Walker (1996)

suggests that people with HIV/AIDS who are more needy can tax their family and friends. Women who are having difficulty accessing supportive networks could be encouraged to join a group as a means of developing support. Veilleux (2004) suggests that during periods of chronic illness, the psychologist's roles are to facilitate wellness and recovery by helping the patient to cope positively with the illness, and to provide a relationship in which the patient can express the anxiety, fearful, and depressive effect related to his or her situation. With HIV/AIDS, patients experiencing chronic illness are confronted by serious psychological problems and emotional and existential crises at a time when their coping resources are compromised by weakened health. The psychological and social disruptions may also undermine the ability of family members and other loved ones to help at a time when their support is more needed (Veilleux, 2004).

Supportive social interactions have been consistently found to be positively associated with psychological adjustments to stress and illness, including HIV infection (Schrimshaw, 2002). More recently, the detrimental effects of negative or unsupportive social interactions on psychological adjustment also have been demonstrated, including research among HIV infected patients (Schrimshaw, 2002). Negative and unsupportive social interactions may be particularly important for the psychological adjustment of individuals living with chronic illness (Schrimshaw, 2003). Illnesses, particularly HIV/AIDS, can be stigmatizing. Fears of contagion and negative attitudes about behaviors associated with HIV/AIDS may lead potentially supportive individuals to engage in negative social interactions (e.g., rejection,

disapproval, conflict), at a time when the individual is most in need of support (Schrimshaw, 2002). These unsupportive interactions may result from misguided attempts to provide support or from failure to provide support to the patient. Unsupportive interactions may have a more detrimental effect for those who are under greater stress (e.g. more physically ill), thereby, exacerbating the negative effects of stress on emotional distress (Schrimshaw, 2003).

Another aspect of social support is that of the need for these women to inform their partners of their HIV status. Disclosure of HIV status is especially difficult for women who fear rejection and abandonment (Sherr, 1996). The horror of what HIV or AIDS means can often place an HIV-positive woman in a position of patronizing victim-hood, rather than empowering her to make choices about how to live her life well (Berer & Ray, 1993). The AIDS epidemic presents society and individuals with multiple challenges. Advances in treatment have changed the way the medical community approaches HIV disease, and people living with HIV are finding that they are staying healthier longer. Schrimshaw (2003) indicates that women who experience unsupportive interactions from multiple sources are likely to experience more depressive symptoms than women who experience unsupportive interactions from only one source. In contrast, an interaction may exist in which any single source of supportive interactions may result in elevated psychological distress.

As more have delved into HIV research, Corea (1992) reports that it has become clearer that in preventing, studying, and treating AIDS in women, the questions chosen by scientists, by physicians, by mental health providers, and

by the federal funding agencies were defined through the lens of women's reproductive function. In so doing, any women's experience of HIV/AIDS that didn't relate to her reproductive function was ignored. In the early days, the onslaught of the AIDS crisis, revealed that no matter what strides were made, women were still considered second-class citizens (Corea, 1992) in HIV/AIDS research and treatment because of their invisibility. Since 1988, the approach to the medical care and monitoring of people living with HIV infection has changed. Professionals have become more proficient and knowledgeable about this disease (Scofield, 1995).

The most current CDC statistics on women and HIV reveal that the number of women living with HIV/AIDS in the United States has grown considerably over the past 20 years. At the end of 2000, approximately 17% of all people who had been diagnosed with AIDS since the beginning of the epidemic were women. There were approximately 68,000 women in the United States living with AIDS at the end of 2000 and more than 67,000 women have died of the disease over the past 20 years. Women are also more likely than their male counterparts to be single heads of households and primary providers for their children (Parrish, Burry, & Pabst, 2003) To manage the complexities of HIV/AIDS, patients are called on to establish rigorously organized lifestyles and to adhere scrupulously to medical regimens (Parrish, et al., 2003). Although people with HIV/AIDS can manage their illness for years, if not decades, such survival entails managing the increasingly rigorous medical demands of combination drug therapies to minimize opportunistic infections (Parrish, et al.,

2003).). Mental health providers are ideally suited to recognize the psychosocial complexities that HIV/AIDS entails for women and how such circumstances can interfere with medical management and meeting children's needs. This suggests a social work role at least as much as a counselor role.

Providers and HIV/AIDS

HIV can now be viewed as a chronic illness that will demand lifelong adaptations and create challenges that will change over time (Kelly, 1989). The advent of the new class of antiretroviral drugs known as *protease inhibitors* has revolutionized care for people living with HIV/AIDS (Shernoff, 1999). People suffering from HIV infection, as indicated earlier, do have vast psychosocial needs evolving with time over the course of the illness. Access to services must be ensured, and research is needed to identify problems and potential solutions. Shernoff (1999) states all therapists and counselors have a prominent role to play in ensuring that their clients are knowledgeable about the medications they are considering, the limitations of their effects, and the implications for choosing or not choosing to use them. Client's capacity to sustain long-term medication adherence has been shown to correlate with other life changes that affect quality of life and, ultimately, beliefs that one can make a difference in his or her health outcomes (Fincham & Wertheimer, 1985).

Interventions with people with HIV/AIDS may serve to address skills on how to provide more effective support. Schrimshaw and Siegel (2003) report that at a larger community level, interventions focused on reducing stigmatization of HIV/AIDS may serve to eliminate potential barriers to support

and a potential cause of unsupportive interactions. Mental health services occur within a broad spectrum of care for most HIV-positive people clients. The providers can help clients address medically related concerns, including treatment attitudes, compliance, and life-and-death issues (Kalichman, 1995). In the early years of the HIV epidemic, most AIDS clients were educated, white, middle-class, gay men. In seeking services from traditional providers, they initially experienced AIDS phobia, homophobia, and discrimination (Jue, 1992). In the United States the delivery of health care was almost exclusively dominated by sometimes homophobic professionals and institutions before the AIDS epidemic (Shernoff, 1999). Now well into the second decade of the HIV/AIDS epidemic, the evolving realities of AIDS has created a need to learn about cultural diversity. As we shall see in the next section, stronger efforts must be made to counter the discrimination and social stigma associated with HIV/AIDS (AIDS Weekly, 2001).

HIV/AIDS Stigma

In 1990, Herek identified six general dimensions of social stigmas: a) concealability, the extent to which a condition is hidden or apparent to others; b) disruptiveness, the extent to which it interferes with social interactions and relationships; c) aesthetics, the degree to which others react to the condition with dislike or disgust; d) origin, the amount of responsibility attributed for causing or maintaining the stigmatized condition; e) course, the degree to which the condition is alterable or progressively degenerative; f) and peril, the degree to which the condition will physically, socially, or morally contaminate others.

AIDS-related stigma (or, more simply, AIDS stigma) refers to prejudice, discounting, discrediting, and discrimination directed at people perceived to have AIDS or HIV, and the individuals, groups, and communities with which they are associated (Herek, 1999).

From the moment scientists identified HIV and AIDS, social responses of fear, denial, stigma and discrimination have accompanied the epidemic. Fredriksson and Kanabus (2003) report that stigma can be used to marginalize, exclude and exercise power over individuals who show certain characteristics. Literature indicates that not only are HIV and AIDS complex medical situations, they also carry societal stigmas and implications for behavior change (Scofield, 1995). AIDS stigma is effectively universal, but its form varies from one country to another, and the specific groups targeted for AIDS stigma (Herek, 1999).

Whatever its form, stigma inflicts suffering on people and interferes with attempts to fight the AIDS epidemic (Fredriksson & Kanabus, 2003). Herek (1999) indicates that AIDS stigma has been manifested in discrimination, violence, and personal rejection of people with AIDS. Whereas the infectious characteristics of AIDS as an illness probably make some degree of stigma inevitable, AIDS has also been used as a symbol for expressing negative attitudes toward groups disproportionately affected by the epidemic, especially gay men and drug users (Herek, 1999).

Literature indicates that researchers found a 40 percent increase between 1991 and 1997 in the number of Americans believing that people who got AIDS

through sex or drug use deserve their illness (Herek, Capitanio, & Widaman, 2002). While 20 percent expressed this view in 1991, 28 percent did so in 1997. By 1999, the figure had declined to 25 percent, though it was still higher than at the beginning of the decade (Herek & et. al., 2002). A 2000 issue of *American Journal of Public Health*, reported a study that indicated that fewer Americans now want to quarantine people with AIDS compared to ten years ago, but growing numbers blame people with AIDS for their illness and don't understand how AIDS is spread.

HIV/AIDS and IDU

In 1992 more than 30 percent of all reported cases of AIDS were directly linked to injection drug use (Stein, 1992). Injection-drug use is a risk factor for acquired immunodeficiency syndrome (AIDS). The CDC (2003) reports that of the 765,559 cumulative AIDS cases diagnosed as of December 2000, a total of 193,527 (25%) occurred among injection-drug users (IDUs). IDUs become infected with human immunodeficiency virus (HIV) through sharing injection-drug equipment with HIV-infected persons or by engaging in other risk behaviors such as having unprotected sex. The data by CDC (1998) suggests that three interrelated issues play a role – the continued health disparities between economic classes, the nation's inability to successfully deal with substance abuse, and the intersection between substance abuse and the epidemic of HIV and other sexually transmitted diseases. For prevention efforts to succeed we must address the dangerous intersection of drug-related and sexual risk. There is no question that drug use is fueling the spread of the epidemic

among African American and Hispanic populations. In addition to the direct impact of injection drug use on the spread of HIV, many people infected heterosexually are infected through sex with an injection drug user or sex in exchange for drugs or money.

Of the reported cases among women, 71 percent were linked directly to IDU or indirectly through sexual contact with an infected drug-using male (Stein, 1992). The CDC (2002) reports that since the epidemic began, injection drug use has directly and indirectly accounted for more than one-third (36%) of AIDS cases in the United States. This disturbing trend appears to be continuing. CDC reports that of the 42,156 new cases of AIDS reported in 2000, 11,635 (28%) were IDU-associated. It is reported that IDU-associated AIDS accounts for a larger proportion of cases among adolescent and adult women than among men. Since the epidemic began, fifty-seven percent of all AIDS cases among women have been attributed to injection drug use or sex with partners who inject drugs, compared with thirty-one percent of cases among men (CDC, 2002). Women who have sexual contact with bisexual men or injection drug users or who use injection drugs themselves are at high risk for contracting HIV (Sternberg, 1992).

The rejection and discrimination experienced by many people with HIV/AIDS can exacerbate their risk. Fear of rejection can be even worse and often stops women from telling anyone or seeking help (Berer & Ray, 1993). This rejection holds as true in the rich countries of the north (European countries) as it does in the poorer countries of the south (African and South

American countries), because stigma is a powerful tool of social control (Fredriksson & Kanabus, 2003).

Literature reveals that continued substance use by an HIV-positive individual might increase viral replication while increasing vulnerability to opportunistic infections associated with HIV (Batki, 1990). Drug use is also often a means of psychological escape, and therefore commonly related to coping deficits for managing serious life stressors (Kalichman, 1995). Therefore, adjustment to HIV infection may be complicated for injection drug users because of vulnerability to social and personal stressors. The diverse needs of HIV-positive substance abusing clients demand that they have access to multiple service systems, including health care, social welfare, mental health, public health, clinical research, and substance –abuse treatment (Stein, 1992). However, the double stigma associated with HIV and substance abuse often prohibits these clients from accessing needed services because they face prejudices and discrimination. Kalichman (1995) reports that this is a major stress for women injection users, and thus maybe have unlimited access to health care and may be unable to obtain treatment in a timely manner. It is important that caregivers must examine their own attitudes toward working with this growing client population, and service agencies must examine policies and procedures that may limit access to services (Land, 1992).

Partnership or client-empowerment models are especially helpful to people with AIDS, particularly because clients are living longer and healthier lives and are more capable of doing more for themselves (Jue, 1992). It is

known that in Western countries such as the United States, people infected with HIV who are privileged enough to be educated, sophisticated consumers of medical care with private insurance are living longer than poor uninsured, who all too often are women and people of color (Shernoff, 1999). Working as an HIV provider, especially in an AIDS service agency, presents unique personal, professional, and organizational challenges. HIV/AIDS-related stigma does affect issues related to HIV testing including delays in testing, the effect of delay on further transmission of HIV, and individuals' responses to testing positive (Chesney & Smith, 1999). Early detection of HIV infection is important, and the knowledge of one's HIV seropositivity can lead to earlier treatment and improved outcomes (Herek, 1990).

Women in the New Era of HIV/AIDS

The roles of women in the HIV pandemic have changed considerably since 1980s. Their roles must be looked at from both a systematic and interpersonal perspective (Rosen & Blank, 1992). From the systematic point of view, the authors indicate it is important to consider the harsh realities of women's political, social, and economic status in the society. They go on to say that from an individual, interpersonal point of view, we must consider how women view themselves and how they relate and are expected to relate to others (Rosen & Blank, 1992).

Women experience HIV/AIDS differently than men do in a number of important respects, some of which are physiological and some of which are social. For example, women have a much higher risk than men for contracting

HIV through heterosexual intercourse. Women progress to AIDS at lower viral load levels and higher CD4 counts than do men, a finding that might have implications for care and treatment of HIV-infected women, particularly with antiretroviral therapies (NIH, 2004). Several studies show that women who are diagnosed with HIV early and who receive appropriate treatment live as long as HIV-positive men; but survival times for women are shorter than for men primarily because women are less likely than men to receive an early diagnosis and treatment (Gaberman & Wolfe, 1999). In a society that places great emphasis on wellness and productivity, all people faced with terminal illness deal with feelings of stigma, lowered self-esteem, loss, as well as economic hardships (Rosen & Blank, 1992). For women with HIV, these issues are magnified. Women may be caregivers in families where their spouse is also HIV-positive, and they may have an HIV-positive child, making it necessary for women to balance their own care with the needs of their family (Minkoff & DeHovitz, 1991). HIV-positive women with uninfected partners may be rejected, emotionally isolated, and financially disconnected. For some women they are dealing with changes brought about by HIV/IDS, such as anger, uncertainty about the future, changed expectations and goals, and sometimes depression (Gifford, Lorig, Laurent, & Gonzalez, 2000). Depression is reported as one of the normal reactions to chronic illness, and along with it come fear and concern for the future (Gifford, et al., 2000). Women therefore need access to social support services such as housing, transportation, and child-care to enable them to adhere to medications (Gaberman & Wolfe, 1999). Mental

health professionals can also offer the needed care to the women with HIV/AIDS by addressing the psychological distress and maladjustment that often accompanies HIV infection (Kalichman, 1995).

HIV/AIDS in Rural Areas

HIV/AIDS surveillance data have allowed the Centers for Disease Control and Prevention (CDC) to monitor the spread of HIV in the United States and guide efforts to prevent and control the disease (CDC, 2000). Close to one million Americans are living with the AIDS virus, seven percent of whom live in rural communities, says Shari Steinberg, an epidemiologist with the HIV/AIDS Surveillance Branch of the CDC (Whitlock, 2002). Research relating to women with HIV/AIDS has focused primarily on urban samples. Although a small number of HIV/AIDS research has been conducted outside of urban settings, recent studies demonstrate an alarming increase in HIV infection rates in rural areas (Kalichman & Heckman, 1999). Over the years, careful attention has been paid to the presence of HIV/AIDS beyond large metropolitan areas in the Northeast and on the West coast, the areas that were initially severely affected by HIV (Whitlock, 2002). Women in rural areas are reported becoming HIV infected at higher rates than men, and that their willingness to engage in risky sexual behavior underscores the need for prevention efforts (Walker, 2002). Studies show that when compared to urban residents with HIV, rural patients are more likely than their urban counterparts to be female, white, unemployed, and have an income of less than \$10,000 annually. They have less access to mental and physical health, feel more isolated, receive less support

from family and friends, suffer from community stigma and discrimination, and have a greater fear that their HIV status will be discovered (Whitlock, 2002).

The southern region of the United States accounts for the largest proportion (34%) of the 641,086 acquired immunodeficiency syndrome (AIDS) cases reported through 1997 and for 54% of the 58,689 AIDS cases among persons residing in rural areas (CDC, 1998). This report describes characteristics of persons infected with human immunodeficiency virus (HIV) who reside in rural areas and small cities of the southern United States and indicates that, before infection, there was a low prevalence of perceived risk. In 1995 CDC stated that from 1991 to 1995, reported AIDS cases in rural areas of the U.S. rose from 4.9 to 8.8 cases per 100,000. This 80 percent increase is far greater than the 64 percent increase and the 47 percent increase that was observed over the same time span for small metropolitan statistical areas (MSAs) and metropolitan statistical areas, respectively. The CDC (1995) reported that additional indications that rural HIV infection rates would continue to rise are provided by the following studies:

- In a report of AIDS cases in all U.S. counties, most of the top 25 counties experienced rapid increases in AIDS cases were predominantly rural. The study concluded that, “the epidemic has... entered a dangerous phase of spreading to rural America.”
- In 1990, the National Commission on AIDS (NCOA) reported that, “The number of new AIDS cases diagnosed in rural communities across the country

was growing at an alarming rate....a 37 percent increase in diagnosed AIDS cases in rural areas compared to a 5 percent increase in metropolitan areas....”

- A 1996 study stated that: “An obvious area of needed epidemiological research and public health intervention would define indigenous HIV infection in small cities and rural areas, particularly in the South.”

The Centers for Disease Control and Prevention now puts the number of rural residents living with AIDS at around 50,000; far greater is the number of people in these small communities who are HIV positive, but who have not yet developed AIDS. (Whitlock, 2002). Even as the spread of AIDS into small towns escalates, HIV-infected patients who live outside urban areas continue to confront significant obstacles to effective care (Ullrich, 2003). Social stigmatization and limited access to health care systems can reduce the benefits of aggressive approaches to AIDS for people in rural areas. The National Rural Health Association (1998) reports that the rural setting provides a set of obstacles to HIV/AIDS prevention and treatment that are entirely different than the challenges faced in the metropolitan areas. Beyond the numbers, there are social issues and challenges unique to the rural setting. In rural areas, acquiring treatment may be difficult, and rural HIV/AIDS patients often travel two or more hours to obtain medical care because getting tested for HIV, discussing sexual practices with health care providers and practicing safe sex can all be difficult to do privately and confidentially in rural areas (NRHA, 1998).

In many rural areas, heterosexual contact accounts for the most HIV transmission (AIDS Research Institute, 1996). In addition, having a sexually

transmitted disease (STD) such as syphilis and gonorrhea may increase the likelihood of HIV transmission. The ARI (1996) reports that injection drug use (IDU) and non-injection drug use, especially crack cocaine use, puts many rural residents at risk for HIV. In rural areas, traditional moral values, conformity to community norms and intolerance of diversity can be strong. ARI (1996) reports that many men who have sex with men in rural areas remain “in the closet” and their sexual lives remain secretive. These men may engage in unprotected sex in anonymous sexual encounters in public places like rest stops and adult bookstores, or may travel to large cities where they encounter a large pool of HIV-infected men. Often these men are married and their secret lives pose a grave danger to their unknowing female partners.

Since the first reports of cases of AIDS in 1981, the Centers for Disease Control and Prevention (CDC) has monitored the epidemic in the United States (National Rural Health Association, 1997). The CDC began reporting AIDS by non-metropolitan area in spring 1991, and most states’ data on rural areas is based on public health reporting. Confidentiality can be hard to maintain in rural areas, yet is crucial for many residents due to fear of stigmatization (ARI, 1996). Rural residents may be more likely to travel to urban areas for HIV testing because of concerns about confidentiality.

Researchers have noted that rural HIV/AIDS patients often travel two or more hours to obtain medical care because they lack confidence in their local physicians, are unable to find a local physician who will see them, and are concerned about confidentiality (Mainous & Matheny, 1996). Other studies

indicate that rural HIV/AIDS patients tend to be diagnosed in later stages of the disease because their physicians do not consider them to be at risk for HIV (NRHA, 1997). Compared to their urban counterparts, rural residents had a lower perception of their risk for HIV (Mainous, Neill, & Matheny, 1995). This creates doubt as to the accuracy of data from rural areas. There is also debate about how many AIDS patients are infected in cities and return home to rural areas for care versus those acquiring AIDS in rural America who then travel to urban areas for the high-tech treatment not available in the countryside (NRHA, 1997). Other service gaps and access barriers frequently noted in the rural HIV/AIDS literature include an inadequate supply of mental health and substance abuse counseling services, the lack of formal and informal support systems, and discriminatory attitudes (Berry, McKinney, & McLain, 1996).

Though much of this research pertains to men, these issues are all the more profound for women. Whitlock (2002) reports that finding a doctor in rural America is difficult for people with HIV, and finding mental health support is nearly impossible. She states that according to the Federal Substance Abuse and Mental Health Services Administration, the nation's mental health care system does not have the resources necessary to provide services for Americans infected with or affected by HIV. Most small communities have no mental health services. Those that do often are unprepared to counsel people living with the virus (Whitlock, 2002).

Improvement in women's social and economic status is a crucial step for increasing their ability to protect themselves and their families and children

from the epidemic. The National Rural Health Association (1997), reports that although most of the women with HIV/AIDS reside in larger cities, 6 percent of the female AIDS cases reported to the CDC during 1994 were residing in non-metropolitan statistical areas (non-MSAs) at the time of AIDS diagnosis (Gwinn & Wortley, 1996). In rural areas, as in the cities, the epidemic further adds to the already formidable burdens women bear, as workers, caregivers, educators and mothers (Global Action, 2001). Shifts from urban-to-rural or rural-to-urban living, coupled with frequently low socioeconomic status for women, have accompanied increase in HIV infections (Cajetan-Luna, 2001). Studies have shown that HIV prevalence rates can be unusually high among mobile populations (Global Action, 2001). In the early 1980s, suburban and rural populations were generally considered to be at low risk for HIV infection according to population-based estimates that identified HIV infections more often among urban populations, particularly gay men and injecting drug users (Cajetan-Luna, 2001). With some justification, AIDS has been identified largely as a disease of the major urban centers, but nonetheless, the urban / nonurban dichotomy has been diminished over time by the pervasive spread of the epidemic (Cajetan-Luna, 2001). Research has indicated that many people living in suburban and rural areas have continued to overlook, ignore or deny their potential risk, and some even believe that HIV/AIDS is a problem for other people, and they may trust sexual partners unquestioningly (Cajetan-Luna, 2001).

In frontier areas with low numbers of cases, there is usually a shortage of primary care providers (NRHA, 1997). Patients may have to travel long distances to access care because few of these providers are trained and willing to care for HIV/AIDS patients. A literature review reveals that there are a few meaningful statistics showing the extent of the epidemic and the health systems' response in rural America (NRHA, 1997).

Voelker (1998), reports that rural communities present unique challenges in the management of HIV disease. There has been a dramatic increase in the number of HIV patients in rural areas, yet there is perception that AIDS is not a problem in rural areas. This, in turn, affects risk assessment, testing, and counseling. Voelker (1998) states that most women affected by the epidemic live in large cities, but about 1 in every 16 women with AIDS lives in a rural area. The proportion is about 1 in 10 in the south. In one study women accounted for a low of 19 percent of patients with HIV and AIDS at the Valley AIDS Council in South Texas and a high of 48 percent at the De Porres Center in northwest Mississippi in 1998 (AIDS Weekly, 2001).

Projections from the CDC suggested that the virus would make even deeper inroads into small-town America. Podolsky (1990), reported that in the following year, as many as 71,000 more Americans, an annual record, would be diagnosed with AIDS. In the rural South and Midwest, as in the rest of the country, most of those who develop the full-blown AIDS disease are homosexual and bisexual men. But southern health officials note a new alarming increase in HIV infection among crack-cocaine addicts, especially

women. People in small towns along the major drug-trafficking routes that shoot northward from Florida become addicted and trade sex for drugs (Podolsky, 1990). Crack use is reported to be as prevalent in rural America as it is in the major metropolitan areas (Podolsky, 1990). The CDC (2002) reports that non-injection drugs (such as “crack” cocaine) also contribute to the spread of the epidemic when users trade sex for drugs or money, or when they engage in risky sexual behaviors that they might not engage in when sober. One CDC study of more than 2,000 young adults found that crack smokers were three times more likely to be infected with HIV than non-smokers. Numerous studies have documented that drug users are at risk for HIV through both drug-related and sexual behaviors, which places their partners at risk as well (CDC, 2000).

A recent report by the state department of human resources indicates that one fourth of those diagnosed with AIDS lived in the rural areas (Voelker, 1998). The spread of AIDS in the Midwest is reported as a bit slower. The meager health care systems that do exist in rural areas are not ready for an influx of chronically ill patients that come home for family support from urban areas (Podolsky, 1990).

With the ruralization of AIDS in the summer of 1990, Podolsky (1990) reported that the system (Health Human Services) was redesigned. A plan was made to make clinical research centers more accessible to country doctors and started providing some system for outreach and patient education (Podolsky, 1990). Thus, rural areas are more aware of and are prepared for treating HIV/AIDS persons.

Literature Review Summary

In this chapter I presented a review of the literature pertaining to various aspects of this research HIV/AIDS. While it might be assumed that HIV/AIDS is a disease that has no boundaries, not much research has been conducted in the resources conducted of the experiences of living with HIV/AIDS from the perspective of women in western rural states. The research currently available which focused on women seemed to concentrate more on the new medications and their side effects, but did not delve deeply into women's experiences of living with the disease every day of their lives. Living with HIV/AIDS might be assumed to be an ordeal by many people, and some might believe with medications things have changed over the years, but not much information is revealed in literature about how women have adjusted to the demands of this disease. Until recently, research has focused on perspective of men in efforts of dealing with HIV/AIDS. Globally, women comprise approximately forty-seven percent of the over thirty-six million adults living with HIV/AIDS, according to a UNAIDS report from the end of the year 2000 (NIH, 2001). Literature indicates that women experience HIV/AIDS differently than men do in a number of important respects, some of which are physiological and some of which are social. There are a number of HIV-related conditions that occur solely or more frequently in women than men. Chief among these are those that relate to gynecological manifestations, like the risk of invasive cervical cancer, which has been found to be greater for HIV infected women than for the general population. This researcher also believes that an understanding of the specific

experiences of women must go beyond sex differences in infection rates and disease manifestations. There are profound differences in the root causes and consequences of HIV/AIDS in females and males that have to do not only with biology, but also with psychology, cultural attitudes, and social economic position.

Literature indicates that in the United States HIV infected women encounter more barriers to care than men, and they enter health care services generally at later stages of infection than do men. Because they tend to be poorer and have dependent children, women with HIV/AIDS receiving care are nearly twice as likely as men to be covered by Medicaid and half as likely as men to be privately insured. HIV/AIDS also has had a tremendous impact on family and other social institutions, such as education and the economy. These consequences have been particularly severe for women because of their cultural roles as primary caretakers of family members and their continued economic dependency on men. Literature reviewed indicates that most HIV infected women are of reproductive age, and they must make difficult choices should they want to have children, including dealing with the social stigma attached to being an HIV infected pregnant woman. This is a source of significant psychological stress, and thus different coping skills have to be employed. As attention to women and HIV/AIDS increases, it is imperative to address issues that relate to them. For all these reasons, this researcher thought it was important to understand HIV infection and AIDS among women in diverse geographical settings and during different stages of their life course. It is for

this purpose that this researcher therefore wished to conduct a study of lived experiences of women with HIV/AIDS in rural areas.

Although society seems to have become more tolerant about HIV/AIDS, rural America has not caught up because they have limited experience with patients dealing with HIV/AIDS. From the onset of the HIV pandemic, the perception that AIDS was a man's disease was widespread among the general public. The CDC failed to include any female-specific conditions until 1993, when the gynecological manifestation of invasive cervical cancer was included as an indicator of AIDS (Shernoff, 1999). Even though women's gynecological needs are obviously extensive and obviously worthy of continued study, as some literature indicates, it is important that providers, researchers and policy makers avoid viewing women only reproductively. It is the purpose of this study to explore the experiences of these women that live in rural areas, their experience of living with HIV/AIDS and their perceptions of living with HIV/AIDS in relationship to the social environment.

Increasing our knowledge and understanding of the experience of women living with HIV/AIDS may be valuable to the Lewis and Clark AIDS project in planning and developing their retreat intervention, but this knowledge might also help us and other caregivers in our day to day interactions with those women that struggle with the disease. And in addition, insights and information gathered in this study will hopefully add to the existing body of knowledge in the area of women living with HIV/AIDS in rural areas.

CHAPTER THREE

Methodology

Since this study sought to understand the experience of living with HIV/AIDS from the perspective of women living with HIV/AIDS, a qualitative approach was taken. The question that was addressed was “What is your experience of living with HIV/AIDS in a rural area?” The question was open-ended in order to find out what the participants’ experiences and interactions meant to them in their own terms.

This researcher gathered the data at a Women’s retreat, initially for the purpose of assisting the Lewis & Clark AIDS Project in improving the planning and evaluation of the retreat intervention. For the purpose of this study, utilizing this data was an attempt to gain a greater understanding of the social dynamics of living with HIV/AIDS. Research in the area of women and HIV/AIDS has developed only in the recent years. This researcher has found little information which describes what happens to women in the process of living with HIV/AIDS, and what this process means to them. In order to answer this question, the women living with HIV/AIDS were recognized as the experts regarding their experience. They know best what it means to live with HIV/AIDS and they can describe the experiences. A qualitative methodology permitted this researcher to emphasize procedures that allowed the women with HIV/AIDS to speak for themselves.

Research Design

In an attempt to gain insight into experiences and personal perspectives of women living with HIV/AIDS in rural areas, using depth interviews provided a means to collect qualitative data. Qualitative data, indicates Charles (1998), are analyzed logical-inductively, a thought process that uses logic to make sense of observations. Certain qualities of qualitative research made it possible for this researcher to accommodate the thought process as described by Charles (1998):

- Observations were made of behaviors, situations, interactions, objects, and environment of the participants;
- Topics were identified through analysis of the interviews; and were
- Scrutinized to discover patterns and categories, then
- Conclusions were induced from what was observed and were stated verbally, and finally,
- Those conclusions were used to answer the research question.

To explicate the inner, subjective meanings of lived experiences of women living with HIV, this researcher considered the merits of qualitative, rather than quantitative research methods for this study. This method allowed for a description of a phenomenon with text, in a way that could not be done with statistics (Eisner, 1991). Certain qualities of qualitative research made it possible for this researcher to accommodate the following characteristics of this study:

- Understand the phenomena and situations of the HIV/AIDS as a whole in context (Patton, 1992),

- Explore, without a formal hypothesis (Bailey, 1978) for meaning where relevant variables had not been identified
- The approach used in this study was unstructured in order to be responsive to the needs of the participants and the nature of the subject matter.

The basic principles of naturalistic systematic inquiry were upheld in this study. There was no manipulation implied on the part of this researcher, and this researcher allowed for the important dimensions to emerge from the analysis of the interviews under study without presupposing what those dimensions would be (Lincoln & Guba, 1985).

Data Collection Methods

In this study the data utilized was already collected through the ‘Women Power’ retreat for HIV-positive women, organized by the Lewis & Clark AIDS Project for the purpose of improving the retreat intervention. This researcher collected the data for a different purpose at the retreat. Later and, with the authorization of the University of Montana Institutional Review Board (IRB) and consent of the participants, the data was analyzed for the purpose of this study.

This researcher chose the in-depth interview as the tool for data collection. This method was used to help in identifying the relevant dimensions of the topic under study, and to reveal the natural frames of reference existing in the minds of the participants. This direct communication allowed for access to the attitudes, perceptions, expectations, and behavior of the participants in the study. The researcher probed for the participants’ experience as lived

subjectively. No claim is made regarding an objective, external “truth” of the participants’ lives.

Semi-structured interviews were conducted for data collection, with the initial question being: What is your experience of living with HIV/AIDS in a rural area? This researcher looked for commonalities and differences in each of the women living with HIV/AIDS as they described their experience. Themes began to emerge after several interviews.

Selection of Participants

The conceptual framework and research question (Appendix C) determined the focus and boundaries within which the participants for this study were selected. This researcher chose to study rural HIV-positive women’s experiences in an effort to achieve depth in an understudied group, given the knowledge that more studies have been done on HIV-positive men. Females that are HIV-positive may experience aspects of their lives differently than men (Gilligan, 1992; Kaschak, 1992), especially if these women reside in rural rather than large urban areas.

Nine women living with HIV/AIDS in rural areas volunteered to be interviewed at a retreat for positive women in October, 2002, for the purpose of gathering information that would assist in the planning and evaluation of the retreat intervention. Thirty women living with HIV/AIDS attended the retreat. The women were all from rural Northwestern states of America, and all between the ages of sixteen and fifty-seven. They included six Caucasian women and one Native American woman.

For the purpose of this dissertation, seven interviews were used for a qualitative analysis with the consent of the participants. The consent form (Appendix B) was mailed to all participants of the study in order for the data to be utilized by this researcher. Though the researcher conducted nine interviews, one involved a minor and the other involved a subject who was unable to adequately respond to the research interest.

Data Collection Procedures

The interview for program improvement of ‘Woman Power’ retreat by the Lewis & Clark AIDS Project provided the data for this study. The sample was purposeful, meaning that the women selected to participate were living with HIV/AIDS in rural areas. Qualitative data collection does not require random participant selection (Creswell, 1994). Important criteria are that the participant must have had the experience that is of interest to the researcher and that the participant is able to adequately describe the experience verbally.

The participants were interviewed separately at a location of their choosing. Privacy was assured during the interview, and each interview was audiotape recorded. Each interview took approximately sixty minutes. The participants gave verbal consent to being interviewed. For the purpose of this study, a consent form (see Appendix B) was mailed to the participants through the coordinator of the retreat. In understanding an interviewing process, Creswell (1998) breaks the process into a series of steps:

- Identify interviewees

- Determine what type of interview is practical and will net the most useful information to answer research questions – the archival data evidences one-on-one interviews.
- Use adequate data recording procedures.
- Design the interview protocol.
- Determine the place for conducting the interview.
- Once arriving at the interview site, obtain consent from the interviewee to participate in the study. This may be done prior to the interview by way of a letter to subjects asking for their participation.

During the interview, stick to the questions, complete within the time specified, be respectful and courteous, and offer few questions and advice. In this study, though, the researcher was directed by the first question and responded flexibly, based on what each participant shared.

Each of the interviews followed a brief introduction to break the ice, and when the participant appeared comfortable and ready to begin, an audiotape was started and this researcher asked an open-ended question, “What is your experience of living with HIV/AIDS in a rural area? The purpose of the open-ended question was to encourage the participants to be open and forthcoming and to give each person plenty of space to converse about her experience from her own unique perspective. This researcher gave the participants considerable latitude in an effort to develop data with full richness of the participant’s experience. This researcher’s interview style was developed for the purpose of

probing further into an experience. At the end of each interview, the interviewer thanked the participants and assured them of their anonymity.

The data for this study represents female participants all of whom live with HIV/AIDS in the rural Northwestern states. They attended the '2002 Woman Power' retreat, for HIV-positive women. This researcher utilized this data for the purpose of this study, upon approval of the Institutional Review Board (IRB) at the University of Montana and the consent of the participants. The researcher requested a letter of consent to use the data from the coordinator of 'Woman Power' retreat at the Lewis & Clark AIDS Project (see letter of consent in Appendix E). A consent form to utilize the data for the purpose of this study was also sent to the participants through the coordinator (see consent in Appendix B). Using Johnson and Christensen (2000) general rule, the following information was provided to each participant in seeking informed consent to utilize the data for the purpose of this study:

- Purpose of the research along with a description of the procedures to be followed and the length of time it would take to analyze the data of the study.
- A description of any risks or discomforts the participant might encounter.
- A description of any benefits the participant or others might expect from the research.
- A description of other procedures or treatment that might be advantageous to the participant.
- A statement of the extent to which the results were to be kept confidential

- Names of people the participant might contact with questions about the study or the research participant's rights.

For the original purpose of the interviews, which was to gather information to assist the Lewis and Clark AIDS Project with the positive Women's retreat, the consent of the participants was granted verbally. For the purpose of this study, the general rule by Johnson and Christensen (2000) regarding requesting informed consent was followed. The informed consent forms were mailed to the participants through the coordinator, and the participants gave the consent for this researcher to analyze that data.

Data Analysis

Bogdan and Biklen (1992) describe data analysis as a process that involves working with data, organizing it, breaking it down into manageable units, synthesizing it, searching for patterns, discovering what is important and what is to be learned, and deciding what will be told to others. In this study, the tape recordings from the interviews were transcribed verbatim. In keeping with the spirit of qualitative research, the participants had the opportunity to offer any background information they felt would relate to the understanding of their experience of living with HIV/AIDS (i.e., age, education, children, if any, etc). Throughout the data analysis process, this researcher sought to identify and describe patterns and themes that emerged. The techniques used follows in the next paragraph.

The entire interview recording was transcribed. The researcher reviewed each transcription, and topic areas or themes were noted. The researcher color-

coded those units of information that emerged from the interviews. When the color-coding was complete, the constant comparative method of data analysis outlined by Strauss and Corbin (1990) for grounded theory was followed. Though this is not technically a grounded theory research project, this data analysis method seemed most useful. The compare and contrast approach is based on the idea that themes represent the ways in which texts are either similar or different from each other (Glaser & Strauss, 1967). In this process, the researcher attempts to saturate categories through constantly comparing incidents with incidents until categories emerge (Creswell, 1994). Data collection, analysis and theory are related reciprocally. After establishing categories that arose from sorting out the data into piles, the researcher counted the number of instances in each of the categories and described the categories with some emphasis based on the number of instances per category. According to Silverman (2000), it is imperative that categories are sufficiently precise to enable different coders to arrive at the same outcome, with the same body of material. The themes and patterns that emerged were explored.

Methodological Issues

Determining the accuracy of the account, discussing the generalizability of it, and advancing possibilities of replicating a study have long been considered the scientific evidence of a scholarly study (Creswell, 1994). Qualitative researchers have no single stance or consensus on addressing traditional topics such as validity and reliability in qualitative studies. Lincoln and Guba (1985) propagate trustworthiness, credibility, dependability,

transferability and confirmability as criteria for qualitative research. The validity of qualitative data is usually established by what is called external criticism. The external criticism has to do with establishing that a given information source is authentic (Charles, 1998). Reliability of qualitative data is relatively difficult to establish objectively, but the prime requirement is to attempt to check multiple sources of qualitative data to reassure consistence of information, and to think carefully about the procedures used to obtain the data and the trustworthiness of the sources of the informants (Borg, Gall, & Gall, 1993).

Lincoln and Guba (1985) have suggested a variety of techniques or steps that increase the validity or rigor in qualitative research, which this researcher followed in preparing the report:

- Indexing: All data, including notes of transcribed tape recordings were indexed.
- Development of a provisional outline: The outline followed the common themes that emerged from the data.
- Cross-referencing the indexed material to the provisional outline: All the materials that were indexed were reviewed. Where each piece of information fit was carefully considered.
- Writing: Writing began after the themes were identified. The report developed as this researcher made the necessary changes, additions, deletions, and even rearrangements.

Lincoln and Denzin (2000) state that the combination of multiple methodological practices, empirical materials, perspectives, and observers in a single study is best understood, then, as a strategy that adds rigor, breadth, complexity, richness, and depth to any inquiry. In this study, the combination of interviewing of the women, literature reviewed by this researcher, the analysis of the collected data, and the consultation with peers in a Qualitative Research class, provided a more comprehensive portrayal of the experience of living with HIV/AIDS. Denzin (1989) emphasizes that this triangulation of method, the investigator, theory, and data remains the soundest strategy of theory construction.

In this study, the task was to portray the world through the participants of the study, to express their constructions in their own natural language. The writing of this theme analysis was informal. All statements made by participants were placed in quotes. This is to clarify to the reader whether the interpretations or evaluations made were those of the participant or this researcher. Promises of anonymity were honored by not using names of the participants.

Ethical Considerations

Qualitative research is interpretive research. As such, the biases, values, and judgment of the researcher become stated explicitly in the research report (Creswell, 1994).

Consideration of the ethics of any research study is necessary to assist the researcher in preventing abuses that could occur and in delineating the responsibilities of the investigator (Johnson & Christensen, 2000). To make sure

that this researcher was responsible, she ensured that the study was ethically acceptable and that everyone involved in the study treated research participants ethically. It was thus important to first identify the ethical issues that were of importance to the researcher and to the well being of the subjects. The following were the procedures to ensure ethical sensitivity.

- Participants were informed of the purpose of the research along with a description of the procedures to be followed and the length of time it would take to analyze the data of the study.
- Participants were provided with description of any risks or discomforts that they might encounter during the study.
- Participants were provided with a description of any benefits the participant or others might expect from the research.
- Participants were provided with a description of other procedures or treatment that might be advantageous to them.
- A statement of the extent to which the results were to be kept confidential was provided to each of the participants.
- A list of names of people the participant might contact with questions about the study or the research participant's rights was provided to them.

Johnson and Christensen (2000) state that assurance of the ethical acceptability of a study means that: The researcher has to get the informed consent of the participant; any deception must be justified by the study's scientific, educational, or applied value; the research participants must know that they are free to withdraw from the study at any time without prejudice; the

research participants are protected from physical and mental discomfort, harm, and danger that may arise from the research procedures, and that; the research participants have a right to remain anonymous, and the confidentiality of the participants and the data must be protected.

This researcher conducted this study with permission of the IRB (see IRB approval in Appendix A) so that the rights of human subjects were protected. Christians (2000) reports that social science research requires that research subjects have the right to be informed about the nature and consequences of experiments in which they are involved. Thus, it was important to address the sensitive ethical issues such as maintaining confidentiality, preserving the anonymity of informants, and using research for the intended purpose (Merriam, 1988).

Qualitative research, as Howe and Dougherty (1993) have pointed out, has two features, intimacy and open-endedness, that muddy the ethical waters and exclude it from the special exemption status reserved for many educational research studies.

CHAPTER FOUR

Results

Introduction

The purpose of this study was to develop the themes involved in the experience of living with HIV/AIDS from the perspective of women in rural areas. The original data was collected by the researcher through one-on-one interviews, at a Women's Positive Retreat held in the fall of 2002. Initially, this data was collected for the purpose of assisting in the improving of the planning and evaluation of the retreat intervention. This researcher, with the authorization of the Institution Review Board (IRB), and the permission of the participants in the interview, utilized the collected data as a qualitative study for the purpose of this dissertation analysis.

During the time when the interviews were conducted, participants were encouraged to talk about the aspects of living with HIV/AIDS that were important to them. This process of integrating the experience of living with HIV/AIDS into their lives was complex and individualized. But in the interviews, common themes emerged. While individuals differed in their experience of living with the HIV/AIDS, fascinating themes emerged and were developed during the data analysis.

A brief description of each of the women living with HIV/AIDS who participated in this study can be found in appendix (D). While not critical in understanding the themes that emerged from the study, these participants' stories may be useful in bringing about a greater depth of understanding of the

various contexts of women living with HIV/AIDS who assisted in this study. In appendix (E) are the entire transcribed interviews that relate to the themes that have been discussed. The interviews remain in the participants' own words. In this chapter, this researcher will examine the common themes that emerged from the data.

Common Themes

The experiences related by each woman living with HIV/AIDS varied. However, basic themes emerged from the analysis of the interview data that were repeated in various ways in all the interviews. These spoke to the research question:

What is your Experience of Living with HIV/AIDS in a Rural Area?

Initially, nine women were interviewed, but for the purpose of this study, only seven interviews were used. One interviewee was a minor and another was not coherent enough to be used. Thus women were the key informants of this study. The interviews were transcribed verbatim. This researcher reviewed the transcripts looking for themes or patterns in the data. The units of information that appeared common in the interviews were identified were color-coded to make analysis easier. This procedure was conducted in the process of breaking down and understanding the text and attaching and developing categories that were put into order during the analysis process. Using the pile-sorting exercise approach of handling the data, this researcher paid close attention to particular words, meaning and to which quotes belong together and why. By asking questions of the data, and the making of the

comparisons for similarities and differences between each experience of the participants, events and other instances of the phenomena of living with HIV/AIDS, the untangling of the dimensions and contents of each category developed.

The themes that emerged from analysis of the interviews included:

1. Unique aspects of emotional stress of living with HIV/AIDS.
2. Social environment and living with HIV/AIDS.
3. Sense of betrayal.
4. Medical treatment issues.
5. Loss and resulting grief.
6. Relationships and good support system.
7. Renewed purpose for living.
8. Personal growth and transition.

It is important to note that these themes not be viewed as the whole experience broken down to a mere list of categories. Rather they need to be looked at as part of the complex nature of the unique experiences that these women participants live through in their daily lives. These themes stand alone in their descriptions to create a better understanding of the experience. These categories are reviewed as if they are separate, but in fact, each interacts with many of the others. For example, aspects of a woman's anger relate to her experience of betrayal by those who should protect her rather than harm her.

Theme #1: Unique aspects of emotional stress of living with HIV/AIDS

In dealing with the difficulty of coping on living with HIV/AIDS, women talked about the various emotions that they experienced:

Depression:

Ra: I'll tell you something, I am not always happy because I do have my own down times, especially... um... it kinda goes from blood test to blood test.

M: I take Zoloft... Once I've had a bout with depression – and I realize that depression comes at many points... I think HIV has a lot to do with... it's always there everyday even though you try to get away from it... and now I take Zoloft just kinda to keep adrift, so I can stress about really big things as opposed to little things – and sometimes when you are dealing with that pink elephant in the room, which is HIV, you know you don't want to talk about it, but then all of a sudden it's right there in your face – and you know it.

Re: For many years later, I figured that my feelings about being HIV-positive were not warranted... I then got distressed. From 1991 till 1998, I had been planning my death... I was told I was going to die, a part of believed it, and I raised my daughter and waited to die.

DD: I felt like I was in this black hole, hanging on for my life but, I didn't want to hang on... I wanted to let go and just go crawl in a black hole and stay there...

These women indicate depressive feelings that are perhaps difficult parts of their illness, through so many different ways, as the above quotes reveal. The following woman beautifully describes her depression with metaphors of the way she felt in her body and mind.

Do: There was one comment I was thinking of with the depression. One of the things that I would always keep thinking of, I was just telling somebody, it seemed as if its like when the seasons change. Like when I'm in the middle of winter and its like a blizzard and its so cold and you just think its never going to quit snowing, never quit blizzarding, its never going to quit, its like that in me...

J: Like seasonal?

Do: Like seasonal, yeah, and then somehow, it just happens, I mean sometime you look outside and all of a sudden its just starting to become spring and you kind of think, how that ever come to be, I don't know but, just within me its almost like I just spend enough time in winter, and pretty soon it just starts, and I will notice little bits of something in me that are not exactly joy, but there's little bits of like green sparking on the trees and just a little bit of almost like give into winter and the next season comes.

It is undeniable that having HIV/AIDS can be depressing for these women. Every woman expressed feeling depressed at some point in her life in dealing with HIV/AIDS. As the excerpts reveal, the connection of the depression to the HIV/AIDS by the participants seems unavoidable, as the one participant indicates, even denial does not help in some instances when one has to face the disease and the moods that it comes with. It is hard to be cheerful when one's condition causes serious problems, and HIV/AIDS does make things look darkly, giving a feeling that nothing can be different. But each of these women in this study seems to force herself into action in order to manage the depression.

Anger:

Women expressed their frustrations of living with HIV/AIDS. This anger was frequently expressed in everyday interactions and events in their living environment. This included interactions with family members, providers, and especially situations that were discriminatory. It also included raging at a probably shortened and difficult life expectancy and at those who had infected the woman or made her life difficult in other ways.

Du: Oh, I was pissed off... it made me mad. Who are they? They are not God. They are not the creator. Besides, myself... I wasn't ready to go, and they weren't going to tell me I had to go... so, that just pissed me off. I am not dying; you can't make me... it just made me mad and more determined.

Ra: The first time was the time I was diagnosed, and I was dealing with anger towards my father because he wasn't the greatest dad growing up... and I felt that in order to really get help and to take care of myself, I have to get rid of these angry feelings.

Do: And the first thing I did was force him to get his test results... see, and I want to know what those results are, and I want to know now... and I just forced him that way, and then I said, as he gets nuts, and then I said the reason I wanted to know is because I am positive, you know?

M: I don't think that we should have to wear a scarlet letter, I think we shouldn't have AIDS on our foreheads, we shouldn't be condemned or ostracized... I think everyone that I've met, and I've met a lot of people... and I've talked to a lot of people in the past eleven years about HIV... in fact, I can

tell you that I've never met anyone who wants to give it someone else, no one wants to pass this on.

Re: Before I went in the operating room I was asked to sign a consent form to have my tubes tied... they insisted that I should not have any more children... I knew I was positive, and I probably wouldn't have had another child, but they took that choice away from me when they made me sign the consent.

Anger is said to be one of the most common responses to having HIV/AIDS. These women seemed to experience a sense of powerlessness, which did provoke a lot of anger in them. At the same time, one can see that they also are fighting to reclaim the power by facing up to themselves, their partners, families, friends, and health care providers. They also all seem to recognize and identify their anger, why or with whom, which might make it easier to manage the anger effectively.

Loneliness:

Participants expressed a sense of aloneness in the life of living with HIV/AIDS.

Du: It is tough... especially when you really have nobody that you can count on.

Even in situations where some participants lived with spouses or other family members, a sense of loneliness and isolation was experienced in relation to having to deal with living with HIV/AIDS. **Ra** reveals this experience when she first found out about her status:

Ra: I think I became isolated, very isolated... um...and, I had already graduated from school and got my paralegal degree, and now I was going backwards because of this illness.

In some instances this sense of aloneness is not so directly noted, but absence of other women infected in the area insinuates the experience, like Pa and M indicate here...

Pa: There is no other woman that I know in my area... the only person I knew was a guy from Louisiana that had AIDS... and he went back to his state.

M: For support group, I do not have one in my area. I tried to get one started, but other people who are HIV-positive don't want to talk about it, they choose not to talk about it.

In this situation, the participants express their loneliness through rejection from either friends or family members in their experience of living with the disease...

DD: My true friends, I mean some of the friends that I had for over 30 years, as soon as I said this, because I didn't keep it a secret, I told everybody the same day... ah... they did act like I was dead, and I've never seen them since, and that was hard.

Do: I wish they would have called even like once a week for ten minutes, but I would go to like four months and no one would call, it was really hard. I have a couple of friends that... ah... a lot of friends pulled away too... it was really, really, I never... I thought I just had tons of friends, and always just had this

busy life, full life, but it's as if I just became really boring and all of a sudden, nobody wanted to be there.

Du: I reconnected with my dad, when Dad needed me at the time. I'd never been close to my mother. I went to my mother when I left my husband and she didn't believe what I was telling her, wanted to know who I had been fooling around with or what drugs I had been using, and pretty much disowned me when I wouldn't go back to my husband and beg him for forgiveness, for leaving him. I am not going there Mom! If you don't want me for a daughter, fine, I'm out of here. I'm not taking this crap, anymore. So, I have spoken to my mom twice since then, and it was in the last couple of years.

A sense of loneliness, isolation, and rejection seems to be evident in these women. It seems like it is disconcerting and overwhelming how HIV/AIDS exacerbates the "trio" of emotional experiences that often occur together.

Shame

Most of these women participants expressed feelings of shame as an emotional stress in living with HIV/AIDS. The belief that one has done something wrong or something immoral in order to be HIV infected creates feelings of shame and fear, which bring up other feelings inside of these women. For example, anger, anxiety, helplessness, and sorrow are all very common with a diagnosis of HIV. The following quotes reveal this stress...

Do: Oh yeah, and it's a lot easier. There is a lot today. There is so much they can do with it now. And that... um...I still think that there is an internal process that first couple years is just going to be hard. There's just...just know its going to be hard, and its really when you don't want to tell people, and you feel all the shame and gradually you work through all of that...its like, but when you see other people living without shame, it makes you feel stronger just to see it and to watch it, so I... it helped me a lot. I have these images of watching people like Terry, the activist in this life, and it would inspire me so much to find your inspiration in other people that live well they give you all the examples. There are so many awesome people.

This participant indicated struggling with telling her daughter about her condition, and expressed the shame she felt about having to tell her daughter that she was HIV-positive...

M: It's a....but...you know...I did think about those kinds of issues...I didn't think about limits when I told my 10yr old that....you know...you're going to be tested...I didn't want the shame...I felt so much shame....

Internalization of the attitudes held by society and by those close to the woman. Shame is about the internal experience of the woman's imagined view of herself from the perspective of general or unique others outside herself. It is also inside herself – herself as she imagines she is in the eyes of others. As the excerpts reveal, there is an internal struggle from some women about how they feel about themselves, and for others how others perceive them.

Suicidal thoughts

Some participants entertained the thoughts of committing suicide as an escape from their struggles of dealing with HIV/AIDS in relation to daily challenges they experienced. One participant, Ra indicated she looked at suicide as an option for her while struggling with her experience of living with the disease...

Ra: I started having problems with my health and with HIV. And it first started with a very bad case of insomnia. I could not sleep at all... and it was like nuts. And I started thinking about suicide... I would never do it, but I fantasized, and I even got to the book in the library that was pretty popular at that time, it's called "Final Exit"... it tells of all these different ways that people can commit suicide... And it was weird, I wasn't planning on it, but it really gave me peace to say, uh! O.K., there's a way out if I have to do it.

Another participant stated she thought about suicide as a way out in dealing with the rejection from her friends after they found out about her HIV status...

DD: Yeah! ...Because there's times that, you know, you wonder if you want to do the... there's times you wonder if... man, why don't I just suicide out? ...there's times that you don't care and you want to go get reckless just because you don't care and then if you die by accident, then it's not your fault.

Having illustrated the emotional stresses of living with HIV/AIDS, we can see that they have critical psychological implications for the participants, which might be influential in their strategies of coping with the illness. Suicidal

thoughts appear to be based on a need to have some power over one's life in the face of extreme suffering.

Theme #2: Social Environment and Living with HIV/AIDS

Participants had different views about how their living with HIV/AIDS impacted those close to them, and the general environment around them. As Klitzman (1997) indicates that problems will emerge not only to losses to AIDS, but to stigma, which complicates the course of HIV. The illness affects patient's views of themselves in their own eyes. The infected come to feel "taboo" and like "second-class citizens." Discrimination arises from families, communities, health care workers, and work settings, and varies in form, content, and social and psychological import. The following are subcategories of theme # 2:

Reactions of Family and Friends:

Most of the participants reported experiencing either positive or negative responses from their families and friends in dealing with them. Though family responses vary, the unifying theme is that the family response is of deep importance to each of the women. In some instances some participants even felt blamed for having contracted the HIV. One participant revealed how her mother treated her when she went back to her for support after finding out about her status...

Du: I went to my mother when I left my husband and she didn't believe what I was telling her, wanted to know who I had been fooling around with or what drugs I had been using, and pretty much disowned me when I wouldn't go back to my husband and beg him for forgiveness, for leaving him. I am not going

there Mom! If you don't want me for a daughter, fine, I'm out of here. I'm not taking this crap, anymore. So, I have spoken to my mom twice since then, and it was in the last couple of years.

In this example, the participant expressed having a supportive family, though some behaviors of the family members seemed to show otherwise...

Ra: Um, my whole family is very supportive. My mom's afraid to drink from the same glass of water... But that doesn't bother me. I don't care about that. Because I know she loves me very much. She gives me hugs and a kiss on the cheek and my families great. Unfortunately they all live in California. So, the only family I have where I'm at is my husband and his mom and his aunt. And that's it... And they are Fantastic... No problem at all...

For this participant, she shares the fact that her family and friends have always been there for her.

Pa: I've got a couple of friends, Yeah, family and friends... I was born and raised in Helena... So I do know a lot of people in Helena and they come over and visit... my daughter was mad at first and then she... she got to know a lot about AIDS and stuff... and, well she spoke at her graduation... speech about her mom... It was really cool... and... ah... Irene's friends come over and visit a lot... a lot of kids come over and see me. They have through the years, ever since they got out of high school... to check and see how I'm doing and stuff... ah... I go to David's on week-ends... and that's about it...

This participant wanted to indicate that her family was there for her and did not reject her for being HIV- positive. She expressed the support of her family which was unconditional...

DD: Most, a lot, I won't say most, but very many people with a sexually transmitted disease like HIV or AIDS... Ahh, their families throw them away. They are ashamed and they don't want anybody to know and they throw them away... my family is not like that.

This participant wanted to show that her family was somewhat there for her, even though so far away, but at the same time expressed how much they haven't been there for her as she has struggled with the experience of living with HIV.AIDS...

Do: I do, but not enough. I had a couple of people that really stuck through with me, by me, that I could call, even the family, I mean our style was to call every three months or every six months, and maybe I'd imagine that when I was hanging in the life and death, they would call more often, but they didn't... No, I think they were really busy and they are raising their kids and they are busy with their lives. What they wanted to know is if I was on the verge of dying. And then if I'm not then... then they want to come, then they all want to call on the same day and then, I'm exhausted, you know, like, but, when I'm just trying to spend six months trying to get strong and I can't hardly get out of bed for six months...

The dimension of interpersonal and understanding, whether positive or negative, was very important in these women's lives. A sense of connectedness

was an important aspect of every woman's need in feeling good about the self. Likewise, when there were disruptions in bonds with family and friends, this caused great suffering for these women.

Dealing with the Social Services

Most of the participants expressed that interacting with social services was not a pleasant experience. From their point of view, the participants indicated struggles in dealing with the system and in some cases even health providers, due to the fact that they were either HIV-positive or living with AIDS. The very people and systems to which these women are referred fail to support them or make their experience of their illness worse. The following excerpts illustrate this:

In this example, the participant expresses the reaction of the provider who provided her with the results of her HIV-positive status, which was not sensitive or supportive...

Do: So, the extent of her counseling was just to keep yelling oh, it's just a horrible disease, it's just a horrible disease, oh, it's just a horrible disease, and she didn't have anybody to tell me where to go or what to do or how to find any help or anything.... she just really panicked... And ah, I actually went to see her about 2 weeks later and she was afraid to see me, afraid to even talk to me.

In this excerpt, the participant is dealing with the Social Security people that seem to be making things very difficult for her with her finances and living conditions. This is more about the agony of being dependent and controlled by the disease in basic aspects of being an adult...

Du: All the rules, its, it is smothering. You know. You can't do this, you can't do that, you can't live here; you can't live with that person. You know, they have all these rules and you know, when you think you're going to die the rules don't mean crap, but if you want to live, you have to follow them? And it really sucks. Because, I want to work, I have always worked. I have never been on welfare, I've never collected unemployment, you know, I've always been there to help everybody else. I've never taken charity and going on Social Security has felt like I've had to take charity? Like I wasn't able to take care of myself anymore? And it really bothers me.

In the following excerpts, **Ra** indicates a positive experience with the system; and **Pa** has had both positive and negative experiences...

Ra: And I'm a little bit fearful about going back fulltime, because I've gotten so used to being on disability. I've been on disability for 7 years now and I'm kind afraid to let go of it...

Pa: Uh...I moved in with my sister and brother-in-law...and basically every counselor and all these people from the Health Dept. just came to my aid...and one was my preacher and one was my AIDS counselor, one was...you know, a therapist...and they were all there... and I ended up with my own place...and taking care of my son...

Pa: Yeah, they took my son away from me when he was two months old...when they found out he had AIDS...and I basically jumped through hoops with social workers and therapists, involved with Healthy Families, Healthy

Pregnancies... through which I met a guy named Greg B, and he ended up being my advocate...

It seems like these women often experience so-called support services and health care providers as having the right to control or dictate aspects of their lives simply because they were HIV-positive or had AIDS. More powerlessness and stigma, and loss of basic defining activities and identity in adult life.

Theme # 3: Sense of Betrayal

This theme seemed to resonate in almost all the participants. Partners who were not truthful to them infected them. Some participants did not know about the behaviors of their partners outside their relationships, and for some, the partners were abusive to them and thus, did not care about telling them the truth about their HIV status. This theme relates to other themes, such as anger or powerlessness over one's life choices...

Pa: Well, I couldn't believe it... and it took me awhile... It took me about 8 months or so to figure it out, that he was lying about it. And when I left him the doctor said to me... (sigh)... that he had it for 14 years and he knew he had it... Yes... I'm very honest. Especially if they come to my home... pretty much people I meet, I've been very honest about it and I think the reason I do that is because Mike lied to me, you know... and it was a pretty big lie, I knew I had a virus, but I didn't know it was the biggest one... (laughs)...

For this participant, the first excerpt revealed the abusive nature of the relationship she was in with the then husband, and the sense of betrayal is

revealed in both the first excerpt and the following short interview exchange with the researcher...

Du: Yes, because my husband at the time, ex-husband now, he had a drug problem. Well, in our relationship it was fairly abusive, and women and children were to be seen and not heard. So, in 1990, I noticed that he kept taking these little pills. I thought it was some new street drug. And after seeing him take them for a couple of months, I started kind of getting worried, and asked him about them. Well that was just the wrong thing to do because I was told to mind my own F-ing business and keep my nose out of where it didn't belong. So I backed off and I was not the person you see here today. I got married at 15 years old; to a man that was 22 years older than me...

Du: I was ah, 27, yeah, 26, 27. And ah, so, I asked him, he says that's AZT. What's AZT? Well, ah, that's what people take when they are dying of AIDS. I was floored.

J: So, for the first time you are hearing this from the pharmacist?

Du: From the pharmacist. And this is what my husband has been taking for 6 months. That I know about.

In this following excerpt, the participant's husband also had a secret life that he later revealed to her, which left her feeling lied to and angry...

Do: and he pretty well knew, he was doing a lot of risky behavior when he would travel on business and it went on-going through the marriage, he told me later and took a lot of risks and um, didn't want to tell me... and so... so, I felt really lied to, but um, but so, when I first went to get tested it was more in

anger, like, well now if I find out you did this, I'm going to go get tested for AIDS, you know...

Do: But I didn't know that he had...you know...HIV...

J: Uh!

Do: And the first thing I did was force him to get his test results and he was so mad. See, and I want to know what those results are, and I want to know now... You know...and I just forced him that way and he was so angry and they called up and they said he's positive. And then, I said, as he's just going nuts...and then I said the reason I wanted to know is because I'm positive, you know?

This participant also expressed lack of knowledge about how she contracted the HIV, except for the fact that the only man she had been with was her husband, which indicated a secret life of the husband that he never shared with her...

Re: She informed my husband and I what HIV was and how it is contracted. After she explained everything she asked my husband and I if we want to sign the form so they could perform the HIV test. I told her that I had only been with him and that I had never used IV drugs so I did not need to take the test. My husband then turned towards me and says, "Maybe we should." I reluctantly signed the consent form...

Re: I was sitting there in the patient room, the mid-wife came in and says to me most of your tests came out fine except for one, but we will talk about that later. She leaves, comes in again, examines me and leaves again. After about fifteen

minutes, she comes back into the room again, and tells me the test for HIV was positive. She asked me if I knew what that meant. I didn't know exactly, but I knew it was terrible news.

After the meeting, the woman drove me to my husband's place of work to let him know of my results. He had to come in later that evening to get his results, of course we knew his was positive because he's the one who gave it to me.

The sense of powerlessness is evident here again. Lies and deception are bad enough, but when a spouse betrays a partner the shock can be devastating. When one partner is believed to have infected the other, there is anger, guilt and other strong feelings to work through. These women express their anger towards the partners that lied and betrayed them. The burden of having to carry this load of HIV/AIDS for the rest of their lives seems like an evident struggle of carrying on with their lives.

Theme # 4: Medical Treatment Issues

Losses mark the course of HIV infection (Klitzman, 1997). Patients struggle to cope not only with the virus, but also with its consequences, each of which hints of further change. Adjusting to the life of being sick from the disease was a common theme that emerged data analysis. Almost all the participants expressed their struggles in living with the virus as time progressed. Their physical health issues were expressed through many ways, be it physical illness, medication side effects, and concerns with T-Cells. When a woman is HIV-positive, and particularly after she develops AIDS, her body becomes a central focus of her awareness and of many of her activities. She recognizes that

careful supervision of her body is vital to her health, comfort and survival. And sometimes, illness unpredictably breaks through and becomes the core of her existence for a time.

In relation to physical illness, some of the participants expressed dealing with *Pneumocystis pneumonia* at some point in their experience of living with HIV/AIDS. The following excerpts illustrate that:

Du: yeah, that he was a no-good SOB, but I knew that before that. But, I guess, in '91, I just kind of ignored it, because I already knew it, that I was positive. And, I wasn't sick. I didn't feel sick. I didn't look sick. So, I just did ignore it. Um, in February of '93, um, I came down with pneumonia. And it was *Pneumocystis pneumonia*, and ended up in the hospital in Las Vegas, Nevada. I was there taking care of my father, because he had to have his... ah!hip replacement. So, I was down there taking care of my Dad.

Do: Well, um, at first I had PCP and I had been working there 6 months, I got PCP pneumonia.

In the following interview excerpts, participants describe other physical conditions in the experience of living with HIV/AIDS ...

Ra: I started having problems with my health and with my HIV. And it first started with a very bad case of insomnia...

Ra: I'm on one about PI's, protease inhibitors, another one is called the lipid list, and it's for people who have Lipodystrophy...

Pa: ...yeah, I was always sick, I was in and out of the hospital... and since I converted... the only time I have been in the hospital is when I converted, just to get me on the meds...

In the following interview excerpt, the participant revealed how she found out about one of the many physical conditions that HIV/AIDS causes, which creates fear in most people living with the disease...

Do: Almost to an extreme. There was one time when I could tell. My doctor we were having a discussion, I could tell he was kind of avoiding something a little bit, and we're talking, I was having so much fatigue, and we were looking at diseases in the medical books actually, and he went to the hospital to go see his patients and came back and I'm reading about things, I could tell, he kind of put it together, he kind of let it filter together and then he came back and I said O.K. (L), I have one question, but I really want a direct answer.

J: uh huh.

Do: Do you think I'm going into dementia?

J: uh huh.

Do: And he said, yes, I do.

Du: Unconditional, they're always there for me and that's what kept me sane and alive. Because, I have gone through a hysterectomy from cervical cancer, I've gone through an appendectomy where they had to take one of the ovaries that they left me after the hysterectomy, um, I went through menopause this year. I've been through toxoplasmosis I've been through wasting, I've had three strokes, in 1996, I lost the use of the right side of my body. I couldn't

speak. I dragged my leg, I couldn't use my hand, I couldn't lift my arm above my shoulder. And my physical therapist is lying right at my feet, I refused to go to physical therapy...

The body as the source of the most important aspects of everyday experience, taking nearly all of a woman's energy away from other life activities. Physical pain and other bodily changes seemed like frequent reminders of the limitedness and eventual mortality of the body.

Participants also expressed the distress of having to live with the side effects of medications, even as the medications were helping them to survive the turmoil of living with HIV/AIDS. The following excerpts reveal the common thread that binds these women interview participants in the struggle of the dealing with new era "cocktail drugs," which ironically, extends their lives...

M: My health in general has been pretty good... most of my problems have been from the medications....

Pa: It's pretty good, actually... I don't get really sick... you know... ah... the side affects are no fun, certainly... you know, but my health is... I think has improved...

Ra: Because my counts were staying great... and then fairly recently, maybe 6 months, 5 months ago... I wanted to change meds, and my doctor said it was time because one of my medications was making my joints ache... and I also had kidney stones removed twice...

On a positive note, **Ra** also revealed how getting on the new drug helped her with her health... as the following excerpt indicates...

Ra: And then when I went on the protease inhibitors and turned around pretty fast, I don't think I would be here if it wasn't for the protease inhibitors.

Do: Um, the illness was so bad... and I was going allergic to every drug, and the first part, it was just hanging on... I was just doing everything in my power to get every pill into me and do all the things I needed to do to get myself through it

Almost all the participants addressed the T-Cells as either a concern when they were down, or something that made them feel stronger in dealing with their physical health...

Pa: ...I don't know, my count went down this year but... ah... they're keeping me on the same meds until November and if it still doesn't go up then they will change my meds. But other than that, I'm doing fine. I've weighed 130 for a year. I used to weigh 99 pounds.

Ra: So, we thought it was time to change... well, when I made the change, I went from undetectable to 400, which is not very high, but it still bummed me out, because I had been undetectable for 6 years...

In the following interview excerpt, the participant was almost close to death, after the T-Cells went as low as 7...

Do: Ahhh, I got so... I was amazed at how well I could live with it... How much even watching my T-cells fall and getting to the bottom, and there were

times I got so low, I was frantic, but by the time I had no T-cells and I knew I only had a limited time to live,

J: So, you had 0 T-cells?

D: Well 3, you know.... I mean like from a 1000, when you get below 50 you're getting pretty low and then you get down to 30 and then you get 12 and then you get, you know, so it's kind of like 7...

The lives of these women seems like a roller coaster. There is intense focus on the "numbers" of T-cells by all the women in dealing with medications. Extreme ups and downs mostly focused on the progress and then remission of the disease and its side effects. One imagines the struggle a person with HIV/AIDS goes through in having to weigh the benefits of HIV cocktail drugs against their undesirable side effects. The women in this study chose them because of their life-saving qualities, and the roller coaster life was accepted.

Theme # 5: Loss and resulting Grief

Almost all the participants expressed grief in the loss of their experience of living HIV/AIDS. The grief was expressed in so many different ways, as the excerpts reveal...

Do: Yeah, oh no, it isn't. To me its just seasons of grieving. And so, what I am doing is grieving the loss, and if I am going into dementia, I'm grieving HIV, I'm grieving a lot of different kinds of grieving. I've just gotten good at grieving. You know.

J: so, that is the way you cope.

Do: Yeah. Yeah. But to run from the grief was when I would really get in trouble. I mean if I try to keep from grieving, you know what I mean, to keep it, that just takes all your energy and its like... um... you know, you just spend a lot longer in it almost.

This participant indicated grief at the loss of her son to AIDS: a cascade of losses - a life suffused in loss – not the expected life, but another life:

Pa: Uh...I moved in with my sister and brother-in-law...and basically every counselor and all these people from the Health Dept. just came to my aid...and one was my preacher and one was my AIDS counselor, one was...you know, a therapist...and they were all there... and I ended up with my own place...and taking care of my son...

J: Uh huh

Pa: ...until he died there... and then we moved. I had moved a couple of times but the place I live now I've been there almost four years.

Another participant shared the loss of friends after they found out she was HIV-positive:

DD: My true friends...I mean some of the friends that I had for over 30 years, as soon as I said this, because I didn't keep it a secret, I told everybody the same day...

J: uh huh.

DD: Ah, they did act like I was already dead, and I've never seen them since. And that was hard...

One participant shared her experience of loss of friends in her support group to AIDS:

Ra: Yeah, so I mean, what's supportive about that? And I think they became more supportive, oh yeah, and then I joined another group and they just, all of them died in two years.

J: That must have been very hard for you...

Ra: There is actually one person left from there, a woman, the rest were all men and they all died in 2 years. So that wasn't a supportive group. There wasn't a facilitator in that group.

J: uh huh.

Ra: We would meet at each other's homes. We traded every other week at each other's house. And we kind of prided ourselves on not having a facilitator that we were independent, and could do it ourselves. Big mistake. Because as we were dying, I mean, I wasn't dying, but they were dying, and we needed somebody there to help us work out feelings all these funerals that we were going to and there was no one. I mean we would sit there and we would look at each other and who's next? Who is the sickest one here?

There is a lot of relinquishment on the part of these women here. The disease demands that so much be given up, much of it the most important things in a woman's life. Loss of loved ones, loss of confidence, the loss of independence and a sense of lifestyle would be hard to take. This is the experience of these women.

Theme # 6: Relationships and good support system

Almost every participant expressed the importance of having a good support system in the experience of living with HIV/AIDS. The women indicated getting this support from different sources such as families, friends, mental health providers, and support groups:

Do: The first support group I went to... um, I was the first woman and they said um like they actually had an argument about whether I belonged there or not. They were saying...some of they guys, a couple of guys were saying this is a gay men's group, and they said no, its an HIV group... and he goes, no its an HIV group for gay men. And they said we've never said anything, it's an HIV group and just because a woman comes along, you know....

J: That makes a difference...

Do: It was hard to meet women. I looked... I treasured it when I finally met women and could connect to women, because it was a whole different experience. The heterosexual men, I related to in some ways more than the gay men, just you know, people from the hemophilic and other ways... um... So, it kind of depends on what, and a lot of the gay guys, when I have them out of their little group, where there're flaming, you know, around each other, it's a different thing too.

In the following interview excerpt, the participant expresses the importance of support groups to her, and has to travel long distance for it because in her community that type of support does not exist...

M: My friend and I travel to another state to go to a support group... He and I travel a 70 miles round trip once a month to this particular support group that I have been involved in for nine years now....

J: How helpful is the support group for you?

M: Um... it is very helpful... you know, I am able to talk about my issues... you know... what you go through on a day to day basis in relation to your health... um... you know you can talk about your problems with your colon... day to day inconveniences that you go through with HIV... and ...um... the fatigue, the tiredness... because no matter how much your family is... because my family is ..you know... is far away... they live on the East coast... so... um... it's my chosen family, my friends in my community, in my states... you know they are great, but they really don't want to hear about constantly from me.... I can really let loose... I can actually talk about those issues, but it's frustrating to me on a day to day basis... and they understand....

This participant revealed that she got her support from her animals...

Du: My animals.

J: Your animals.

Du: they help me. They keep me calm. When I get really upset, and angry, one of them will come and set their head in my lap or something or one of the horses will come and put their head over my shoulder and just you know, its kind of like they're saying, don't sweat the small stuff. Let it go, its not worth it. And they are so calm, and they are so peaceful, and they don't get upset over

the little stuff. You know the stuff you can't do anything about. And they are always there for me. No matter what, you know . . .

In the following interview excerpt, the participant talks about her relationship with her counselor, one of her sources of support:

DD: I mean the emotional roller coaster the first couple of years is horrendous...

J: uh huh.

DD: And, and, they are all flooding so fast that you really need a safety valve, a friend, a counselor, a somebody...

J: uh huh.

DD: I was one of those that holed up and didn't believe in that. My counselor got worried and had a hospice worker sent to my door, her name K... And ah, she came to the door and she told me her name was K and she was from Hospice... Did I want to talk? And I said, lady how do I know if I want to talk... I don't even know if I give a fuck if I live or die.

J: uh huh.

DD: I said, come in if you want, it don't matter to me...

J: Uh huh.

DD: And we went up to my bedroom... she stayed... (laughs)... She's still my hospice worker...

In the following excerpt, the participant relates the importance of counseling in her life, and how it helps her also deal with being a caregiver to other family members...

Pa: Well, not really... ah... Pat T came back last year, and she's my AIDS counselor... and I heard she's back to work... so I'm thinking of calling her up at the AIDS Project... to counsel me and I will start up again if she will have me as a client... she did last year, so...

J: Uh huh

Pa: She's back to work now... so... I just talked to Claudia about it this weekend...

J: Uh huh...

Pa: ...because I think it will help... you know... If anything it helps with the stress in my life... Like my sister is mentally ill, and she's on a lot of meds too... but we get along great... you know... I have learned a lot about her moods and everything...

This participant indicated how a support group helped her to create friendships that lasted longer than the group itself...

R: But I do um get support from the people that I know I've met people through support group and then what happens, I didn't really, but I remained friends with those people that I clicked with, that I liked the most... and we became friends outside the support group....

In this situation it seems like support is so important to the women, but also that the ups and downs of the illness mean that those who care for the woman must

be ready to give the support but also to wait until it is clearly wanted, a kind of perfect hovering.

Theme # 7: Renewed Purpose for Living

This theme resonated across all the participants' experiences of living with HIV/AIDS. Each one of them seemed to express the ability to integrate desired and undesired aspects of their lives, and saw this as a renewed purpose for living in their struggle of dealing with the disease. The following interview excerpts reveal this sense of purpose...

M: My basic goal was to take care of my daughter while I was with her... she was my responsibility... you know... I wanted to be proud of her... I brought her to this planet, put her there... so it's my job to see her get through... be raised into a... young... you know, individual... progressive, you know... made her into the society... that's what I did... an adaptive person.

The following participants indicated that educating others about HIV/AIDS gave them a sense of renewed purpose for living...

Do: There was something about, about me that needed to speak. And I would go down to San Diego State, they had a training for Social Workers... and I would go talk to the Master's in Social Work classes all the time, I mean just anything I got... um, it was easy for me to get away with it because school thought I was at work and work thought I was at school and I could go other places...

DD: Because I go to Juvenile Hall and talk to the kids and I go out to the Women's Prison and talk to the women out there about what it's really like to live with this, and if you don't got it, and here I can give you a list why not...and I love doing that sort of thing... It helps me kind of work through my own stuff better too... And I tell my girls in person, you know, I'm not there to tell you to stay straight, I'm not there to tell you not to use drugs or booze, those are all your choices...

J: uh huh.

DD: What I am here about is to give you the nightmare of living with HIV... The straight down school... All I'm here to tell you is there's not anybody cute enough to have sex with that's worth your life... and there's ways not to become HIV positive...

J: uh huh.

DD: That's my only goal...

J: uh huh.

DD: And so the girls and I get along real pretty well, and they ask me lot's of questions...

Even in the midst of some resistance from some members of the community, **Du** has found a renewed sense of purpose in educating young people, as the following interview excerpt shows...

Du: Yeah, I have been doing AIDS education for the county I live in. and that's been just wonderful therapy.

J: How has the community welcomed you in there, as a woman living with HIV?

Du: you know, it hasn't, you've seen enough to know, if you don't like it, don't look. The kids accept me. The kids care. And the rest of the world, I don't give a flip. I don't care.

J: So, you are going to educate those kids anyway...

Du: yeah. I really don't care what their parents think or what they say, you know, I don't care... because if I can get to the young people, we can change the attitudes. Talking to a bunch of grown-ups... its like talking to the wall. They already have their opinions. I can't change them. Don't necessarily want to. I don't care what they think.

J: So, it sounds like it does helps you to go into the community and speak with the kids..

Du: It helps me a lot.

J: And you said that is your therapy?

Du: that is my therapy...connecting with the kids. If I can help one child, understand, stay safe, and maybe not make the same mistakes I made... its all worth it...

Pa expressed a new sense of purpose for living through being a caretaker for her sister's baby...

Pa: ... So, taking care of her has been my life since she's been born... Her mom went to work when she was six months old... and ah... I have babysat ever since.

J: So, you have been babysitting since she was a little girl?

Pa: Yea...Monday through Friday...(laughs)...

J: So, it sounds like this is helpful to you?

Pa: Yes, I think it's very good for me...

J: Uh huh

Pa: ...because it was really hard when my boy was alive because he was so sick...and I think after that, taking care of a healthy baby is kind of nicer...you know, and I'm a little bit older...I can feel it...

Ra indicated her sense of purpose for living in the following interview excerpt by expressing her passion for public speaking...

Ra: Um...and I've been public speaking for a year now...I've talked to about 3 classes a month...

J: uh huh,

Ra: ...and I don't seem to be having any negative feedback from people...they even want to come up to me after classes and give me a hug...and they just feel so moved by the fact that I shared so much of myself with them...

J: uh huh

Ra: ...and I answered all their questions, and some of them are very intimate personal questions and I was happy to share it and I appreciate that...

J: uh huh.

Ra: So, I've gotten to a point where I went from being very withdrawn and very shy and isolated to feeling much more confident now, having a passion in life, which is public speaking...and I mean I wish I didn't have HIV, but, I still

like public speaking. I found something now that makes me want to live and do something...

This theme is about finding meaning in life as it is now and giving that meaning to others. Getting involved in HIV and AIDS work outside of the immediate self-care and care-giving relationship was evident. The motivation for this was in part a reaction to prevailing societal views on HIV and in part altruistic in that it provided further meaning for the care-giving experience. This is also about transformation. The former self, the old identity must be transformed into a new self with a purpose, a reason for being.

Theme # 8: Personal Growth and Transformation

The theme of personal growth emerged in all the participants' experiences of living with HIV/AIDS. In coming to terms with stresses in their lives, the participants expressed finding meaning in the illness and in their lives ... a sense of personal growth, described in their own unique way...

Do: Right. And I did notice somewhere too, like the grief with my husband that infected me, like there was very much a point where he just became insignificant. This disease, like within a couple of years, quit being about him at all. It's just a piece of my life and its just who I am here, and it... um... I owned it? It's mine, and its only one part of what I own, you know?

Du: oh, I was pissed. It made me mad. Who are they? They are not God. They are not the Creator. That's the only person that can say whether I am going to live or die. Beside, myself. I wasn't ready to go, and they weren't going to tell me I had to go. So, that just pissed me off. Like Hell. I'm not

dying. You can't make me. I just laughed. It just made me mad and more determined. What do you know? Obviously, they were wrong.

In the following interview excerpt, **M** expresses personal growth that she experienced in her life of living with an HIV-positive status...

M: Thank you... well... um... I think HIV has definitely... um... made me stronger... it definitely has... um... I... um... you know... I wasn't really given confidence as a base as a child... what we are supposed to get for our foundation from our parents... um... I wasn't blessed with it yet... um... from any one of my parents...

J: Uh!

M: Well, I didn't get the... um... um... I didn't get the confidence... um... the tools to actually... in some ways and a lot of other ways which I recall there really wasn't confidence building structure there... in my background... so, it was something that just strived for on my own...

J: Uh!

M: Um... and I knew that I was a good trip of a whole person... and I think I just liked being confident... things that I had overcome in the past... I felt as though... um... you know... this was just another... another path... another obstacle that... um... my God had thrown at me... God gives us what we can handle... that's what my father taught me... I whole heartedly believe that now... um... I have to say, HIV has given me more confidence... yes!... um... I never really thought of it as courageous or anything... you know... to be open about my HIV status... talk about it, especially in rural area...

In the following interview excerpt, Du expresses her personal growth in relating with others in this challenge of living with HIV/AIDS...

Du: It is tough. Especially when you really have nobody that you can count on.

J: But it sounds like you have turned things around for yourself..

Du: I have created a family around me.

J: A family around you...and now you are talking about Becky, talking about Jay, all those people.

Du: I have loving people around me.

J: You have opened yourself up to going to talk to someone. Talking to Ann. That is a big step for you. It looks like you are turning things around for yourself.

Du: I'm pulling out of it. I have been a loner. Because my whole life I never had anyone that I could count on to be there. Always me. The only one who has ever been there for me are my animals because I could take them with me. They were always there.

In the following interview excerpt, Do expresses her reconnecting with other people and also finding newer personal strength and growth...

Do: Well, I found out in '89, so it's 13 years, but I think I was infected in '84. Oh, that would be like 18 years.

J: It's been a long time...

Do: Yeah. And so now I'm coming out of this time of being ill and I'm...just this year, I'm starting to be able to travel a little bit...uh, I came up this summer

for a couple weeks, but I had a broken foot and I was kind of still a lot of a mess, and this trip I was a lot stronger,

J: uh huh.

Do: Just to start to get to know people, and start to reconnect again... Start to come out, and I'm still real fragile and I cry easy and I have to get away from people, and I...you know... things, but underneath I find an immense strength. I just, am so much stronger, I was strong before,...

J: uh huh.

Do: I was telling somebody, if you are strong in the broken places... there is nothing left but strength in me now.... It amazes me. I get glimpses of it. It's like I'm... ah... like a chicken hatching, or like the surface is still fragile, but not inside...

J: uh huh.

Do: There's an amazing power in me coming through all this.

This participant described her personal growth through living with the disease..

Pa: (long silence)... I think since I got the disease that I'm stronger than ever before... I eat better (laughs)...

This participant expressed her personal growth through the experience that she had of living with HIV/AIDS through gathering with other women. The strength to overcome all obstacles and the courage to face others creates a growth that has unique characteristics in the experience of the participant and the other participants.

J: ...and still do...is it the same counselor you see for HIV related issues?

DD: Yeah...it's still...you see, she's going to be so proud of me when I go back and see my counselor. Do you know I have been going to my Vietnam Vet counselor out there for about 13 years and they still can't get me in group...I won't go unless they go one on one...

J: And they'll be so proud of you...

DD: And they'll be so proud that, not only did I walk into a group, but I walked into a group of women...They're going to go, what?

Finally, in the following interview excerpt, the participant expressed how a good support group helped her with her personal growth...

Ra: And now, and the protease inhibitors came, and I was telling you about this earlier, but I want to capture it on tape, because I joined another group and all of us were feeling well and we decided to have a group that wasn't like a typical support group...

J: uh huh.

Ra: But we would talk about this book, and we would work on each chapter, and we would discuss how we could help ourselves to nutrition, with supplements, um, positive thinking, so it was a very, very constructive kind of group because that's what the book was about.

J: What is the book?

Ra: The book is called Healing HIV by Building your Immune System., by Dr. John Kaiser.

Finding positive meaning in the experience of living with HIV/AIDS, including finding new perspectives and insights regarding the self and the world, may favorably affect adjustment to adversity. In the experiences of these women, adjusting to adversity was a toll, but they managed to ascribe more positive meaning to their illness in order to become what they chose to be in the struggle with HIV/AIDS.

CHAPTER FIVE

Discussion and Dialogue with the Literature

The purpose of this study was to explore the experience of living with HIV/AIDS from the perspective of the women living with HIV/AIDS in rural areas. To gain an understanding of this experience, the researcher analyzed the themes present in the interviews of seven participants. The depth interviews allowed the participants to express their understanding of living with HIV/AIDS on their own terms. The researcher conducted unstructured interviews of detailed descriptions of situations, people, and interactions, about their experiences and attitudes about living with HIV/AIDS.

Following is a discussion of each of the themes that emerged from the analysis of the interview data and a comparison of the commonalities as they overlap across the participants. Though participants expressed common themes, each person lived these themes in her everyday life in unique concrete ways.

Emotional stress of living with HIV/AIDS

Almost all the participants spoke at length of the emotions involved in living with HIV/AIDS. The depression, anger, loneliness, shame, and suicidal thoughts expressed by at least each one of the women, indicated the frustration of realizing the feeling of helplessness, worries about the disease process, the loss of control over one's life by depending on the meds, and the anxiety or uncertainty about the future. One of the participants summarized this so well when she stated, *"I take Zoloft just kinda to keep rift, so I can stress about really big things as opposed to little things -- and sometimes when you are dealing*

with that pink elephant in the room, which is HIV, you know you don't want to talk about it, but then all of a sudden it's right there in your face and you know it."

In review, emotional stress is reported as a common problem for everyone. But, what is stress? In the 1950s, physiologist Hans Selye described stress as "*the nonspecific response of the body to any demand upon it.*" Others have expanded this definition to define stress as the body's adaptation to demands, whether pleasant or unpleasant (Gifford et. al., 2000). Physical and emotional stressors are some of the common sources and types of stress. The women expressed the difficulties of coping with emotional stress in dealing with HIV/AIDS. The depression, anger, loneliness, shame, and suicidal thoughts, clearly compose, together significant to extreme emotional stress. And depression is described as a normal reaction to HIV/AIDS (Gifford et.al., 2000). It causes one to feel helpless and hopeless, and to let go of many of the normally pleasurable activities, which in turn makes life seem even bleaker. One participant described this sense of helplessness and hopelessness as a middle of winter blizzard that was so cold and it felt like it was never going to quit snowing and the blizzard was not going stop. She expressed this feeling profoundly from her own experience of what depression meant to her. Studies have found that HIV infected women may experience significant difficulty adjusting to their illness. Schrimshaw (2003) actually states that seventy-seven percent of HIV infected women have been identified with chronic or intermittent symptoms of clinical depression. All the participants in this study

addressed the struggle with depression. Thus we can consider emotional stress a central organizing theme underlying the experience of living with HIV/AIDS.

Anger is another common response to having HIV/AIDS and was also evident in describing the emotional stress. Living with HIV/AIDS presents the uncertainty and the unpredictability of living with this disease, which threatens what many have struggled a lifetime to achieve – independence and control. The loss of control over one's body and loss of independence in life, as literature indicates (Gifford et. al, 2000) creates feelings of frustration, helplessness, and hopelessness, all of which fuel anger. Anger is not only seen as a response to having HIV/AIDS, but it is actually the result of the disease process itself (Gifford & et.al., 2000). The women in this study expressed feelings of anger in different ways and situations relating to their being HIV-positive. For example, one of the women, frustrated about how the doctors had treated her when she was in the hospital, and they told her that she would die from AIDS, *"It made me mad. Who are they? They are not God. They are not the Creator. So, that just pissed me off like hell. It just made me mad and more determined."* This woman expressed her anger towards her providers because she did not feel supported. She seemed to be displacing her anger since it is easier to do that than to blame oneself, God, or a loved one. Her frustration with the providers was evident during the interview when she shared this information, but the strength in how she expressed herself also showed a confidence that could not be overlooked. Kalichman (1995) states that anger is a common reaction to a life-threatening illness, and also that anger and guilt can also come from

attributions of blame for HIV infection, and in some instances the anger can be directed toward the person believed to have transmitted the virus to the infected person, medical caretakers for being unable to cure the disease, or society for failing to respond with urgency and compassion.

In this study, the women all did express their anger in many different ways and to different situations. Anger was expressed towards family. For example, one woman was angry with her father for not being the greatest dad when she was growing up. She believed her father was not available for her when she was growing up, and her anger helped her to confront him and let him face up to the failures as a parent. She indicated that by doing so, it helped her to move on with her life better. Other women's targets of anger included partners that infected some of the women, providers that were not compassionate enough, and the society for trying to condemn and ostracize the infected women. One woman strongly stated that she had never met anyone that was HIV-positive that wanted to give the HIV to another person, and did not see the reason for the society to condemn or ostracize her for living with HIV/AIDS. The expression of anger for almost all the participants seemed to stem from frustration of the negative experiences of dealing with other people, be it family or friends, or providers and social services, and having to put energy into that instead of paying attention to their health needs.

Social Environment and living with HIV/AIDS:

This theme was prevalent among the participants. In one-way or another, the participants experienced the impact of those around them and how they were

affected, be it family, friends, and even the social services in their different communities. The experiences were positive in some cases and negative in others, but this domain was always important. One participant explained her negative encounter with her mother when she went back home after running away from an abusive husband who had infected her with the virus, *“I went to my mother when I left my husband and she didn’t believe what I was telling her... wanted to know who I had been fooling around with or what drugs I had been using, and pretty much disowned me when I wouldn’t go back to my husband and beg him for forgiveness, for leaving him.”* This woman felt rejected and not understood by her own mother. The tone in which she shares this information is that of a frustrated person. She went back to her mother for support, but what she experienced was rejection and blame. Klitzman (1997) states responses to rejection and threats of annihilation have high stakes. Feelings about the self can hamper health inadvertently or unconsciously. The low self-esteem, exacerbated by HIV, as well as a sense of fatalism about the illness, can foster high-risk behaviors (Klitzman, 1997). Infected men and women face difficult decisions about disclosing their status, determining who, when, and what to tell. The experiences of the women in this study seem to reveal that disclosure of HIV status presents a problem for both the infected and the uninfected. Some people are shunned and suffer broken relationships. Others like the woman above, experience violence, and/or the loss of housing and jobs. Even after all the rejection, the need to connect with family, friends and others was huge for the participants, and there were some successes and

failures in this need as the excerpts indicate. While people living with HIV/AIDS have to deal with the physical impact of HIV/AIDS, we see that in this case these women are also dealing with emotional reactions, changes in their role performances, and even changes in their relationships with others (Furstenberg and Olson, 1984).

Another participant described a positive experience with her family stating that her whole family was very supportive even though her mom was afraid to drink from the same glass of water, and she was not bothered by it. Her experience, even with the mother's behavior of not sharing the same glass of water, seems to be a positive one. The different views represent the experiences of most of the participants in this study about how they were treated by either family or friends. This disease profoundly affects interpersonal relationships. A woman's need for understanding and connection increases at the same time that important others in her life are themselves adjusting to her diagnosis. Walker (1996) has suggested that people with HIV/AIDS who are needy can tax their family and friends, and thus it is important to encourage them to join groups as a means to access supportive networks. The various aspects of the disease and its treatment can cause the feeling of lack of control and the sense of powerlessness over one's life.

Participants also described the struggles of dealing with the system in trying to get their needs met. Because they were living with HIV/AIDS, daily living became much more difficult, though for some systematic support services did work out well. However, one participant discussed losing her children and

when she wanted the DFS to help, they refused to do so. This is how she explained her dealing with the system when it came to living on disability, “*Um, living with this disease humbles you; it makes you dependent on the system. Um, the system sucks. I mean because you become helpless, when you don’t want to be helpless. I know they are trying to help us, but it really isn’t helping because its not letting us be our own person... And it really bothers me.*” The role of being a mother and a sense of independence have been taken away from this woman. This sense of loss of relinquishing certain aspects and functions of one’s life to others seems evident in all the women in this study. It is thus important, as Macks (1989) states, that when providers, in any setting, provide information, emotional support, assist with problem solving, and enhance coping skills, they should empower people living with HIV/AIDS to manage their lives. The sense of powerlessness for women dealing with HIV/AIDS is great so that providing them with a sense of feeling independent and of worthiness is important. There is also ambivalence about needing and accepting help.

Another example of dealing with the system is portrayed by a participant who lost her son after he was diagnosed as being HIV-positive, she stated, “*Yeah, they took my son away from me when he was two months old when they found out he had AIDS. I basically jumped through hoops with social workers and therapists to get him back.*”

In one way or another, living with HIV/AIDS forces individuals to deal with the system. Almost all the participants in this study dealt with the system in

one-way or another to make a difference in their lives. One participant helped change a law in her state so that it would apply for women or people living with HIV/AIDS. She indicated that realizing the chances of losing her daughter in the event that she got very sick and was admitted in the hospital, she pushed for the law of Stand by Guardianship to apply to HIV/AIDS patients just as it did for people with cancer. HIV/AIDS is an intrusive and unwanted guest demanding change in every aspect of one's life, and for this woman to demand as little interference as possible in her life by campaigning to have the law of Stand by Guardianship, was an accomplishment. This does sound like a positive fight for this participant, but she did have to fight for this right, dealt with the system and had a positive outcome. These findings seem to show that these women have had to fight every step of the way in trying to keep their children, find their children, be on disability, and even find love with their loved ones, meaning family and friends, as they deal with the experience of living with HIV/AIDS.

Land (1992) states that HIV/AIDS is a crisis in which the individual anticipates the disease state; copes with the innumerable vicissitudes of the disease; undergoes the physical, social economic, psychological, and spiritual changes that the disease brings; and lives with the devastating consequences of its aftermath.

Sense of Betrayal:

Participants expressed feeling a sense of betrayal in how they contracted the HIV/AIDS. As one of the participants described about her situation, *“Well, I couldn't believe it. It took me about 8 months or so to figure it out, that he was*

lying about it. And when I left him the doctor said to me (sigh) that he had it for 14 years and he knew he had it." This was the theme that resonated amongst the participants. Each one of them had a story about how their partners never revealed the truth about their HIV/AIDS status. The World Health Organization (2000) reports that women are infected with HIV through sex with a bisexual or drug-injecting partner, their own injecting drug use, and heterosexual sex without these factors like drug use, and through blood transfusions. The women in this study reported being infected by drug injecting partners, bisexual partners, and one by a hemophiliac.

One woman found out by accident because she observed the partner taking medications that she found out later were AIDS medications. There had been drug abuse before in the home and so the participant thought the husband was getting back on the drugs, only to find out otherwise. *"Yes, because my husband at the time, ex-husband now, he had a drug problem. So, in 1990, I noticed that he kept taking these little pills. I thought it was some new street drug. And after seeing him take them for a couple of months, I started kind of getting worried, and asked him about them. I got married at 15 years old; to a man that was 22 years older than me... right. So um, I was really a child. I didn't know any better."* Numerous studies have documented that drug users are at risk for HIV through both drug-related and sexual behaviors, which places their partners at risk as well (CDC, 2000).

Profound, life-altering deceit was experienced by most of the women. Many had similar stories in how they found out about their HIV-positive status.

In one-way or another, the sense of betrayal was a common experience that every woman shared in this study. The participants so evidently expressed anger and frustration towards the partners when they described their experiences. One woman felt very angry towards her husband saying, *“I felt lied to.”* Her story was about a husband who involved himself in high-risk behaviors, basically lived a double life. This is how she described her situation, *“He pretty well knew, he was doing a lot of risky behavior when he would travel on business and it went on through the marriage, he told me later that he took a lot of risks and um, didn’t want to tell me. Then he’s telling me how he goes to the gay bathhouse and gets royally drunk and doesn’t even know what happens.”* This participant indicated devastation after she found out about her husband’s other life, and more when she realized that this meant she was definitely at risk for HIV/AIDS.

One participant expressed feeling robbed of sense of her self when she found out about her HIV-positive status, *“ I felt that Mike took something from me.”* She claimed the husband was open about his drug use, but not honest about his HIV-positive status. This sense of loss of self, because of the betrayal, seemed to be the sentiment shared by most of the participants, even though not expressed in the exact words. All these women accidentally stumbled on the truth about their HIV-positive status, and all seemed to feel a sense of being lied to and betrayed by their partners.

Medical Treatment Issues:

All the participants reported dealing with medical health struggles in their years of living with HIV/AIDS. This included physical health, medication side effects, and even the importance of T-cells. In the earliest studies of the natural history of HIV disease and the majority of treatment, studies only included gay men, and less was known about HIV infection and effects of treatment among women. In the recent years studies have shown that women with HIV/AIDS are susceptible to a number of gynecological infections and cancers related to HIV infection (Kalichman, 1995). One woman shared such medical conditions, *“I have gone through a hysterectomy from cervical cancer, I’ve gone through an appendectomy where they had to take one of the ovaries. I went through menopause this year. I’ve been through toxoplasmosis; I’ve been through wasting. I’ve had three strokes. In 1996, I lost the use of the right side of my body. I couldn’t speak. I dragged my leg, I couldn’t use my hand, I couldn’t lift my arm above my shoulder. And my physical therapist is lying right at my feet, I refused to go to physical therapy.”* The recovery this woman went through is supported by literature that indicates that rapid advances in the medical management of HIV disease have improved both the quantity and quality of life for countless people who have access to care (Kalichman, 1996).

The medical conditions described by this woman illustrate the struggles that each one of these women involved in this study has been dealing with in all the years of living with the disease. In light of HIV-positive women’s increased susceptibility to breast and cervical cancer, cervical and anal dysplasia, and

menstrual problems related to hormone fluctuations, it is especially important that women have access to and are encouraged to use all HIV-related health facilities and programs in their communities (Cohen & Doner, 1998). Equally important to pay attention to about women living with HIV/AIDS are social and psychological support. Because the physical and the psychological are intimately connected, family and friends may provide the social support. Health care providers, be it medical or mental health providers, and need to do their part as well. Providers need to instruct all clients on how to become self-empowered, self-advocating consumers of medical and mental health care (Wheeler & Shernoff, 1999). The importance of support cannot be stressed enough for people dealing with HIV/AIDS. Learning to live with all the body changes that these women have experienced because of the disease calls for necessary psychological evaluation, for example, a psychosocial history needs to be used to evaluate the woman's mental health, including appearance, behavior and attitude, and thought process. Schrimshaw (2003) suggests that it should be urgent to identify factors associated with the adjustment needs of women living with HIV/AIDS, so that effective interventions, physical, social, or psychological can be designed, a total holistic approach to well-being.

The other common medical condition addressed by many of the participants is *Pneumocystis pneumonia*, a bacterial infection of the lungs that causes dry cough and shortness of breath (Gifford et. al., 1997), which is common in people with AIDS. Kalichman (1995) reports that compromised immune systems increase susceptibility to a wide range of bacterial infections.

One participant talked about her experience of being in the hospital due to the *Pneumocystis pneumonia* after being in denial about her HIV status due to circumstances in her life saying, *“I just kind of ignored it because I already knew it, that I was positive. And, I wasn’t sick. I didn’t feel sick. I didn’t look sick. Um, in February of ’93, um, I came down with pneumonia, and it was Pneumocystis pneumonia. I ended up in the hospital in Las Vegas, Nevada.”*

This experience of having the *Pneumocystis pneumonia* by this woman was common amongst the participants. Each one of them talked about it as one medical condition that they had to deal with. Unlike people with functional immune systems, symptoms of pneumonia in HIV infection persist for long periods of time. Recurrent bacterial pneumonia, which is *Pneumocystis pneumonia*, is now an AIDS-defining condition according to the CDC. Those most common infections associated with HIV involve the gastrointestinal system, skin, meningitis, and sinuses (Chaisson, 1999). Dealing with recurrent *Pneumonia* and other medical issues, and the effort of facing all the stressors of living with the disease seem tremendous. The women in this study show great strength of survival. Schrimshaw, (2002) states that the extended survival and increased rates of infection result in substantial increase in the number of women confronting the psychological challenges of living with HIV/AIDS as a chronic illness.

Another participant indicated that, *“Well, um, at first I had PCP and I had been working there 6 months, I got PCP. And I actually got through that, and went back to work. And then I got really sick... and it was IV lines... and we*

had to do a blood transfusion too... a couple of different blood transfusions and trying to just keep me going." The antibiotic medications taken for PCP also have side effects that the women have to deal with just like taking antiviral medicines. The most common side effects include allergic skin reaction resulting in rashes, which can be managed, minor fevers, nausea, white count suppression, decreased platelet count, and liver irritation (Gifford et al., 1997). The stress of going through the treatments for most of these women, whether dealing with pneumonia or any other medical condition, created psychological distress, and strong therapeutic alliance is an important facet of working toward a healthy adaptation to life with HIV (Veilleux, 2004).

Other medical issues that the participants reported experiencing included dementia, like this experience of one woman after learning about her condition from her doctor, *"I freaked out when he said he really thought I was going into dementia, that whatever it was that was causing the fatigue was taking my brain down too, that there was really a loss from even 6 months before."* This participant reported that she was filled with a lot of fear when she was informed about her dementia, and this fear is shared by everyone as they deal with all other medical issues. Fear may result from worries about physical health, finances, the disease process, and even family, which may result in depression. Gifford et al. (1997) state that just as the physical de-conditioning that happens as a result of HIV/AIDS can make you feel weak and helpless, leading to less physical activity and even more de-conditioning, depression can be a vicious cycle of emotional "de-conditioning." Depression can cause one to feel helpless

and hopeless and to let go of many of one's normally pleasurable activities, which in turn makes life seem more discouraging. This is what these women experience in all their years of living with this disease.

Besides the medical physical condition that each of the participant described, they also all spoke of the bad experiences of living with the side effects of medications. Gifford et. al. (2000) report that it is common for people with HIV to be taking many medications: anti-HIV "Cocktail" medications, anti-inflammatory drugs for pain or fever, a pill for depression, an antibiotic to prevent Pneumocystis, antacids for heartburn, a tranquilizer for anxiety, plus a handful of over-the-counter (OTC) remedies. With so many medications to take, though not all of them are taken at the same time, the risk of drug reactions is inevitable.

The Protease inhibitors, the "Wonder drugs" or the "Cocktail drugs" appear to offer great hope, but their side effects have caused problems for some people taking them as the following excerpt reveals, "*Um, the illness was so bad...and I was going allergic to every drug, and the first part, it was just hanging on. I was just doing everything in my power to get every pill into me and do all the things I needed to do to get myself through it. I was really sick.*"

Appropriate therapy and preventive drugs can forestall the development of AIDS-related symptoms and prolong life in HIV infected men and women. At the same time, although these current HIV treatments are extremely effective at reducing viral load for many, a host of aversive side effects. Common side effects include nausea, diarrhea, headache, rash, vomiting, and sleep

disturbance. These may accompany highly active antiretroviral therapy (Remien, Hirky, Johnson, Weinhardt, Whittier, and Min Le, 2003). These side effects may actually interfere with medication adherence because they can interfere with daily routines, obligations, and quality of life. Then it becomes a psychological issue that the individual that has HIV/AIDS has to deal with. This calls for health care providers to be aware that there are typically multiple emotional, cognitive, and behavioral factors that influence people's compliance with medication.

The attitude of "hanging on no matter what" is the experience of participants in dealing with the medication side effects. In another situation, one participant reported that her health was generally good except for the side effects of the medications, and she believed her problems were more to do with the side effects than the HIV, "*My health in general has been pretty good... most of my problems have been from the medications.*" In addition to AIDS medications, this participant also reported taking Zoloft for depression. Even when life was great for them due to the medications that they were taking, most participants reported the realization that HIV cocktail drugs are medications whose benefits have to be weighed against their undesirable side effects.

Every participant also addressed the importance of T Cell or CD4+ Cell Count when they discussed the medical treatment issues. As Kalichman (1995) indicates, following long periods of asymptomatic infection, any number of general and nonspecific early symptoms may develop for a person living with HIV/AIDS, and later stages may be characterized by severe depletion of CD4

cells or T helper cells and the onset of specific illness. The immune system is vital to proper functioning of the human body, and that is why people with HIV infection can have so much trouble. All the women in this study indicated that it was important for them to know something about their T-cell count because it gave them hope. The T Cell count is believed to be the most useful test available for monitoring how much HIV affects the immune system. It is defined as simply a blood test that measures the number of T helper cells (or CD4+ cells) in each microliter of blood (Gifford et. al., 2000). Because T cells are important in fighting infections and cancers, having a low T cell count increases the risk of illness.

All the women in this study expressed the importance of maintaining good counts of their T cells. One participant even attributed to how she dealt and lived with depression related to having good T cell numbers, *“I’m not always happy. I do have my down times. If my blood tests are great, I’m undetectable, I have good numbers, and T-Cell, I’m feeling relaxed... but if stuff starts to go array with my counts. I think it affects my emotions.”* In a different example, this participant’s counts went so low that she thought she was going to die, but an encounter with another person with an even lower count, she got through a rough moment. The exchange below describes her situation and emphasizes the importance of T-cells: *“I was amazed at how well I could live with it... How much even watching my T-cells fall and getting to the bottom, and there were times I got so low, I was frantic, but by the time I had no T-cells and I knew I only had a limited time to live, Well, 3, you know.... I mean like from a*

1000, when you get below 50 you're getting pretty low and then you get down to 30 and then you get 12 and then you get, you know, so it's kind of like 7." With such a low T cell count, especially below 50, literature indicates that it means the T-cell part of the immune system is not functioning. In this case, good, comprehensive medical care is vital, and treatment with medicines to prevent opportunistic infections is very important (Gifford et. al., 2000).

The women in this study all indicated how important it was for them to monitor their T-cell counts in order to stay on top of their health. The high numbers give them hope to face everyday challenges of having to be parents, spouses, family members, and friends. The roller coaster ride of having to go through changes that affect every aspect of life, the pain, and the body-related losses is overwhelming for a woman. The concrete details of treatment are important to these women, but on another level, at times, a focus on the body becomes the most necessary and only focus of attention and life. The disease takes complete charge of not only the woman's life, but of whether or not she will continue to exist.

Loss and Resulting Grief:

The theme of dealing with grief was so prevalent and resonated with all the participants. When we experience any kind of a loss, small (such as losing a favorite possession) or large (such as losing a life partner or facing a disabling or terminal illness), we go through an emotional process of grieving and coming to terms with the loss. There are major personal losses associated with having HIV infection, and the women in this study expressed those many losses in their

lives. What literature reveals to us is that although loss and bereavement are universal experiences, individuals react to and cope with these experiences uniquely (Bidgood, 1992).

The women did have different experiences of the types of losses. To talk about her loss of time and sense of control of her life in general, this participant described her grief saying, *“Like seasonal, yeah, and then somehow, it just happens, I mean sometime just within me its almost like I just spend enough time in winter, and pretty soon it just starts, and I will notice little bits of something in me that are not exactly joy, but there’s little bits of like green sparking on the trees and just a little bit of almost like give into winter and the next season comes. To me it’s just seasons of grieving. And so, what I am doing is grieving the loss, and if I am going into dementia, I’m grieving HIV, I’m grieving a lot of different kinds of grieving. I’ve just gotten good at grieving, you know.”* This woman is expressed grief and bereavement stemming from a self-reflective process in her living with HIV/AIDS. Any significant change in a person’s life, including a positive one, is said to have a potential to evoke feelings of loss and a need to grieve for what has been lost (Shernoff, 1999), in this case, this woman seems to express grief from losing her healthy life and all the other losses in her life. Other women in the study shared this sentiment.

Kalichman (1995), reports that the most common source of loss for many HIV-positive people, is the death of partners and friends because of AIDS. Many participants in this study reported losing friends to the disease, *“then I would see a counselor regarding that issue, that you know, I’m afraid,*

I've got this disease, all my friends are dying, then we'd discuss that. And she worked with me. This was a woman who works with people who have HIV."

Another woman shared an experience of losing friends not necessarily to HIV/AIDS, but actually lost friends because she had HIV/AIDS. The following exchange describes this experience:

My true friends... I mean some of the friends that I had for over 30 years, as soon as I said this, because I didn't keep it a secret, I told everybody the same day. Ah, they did act like I was already dead, and I've never seen them since. And that was hard... People that I knew 20 to 30 years. Now I wasn't worth knowing because they were ashamed of me... and it about drove me to the edge of my sanity...

The loss of friends and family was prevalent. In some cases relationships continued, but friends and family changed their attitudes towards the participants, creating a sense of loss of the old friendship that used to be safer or offered support. Schrimshaw (2002) states that illnesses, particularly HIV/AIDS, can be stigmatizing. Fears of contagion and negative attitudes about behaviors associated with HIV/AIDS may lead potentially supportive individuals to engage in negative social engagements (e.g., rejection, disapproval, conflict) at a time when an individual is most in need of support.

Some women shared the experience of losing their children to adoption, to ex-husbands and even to death, like in the following example, in which a participant shared about the death of her 2 year old son who died from AIDS, *"I think the most challenging thing I have done, is taking care of my son...from*

birth to death.” Obviously, having an HIV-positive child contributes to the stress that a mother who is positive herself endures. No one can tell anyone how to grieve. This slow process of redefining our world without the presence of someone we love, takes time, and is unique for everyone. The losses experienced by these women are so profound, and it might speak to their identities as mothers, partners, family members, and even friends. They don’t only lose the children; they must construct a whole, major aspect of their identity. The AIDS-related stigma also seems at play about these women’s experiences, for example the woman in the excerpt, DD, was rejected by her friends her for being HIV-positive. Literature does show that people with HIV are discriminated against, and may also be rejected by family members and friends. This also speaks to the AIDS-related stigma, and what Herek (1999) reports about this is that AIDS-related stigma refers to prejudice, discounting, discrediting, and discrimination directed at people perceived to have AIDS or HIV, and the individuals, groups, and communities with which they are associated.

Relationships and Support System:

Participants expressed the importance of a good support system in their lives to help them deal with living with HIV/AIDS. Lennon, Martin, & Dean, (1990) note that relationships can establish and maintain emotional balance and therefore can be considered a high priority in coping with HIV. Emotional support can result from simply being with someone and enjoying his or her companionship. The participants expressed their views on the importance of a

supportive environment, a need for a connection to other people for them to deal with their issues in relation to HIV/AIDS. Literature shows that for gay men emotional support occurs when feelings are acknowledged, regardless of whether the contact is in close and intimate relationships, among friends, in support groups, or within a professional helping relationship (Wolcott, Namir, Fawzy, Gottlieb, & Mitsuyasu, 1986). Some of the women in this study indicated traveling distances to get this contact with others, and to get the acknowledgement of their feelings. Because rural women with HIV/AIDS are relatively invisible and more likely to be harshly judged, lack of support and the search for support are of critical importance to these women. Traveling long distances for some women was to seek support groups because they did not have these in their small communities.

All the women expressed the need for support. One woman illustrated it so clearly when she stated, *“I treasured it when I finally met women and could connect to women, because it was a whole different experience. The heterosexual men, I related to in some ways more than the gay men, just you know, people from the hemophiliac and other ways.”* Another woman indicated that importance by stating that she traveled with a friend every once a month to another state to meet with other people living with HIV/AIDS for emotional support, because in her small rural town there was no support group, *“My friend and I travel to another state to go to a support group. We travel a 70 miles round trip once a month to this particular support group that I have been involved in for nine years now. It is very helpful. I am able to talk about my*

issues, what you go through on a day-to-day basis in relation to your health. You know you can talk about your problems with your colon, day to day inconveniences that you go through with HIV, the fatigue, the tiredness and they understand.” The NRHA (1998) report that in rural areas, acquiring treatment may be difficult, and rural HIV/AIDS patients often travel two or more hours to obtain medical care because getting tested for HIV, discussing sexual practices with health care providers and practicing safe sex can all be difficult to do privately and confidentially in rural areas. The fact that some women with HIV/AIDS make travel for support and connection a priority reveals how important this factor is for them. There is possibility, though, that the women in this study who traveled to the retreat may value traveling more than most HIV/AIDS individuals.

Whitlock (2002) reports that women in rural areas have less access to mental and physical health, feel more isolated, receive less support from family and friends, suffer from community stigma and discrimination, and have a greater fear that their HIV status will be discovered. Because these women live in rural, more geographically isolated areas, support and companionship are especially pressing needs. Hence comes the need to go to other states or bigger cities to meet with other HIV-positive people and attend support groups. The NRHA (1998) also report that the rural setting provides a set of obstacles to HIV/AIDS prevention and treatment that are different than the challenges faced in the metropolitan areas. The traditional moral values, conformity to community norms and intolerance of diversity can be strong, creating dilemmas

for HIV-positive women and men. The women in this study shared their experiences of attending support groups, but yet others still indicated not to have in their towns because no one would facilitate them. One woman reported of not being aware of any support groups in her area, but expressed having support of family and friends.

One of the participants talked about the importance of her animals as a means of support. She stated that they kept her grounded and helped her to deal with issues that came up, especially when she felt a sense of helplessness and anger, *“they help me, they keep me calm. When I get really upset and angry, one of them will come and set their head in my lap or something or one of the horses will come and put their head over my shoulder and just you know, its kind of like they’re saying, don’t sweat the small stuff. And they are always there for me. No matter what.”* This excerpt illustrates the importance of the comfort of having a connection to another, be it a human or animal.

Participants in this study also addressed the importance of support from providers, even though some situations were not a good experience. Professional caregivers are crucial to social support systems in HIV infection. Although relationship partners, friends, and family provide emotional support and assistance with daily tasks, professional helpers are perceived as a critical link to health-related information resources and advice to people with HIV (Hays, Catania, McKusick, & Coates, 1990). A participant indicated that she had resisted the support for a while because she did not believe in counselors, especially in the first two years of living with HIV/AIDS, *“I was one of those*

that holed up and didn't believe in that. My counselor got worried and had a hospice worker sent to my door. She's still my hospice worker." There were more examples like this that were presented by the participants, the dilemma of not wanting help, but yet needing it.

Support groups were also described as providing a good support system for almost all the participants. Klitzman (1997) describes support groups as a subculture that places a premium on discussing one's experience, and are viewed as a "solution" in and of themselves, imbued with an almost magical sense of hope that is often a key ingredient in their overall appeal and effect. Support groups vary widely in structure and format. They can include information dissemination pertinent to HIV infection and treatment, or alternatively, the groups can focus exclusively on delivering and exchanging information, providing a forum for people with HIV infection to share experiences, knowledge, and ideas (Hedge & Glover, 1990). Most of the support group experiences of the participants seemed positive, and showed that they shared their experiences and knowledge about HIV with others, and also learnt a lot from the other group members. They created friendships that lasted well beyond the group experience, as one of the participants shared, "*But I do um get support from the people that I know I've met people through support group. I remained friends with those people that I clicked with, that I liked the most... and we became friends outside the support group.*" Klitzman (1997) states that losses and rejections prompt these patterns of response, which are common ways of continuing on and looking for hope. He says that many

individuals enter, what he calls HIV-Land, or AIDS community because it has developed its own customs and language. One woman in the study talked about how she felt comfortable and at ease sharing about her discomforts of living with HIV/AIDS with the members in her group, without holding back because she felt they understood what she was talking about. HIV-Land, which could be referred to as an HIV-positive support group, fills needs and desires that the rest of the society has been slow to meet or refused to consider. This appears to be true for women in rural areas; they go to these groups to meet the people that share the same struggles or joys of living with this disease.

Each of the participants indicated the importance of family support, whether in the form of family of origin or family created through friendships met along the struggle of living with HIV/AIDS. Some participants put this in very simple terms, for example, one woman stated, *“Um, my whole family is very supportive.”* And another woman indicated *“Yeah, family and friends... I was born and raised in Helena... So I do know a lot of people in Helena.”* It is essential for the psychotherapist and the counselor to conduct a thorough assessment of all issues that may affect psychological functioning. And Veilleux (2004) suggests that during periods of chronic illness, the psychologist's or counselor's roles are to facilitate wellness and recovery by helping the patient to cope positively with the illness, and to provide a relationship in which the patient can express herself. This is about a counseling relationship, which can be applied in a support group setting.

Renewed Purpose for Living:

Each of the participants expressed the ability to integrate desired and undesired aspects of their lives in order to find a renewed purpose for living, even while they struggled dealing with the experience of living with HIV/AIDS. This was addressed by the participants through their desires to educate others about their experiences of living with HIV/AIDS, and about HIV/AIDS as a disease. This theme emerged through the message of hope. Shernoff (1997) states that hope is essential for all people in order to create meaning in our lives, but it is especially crucial in the depths of an epidemic. The ways that people with HIV disease hold onto hope and allow what they hope for to expand, contract, and evolve over the course of their illness is essential to living well with this disease. The participants in this study expressed this hope by realizing positive aspects of themselves that they wanted to share.

One participant shared her experience of contemplating going back on drugs after she found out about her HIV-positive status, but when considering the importance of her daughter and those around her, she found the necessary hope and purpose in herself to stay on track. *“ When I first sought out care, six weeks after being diagnosed, I bought a big piece of half a gram of cocaine, trying to light cocaine to numb me, and of course I just flushed it and I never thought about it again. My basic goal was to take care of my daughter while I was with her, she was my responsibility, you know. I wanted to be proud of her. I brought her to this planet, put her there, so it’s my job to see her get through, be raised into a young, you know, individual, progressive, you know, mode her*

into the society. That's what I did, an adaptive individual." This woman chose to keep away from drowning herself into drugs again, which as she states would have been very easy to do, but instead she focused on the needs of her daughter.

Women may be caregivers in families where their spouse is HIV-positive, and they may have an HIV-positive child, making it necessary for women to balance their own care with the needs of their family (Minkoff & DeHovitz, 1991). The woman in the excerpt pushed herself forward for the sake of being a mother, with a sense of purpose, and felt the responsibility to do so. These women are finding power in their sense of transcending the illness through purpose and spiritedness. This is in contrast to the many ways being a woman with HIV/AIDS finds herself powerless in fact or feeling powerless in her relationships to others.

Most of the participants also found sense of purpose as caregivers, took care of their families, children and even animals that they loved. One participant shared her experience of finding reason to live by taking care of her sister's child. She lost her own baby to AIDS. When asked how she was dealing with the babysitting of her sister's daughter, her response was, *"taking care of her has been my life since she's been born. I think it's very good for me because it was really hard when my boy was alive because he was so sick, and I think after that, taking care of a healthy baby is kind of nicer, you know, and I'm a little bit older, I can feel it."* The participant seems to feel alive even after losing her own child to AIDS from this experience. During the interview she was very soft-spoken, but when she said, *"I think it's very good for me,"* meaning the

taking care of her sister's baby, she expressed this with a lot of confidence.

Almost all the participants addressed care giving as their main priority. Through loving and caring for important others in their lives, these women again transcended illness, disability and potential death.

Studies show that women with HIV infection are likely to suffer additional stress, and this is due to the fact that they often contend with their own HIV infection while serving as the primary caregiver for their HIV-positive partner (not unique to women with HIV), as well as caring for their children (Martin, 1988). But in this study, for the women with children, just like the experience of the above participant, taking care of the children is what gave them hope and a purpose in life. Living with HIV didn't stop these women from realizing their hopes. They found power in contributing to the lives of others.

Through a variety of experiences, the participants of this study discovered their sense of purpose. From sharing themselves with others, they realized that there were still chores to do, their lives to live, and sharing the experience of living with HIV/AIDS and teaching others about the disease. Participants addressed the satisfaction and strength that they experienced from speaking and educating others about HIV/AIDS. As this excerpt illustrates, *“Um... and I've been public speaking for a year now. I've gotten to a point where I went from being very withdrawn and very shy and isolated, to feeling much more confident now, having a passion in life, which is public speaking... and I mean I wish I didn't have HIV, but, I still like public speaking. I found something now that makes me want to live and do something.”* This

sentiment was shared by many of the participants, even in circumstances where resistance was experienced. One woman chose to keep pushing for hopes of educating students, even when their parents were resistant, *“yeah. I really don’t care what their parents think or what they say, you know, I don’t care... because if I can get to the young people, we can change the attitudes.”* She stated that it helped her a lot to speak with the kids, *“that is my therapy, connecting with the kids. If I can help one child understand, stay safe, and maybe not make the same mistakes I made, it’s all worth it.”* These women affirm that they want to continue to have a life that matters, both to them and to those they may eventually leave behind.

Another woman found her renewed purpose for living by speaking to kids at the Juvenile Hall and to other women at the Women’s Prison. She expressed great passion in doing this work. She also addressed how the whole process helped her deal with her own issues better, *“Because I go to Juvenile Hall and talk to the kids and I go out to the Women’s Prison and talk to the women out there about what it’s really like to live with this. I love doing that sort of thing, it helps me kind of work through my own stuff better too.”*

Educating others about HIV/AIDS seems to be the only way that prevention of the disease can happen. The determination and passion of the women in this study to educate others is heartening. Kalitzman (1997) reports that as a result of this illness, work has taken new forms and meanings. For many people living with HIV/AIDS, volunteering for HIV-related organizations has replaced previous employment and provides purpose, identity, and a means

of contributing to others after one's own death. Infected individuals, based on their backgrounds and experiences, choose different types and functions of work and volunteerism. The women in this study all expressed their enthusiasm in teaching about HIV/AIDS to different groups of people in their communities. The well being of young people and even future generations drives these women, even as they struggle with the disease, the medication side effects, and all the different losses experienced in their lives.

Personal growth and transformation:

Related to the previous theme, participants of the study expressed a sense of personal growth. Through their self-confidence, courage, acceptance, and hope in their experience of living with HIV/AIDS, the participants all shared stories relating to how much stronger the disease made them feel. Even in the midst of emotional stress, social environmental impact, sense of betrayal, medical issues, dealing with grief, stress of relationships and need for support, the participants expressed feeling a sense of an inner growth and maturity in dealing with the disease in their own unique experiences. The demands of their lives with the disease helped them find parts of themselves they did not know they had.

In expressing personal growth, the participants addressed self-confidence as one of the qualities that they felt they had achieved in their dealing with HIV/AIDS. Self-confidence is viewed as an attitude that allows individuals to have positive yet realistic views of themselves and their situations. Self-confident people are viewed as people who trust their own

abilities, have a general sense of control in their lives, and believe that, within reason, they will be able to do what they wish, plan, and expect (Gifford et al., 2000). This excerpt from one of the participants is illustrative of this, and it is a sentiment also shared by all the participants. She shares about her confidence and about how HIV has made her stronger, *“Um, and I knew that I was a good trip of a whole person and I think I just liked being confident. Things that I had overcome in the past, I felt as though, um, you know, this was just another obstacle that my God had thrown at me. God gives us what we can handle, that’s what my father taught me, I whole-heartedly believe that now. I have to say, HIV has given me more confidence, yes! Um, I never really thought of it as courageous or anything, you know... to be open about my HIV status, talk about it especially in rural a area.”* Again this woman addresses the issue of disclosure, which was also an issue for another woman. Being open about one’s status, as noted in the literature, is a challenge for many people living with HIV/AIDS, especially in rural areas. Women in rural areas have a greater fear of having their HIV status being known by the people in their communities (Whitlock, 2002)

Having self-confidence does not mean that individuals will be able to do everything. Self-confident people have expectations that are realistic. Even when some of their expectations are not met, they continue to be positive and to accept themselves. The following participant describes this notion in the following excerpt in which she talks about acceptance and owning the HIV/AIDS, and also coming to terms with the grief she experienced with her

husband who infected her, *“And I did notice somewhere too, like the grief with my husband that infected me, like there was very much a point where he just became insignificant. This disease, like within a couple of years, quit being about him at all. It’s just a piece of my life and its just who I am here, and it... um... I owned it? It’s mine, and its only one part of what I own, you know?”*

This woman is expressing the strength from within her, which has grown with time.

The acceptance and sense of owning the HIV/AIDS was one of the sentiments shared by participants when they described their personal growth while living with this disease. Every participant seemed to have come to a point when she faced HIV/AIDS head-on, and accepted her diagnosis in order to start adjusting her lifestyle to the demands of the disease. Even as the conditions changed in their lives, these women seemed to have come to a place at which they carefully evaluated their lives as to what they could do for themselves. Becoming helpless and dependent is the most basic fear among people who have potentially disabling health problems, and in expressing acceptance of the HIV/AIDS; these women seemed to want to indicate their independence and their usefulness to their families and friends. Shernoff (1999) states that the task of forming new coping skills is important for not only practical issues, but also to address psychological issues as well. By being nurturers, that is, mothers and caregivers, they managed to maintain the basic responsibilities that go with it. The analysis of the interviews reveals that the women felt the importance of

being the caregivers in their households. Because many of the households were those of single mothers, the obligation was inevitable.

Almost all the participants addressed the sense of courage in the inner-self to face new challenges as part of their personal growth. One participant described how she started to open up to meeting new people, saying, *"I'm pulling out of it. I have been a loner because my whole life I never had anyone that I could count on to be there. Always me. The only one who has ever been there for me are my animals because I could take them with me. They were always there."* Another participant spoke about the immense strength that she felt, after coming out of an experience of being sick for a long time, *"I was telling somebody, if you are strong in the broken places... there is nothing left but strength in me now, It amazes me. I get glimpses of it. It's like a chicken hatching, or like the surface is still fragile, but not inside. There's an amazing power in me coming through all this."* The hope and strength was also experienced by most of the participants through the support that was available to them. One of the participants shared how, through the her support group, she experienced personal growth and ways to take care of her health: *The protease inhibitors came, and I was telling you about this earlier, well and we decided to have a group that wasn't like a typical support group. We talked about a book, and we would work on each chapter, and we would discuss how we could help ourselves to nutrition, with supplements, um, positive thinking, so it was a very, very constructive kind of group because that's what the book was about."*

These experiences of inner growth by these women, as the excerpts reveal, reveal enormous strength and courage. After living with HIV/AIDS for years, what is so noticeable is their learning from themselves and others about how to live with HIV/AIDS. In their personal experiences, all the participants experience the inner sense of growth through the huge challenges presented to them by their illness.

Conclusions

Based upon the findings in this study, this researcher drew the following conclusions:

1. The themes that have been addressed in this study (i.e., emotional stress of living with HIV/AIDS, social environment and living with HIV/AIDS, sense of betrayal, medical treatment issues, dealing with grief, relationships and good support system, renewed purpose for living, and personal growth) were topics that were addressed and discussed by most of the women living with HIV/AIDS, and emerged from analysis of the data.
2. The women in this study have struggled with discrimination, secrecy, absence of family, fears of rejection, and frustrations with finances and social services, and yet each one of them seems to have found something positive to live for.
3. No one attitude, belief, or handling of issues with HIV/AIDS seemed to be indicative of a successive way of dealing with living with the disease. Through self-reflection the women found different positive ways to adjust to the new lifestyle of living with HIV/AIDS.
4. Living with HIV/AIDS seemed a constant challenge in the lives of the participants, magnified by the sheer realization that a cure was nowhere in sight. What was important to the experience of living with HIV/AIDS was the living effectively with emotional stress; creating a supportive social environment, and developing a renewed purpose for living and personal growth.

5. All the participants recognized the benefits of good health. They learned the importance of taking medications, despite frequent major side effects, having a good support system, and sharing themselves through education and public speaking. They all tolerated the side effects of medications, knowing their lives depend on it. Having knowledge of health information related to HIV/AIDS was important to the women. Each woman persevered through all the complications of relationships with either family or friends because they valued the importance of support. It was important to consider how others perceived them so social acceptance is also a focus for these women.
6. In almost all cases, the issue of betrayal and abuse is apparent from their experiences of living with HIV/AIDS. All the women participants in this study were influenced and not separated by their social environment.

CDC (1995) has reported that HIV infections among women are often associated with involvement in illegal drug cultures. The results of this study reveal that by their own reports, the women did not directly use the drugs, but for some, their partners did. Heterosexual contact is the most obvious category through which their partners infected the women in this study. Whether contracting the disease through heterosexual contact with a previously trusted partner is more common for women living with HIV/AIDS in rural areas is not known.

CHAPTER SIX

Implications

Although research regarding HIV/AIDS and its effect continues to be conducted by scientists, much remains to be discovered in how it affects the experiences of women in their every day life. Current studies primarily provide us with information about HIV/AIDS and men's experiences. This study contributes to the scant information that is known about the experiences of living with HIV/AIDS by women, and especially those in rural areas.

Implications for Caregivers

The challenge of living with HIV/AIDS in a small rural setting is the experience of the women in this study. Interviewing these women opened up an awareness of the pressures that they experience everyday in dealing with staying health by taking their medications and all the side effects, the emotional stress of trying to balance their lives, trying to take care of their families, physical concerns of day to day living, "what if I can't take care of myself?" HIV/AIDS has become a chronic disease in the recent years due to the new medications. The health problems experienced may involve loss of confidence, loss of self-esteem, loss of independence, loss of lifestyle, and perhaps the most painful of all, the loss of positive self-image as the condition has an effect on personal appearance. These issues do create a negative effect on lives of those living with HIV/AIDS. This has implications for those who work or have contact with women living with HIV/AIDS, be they medical or mental health providers. Aside from clinical care, though, health care workers should be aware that

clients living with HIV require a wide range of services, and that infected clients also often face difficult psychosocial issues, including a high incidence of depression. Health care providers need an understanding of the social, economic, psychological, behavioral, and philosophic factors that affect management of the infection and should consider all aspects of a client's life when making management and drug recommendations.

Notably, living successfully with HIV/AIDS necessitates a woman rediscovering her power in the presence of aspects of the illness that render her powerless. Caregivers must take care that their patients participate with an equal voice in the determination of their care.

Medical Health Providers:

Since living with HIV/AIDS requires visits with doctors and nurses to have better health, it is necessary for the medical providers to be sensitive to medical needs of those they treat. An increased awareness of negative interactions of medications and appropriate interventions for women living with HIV/AIDS may help to lessen the stigma experienced by these women. Knowledge of medical illnesses specifically related to women living with HIV/AIDS will be helpful in destroying the stereotype that providers don't know much about women and AIDS, but have all the information on men and HIV/AIDS. It would be very helpful for providers to join the fight against discrimination and stigmatization of women living with HIV/AIDS, and campaign for full human rights, help eliminate the invisibility, and break down the isolation of HIV-positive women. In rural settings this challenge is larger for

providers because literature reveals that some providers in small rural areas refuse to attend to people infected with HIV/AIDS because they do not want to lose other clients. Even well intentioned providers have been known to refer their patients, when they know about their HIV status, to other providers outside their communities. However, this may be necessary because of complicated health issues. The key is for the rural providers to also continue the connection.

Clients with HIV/AIDS often experience shame or social stigma either because of the infection itself or because of risk behaviors leading to infection. In addition, some clients may have experienced biases or had negative interactions within the health care system. Medical health, social environment, relationships and good support system are challenges that women living with HIV/AIDS can best deal with if providers don't contribute to the stress by being available without judgment.

Mental Health Providers:

The themes that emerged from this research were primarily psychological in nature: emotional stress, social environment, sense of betrayal, medical treatment issues, dealing with grief, relationships and support, renewed purpose for living, and a sense of personal growth. In dealing with the identified themes, almost all the women of this study initially cope with the issues individually due to confidentiality issues, but eventually opted to seek professional mental health assistance. It is well documented that most people with HIV adjust after learning they are HIV-positive and continue adjusting over the course of infection (Perry, & Fishman, 1993). Coping strategies

address a number of adaptational tasks in chronic illness, including harm reduction, tolerance of negative events, maintenance of positive self-image, establishing emotional equilibrium, and maintenance of interpersonal relationships (J. F. Miller, 1983). Sally Jue, in Shernoff (1999) describes the characteristics and coping skills of long-term survivors of HIV/AIDS. She states that she found that although beliefs vary, those who survive long term have an active and flexible coping style that includes the importance of forming supportive, close relationships with others. They are active, using traditional medical treatment in an equal and collaborative partnership with their medical providers. They accept HIV as a part of their lives and have some degree of good luck.

Counseling is identified as a relationship between a trained helper and a person seeking help in which both skills of the helper and the atmosphere that he or she creates help people learn to relate with themselves and others in more growth-producing ways (Cavanagh, 1982). Although the literature on counseling with individual HIV-positive clients is sparse, Perry (1993) reports that evidence suggests that psychological treatment for clients with HIV infection can be beneficial. Another suggestion is:

‘Therapy with an HIV/AIDS person is the most effective when it approached from a client-empowerment perspective... as equal partners with the therapist in determining the direction of therapy and forming treatment goals and plans, in a way that supports their right to self-determination and their ability to manage their lives responsibly. The AIDS pandemic has resulted in irrevocable losses, which in turn, have led to pervasive and chronic grief for persons living with HIV/AIDS, to confront this growing problem, it is important to encourage the use of individual counseling’ (Jue, 1994).

There is also evidence that clients with HIV infection and AIDS can benefit from group psychotherapy (Kalichman, 1995). The participants of this study described the importance of meeting with other people, including men or women, in support groups. Support groups and therapy groups should not be confused as meaning the same. This researcher is not sure that any of these women in this study were in any therapy groups. By definition, trained therapists rather than peer facilitators conduct therapy, and therapeutic techniques are a part of the group experience (Beckett & Rutan, 1990). HIV-related group therapy can be based on models designed for other chronic illnesses (Yolam & Greaves, 1977). The women in this study reported feeling supported psychologically in their support groups, but also included the fact that they learned accurate HIV-related information, instruction in adaptive coping strategies, and worked through losses and anticipatory grief. Levin and Bystritsky (1991) state that treatment in such groups center around a supportive atmosphere that may reduce HIV-related fears, and probably address relationship issues, and built social supports, and thus participants experience reductions in psychological distress.

In addition to the usual stress of working with terminally ill patients, HIV infection involves social stigma, prejudice, and bias. The challenge for professional helpers becomes larger because people with HIV/AIDS perceive them as a critical link to health-related information resources. HIV-positive people come to providers with the hope that they will learn more from about their illness. The challenge for mental health providers, thus, is to equip

themselves with most current information on HIV/AIDS if they are going to be working with HIV positive people.

Recommendations for further Research

The following section includes recommendations for researchers who plan to conduct investigations into the area of women living with HIV/AIDS in rural areas. These suggestions are limited to those made apparent by this particular study.

A. Research suggestions:

The experience of being a woman who is HIV-positive must be examined from several unique perspectives:

1. From the perspective of the individual seropositive woman as she makes the journey through the common emotional milestones of HIV;
2. From the perspective of women as a group, because women, in contrast to men, tend to cope with HIV within the context of the relationships that are important to their self definition;
3. From the perspective of the modern context of most HIV-positive women who are living and needing to survive in poverty, in the midst of alcohol and drugs and commonly with personal experiences of sexual, emotional or physical abuse.

The experience of the woman living with HIV/AIDS may be affected by the emotional dynamics described by any of the three perspectives. There is need for long-term studies to delve into all these aspects in order to create a much

deeper understanding and more precise appreciation of her daily struggles with this disease.

Women in this study were a special group of women because they chose to attend a retreat and were therefore more likely to be socially connected and to seek such connection. In further recommendation for research,

4. This researcher suggests that women who are presently more isolated than those that attend retreats or conferences to should be studied to understand their experiences of dealing with HIV/AIDS.
5. Another suggestion for research is to explore more fully the depression experienced by women. It may have unique qualities that would assist providers to provide better care.
6. This study was conducted on western rural women that volunteered to speak to this researcher about their experiences of living with HIV/AIDS. Continued research needs to be conducted regarding psychological needs specific to rural women.
7. We need more psychosocial research on HIV as distinct from other chronic illnesses.

B. Practice Suggestions:

1. To reduce stress and discomfort among women living with HIV/AIDS, family members and friends, and social services should have adequate, ongoing education and understanding about HIV and AIDS.

2. The HIV-positive women seem to show a lot of enthusiasm in sharing their experiences, educating other people, communities, especially schools, should welcome this idea.
3. No matter where we work, chances are that sooner or later we meet someone who either has HIV disease or is caring for someone who does. Some providers may wish to fight discrimination and stigmatization of women living with HIV and AIDS, and campaign for full human rights. All employees of health care providers require continuing education.
4. HIV prevention initiative need to bring together knowledge of the diversity of sexual meaning within women's lives, the limited range of representations of women's sexuality, and the urgency of women's vulnerabilities.
5. Providers need to develop collaborative relationships to relate better with people with HIV/AIDS.
6. It is only from a place of relative freedom and power that people can make choices and develop strategies for self-protection. It is therefore important for women to acquire not only economic and social freedom and power, but importantly power and freedom in living their individual sexualities.
7. Address the ways in which women are 'victims' of the AIDS crisis – think more broadly than the women who are already infected.
8. Pay attention to the real lives of women with HIV/AIDS who live in the margins of society.

9. In examining the role women play in the heterosexual AIDS discourse, it is important to understand that the majority of HIV-positive world-wide have acquired the infection through sex with a man, and the vast majority of women with HIV and AIDS are heterosexual in their orientation or identity.
10. The reason for discussing women and AIDS is to understand the real needs of women living with HIV and AIDS, affected by the AIDS crisis and vulnerable to HIV infection.
11. Partners of people with HIV/AIDS also require emotional support.

Conclusion

The purpose in this study was to explore people's experiences in living with HIV/AIDS, not to determine the "truth" of their experience from an external, objective viewpoint. The data was gathered in an attempt to gain a greater understanding of the dynamics of living with HIV/AIDS on a day-to-day basis. The participants of this study wanted to share their experiences, and their courage and strength to do so was exceptional. A qualitative method was used to gather the data used in this study. Interviews were conducted and recorded, then transcribed. Through the process of constant comparative analysis, the participants' own descriptions of their experiences developed. Seven women were informants of the data.

In order to fully understand the experience of living with HIV/AIDS, eight themes were identified and detailed. These were: 1) Unique aspects of emotional stress of living with HIV/AIDS; 2) Social environment and living with HIV/AIDS; 3) Sense of betrayal; 4) Medical treatment issues; 5) Loss and

resulting Grief; 6) Relationships and Good Support System; 7) Renewed Purpose for Living; and 8) Personal growth and transformation. These basic principles identified in this study may provide us with a somewhat better understanding of these women's experience of living with HIV/AIDS. What should be noted, though, is that these themes overlap with one another, and each affects the other in ways more complex than a simple list can describe. While the themes were evident and consistent across the participants interviewed, it should be clear that some of the themes held certain significance over others for the participants. The uniqueness of the experiences of these women cannot also be overlooked, even as the themes overlapped with one another.

In an attempt to understand women living with HIV/AIDS in rural areas, what this study does is to contribute to the expanding and deepening of current understanding of women living with HIV/AIDS. The women in this study did report health problems, including reports of recent periods of serious illness or symptoms of pain, respiratory distress, or other problems that diminished their ability to function. Gardner and Preator (1996) report that all these components of quality of life bear directly on clients ability to be strong in taking care of one's own physical and mental health. At local, national and global levels the absolute numbers, percentages and rates of increase of women with HIV and AIDS have grown steeply since AIDS was first identified (Gorna, 1996). As of 1999 women makeup 17 percent of all people with AIDS and 27 percent of HIV-positive individuals in the United States (CDC and Prevention, 1999a). In the current years, though, studies seem to be concentrating on the unique

features of HIV/AIDS in women and developing treatment regimens for them. More studies on medical conditions related to women are being conducted. There is an additional need to understand the complexity of HIV-positive women's psychosocial needs, not only in respect of reproductive rights, but also sexual fulfillment, empowerment and social and practical needs.

Local AIDS organizations, which provide various services for people diagnosed with HIV/AIDS, have had their budgets reduced or eliminated as a result of funding cutbacks by state and local governments even though the number of persons newly diagnosed keeps rising (Sternberg, 1992). Both patients and families experience a sense of isolation and aloneness as well as intense feelings or emotions related to HIV or AIDS diagnosis. Support groups work well with this population. In a society that does not produce or reflect accurate images of women living with HIV/AIDS, the support groups offer them reassuring opportunity to meet other HIV-positive women, hear their stories and realize they are not victims but survivors.

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APPENDICES

APPENDIX A
INSTITUTION REVIEW BOARD (IRB)
LETTER



The University of
Montana

7/10/03

Office of the Vice President
Research and Development
University Hall 116
(406) 243-6670
(406) 243-6330 Fax

Date: November 20, 2003

To: Joyce Tinanui Mphande, Cathy Jenni, John Sommers-Flanagan, Education

From: Sheila Hoffland, IRB Chair

RE: UM IRB approval of your proposal titled "HIV-Positive Women's Lived Experiences Rural Areas"

Your modified 11-point summary and Informed Consent Form (ICF) satisfactorily address the conditions that the IRB placed on approval of the proposal cited above. Please use the "signed and dated" ICF as the "master" for preparing copies for your study. Approval for this study is granted as of the date of this memo and continues for one year from the date of the Conditional Approval. If the study runs for more than one year, a continuation must be requested. Also, you are required to notify the IRB if there are any significant changes in the study or if unanticipated or adverse events occur during the study.



Sheila Hoffland

Attachment

APPENDIX B
INFORMED CONSENT FORM SENT TO PARTICIPANTS

INFORMED CONSENT FORM
For Key Informants

TITLE: Determining the Experience of Women living with HIV/AIDS in Rural Areas.

CONTACT PERSONS: Claudia Montagne ('Woman Power' Retreat Coordinator):

406-449-1357;

Lewis and Clark AIDS Project, P.O. Box 832, Helena, MT 59624

Joyce T. Mphande: 406-243-5252; UM, Counselor education, Missoula, MT 59812

Dr. Cathy Jenni (Dissertation Co-Chair), 406-243-2608, UM, Counselor Education, Missoula, MT 59812

Dr. John Sommers-Flanagan (Dissertation Co-Chair), 406-243-5252, UM, Missoula, MT 59812

Please read this information carefully before you make a decision about whether to consent to an additional use of your interview transcript. If this information contains any words that are new or not clear for you, please ask the contact persons for clarification.

PURPOSE

The purpose of this study is to analyze interviews previously conducted with women living with HIV/AIDS in rural areas of Northwest United States. These interviews were conducted in October, 2002 at the retreat for women living with HIV/AIDS you attended. The original purpose of the interviews was to assist in future program planning for similar retreats. This form requests your consent to an additional use of the data you previously provided—that of allowing your interviews to be used for a doctoral student's dissertation project. By granting permission to use the data, you will provide valuable information to better plan and evaluate the retreats and other interventions for HIV-positive women in rural areas.

PROCEDURES

Participation in this study is **VOLUNTARY**. If you consent to your interview transcript being used for this study, please put a check mark on the enclosed postcard and mail it to Claudia Montagne, the coordinator of the retreat, using the addressed stamped envelope provided. During this project, all data will be stored in a locked filing cabinet in a locked office in the Counseling Department, however, faculty members of the researcher's dissertation committee will read your interview transcripts after all identifying information has been removed by the researcher.

RISKS /DISCOMFORTS

1. You may find that participation in this process may again raise questions or issues related to HIV/AIDS.
2. You may be concerned about your privacy and confidentiality. Identifying information will be removed.

METHODS FOR REDUCING RISKS

1. Your consent to this additional use of your interview data is voluntary. You may decline your consent.
2. You will receive a list of available resources if you would like more information or someone to talk to following this request. A list of resources has been included in the envelope or you may contact Claudia for additional resources.
3. Your name and identity will not appear on the transcripts or on any project reports.

All transcripts will be stored in a locked filing cabinet in a locked office in the Counseling Department at the University of Montana.

BENEFITS

Your help with this project will provide valuable information to assist healthcare providers working with individuals with HIV/AIDS. People who have HIV/AIDS may experience decreased isolation and enhanced self-understanding as a result of this study. Your consent may also assist the Lewis and Clark AIDS project in planning and evaluation of the 'Woman Power' retreats.

CONFIDENTIALITY

All information you have provided is confidential.

1. Participants' identities will remain anonymous and will not be associated with research findings in any way.

This has already occurred.

2. No identifiers will appear on the transcriptions.
3. No identifiers will appear on any project reports.
4. Data will be stored in a locked filing cabinet in a locked office in the Counseling Department.

At the conclusion of this study, transcripts, without any identifying information, will be in the public domain via "Dissertation Abstracts." If, however, at any point you choose to withdraw from the study, Claudia Montagne, the retreat coordinator, can be contacted and your transcripts and data will be destroyed by shredding.

COMPENSATION FOR INJURY

Although we believe that the risk of taking part in this project is minimal, the following liability statement is required in all University of Montana consent forms:

In the event that you are injured as a result of this research you should individually seek appropriate medical treatment. If the injury is caused by the negligence of the University or any of its employees, you may be entitled to reimbursement or compensation pursuant to the Comprehensive State Insurance Plan established by the department of Administration under the authority of MCA, Title 2, Chapter 9. In the event of a claim of such injury, further information may be obtained from the University's claims Representative or University Legal Counsel.

VOLUNTEER PARTICIPATION/WITHDRAWAL

Your decision to take part in this project is entirely voluntary. You may choose not to participate in this project for any reason. You may also withdraw at any time during the study, and if so, contact the retreat coordinator, Claudia Montagne, and your transcript and data will be destroyed by shredding.

QUESTIONS

If you have any questions about this project now or later, you may contact Claudia Montagne: 406-449-1357, or Joyce T. Mphande: 406-243-5252.

I have read the above description of this project. I have been informed of the risks and benefits involved. I have been provided with the contacts and resources for questions or concerns I may have. I voluntarily agree to take part in this project. I am at least 18 years old. Because my name will not be associated with this project, I am keeping my consent form and returning a postcard indicating my consent to this additional use of the data I provided in October, 2002.

APPENDIX C
RESEARCH QUESTION

Research Question

**WHAT IS YOUR EXPERIENCE OF LIVING WITH HIV/AIDS IN
A RURAL AREA?**

APPENDIX D
PARTICIPANT PROFILES

Profiles of Participants

Following is a general description of participants of the study. Due to the sensitive nature of the topic of study, the profiles have been presented in a general form without in-depth descriptions of individual participants.

Age:

The women in this study were of ages ranging from thirty-three to fifty seven years old.

Marital status:

- One married, with no children.
- One dating, with two grown children.
- Two single, both single mothers.
- Three divorced, not dating, all with children.

Race:

Inclusive of Caucasian and Native American women.

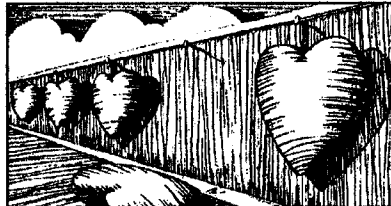
Education:

Ranging from high school diploma to Ph.D.

Work Status:

- Four women working.
- One cannot work due to health issues.
- One hopes to start working again.
- One full time mother.

APPENDIX E
LETTER FROM LEWIS & CLARK AIDS PROJECT



Lewis & Clark AIDS Project
PO Box 832 Helena, Montana 59601
406-449-1357

April 3, 2003

Joyce Mphande
600 Whitaker Drive #2C
Missoula, MT 59803

Dear Joyce:

This letter is to confirm that the data you collected from the HIV+ women participating in the 2002 Woman Power retreat were for the Lewis and Clark AIDS Project to be used to assist in the planning and evaluation of the retreat intervention.

We look forward to learning your findings.

Sincerely,

Claudia Montagne
Lewis and Clark AIDS Project
Woman Power Coordinator

APPENDIX F
TRANSCRIPTS

Transcripts of Participants

Do: 49

J: Hi, Hello. Well, we... with all the noises around us, but I'm sure we're going to achieve our purpose, so, hi. I'm so glad... um, you were able to make it. I know you went out of your way...

Do: Well, it's interesting for me, and I like to travel and talk a lot, in a lot of ways,

J: Thanks... so, like I told you, this is an interview to find out about your experiences of living with HIV/AIDS. Thank you for being here. I'm so glad that you were able to actually come down here to Missoula to do this with me..

Do: It's a gorgeous day, I hope this music doesn't interfere on the tape, I hope the tape is clear enough so you can hear it... Does that make sense?

J: Yes, I hope so too. Anyway, as I told you, I just wanted to find out about your story, when you were diagnosed...

Do: With HIV?

J: Yes..

Do: I have one daughter that I gave up for adoption when I was 16, that I have reconnected with and we have a lot of fun together.

J: uh huh

Do: You know, we have a lot of fun and some communication issues.....you know, she still has her family, but that's the only child that I have.

J: uh huh.

Do: I was married at the time I found out, I was going through a divorce, when I found out, and we didn't have any kids together there,

J: uh huh

Do: And I haven't married since.

J: Uh huh!

Do: Well, I was doing a lot of working... I had a couple of different careers, but the last 7 years I've been in bed, I've been really ill.

J: Uh!

Do: So, I'm still... am not at the point... I'm just getting to the point where I'm starting to be able to like to come up to this and to travel some, and to begin to take care of myself,

J: uh huh

Do: Um, I have a lot of cleaning up in my life, from being sick so long,

J: uh huh

Do: Um, there's just a lot of mess, I moved into this house a couple of years ago and I haven't been able to even unpack, my bed is in pieces, I sleep on a mattress on the floor, right now,

J: uh huh

Do: So, I'm starting to get those things put together with the energy that I have, and it will be awhile before I can work again.

J: What was your job before?

Do: Well, first I worked in computer work, as an engineer, um, my degree's in math, and electrical engineering and I did things like, oh, robotic welding machines, and I worked on the Jupiter probe, and I worked on things, um, big engineering and computer projects.

J: Uh!

Do: and, that was good, and I made good money, and then I said, now I'm making good money, and I'm bored.

J: uh huh

Do: I'm doing the same thing again and again. It wasn't so much what I loved, I never loved computers, but they were always ah....I was good at them, so then I started to see what I wanted to do and I went.... oh, started taking a lot of classes. I lived in L.A. then,

J: uh huh

Do: And I, did a lot of classes and I got really hooked on psychology finally and I did a second Bachelor's and a Master's in psychology,

J: uh huh

Do: and then, I finally dived into....I went into a PhD program and I was trying to decide between clinical and experimental and I finally went experimental....and I thought I might do that first and I might come back to clinical some day.

J: uh huh

Do: But, I've kind of worn a lot of different hats, so, I went to San Diego because they had a program that was inter-disciplinary to study the brain,

J: uh huh

Do: It's what they called cognitive science, it is the mix of oh, philosophy, neuroscience, music, computer science, psychology, kind of, and all of the professors would work together in the afternoons, on Fridays at noon, they would have seminars with all the professors talking about brains.... a lot, all different kinds of topics from what is dreaming for in the brain? and how does this work and why this, and what, and discussions about language and things. It was just a really, really fun experience,

J: uh huh

Do: and I really had hoped to go on and do research, but half way through that PhD program, it was about a 6 year program and about half way through I found out I had HIV.

J: that was the PhD in psychology?

Do: Yes, I was in the Psychology Department but my degree says that it's Cognitive Science. Well, a lot of my school I did, even while I was working, cuz it was so much fun..

J: Uh!

Do: Yeah.....yeah.... I was telling these kids recently, I'm a nerd, you know, I just like..... I like to study, I like to learn, I like, and I love to travel, that's my other one. I love adventure, and, there's a lot of things I love.

J: So, while you were still working on your PhD, that's when you found out you were HIV positive?

Do: Yes,

J: Uh huh. So what was that like for you?

Do: Oh, well it came so out of the blue, um, it wasn't something that I just thought....you know....wasn't possible for me...you know... then, I was in a marriage and I thought... you know....almost like this is such a good time to be in a good solid monogamous marriage, because you know, I had fun years before, but not, you know.....knowing about it....

J: uh huh

Do: But I didn't know that he had....you know... HIV.....

J: Uh!

Do: and he pretty well knew, he was doing a lot of risky behavior when he would travel on business and it went on-going through the marriage, he told me later and took a lot of risks and um, didn't want to tell me...and so.....so, I felt really lied to, but um, but so, when I first went to get tested it was more in anger, like, well now if I find out you did this, I'm going to go get tested for AIDS, you know,

J: So, did he disclose it to you? Or, how did you find out,

Do: Slowly, slowly over time.

J: Uh!

Do: There was just something that started to be bigger and bigger in the marriage, and I didn't know what it was and I would go through cycles of getting closer and farther away, and different, there was a lot of problems, and I mean, I was just so glad to be getting out of it, finally I filed for divorce, and...and partly he would.....there was just all this stuff and I would say, what is going on?...and he would say, I'm not going to tell you.

J: uh huh

Do: and he would just clam up and he would say..... he just wouldn't talk and he wouldn't go to a counselor and he wouldn't do anything about it and so finally, I just felt like there wasn't anything I could do more to shake him up than anything, I think I filed for divorce.

J: and then what,

Do: then he went to counseling, then he'd say, O.K., I'll go to a counselor, we'll go to therapy and then the counselor got him talking...pulled him apart, one on one, and started talking, and then um, it was unraveling really fast,

J: uh huh

Do: So, we were still in the same place and the same apartment, in different bedrooms and, but he would come home and he would get really drunk,...and he would come home and he would start telling me

things,..... and I would work really hard at not getting mad or anything, I would just pull it from him, just to keep talking and talking and talking, I really wanted to know the whole story.

J: uh huh

Do: So, somewhere in there I had gone and gotten an AIDS test and I just went to my little gynecologist doctor, I didn't even know how to get one that was anonymous or anything and she sent it to the lab with my name all over it,

J: Really,

Do: All this stuff, it wasn't a very good thing, and um, it was like two weeks that it took to get the results back, and in that time, he is telling me all the stories, and they are getting worse, and worse and worse,

J: uh huh

Do: And I'm thinking, oh, no, he's telling me how he goes to the gay bathhouse and gets royally drunk and doesn't even know what happens.

J: uh huh

Do: You know, at different times, and I'm thinking, oh no, I am in trouble. You know what, but maybe this is long enough, you know, maybe I've escaped, you know maybe, all these things you keep hoping..... But, when I got the news, I called my gynecologist from work, she was up in L.A. and I was in San Diego, its 90 miles,

J: uh huh

Do: So, I called her from a little payphone, and she just told me over the phone and she couldn't even bring herself to say the name of the test.... she was just saying, oh that test, that test, oh, it's just not good, it's just not good, oh, it's just a horrible disease, it's just a horrible disease, she kept just saying it's a horrible disease, it's a horrible disease, and then she got off the phone.

J: You had told her that you found out about it?

Do: I went to her to get the AIDS test

J: I see.....

Do: And so I called to get the test results,

J: So she told you the results on the phone?

Do: She told me the results on the phone, told me I had it,

J: Which is illegal, to tell somebody results on the phone,

Do: Yes, and the little lady, she looked about 70 with a little crucifix here, and when I wanted to get the AIDS test from her she said oh, I would never worry about that, you might get syphilis but nobody ever gets that, and on and on and on, and finally I said I really wanted the test, anyway,

J: Is this because you were a woman? Is this why she said that?

Do: I think she'd never..... she'd never had anybody, in her practice... Um, she'd never seen of it, but she'd been to, she said she'd been to a conference and heard about it about a.... a few weeks before, she went to a weekend conference about a month before,

J: uh huh

Do: So, the extent of her counseling was just to keep yelling oh, it's just a horrible disease, it's just a horrible disease, oh, it's just a horrible disease, and she didn't have anybody to tell me where to go or what to do or how to find any help or anything.... she just really panicked..... And ah, I actually went to see her about 2 weeks later and she was afraid to see me, afraid to even talk to me.

J: And so what did you do?

Do: Oh, I'm just having a panic, I mean I'm just, I'm sitting, I found a little phone booth that was real private, it was one of those old kind that you can sit in a little booth, you can sit on a chair and close this old wooden door in there, but I'm just hyperventilating. I'm just thinking, you know, I'm breathing real fast and I'm getting dizzy and I can't figure out what to do, and I'm just sitting there in this phone booth, thinking,

J: What's going on in your mind then?

Do: Yeah, what do I do, what do I do? And I thought there's a hotline someplace, there's a hotline.

J: uh huh

Do: And so, I just started calling, I called 1-800-555-1212, and said I need an AIDS hotline, you know?

J: uh huh

Do: And she gave me a phone number and I called and there was somebody there that just started to talk to me,

J: uh huh

Do: About what HIV is and even what a T-cell is and how I find a doctor and how I find a doctor in San Diego and how I even find out where I am and how I'm doing in the whole thing,

J: uh huh

Do: And then I went down town, I looked in the phone book and I went down to a couple of places in San Diego, there was a San Diego AIDS foundation, and so I thought, well here's somebody that can help me, and I went down to talk to them and they were really mean. And they said like.....

J: How come?

Do: They were just really abrupt and curt. And they said like um, so do you have full-blown AIDS or are you just HIV? And I said, I don't know, I have to get to a doctor, I have to find out, I don't know what's going on, and I'm just like talking really fast and stumbling over my words, and they said, well see, come back when you know, cuz if you are full-blown AIDS, we can do some help for you. And nobody talked to me.....

J: How overwhelming for you.....

Do: I know, and nobody would even talk to me or do anything like that. And I went back later and I tried to put up a notice because I wanted to try to meet some other women over there.... like the next two weeks....

J: uh huh

Do: I worked with them a couple of different times and it was always that bad, and it was like..... so I've been really reluctant to get involved with any of the other foundations,

J: uh huh

Do: And then you find out that the directors are making a lot of money..... and it began to feel more like..... you know..... I always thought those things would help people more, but now it feels more like a scam to me.

J: uh huh

Do: You know.

J: When you found out about your status, did you know of any women or men with the virus?

Do: I didn't know of any men. I had never met....I didn't know a living soul that had HIV, so I just... ah, and I thought I was pretty aware, I had a lot of friends, I had a lot of friends that were lesbian, I didn't know any gay men....or, I didn't think I knew anybody then, you know, there wasn't anybody I could call up and talk to about it or something.

J: uh huh

Do: And I was really terrified to let anybody know.

J: Uh huh.

Do: So, um, with the next following night, I think that was like a Wednesday and the following night was a Thursday..... And I went to a support group and actually that night that Wednesday, I was so terrified, and I was in the PhD and I was working so many hours on that, and going through this divorce and all and by then we were separated, he was..... he had moved out of the house

J: Uh huh

Do: I actually called him, it's a crazy thing, but he was like my best friend still.

J: uh huh,

Do: And I didn't want to tell him what was going on, but I told him and said something had really happened and that maybe I wanted him to be available, maybe I could talk to him that night on the phone, and he drove down to where I was staying,.....and he called me up and he said you know, I'm just down on the corner, and he came over, and we slept in the same bed and held hands all night and just talked. I mean it's a funny thing how you're.....you can hate somebody and still care about them and still be so attached and all of that mixed up together.

J: uh huh

Do: And I knew he wouldn't be able to handle it, at all, and I just.....I wasn't ready to tell him about it...I mean he had told me he got an AIDS test about a year before and he couldn't get the test results... he couldn't bring himself.....he couldn't face it. And he said someday, when I'm good and ready, I'll let you know, when I'm really ready, I'll let you know and I'll go get those results and I'll do this.....and

so....um....I went back to this counselor that we had been talking to a little bit,

J: uh huh

Do: And I said well, technically I guess I should tell him, since he's my sex partner and I have this disease, I should at least let him know that I have this disease, but more our goal was that he's out there sleeping around a lot and he's not being careful and he needs to know that

J: That he passed it on to you.

Do: Yeah,

J: Or he might have passed it on to you,

Do: Yeah, and just in whatever frame it is....and so....um.... it was about 2 weeks later when we made an appointment, we called him in and I told him there was something else I just wanted to go through with him. But, what I had done secretly is call this place where his AIDS test was in Chicago.....and find a time frame when he could get his results and I made sure our appointment was during that.

J: Uh huh

Do: And the first thing I did was force him to get his test results and he was so mad. See, and I want to know what those results are, and I want to know now..... You know....and I just forced him that way and he was so angry and they called up and they said he's positive. And then, I said, as he's just going nuts.....and then I said the reason I wanted to know is because I'm positive, you know?

J: uh huh

Do: And then he just kind of melted into a puddle. We were really worried he was going to commit suicide over the next few days,

J: uh huh

Do: Yeah, he's that, very much, that's what he would do.... but he....you know....he did a lot of alcohol, I think instead, but anyway. I didn't see him a lot after that. We see each other once in awhile....um, he could be very manipulative and so there was a lot, he was the one that was going to show up on my doorstep....um....when he was sick and I would want me to take care of him and all and I would give him my phone number, but not my address.

J: uh huh

Do: And uh, oh it's a long story, finishing, getting the divorce through and all of those things that happened, but, but I remember such a sense of freedom too about moving away, about just being apart from him with the manipulation and all the little stuff going on.

J: uh huh

Do: But, those first days, yeah, thanks, the....um....the thing that I was imagining those first days was that somebody had put like 20 pound weights on my arms and legs. I remember just laying down in the living room floor and hardly being able to get up, and just like to walk up a flight of stairs, and every step, like each leg was just so heavy, ohh, and I'm in the middle of a lot of pressure in the middle of the PhD

program.... And I just wanted to tell people, but I was talking to this therapist and they were saying just let it be.... just the divorce for now, you know, because I was terrified to tell people.

J: uh huh

Do: And..... Oh, I think it was an amazing, and scary position,.....I think the advisor I had....um....they made a lot of jokes about all gays and a lot of different things, they made a lot of jokes, they were very sexist, in that little crew, and the whole.... I was still... you know, thinking of going into a post-doc and its so competitive, extremely competitive, it just wouldn't have happened..... You know, there's just a whole bunch of things that would have been.....um....to reveal that I had HIV in that situation would have been very bad.

J: uh huh

Do: And just in the last year, when I was getting ready to graduate, there were only two of us students under this one professor, they only take in a student every couple years,

J: uh huh

Do: And I needed to get in, there was a drug study and the drug that I needed, but it was in this program downtown,

J: uh huh

Do: In this experimental AIDS thing,

J: Yeah,

Do: But, in the same lab, I mean, in the next floor up of the same building, just like right next to each other, same elevator, they had....um,....like the Eye Institute that was studying CMV the AIDS eye disease,

J: uh huh

Do: And my....um....the other guy in my lab actually went in and he became involved in that study and he became the post doc there.

J: ohh.

Do: And so at one this time when they were coming in, we were studying visual perception.

J: uh huh

Do: So, I come in and they have on the computer all these little files called HIV 1, HIV 2 and things, there was another woman in the next lab that was actually running that group down there and he went to work for her as a post doc and all of these, and so they kept trying, they were asking me to be a, they needed controls, to test their eyesight against the people that were HIV,

J: And they didn't know about your status,

Do: Right, and so they are asking me to be one of the controls,

J: uh huh

Do: Because it takes a lot of time and they need volunteers and I just keep trying to make excuses and they are a little frustrated that I'm just so noncooperative with their research when they are willing to help me out, you know, it's such a pain..... And I'm thinking I wonder if they

even do HIV tests on the negatives. I wonder if they know..... Even have verified that the controls are negative?

J: Yeah, how do they determine that?

Do: I mean the disease is in the very late stages, but I mean even if you are trying to test early vision, like before CMV, between HIV negatives and positives, you know, like they would never have dreamed I was positive.....But, um, you know and, and maybe 6 months before they might have tested me and I had been in there, and I wouldn't know, I'd say, yeah I'll be a negative control, sure, you know,

J: So did you get to do it?

Do: No, I stayed, I got to stay out of that one. But so, I went down to the study and they said everybody at the University...like um.....they said well it's all confidential, you have to be on the faculty of the university to go into the computer, like I was so scared, my name is a little unusual,

J: uh huh

Do: And to be in the computer with all my data for this drug study,

J: It would be known.

Do: Yeah, I mean it's like somebody could just stumble across it so easy.

J: uh huh

Do: So, I talked them into it and they finally let me go in under a pseudonym..... So, I was... um.... oh it was weird because I was so active and I became Dorothy Malone. Somebody dubbed me that. Dorothy Malone, and it's a movie star from.....ah.....1940's.

J: Uh huh

Do: With Payton Place and all of these issues in these old movies and somebody in there said um, don't I know you from some place and the other woman that knows I'm using the pseudomonad says she's a movie star.

J: Sort of like a joke?

Do: Oh, and I did a lot of talks around town...it was pretty quick, it was about a year, a year to a year and a half I was very much inside myself and not um, telling anybody, I went to a lot of support groups for about 3 months, then I gradually shifted gears. I had to do tests, there was a deadline at 6 months after I was diagnosed.....

J: uh huh

Do: then I was supposed to have to be qualified for my.....,qualified and supposed to defend my background and defend my dissertation proposal.

J: Yes....

Do: and I had that whole summer. And my advisor was out of town and it was a nice time, I actually started switching between the few less support groups and a little bit more on the dissertation and I, I knew I could get an extension on it, but it was kind of nice to just have it as a deadline and just do this exam in front of my committee and go through

all of it, so...um, I managed to do that in September, that first year and then I took a little time off, I took like 10 days and said O.K., now, it was just night and day, a lot of crazy work and then I took the time and I went up to San Francisco, threw my sleeping bag in my car and I went up alone and I camped under the redwoods and I went to San Francisco and did...um...some different AIDS events.

J: uh huh

Do: I saw a movie about the quilt that was down at the Castro, the Castro Theater, so I went down there and it was just...it was amazing, I'd only been diagnosed 6 months and it's like these are my people, you know, this is just... this whole world and crying and mixing with all of these people and then I went to a lab the next day...of this guy that does ah...the vision, that they were opening up a Job Corps at Harvard...And um, well he was saying like... you know... we should talk about a post doc and things, and then, it was just beyond my wildest dreams,...all the things I wanted to do, and so like my world is just opening up so fast, I can't believe it, and then at night I go to one of these films or something and its just slamming shut so fast,

J: umm,

Do: And it's all about death and dying and my world is just coming apart and just closing down,

J: uh huh

Do: And then um, I went to this other professor over at Berkeley

J: Yeah,

Do: that had moved down and she had half a floor there to do research and treatment and she's like...you know...and she took me out to lunch and she asked me all about my dissertation proposal... she knew me from my...the lab down there with this guy that I worked for, and its ah...talked all about these different things and it was like for somebody that is such a famous name to be so interested and we talked away and all these things and its just like I never would have believed 5 years before that I could ever even do these things and how much I want all of this so bad.

J: uh huh

Do: And then one of those nights I went down and there was a whole group of people camped, kind of homeless but HIV people,

J: uh huh

Do: And they had a little encampment down at City Hall, and it was a protest encampment and all over the steps and around there and they have never been evicted by the police but there were these people down there that were poor but amazingly strong...and I think of this guy I sat and talked to for quite a while...and he didn't have very many teeth left, he's a young guy but every time he was on...like not Medicare, but the indigent care where he didn't have any money,

J: uh huh

Do: But if he needed dental problems, they couldn't repair any of your teeth, all they could do is pull it, and a filling.

J: Really?

Do: At that time. So he only had a few teeth left. And it was kind of, this was in '89 and so it was before, but it was still in San Francisco, they were just at a big camp and people were bringing in sandwiches, it was an amazing place down there,

J: uh huh

Do: And there was a....and they said one time some guys came running up in a pickup and yelling about God-damned fags and we're going to kill the fags and all this stuff.... Well I know they chained themselves to the door up there....And this guy came up and put a knife up at his throat and he really thought he was going to kill him. He was saying... like....um....we're going to get rid of AIDS in this town, we're going to clean up this town and things like that.....just a real redneck attitude.

J: uh huh

Do: He said all he could think of to do was to say well, just don't get any blood on you.... Because you might just catch it....And the guy just panicked and pulled the knife away, and ran away and got in his truck and left.

J: umm, were there any women around?

Do: Yeah, but I don't know if any of them had HIV.

J: uh huh.

Do: And the next year I found a course in San Diego, someone there was offering a course called Fight Back....um.....to teach, to learn about HIV.

J: uh huh

Do: And I went and I got in this course, I was so anxious to know already, that I went and got in this course,

J: uh huh

Do: And the next weekend they were having a course, um a teacher training and so I got in teacher training and started to teach the course the very next weekend, well it was 3 weekends on, so the next month and then the next month and then just you know, and already I'm working full time and I'm doing my dissertation and I'm crazy but I'm going, I still have to be in this, you know, and there I met....um.... a couple more women were teaching and some other men and just got really into it....

J: Who were HIV positive?

Do: were HIV, it was all taught by HIV people and I started to really open up and know a lot more people and get...and it was also, they were teaching me how to get involved, there, some of the local activists, how to find a good doctor, how to.... how to strategize your own care, figure out how to get it if your doctor won't, and they hooked me up with this doctor that does all this research in town, he hardly ever sees any patients, but he took me in as a patient

J: Oh, you were lucky.

Do: And I did a lot of talks around town, I talked all over, and I would talk all over my campus even, so people would call me up to come and give a speech to them...

J: So, now people knew?

Do: No, and I would never give my name and I don't know if they knew, and so I would keep it secret, but I mean there were kind of different worlds so I would go talk to all these undergraduates,

J: Did you go as somebody who was teaching about HIV but never disclosed that you had it yourself?

Do: No, I would disclose, but so, like say, somebody would meet me from this Fight Back class and they'd say... you know....

I..... somebody would know somebody and they're teaching in a completely different department, so they are not teaching in psychology, they're teaching over in the Health Department and they need some people to come and talk about, people that have HIV to come and talk.

J: uh huh

Do: So, it was like completely separate departments and it's a big University,

J: oh, so your department didn't know,

Do: My department didn't know but I would go talk for other departments and they didn't necessarily even know what department I was in,

J: uh huh,

Do: but I would tell them... I am a student on campus, and I have HIV.... and I would tell them the whole story, and I was a TA, a teaching assistant and for a lot of classes and people must have connected it sometimes.....and... well.....

J: I mean, what did you feel about that?

Do: I really didn't want people to know, but the feeling about people knowing varied all the time.

J: uh huh

Do: So, people that liked me, it was O.K. if they knew.... But there were a lot of.....there are some just mean, vicious people out there....and you know some people on the faculty that are mean and vicious and....um.....my advisor was one of them and I just didn't want them to know..... but you can't just....you know....pick and choose

J: uh huh

Do: But there was.....it did so much healing to me to go out and talk to all these people.....when I would talk to all these students....um,

J: It sounds like that's how you were dealing with your HIV.

Do: There was a lot to do with it.

J: uh huh

Do: And I had this good friend David and he worked for the Mayor's office by then, he was working for the Mayor of San Diego and he was an artist and a dancer and he was the Arts Liaison to all of San Diego....

J: uh huh

Do: And we were best friends.... and so we would go give these talks together. And it was.....you would watch these students.....we'd have a lot of sadness and a lot of laughter and we'd talk about how, David and I, we would go out to a movie and we would check out the guys together, I mean, you know, it was just fun,.....

J: uh huh

Do: And we would tell these different stories about things that happened to us that were really sad but how they.....he'd talk about being a gay man and I would talk about a woman..... but then they threaded together, cuz we had stories about different things and if you just see the impact on people.....and it's kind of like living as a leper.....its never going to change until I talk...

J: uh huh

Do: There was something about, about me that needed to speak. And I would go down to San Diego State, they had a training for Social Workers.....and I would go talk to the Master's in Social Work classes all the time, I mean just anything I got.....um, it was easy for me to get away with it because school thought I was at work and work thought I was at school and I could go other places...

J: Uh huh

Do: And even to go to doctor's appointments was pretty easy, I had a job, but it was flexible where they knew I had things to do at school and I could work my hours around. I went back to doing computer-consulting work, just to make good money....you know... to support my illness.

J: uh huh.

Do: Ahhh, I got so...I was amazed at how well I could live with it....How much even watching my T-cells fall and getting to the bottom, and there were times I got so low, I was frantic, but by the time I had no T-cells and I knew I only had a limited time to live,

J: So, you had 0 T-cells?

Do: Well 3, you know.... I mean like from a 1000, when you get below 50 you're getting pretty low and then you get down to 30 and then you get 12 and then you get, you know, so it's kind of like 7,

J: So, how was your health like when you got to 3 or 7 t-cells?

Do: I had good health,

J: Even with 3 T-cells or 7 T-cells?

Do: Yeah, I had really good health, and the first time I went below 50 I really panicked and I was at the doctor's office.... I'm like oh my gosh, and I kept pestering this other guy in there that was trying to read the paper, and I kept pestering and pestering him and pretty soon he puts the paper down and he listens to me for a couple of minutes and he goes back to reading...and I just start talking again and he kind of like, and then I'm so panicked I just I only have you know I'm down below 50 T-cells and I just think that I'm not going to live very long and I don't

know what I'm going to do... just so you know... and he said well, I've been below 10 T-cells for at least 5 years.

J: That must have given you a lot of strength.

Do: I know, I'm like you're the one I wanted to meet today. And so we became friends. He was a good friend for a long time, but he was also so amazed that I would talk about it to people.

J: uh huh

Do: anywhere. And so we had all these different things. He was a hemophiliac that had been infected for a long, long time.... really sad... All these people I talk about are dead now. And I went all through this class, they gave me... somebody gave me a... somebody had given somebody some money and I got a scholarship, they asked me to accept a scholarship to go to the acupuncturist for HIV,

J: uh huh

Do: And then, he was a really neat guy, and there was a woman there that I met that became a really good friend and then gradually I met some other women around, but Sharon was always a really close friend.

J: uh huh

Do: And, um, she and David, that worked for the Mayor's office died, within a month of each other, down there in San Diego, that was hard.

J: Losing friends over the years must be very hard.

Do: It was really, really hard. People that I would get really close to. Um, then I looked around, I finished my PhD and I lived there for about another year, and one job was ending and there was kind of a change time in there. I could tell this one was going to wind down and close and it's like I didn't really like San Diego, it's not my favorite town. I had come there to do school and everybody kind of knew that I was moving away too.

J: uh huh

Do: Sort of when people come together for just a program like that. So, I thought about where I wanted to live and I was saying ahh, I think I need to be in San Francisco. And actually I love San Francisco and for my health.

J: Where you know many doctors?

Do: Well, top doctors. I was having trouble actually finding a doctor that I really liked in San Diego. They were either this way or that way, you know, either it they were really smart, they were really dictatorial, and not, didn't want you to take acupuncture or any vitamin C or anything else.... and they wanted you to stick with the Western medications... which there weren't very many of yet, but also kind of like if you're having side effects they say will just stick through them. Well... you know... I knew just enough about different people, I couldn't find quite the right mix, either and a lot of it, it was just like well, if I need to find a new job, let me just find one in San Francisco.

J: uh huh

Do: And then I got a phone call about a really neat job up there. And um.....

J: In computers?

Do: In computers, but they were looking for somebody to.....to be willing to get out from behind the computer to work on the technical....but to work....it was....um....to work between some corporations.....To make all the programs interoperate together....to travel and to work uh....some of the companies are in Germany and Japan and places and do some travel and work with the technical people, but....um, and I also started thinking, I'd been a consultant a long time, but it's like, it's a good time to go corporate where they have like benefits and all those things....

J: uh huh

Do: When I finished the PhD, I looked at doing post doc, but part of the problem was just that the benefits were so bad....so, that even if they had health insurance, they have like a one year pre-existing condition clause on it.

J: Uh huh

Do: And so, it was just.... Um....seemed like to go where I actually had health insurance and then, this company had a really good disability policy, and I was in San Francisco and I got really sick and I finally had to go out, but it gives me money to live on, which is really a, really, really been good.

J: Yeah, O.K.

Do: So, it actually got so that living at this company I working for in San Francisco, they were so astonished when they found out I had HIV. Because I lived happy.....you know.... they just couldn't believe I was near dying, because it's just....but I found that I could live, dying wasn't so bad.

J: uh huh, uh

Do: What I did find was bad, was being sick.

J: Yeah.

Do: Um, that's much worse. And I thought maybe I would be sick for a year or two before I died. But then the drugs came out just after I went out on disability, but I was almost dead, and I was just like.....I've been trying to crawl back for a long time. And the isolation of being ill is just real....and really does something to the brain.

J: Uh huh

Do: I mean I kind of..... it's like I know now why they can't put prisoners in solitary confinement for a long time.

J: Yeah.

Do: It's like I've had a lot of it. Even if I talk to people sometimes about things, it's not the same any more....

J: It's not the same..what do you mean?

Do: Um, those years were really, really tough. And I'm starting to come out of that now.

J: How did you move from that place where you were very happy and living healthy to the moment when things just...

Do: fell apart?

J: Yeah....or out of control for you?

Do: Came really quite sudden.

J: Explain that to me....

Do: Well, um, at first I had PCP and I had been working there 6 months, I got PCP pneumonia.

J: uh huh.

Do: And I actually got through that, and went back to work.

J: uh huh.

Do: And the doctor was going nuts, like you can't go back to work, you have to be on disability now. You don't have any T-cells and you've had PCP,...I mean there's just.....I was going no I don't. I mean, I like this job.....I love this job.... You know, I'm having fun and what am I going to do, go home and sit and wait to die. I just, I'm not that kind of person. I'm just, so I didn't like own a TV hardly or if I had one I kept it in the closet. It was just the way I lived my life. I hadn't watched TV in years and years and years. And then I got really sick...and it was IV lines.....and we had to do a blood transfusion too.....a couple of different blood transfusions and trying to just keep me going.

J: uh huh.

Do: Um, the illness was so bad....and I was going allergic to every drug, and the first part, it was just hanging on. I was just doing everything in my power to get every pill into me and do all the things I needed to do to get myself through it....

J: uh huh.

Do: Um, I was really stubborn about it, just really, the doctor kept trying to put me in the hospital. I was really sick. I mean he was really worried I was just going to die one night at home by myself.

J: uh huh.

Do: And he made me call in every morning before noon and if I hadn't called.... I felt like I was pestering him so then I didn't call... and he calls me up at noon and he's all mad because I haven't called.... I'm so worried about you. And I just didn't want to go in the hospital. I just had a feeling I wouldn't like it at all, and I finally had to go in the hospital once when they collapsed my lung, I had to go, and it was like....it was so awful. I'm just not a good hospital person.

J: So, did you talk to anybody during this time? Were you talking to friends, to family?

Do: I do, but not enough. I had a couple of people that really stuck through with me, by me, that I could call, even the family, I mean our style was to call every three months or every six months, and maybe I'd imagine that when I was hanging in the life and death, they would call more often, but they didn't.

J: And they knew what was going on with you?

Do: Yes, and I was really.....been really mad at them..... It's still taking some healing to get over it.

J: uh huh, was this because of the way they were responding to your disease or what was that about?

Do: No, I think they were really busy and they are raising their kids and they are busy with their lives. What they wanted to know is if I was on the verge of dying. And then if I'm not then.....then they want to come, then they all want to call on the same day and then, I'm exhausted, you know, like, but, when I'm just trying to spend six months trying to get strong and I can't hardly get out of bed for six months,

J: uh huh

Do: I wish they would have called even like once a week for 10 minutes, but I would go like four months and no one would call, you know....It was really hard. I have a couple friends that....ah....a lot of friends pulled away too. It was really..... really....I never, I thought I just had tons and tons of friends, and I always just had this busy, full life.... but, it's as if I just became really boring all of a sudden....nobody wanted to be there.....

J: uh huh. .

Do: You know, and even when they do call, all I can talk about is like....you know....well, the diahhrea is a little less, and....ah....they changed the pink pills to blue ones and...and my brain was exhausted and I was so tired, I couldn't even hardly focus on things,

J: uh huh

Do: I'd watch the television and kind of go in and out of sleep and then I'm watching....this is my television period....you know....and all I watch are....even like the complex movie, where they do character development for people, and the kind of things like on NPR public radio, public television that I would have loved before....I can't even track who the characters are well enough.....

J: uh huh.

Do: The only kind of thing I can watch are like....uh....Bonanza with black hats and white hats, like....you know...an old western where you can tell who the good guys are and the bad guys are....and my brain was just so tired along with the rest of my body... just, I was, at the same time.....I was just so bored.....

J: How about, did you have any kind of fears and.....

Do: Umm, I did some things early on about death that, at the very beginning, the first couple years, I had a lot of panic about death....and I remember my way of dealing with fear, is to take it head on.....in some ways it might be bad....I remember I panicked.... I was seeing a therapist in San Diego and he was like, I would drive him crazy because I would do all these things. I wanted to know all about this disease...

J: uh huh.

Do: Well, I was already in the medical library doing research, so I would go and I would read about it and I'd look at these books and I

would see these pictures of all this awful stuff...and it would just freak me out. And I would go home for about two days, I couldn't even get out of bed, I'd be so depressed...

J: uh huh.

Do: But then I would come out the other side....and then I'm a lot stronger....So that like....um.....I remember just being panicked....there's all this stuff about eye diseases, of AIDS patients....when I first had HIV and I was going off to a vision conference, there was whole big seminar, four hour seminar on HIV and vision.....and I remember telling my therapist then, like I can't go to that..... I'm not going to that, no....

J: And what did she say?

Do: And she said yes you are.... Ha! She said, yeah, you can go. And I remember thinking everything I ever thought about blindness.... I had such panics that all these people just go blind and all this stuff....

J: uh huh.

Do: And then I go, oh no, it's just this one disease....

J: uh huh.

Do: And it's very specific and there's treatments for it and it only happens when you are less than 50 T-cells... you know....and there are treatments for it...and there's this and this... and they can measure it and they can do all these things and it... um... AIDS became such a big scary whole block that when I broke it down and faced the individual fears, I found it to be way less than a boogy man than I had always thought.

J: So, it sounds like your being educated also had a lot to do with how you dealt with your disease.

Do: Being educated about HIV,

J: Being educated about HIV, and just being aware of yourself, too....

Do: Yeah, it did...It seems like.... I guess I think there's three things. I did a search for my daughter, and it took me a couple of years, the daughter I gave up for adoption.... and I met women in L.A. that were searching for their kids...even when they were young.

J: uh huh.

Do: I started looking for my daughter when she was 10, and the world panicked, my dad started screaming at me, don't you dare, don't you dare, and it's like....I don't necessarily.....I'm not necessarily going to contact her...but I need to know that she's O.K. I need to know where she is..and with these other women, and with this support group.....and I was telling somebody recently, we used kind of an example of saying....um, in the car of your life, people who are victimized are often in the trunk. It's kind of like are you in the driver's seat or the passenger seat or in the back seat? ...or the trunk....I mean....I just didn't have a lot of say maybe, about my life....but deciding that I needed to do this and going against everybody that was telling me not to....I just panicked about birth mother searching at that point...I was so panicked, but I did it anyway.....

J: It sounds like you were very brave to take on this

Do: I went deep in my heart and did what I needed to do and I really feel like I kind of got in the driver's seat of my own life...and it helped me a lot by the time HIV kind of came along. It was like.... I'd see this thing, and I need to get there.... I need to do this, I need to do this, I need to learn, I need to teach this class downtown....

J: uh huh.

Do: And it may be that somebody I know is going to come walking in to it, if it's open to people without HIV.... It's just a risk I need to take anyway... I need to be here first and then the rest and then... I want to keep it secret but, oh...there was so many things.. I got really not scared of death...

J: uh huh. So, that was the main thing...

Do: And I really faced the disease, but I remember doing some other things too. I was reading all these different books and one of them had a thing on death, there was a meditation on death, by somebody....

J: uh huh.

Do: I had a lot of different New Age books and a lot of readings and one of them had a meditation on death. But I just was like...it's like, imagine your own death, imagine stepping through it and I was like, are you nuts? You know.... So... then...I want to do it, but....um...it took away....I don't know...I gradually, gradually and through some of these exercises and imagined my own death and what it's like....

J: uh huh.

Do: And a friend of mine that was a nurse...I remember her saying, people kind of die the way they live. And I thought...how wonderful....It was a freedom like I lived strong. I take a lot of risks. I moved to L.A. with \$300. You know, I had put everything in my car and I moved to L.A. And I needed to go. I needed to get out of Montana and find some rest of the world and I had worked six months to get that much money together,

J: uh huh.

Do: I've done a lot of calculated risks....so...um.... it's like, I'll fight like crazy to stay alive, but once I know I have to die....I can go out doing a Reggae dance, I would tell them....you know, I mean, I can, I don't have to go out kicking and screaming and crying,

J: uh huh.

Do: I would tell it became an adventure. I love to travel, I love to go to Bulgaria, and I've driven down the coast of Turkey, and through Istanbul and things. I love to go seeing places... and actually death, we just don't know it's there.... and it became like um, I'm agnostic, I don't really believe in an after life, but I don't know what's going to happen.

J: uh huh.

Do: It's sort of like alright, I may as well go find out...you know...if I have to die, I may as well not just be crying. And then really, I would

freak people out, I would be telling them, yeah.... and it helped....And I think that helped me save my life...

J: uh huh.

Do: When I was really sick, even with the pneumonia and some of these things and I went allergic to all these drugs, there were a lot of times I saved my own life, I would scramble... I went allergic to every drug we had, to treat the pneumonia, and by now it had stretched out like six weeks and it was getting really bad and the doctor came and told me, he sat me down and he said O.K. we have one more treatment and we have to put you in the hospital before we do it...and it's probably not going to work... I need to make sure you have your Will in order....

J: uh huh.

Do: Before you go....And I kind of went home....And he said, and unless, if it starts coming back, we can put you in the hospital. And I went back and within a day I could feel it coming back and getting tighter in there and all that stuff, and I kind of get these waves of panic and I laughed at myself, thinking oh, so you think you're not afraid to die, do you? So, what's this panic about?

J: What did you do?

Do: oh, O.K., and just laughed at myself...but then deep in the night I woke up and there were things...and it was...ah...clear and quiet, and my body was calm and I knew I would need more people involved....before I go, I need more....and I came into the office the next day and I scrambled and I found an allergist that knew how to help me and we saved my life and maybe some people after me. We found a new way to deal with some of the things you get....but I also listened deep in my body....I took a massage course when I was in San Diego,

J: uh huh.

Do: I think that even helped me to become a massage therapist but I had to give other people feed back and to go inside and know about...um...myself... I'd call my doctor and I'd tell him, I think I know this is what the problem is. And you know, after....at first he was like, you know...and after awhile we have this relationship where he's like, I'll run the test, O.K., you know, I would just say, you know... We got this really good relationship worked out....

J: Uh huh

Do: And I worked with acupuncturists , ah people there, and I had a Tibetan Monk that was doing body work on me and some of these people would tell me things about my body that, like I'd be throwing up and high fever and the doctor can't find anything and they don't know what it is and the acupuncturist, the acupuncture didn't help but she'd say, this is an allergic reaction. She would look at all the things in my body, my tongue and she'd say well O.K.... I wonder if this is an allergic reaction? And I'd say,

J: So they all worked together?

Do: Yeah, through me, they didn't really talk to each other... but I'd take ideas from different places and then I would listen to my body deep in the night, I'd wake up about 4 in the morning, quiet, and I'd go, what is it, what is it? I've felt this before, I know now, kind of do a body scan where you feel each muscle and you feel each thing in you so you know where it is... what is this feeling and how do I pull it apart?... Aand then I get my books and I'd read and then I... yeah! it's really amazing that I'm alive. A lot of the doctors look at my stuff and they look at what I went through and they're just like, no, you know, it was amazing to pull through that.

J: How long have you lived with HIV?

Do: Well, I found out in '89, so it's 13 years, but I think I was infected in '84. Oh, that would be like 18 years.

J: It's been a long time...

Do: Yeah. And so now I'm coming out of this time of being ill and I'm... just this year, I'm starting to be able to travel a little bit... uh, I came up this summer for a couple weeks, but I had a broken foot and I was kind of still a lot of a mess, and this trip I was a lot stronger,

J: uh huh.

Do: Just to start to get to know people, and start to reconnect again... Start to come out, and I'm still real fragile and I cry easy and I have to get away from people, and I... you know... things, but underneath I find an immense strength. I just, am so much stronger, I was strong before,...

J: uh huh.

Do: I was telling somebody, if you are strong in the broken places... there is nothing left but strength in me now... It amazes me. I get glimpses of it. It's like I'm... ah... like a chicken hatching, or like the surface is still fragile, but not inside...

J: uh huh.

Do: There's an amazing power in me coming through all this.

J: I've heard you talk about support groups, I've heard you talk about seeing therapists,

Do: uh huh.

J: ... visits to therapy or wanting support groups, was that something you did before HIV?

Do: Yeah, during the time when I was searching for my daughter and before that. I've been, I was in therapy for even like 5 or 6 years and had done a lot. I think what I mostly wanted was coping... and it's a funny thing, because the more I study it, the more I think it's not a part of psychology.

J: What do you mean?

Do: They're used to dealing with something that goes wrong in the processes and there isn't really a place for just general coping with something that's really hard.

J: So what you are saying is that there is a lot of pathologizing in psychology?

Do: It's really about pathology in a lot of ways. And they are coming to help you even in grief processing. They can't take the grief away. All they can help you is if you're stuck in your grief someplace.

J: uh huh

Do: And I had a really hard time finding therapists who could help me at all. Partly I needed somebody, I'm going I don't want 101, I need the graduate level therapy, I don't want to say like this might have something to do with your mother, you know.

J: uh huh.

Do: It's like O.K., I need something far beyond that, um, and I would freak therapists out a little bit, you know... the guy was like you can't go read about HIV and I was like of course I can. You know what, a couple of different people... I tried, and... well, and I'd find people that weren't as strong as me....

J: uh huh.

Do: You know, and I know what he was telling me... like this one guy, who was a therapist I'm seeing and he's saying how... um... we were talking about trying to find a dentist and he was saying how he wouldn't take his kids to the dentist anymore. Cuz he saw these gay men in the dentist's office, and I said well, you really... you know... you really can't catch it that way. And he said, no, no, no, I read a really good article about how you can catch it from the dentist's office, and I thought well, I'd like to read it you know, cuz I really don't think you can. Where, where, where did you find that? And then all of a sudden he turned bright red and he goes... oh it was in Playboy...

J: Uh.huh

Do: Oh sure, Playboy writes an article about AIDS finally, this is like 15 years into the epidemic and they write it about going to the dentist's office... you know... But, but, I'm like this guy can't help me. I mean, he's way more scared of this disease then, I, I think he's probably wiping down the chairs....

J: After you leave the room...

Do: Yes... and I had one in San Francisco that I went to about a year, but I'm stuck in this bed, I'm almost bed bound and I'm so ill and it's really hard to cope with this and all she could think of is, could we put pretty sheets on the bed, and maybe you could listen to public radio or something there just to relax, and I'm going that's just social worky kind of things you know, I'm talking about the psychology, the coping... what skills to cope with.... That's what I was looking for..... That really isn't a piece of psychology anyplace. People study coping strategies, but they don't teach you coping strategies...

J: uh huh.

Do: Um, it really is, and even, it's, it's kind of funny, people say like you know you lost a special loved one, you should go to therapy.

J: uh huh.

Do: Um, the therapist can't necessarily help you. It's going to hurt for awhile, it's just going to hurt. You kind of just have to go through a lot of the steps...so, I can study my own coping... and people cope in a lot of different ways and literature is actually...um... pretty complex about all the different ways people cope. But, it's kind of interesting...

What...um, there isn't...

J: uh huh.

Do: You get thrown into prison for something you didn't do. You get accused of a crime, you're in the wrong place at the wrong time, you are put into prison, you go to psychology and you say how do I cope? They don't have answers.

J: uh huh.

Do: That's not what psychology is for.

J: So, what it sounds like is you are saying coping strategies are within, and somebody has to make you aware of them, is that what you are saying?

Do: No, I actually think they could teach them, but psychology doesn't now. I think it actually could be taught, of how people cope and give people possible strategies for coping,

J: O.K.

Do: What they'll do is tell you to go see your minister,

J: uh huh.

Do: We delegate coping,

J: uh huh.

Do: Um, psychology is a field in a lot of ways therapy as its structured now is really about looking for what's wrong or, there just, it could use a field of like um, talking about coping strategies, how do you cope with an awful situation, if you go to them and you say, I have a lot of anxiety they say, it's normal. For what's normal, they don't really have an answer.

J: uh huh.

Do: You just have to go through it, but maybe it could be. But that's...ah,..yeah... psychology is about the...um... the things that are wrong.

J: just hearing your story, it seems like there are a whole bunch of things going on there for you and over the 18 years that you have been dealing with this, you've gone up and down, but then I also sense a lot of strength in you...

Do: Yes, I do have a lot of strength....I believe..

J: How you've tried to deal with this disease, even though it has brought you down at some point, you've managed to say, I'm not going down screaming, but I'm going down strong,

Do: Yeah,

J: and I'm going to go the way I want to go.

Do: uh huh.

J: That's what I'm sensing in you, and your use of therapy, you know, your use of group, your trying to use everything available at your services, to make your life better, it sounds like is the coping....

Do: Is coping,

J: Yeah,

Do: Maybe groups can teach you more about coping than a therapist can.

J: Than one on one therapy? That's what you think?

Do: And I have a therapist now I like very much.

J: uh huh.

Do: Um, we don't necessarily deal with coping, you know, there's a lot of....she kind of goes...you know... we talk about other issues that come up and other things, you can take away other stressors in your life and work on those, even if you can't get rid of the coping....

J: Because to me, you're going to a therapist, and working on those things that you work on, that's a means of coping...you are coping with your illness, that way, by seeing a therapist, by working with your doctors, by reading whatever you read....

Do: uh huh....I guess so....

J: It sounds like that's how you cope with this disease.

Do: Yes, and my coping style I would say, when I read about coping styles, some people don't want to know anything about the disease, don't tell me anything, tell me which pills I need to take, and mine is I want to know everything.

J: That's what it sounds like....

Do: Almost to an extreme. There was one time when I could tell. My doctor we were having a discussion, I could tell he was kind of avoiding something a little bit, and we're talking, I was having so much fatigue, and we were looking at diseases in the medical books actually, and he went to the hospital to go see his patients and came back and I'm reading about things, I could tell, he kind of put it together, he kind of let it filter together and then he came back and I said O.K., Lee, I have one question, but I really want a direct answer.

J: uh huh.

Do: Do you think I'm going into dementia?

J: uh huh.

Do: And he said, yes, I do.

J: So, he was honest with you.

Do: Yes, I wanted, and he would be and I needed, I need somebody, some doctors, doctors have styles, coping styles too,

J: uh huh

Do: And some of them assume the patients never want to know, and some assume the patient always wants to know and I think doctors should be able to adapt to the patient's coping styles.

J: Yes.

Do: Even that simple, do you want to know or not? You know if you have something.... Um... and like with that one, I freaked out when he said he really thought I was going into dementia, that whatever it was that was causing the fatigue was taking my brain down too, that there was really a loss from even 6 months before.

J: uh huh

Do: And I went home and I just panicked and I didn't take any of my AIDS drugs through the weekend for the next 3 days and I was just massively depressed, and then I came out of it though.

J: How did you do that?

Do: I don't know... well, I don't know of any one thing. It just seems like it kind of just happens. You know? Almost it just seems like the storm comes and it passes. You know and it's hard to dive into it, and go into it and to just trust in the process that you will come out the other side. I feel like it just happens I don't know how many times in my life, that I know it by now....then I know I will....

J: So, you know when you are in there you are aware of it, do you have to work hard to get out of it?

Do: No. But when I'm in there, it seems I will never come out. It just really seems like I'm in there forever. You know.

J: So, when you are in there, though, what are you dealing with?

Do: I just think of a churning and churning, umm, I can't even think of it like its fractured thoughts and just... I do have things I go to like a lot of different books around my house. I have a lot of books in my house... Umm, some that are inspirational or different thoughts and different kinds of, I don't even know. And I live in whatever I want in the moment. If I feel like eating, I eat, if I feel like, you know I pull out books and you know when I come out of one of these, I might have books all over the house or poems or things upside down and thrown around and just, but I'm so depressed that I'm not going to clean up anything. I might eat like a whole thing of ice cream, if I want...

J: so, when you are depressed, what are the thoughts that come into your mind at that particular time?

Do: What I think of is like I remember like when I was searching for my daughter and there was a massive depression, that was like six months, I was just so depressed, it was like a delayed grief and all of that depression, and I think of how I started having all these dreams that she was dead. That I would search for her and find and I would have dreams and I'd find in the cemetery, and just find her grave and all that and then there was just a part of me, I remember like saying I want to find her anyway. I would come up and I would just be almost seasick and just queasy and I couldn't eat for a long time and just thinking you know I still, even if that is her grave, I want to see her grave. I still want to know. And just have...I really have to think about that how that actually happens, how I come through that. But, there is something about just really biting it off and just really looking, maybe looking at the worst of

it, and then kind of saying, O.K., even if this is dementia, and my brain doesn't work as well as it used to, and then what I remember is after a couple of days kind of saying well, thinking but there is a lot here still, and maybe a lot of my brain is gone, but there is some left, and there is enough left and...

J: that's what it seems like...

Do: Well, and even then, I would be... and I was thinking, you know, I didn't think, I really was telling him that whatever it is that fuels all the muscles in the body, fuels my brain too... I mean, I was so tired, I had been to all these specialists and nobody could find any answers. And just extreme fatigue, where its hard to breath sometimes, Uhh, and I thought maybe I don't think it is dementia, but if he does, a lot of times people I know that people don't always know when it is. I just remember thinking, yeah; I don't know exactly what happens over those days. What exactly I do.

J: So, on those days do you interact with people more, or less.

Do: I think some times, yeah I might be calling people frantically for awhile until they are tired of talking to me and then, go oh...

J: So, at this point, of your disease, do you feel like you have enough good support system around you?

Do: No!... But, I'm just at the point where I am starting to build them. I went through that seven years without nearly hardly any support...

J: So it sounds like the last seven years have been rough?

Do: Really, really rough.... Some of it, like last year, I went a couple of months without hardly seeing a soul. I was so bad with the thyroid, I couldn't get out of bed really. I had things delivered and stuff.

Sometimes I'd get a day or two in there and I would go to the store and grab a whole bunch of food and put it in the freezer and stock up and then be down for another two weeks, but you don't really even see people when you go to the store necessarily, if you are sick. I went through really, really bad times. Astonishingly bad.

J: Uh huh.

Do: There was one comment I was thinking of with the depression. One of the things that I would always keep thinking of, I was just telling somebody, it seemed as if its like when the seasons change. Like when I'm in the middle of winter and its like a blizzard and its so cold and you just think its never going to quit snowing, never quit blizzarding, its never going to quit, its like that in me...

J: Like seasonal?

Do: Like seasonal, yeah, and then somehow, it just happens, I mean sometime you look outside and all of a sudden its just starting to become spring and you kind of think, how that ever come to be, I don't know but, just within me its almost like I just spend enough time in winter, and pretty soon it just starts, and I will notice little bits of something in me that are not exactly joy, but there's little bits of like green sparking on

the trees and just a little bit of almost like give into winter and the next season comes.

J: So, it's like something that might not even be related to HIV?

Do: Yeah, oh no, it isn't. To me it's just seasons of grieving. And so, what I am doing is grieving the loss, and if I am going into dementia, I'm grieving HIV, I'm grieving a lot of different kinds of grieving. I've just gotten good at grieving. You know.

J: so, that is the way you cope.

Do: Yeah. Yeah. But to run from the grief was when I would really get in trouble. I mean if I try to keep from grieving, you know what I mean, to keep it, that just takes all your energy and its like... um..., you know, you just spend a lot longer in it almost.

J: Yeah, uh huh.

Do: I don't know. As if we have a choice though. You know, I don't know, I think sometimes when we are at that point... I don't even know, can we change our coping style? I'm not sure if we can. You know, or,

J: Well, I don't know, because if at all your coping style is what makes you cope, it means that makes your life seem better.

Do: Well, but we could also measure how successful somebody's coping style is. Just because that's your coping style, doesn't mean you cope well. I mean there is a lot of coping styles that are unsuccessful.

J: There is the scientist coming out of you. Measure, the word, measure.

Do: You know, but even as a psychologist, you'd say well, you know, if we were going to start an area of psychology that talked about coping and talked about how you cope, I mean you'd want to talk to people about how they cope and how successful is it?

J: uh huh.

Do: You know... is it working for you?

J: Because if you start working then you have to think of different ways of coping....

Do: There is a lot of different ways people cope. And church is a big one. People turn to religion a lot.

J: uh huh. People do.

Do: and there is... uh..I'm just very non-religious. And it just was something that felt so comfortable with my feelings, it wasn't a problem.

J: uh huh.

Do: My family was all positive that I would become religious as soon as I got... you know... as soon as I was close to death, everybody does.

But it wasn't, it just didn't happen....

J: Well, you brought up religion... Is your family religious?

Do: Extremely. And the whole family is and they were so upset. And it was beginning to be O.K., until I told I had HIV.

J: uh huh.

Do: Then there was a lot of um, discomfort in them, you know.

J: Discomfort in them?

Do: they had to save my soul.

J: What's your ethnicity?

Do: Umm, a lot of German, and a lot of mixed things.

J: uh huh, O.K.

Do: Yeah.

J: I was wondering about that religious pull

Do: I was raised catholic.

J: Oh, you were raised catholic. Uh huh.

Do: But still, there's a lot of different ways, I mean they were just um, on a sense that if I'm going to die, its O.K. if I spent some time being unreligious, but they needed to save my soul before I died? But they will never see you again....Was their idea...

J: uh huh. O.K.

Do: It was hard on them....it was, yeah....

J: It was, or is it still?

Do: Well, they keep...I mean...they watch me and they keep getting confused and they say well, you are such a nice person, you really are religious you just don't know you are... you know... really, you just don't know you are a Christian. And I'm going, no, no, no. What you don't know is that there is nice people who are not Christians... you know, to them. And as time goes on they get more confused and finally they have decided, I got so mad at them for harassing me, constantly about that... yeah, when I was ill, I mean it gets in the way. Like I need support, and I don't need to be just yelled at to pray. I need real support... kind of. So, they have changed immensely.

J: Do you have siblings?

Do: Yes, I have six of them.

J: O.K., sisters and brothers?

Do: Sisters and brothers, yeah, and they all live around here.

J: Around here, in Montana? Well, I have another question for you, as a woman, that has been dealing with this disease, what has been your impression, compared to men since you live in San Francisco?

Do: uh huh.

J: Where more men maybe have HIV,

Do: Oh yeah.

J: What's your experience as a woman dealing with this disease in the midst of men in relation to treatment and all that?

Do: Umm, that's a complex question. I was used to living in a world of men. I often worked in engineering groups with... where I was the only woman and 50 men. When I was in college, there were a lot of classes, I was the only woman in all the classes....

J: ...and because of that....

Do: I went down and I worked at Montana Power one summer as an engineer, and they called and they go, we got your application, you're the first woman that has ever applied for an engineering job in Montana Power. O.K... so, I always felt really bizarre and really weird but I

always kind of felt like I was a little bit part man, you know, kind of a little bit... um... ambidextrous, but there is a word you know, like a little, so then it depends on which guys. Like even where I am now in Marin, there will be a party for people with HIV, a pool party, and oh, one time, Like I went to one where there was a pool party and there was 30 gay men walking around in tiny little swimsuits, doing there little flaming thing at each other and then I'm just like, I want to be out of there... gone... like you know, I just don't belong in the middle of it when they are flaming. But then there is all different kinds of guys. So, like my friend David, umm, very gay, but I felt so comfortable with him. He was a very balanced person and just wonderful. We went to Hawaii together, six months before he died. And we did a lot of different things, and we had so much fun. He was a really good friend. Umm, and then my friend Mark, the hemophiliac, and I learned a lot about that whole side, um, sometimes I'm uncomfortable with the men, when there is a whole group of flaming gay men there.

J: What does "Flaming" mean?

Do: Um, what I use it to mean is something like when they are right in the middle of trying to pick each other up and have a lot of sex. Kind of where they are flaming right now, there.. you know, walking around wiggling their butts right in front of each other and watching each other's eyes to see how they are and I am just like Ohhhooohhh. You know. Like there is these moments like that, when it is like um, I just don't belong in the middle of this... or, in some of these classes we would be teaching about HIV and there is 30 guys there and on break... Saturday morning, and they are on break, but guys are talking about how they have lost so much weight, that their leathers don't fit anymore, and the other guy that they are talking about... and they are talking about these things and I go, David, I don't know what they are even talking about. And he would go, uh, I don't know either, but if I know, I will tell you, you can always ask me. So, there is some of the gay world that seems extreme to me and gets carried away and its hard for me to just... it feels alien, and I don't feel a part of. But um, and sometimes that's even closed kind of to me. The first support group I went to... um, I was the first woman and they said um like they actually had an argument about whether I belonged there or not. They were saying... some of they guys, a couple of guys were saying this is a gay men's group, and they said no, its an HIV group... and he goes, no its an HIV group for gay men. And they said we've never said anything, its an HIV group and just because a woman comes along, you know....

J: That makes a difference?

Do: It was hard to meet women. I looked... I treasured it when I finally met women and could connect to women, because it was a whole different experience. The heterosexual men, I related to in some ways more than the gay men, just you know, people from the hemophiliac and other ways... um... So, it kind of depends on what, and a lot of the gay

guys, when I have them out of their little group, where there're flaming, you know, around each other, it's a different thing too. So it depends on the situation. Sometimes it was hard like, especially in San Francisco, when you go the doctor's office, and they have a little room where they do the blood draws, and its all covered with naked men, bodies and all this stuff. Kind of early on I thought maybe one of my coping styles was to think, O.K., I always loved to travel, like I drove through Bulgaria once and the hand signals are reversed in Bulgaria, like this (uses hand gestures) means no, and this means yes and you know, and I loved that and I loved living simple where you live in the hotels where the people are, and you meet people and see all the different things that happen. In Istanbul we found an old hotel way up in the place where the people from Istanbul would stay... it is such a different experience if you go across town to the Holiday Inn,... so somewhere, I decided O.K., here is my image of where I want to travel, but D, with this HIV.. here you're traveling, and you're seeing cultures, and I say my name on here but, um.

J: I'll take care of it....

Do: Umm, its like this is a kind of traveling. It's just a different journey. I stepping into cultures I never would have been allowed into, in another way. I'm seeing all kinds of things and I just have to accept it as a journey. You know. Maybe I think I want to go to Paris on the plane, and what I would tell myself in the plane, is like, you have this trip all planned and you have got an adventure planned to go to Paris and instead the plane gets hijacked to Bulgaria and you watch and the plane breaks down and now we are all stranded in Bulgaria, and you watch all the different people with HIV and how they handle it and what they do with that now. We are someplace we don't want to be....

J: uh huh.

Do: And some people are busy spending the next 10 years trying to fix the airplane and um, after a little bit, I kind of said well, I don't know, but there is people out there and I might as well try and learn the language and go meet the people and talk to them and it's a nice place here and the food is different and its different than it was if I had gone to Paris, but its going to be an adventure, there's an adventure to be had here, so

J: so, it's a journey. So, how would you describe your journey, since that's the analogy you made?

Do: It's been my journey then. I might as well accept it as my journey.

J: So, how, how, what would you say about your journey? How has the journey been?

Do: Oh, way more adventurous than different kinds of adventures, you know. The first part wasn't bad. Um, oh I don't know if I could sum it up in one sentence. It's like different phases. Up to getting sick, it really wasn't bad. There were a lot of adventures and a lot of things, and then being sick was just holy hell. That time, that isolation, that was a

brutally bad time. Then um, then when I look at it, I had a lot of talents and gifts, devastated my life, you know? I'm coming up on 50, and now in a few years I might be able to pick up the pieces and try to think about working again. But, a lot of the... you know... in this company where I was working, even within six months, they were grooming me really fast to way move up in the company. And they were giving me all different responsibility and I just loved it and I was just thriving and growing there. But that's 10 years ago, you know? They groom people at 40, they don't groom them at 50. Um, it could be possible, you know, I mean it just might be.....

J: You might be groomed at 50, who knows?

Do: I know, so its just like um, sometimes I look at it like with a lot of sadness, like all the different things I could have done. And then in another way, I kind of go, like you say, there is this whole experience of just kind of, maybe what I was doing was just tedious things, if I'm just doing computer work before, and then you kind of come along at a whole other level, you know, where I just kind of look at it and go, alright, no I come in like five levels above, because of what I have been through, and just say I'm going to do this, but I wouldn't, in some ways it frees me from the corporate life... just like you can also be stuck in the little corporate world, climbing the little corporate ladder, you know, and uh, its hard to leave and its hard to find a way out... I'm actually coming into a time that could be interesting, where I am not able to work, but I have the money? And so I have some time. Something I always to have was some time where I had enough money to do what I wanted to do, without having to work so hard to support myself... you know... So, it's kind of interesting. You know, I don't know. The last chapter is not written yet, you know?

J: The last chapter is not written yet, and we hope it is not written so soon.

Do: Well, and there is more chapters, you know?

J: More chapters to come. And so, today, what do you say about HIV in relation to your life?

Do: In relation to my life?

J: Yeah, today?

Do: It's just um, it's just a piece of it.

J: It's just a piece of it....

Do: yeah, it's definitely a piece of my life, but it's like its only one piece of my life. You know... It's like, um, I don't know, I have brown hair and I have... you know... and I have HIV and you know, I have long fingers and I have you know this and this and this, like um..(laughs)

J: So, it sounds like there is more to you than HIV?

Do: Right. And I did notice somewhere too, like the grief with my husband that infected me, like there was very much a point where he just became insignificant. This disease, like within a couple of years, quit being about him at all. It's just a piece of my life and its just who I am

here, and it... um... I owned it? It's mine, and its only one part of what I own, you know?

J: There is more to you....

Do: Yeah... Yeah... there is a lot more to me And I wouldn't say it's little... it's been a big impact.

J: Uh huh

Do: And yet you know, like in choosing gifts, I have a really strong gift in mathematics and abstract, which made me good at computers, so I could just see all these things in a computer, and that's one part of me. So, when I'm looking for a job, that's one of the definitions of me. But I also have a lot of ability like they would tell me in the Master's program that I was a natural therapist, that I should have been a therapist, you know, but then I had these skills and that's something else....um, but now I have this fatigue and this ability, like I say, even though I gain energy, I don't have stamina, you know, and its just like yeah, to figure out who you are and how you fit and what kind of job you are going to do and how you interact with people and all of those are hard... I don't know...

J: I feel like I am fortunate to talk with you today.

Do: Well, thank you.

J: Because,

Do: And I'm getting to know you. I always like you,

J: Because you have taken me quite back there...and we are talking about the beginnings of HIV, when HIV was really at its climax, and yet for women, there wasn't a whole bunch of stuff for women,

Do: No.

J: In relation to HIV, so what you have done, is taken me back there, and you have just allowed me to be in the journey with you, in your journey, where you have struggled, where you have, I mean your life has been good, you have enjoyed your life, and then there came a time where maybe that disease now did come and bring you down, but you've also, I've also heard a lot of strength in you and that too, how you have worked yourself out of this and now, here you are again.

Do: I'm coming out, I'm still coming out

J: But you are coming out of that place where it has been rough for you and you just the way you looked at the disease from the beginning, you know, the strength, the way you looked at the disease in the beginning, there was a lot of panic, because you didn't know much about it, but you educated yourself. And in the process, I'm sure you educated a lot of people, doctors, people that you were in contact with, your friends, and everybody, and here you are now, looking at that disease as if its not in control of you, but you are in control of it. That's the message I get tonight.

Do: That's true. Uh huh.

J: That's very impressive. Because it seems like what you are giving, no, what you are saying to someone who maybe diagnosed today, is that they might go through these ups and downs, but there is always hope.....

Do: Oh yeah, and it's a lot easier. There is a lot today. There is so much they can do with it now. And that... um..I still think that there is an internal process that first couple years is just going to be hard. There's just...just know its going to be hard, and its really when you don't want to tell people, and you feel all the shame and gradually you work through all of that...its like, but when you see other people living without shame, it makes you feel stronger just to see it and to watch it, so I... it helped me a lot. I have these images of watching people like Terry, the activist in this life, and it would inspire me so much to find your inspiration in other people that live well they give you all the examples. There are so many awesome people. You talk about that one...you talk about differences between women and men, I felt like a lot of the support of living with this disease came from the support groups, and that was O.K. to have a lot of men. And when we got groups of women together though, I mean really the number one difference that we would have, what would come out, is we would start talking about sex. It was just... um... and I remember Sharon talking about dating her boyfriend and you know what they learned and how, and starting to learn how hard it was to pass it on... and different peoples' stories and often that didn't happen in support groups with the leader present. It just used to stun me, it was almost like having Mom in the room, and we never talked about sex until we were off by ourselves.

J: So, when the leader was not there, the facilitator of the group was not there, that's when you talked about sex?

Do: And maybe it was just the ones that we had, that were very tidy, and everything was very formal, and O.K., now let's all talk about this and they...I think there is a lot of people that don't know how to help and they are very well meaning, but we were supposed to be really sad when we came in, we were supposed to be happy as we left and gradually evolve.....

J: What did you guys talk about in relation to sex?

Do: Well, what I remember is that there was a woman's conference there, and there was all this stuff going on, and I helped even plan the conference, but then over lunch time... and they are having all these meetings about this and some humor and some writings and there is different things that came up over lunch and some of the women gathered downstairs and there were some more over here and some were from Kansas and you get a big table, and you know women that are very isolated and then somebody was saying, oh, to this woman, talking about her boyfriend, and somebody says you're dating? What? You know? Like, you know? Her husband died the year before, you know, he was a hemophiliac, and some woman had never talked about sex in their life, but they are like, your kidding, you mean its possible, like oh my gosh,

you know like, and they want to know, and then the other says yeah blah! Blah! Blah!... and then this one says yeah I'm dating somebody, and so its kind of like, how did you tell them, how did you?... You mean he's negative, and how did you meet him?.. How did you tell him?... what do you use?... I mean... and they are like details, how do you do it, are condoms really enough? Or do you need this, or do you need that? And they were talking about the Saran Wrap you could use for oral sex, and Sharon said her boyfriend showed up the next time they learned about this and the next time he showed up at the door, he rang the doorbell and she opened the door and he had a big grin and he was just tapping the Saran Wrap on his hand. And we would, with that look on his face and we would start screaming with laughter... and some were so embarrassed and people were turning red, but they are asking the questions anyway and we would laugh and laugh and laugh until our stomachs hurt... you know, its just our own embarrassment and yet we want to know and what worked and this and this and this... and Michelle had been married for eight years and her husband was negative and Sharon's boyfriend was negative for 3 years and she had known that for 3 years he was negative... and all this, and you start to go... and you start putting the pieces together and then somebody says, I finally met... I met somebody, I'm happy....and we'd laugh.....

J: So, it sounds like in those groups people felt that there was life even when one lived with HIV after all.

Do: And this was the most important part that we hadn't been able to get in the male support groups... about how, their, how do you say, their dating methods are completely different than the women's. And they are um, you know, yeah, the rules are different and stuff, and so it was like, just trying to make our own lives work.

J: So it gave the women in the women only group hope that there is sex life even with HIV...

Do: That they could even have a relationship again, somebody gets married again, and so we would come together in this group, we had about 30 women just talking in there saying she got married, and you know they are just, it gave them hope, and this whole idea, and we would laugh and we would share. That was the most important part that came from women.

J: Uh huh

Do: Yeah, and then I finally started dating somebody... you know that I thought I would never want to get involved, and then, yeah, I could talk for hours, but you know, and each one goes through your own experiences but you come back and tell about it, and I'm coming and telling lalalalala, and they are laughing and laughing and laughing, but I was amazed at how I never saw that in support groups. It was always kind of, it was something that happened somewhere else, in the support groups that I was in, but they were kind of a little bit too proper, for you know, to bring up things like that...

J: So, that helped people to understand that HIV was not the end of the world.

Do: Yes. And then it began to be like sometimes I would talk to them about like some of these support groups would say, well the women just don't come to these support groups, you know, they need to know that this is so important in their lives, and this is the one thing that matters, and I'd be saying, well, it just isn't a very good support group, you know, I mean...

J: You mean with the men?

Do: Even with the women, where we just talked about tidy little things, you know. So, how are you feeling about your grief this week, you know,

J: Oh, I see....

Do: and it was like so, I would quit going to these things, but then you would bump into the women somewhere else, and we would scream with laughter and all, and they would be going what are those women talking about?

J: It sounds like you have had different types of experiences...

Do: Oh yes, one of the things I would really like to write about, is just how to teach people how to help when they want to help. I am amazed too at how, when people come to help me, um, they treat me like I'm three, they take over my life, without you know, without going through what helps me? They want to be helpful and they do what they think, what they choose, rather than what I want..., so I have somebody that comes to help in the house and they decide to remodel the kitchen instead of mopping the floor, you know, the things, sometimes they made sure everything was tidy and the counter was cleaned off but then I couldn't find those medical records I was going to take back to my doctor. It took me three days of looking through, I found them across the room in a pile of boxes, they had opened up a box and put them in a box of old tax records. But I, you know, I spent so much energy trying to get everything back that I needed back again, that sometimes it was too hard to get help, because the help wasn't helpful.

J: So, what you are saying, let's say if you were working with a therapist, you want the therapist to know you.

Do: Yes.

J: To know you, to explore your needs, to look at what you need, your wants, instead,

Do: Well, a lot of them do that, I wasn't even thinking of therapy, I mean that people that physically want to help, like um, oh I was in a group one time where we were looking for ways to serve the community, and we were thinking, oh we could go out to an older person's home, somebody, an elderly person who's house needs painting really bad, and maybe we could paint their house one weekend.

J: Yeah,

Do: We were thinking of things like that. And now I think, O.K., what I imagine is this group of 18 people, very well-minded, showing up with brushes and rollers and paint and saying, Mom, we're just going to paint your house here you know. And then you find out, nobody took the time to ask her what she needs, and maybe she has all the money she needs to paint the house, but she doesn't know how to work with the professional painters, she gets ripped off, or maybe its these little bushes under the window that they say they would cut and her husband planted them and she doesn't want to lose them...

J: Uh huh

Do: She doesn't want to lose them, so we come, and in the process of painting the house, stomp all over them. You know. There is all these things when they leave the person they are trying to help out of the loop. They forget to ask them. Um, you know is there some, now I would say, what we should do is go to visit this woman and say, is there something we can help you with? We are a group of people who would like to give something to the community and we just would like to see and maybe she wants you to go weed the garden.

J: Yeah.

Do: and maybe she... you know... I mean... I have been tractored over so many time, and its like they wait until you're tired, so tired that you almost can't work and then people that mean well but they do like, they throw away things I needed, and like if I got, people, I would hire people to come and help me in the house, when I was really sick, I had some real disasters. It was amazing how much, think of how, oh I can imagine, like saying go down to the poverty areas of Louisiana and they would say, O.K. there is a story that says if you teach the people if you give the people the fish, you feed them for a day, but if you teach them how to fish, they, oh I know, let's go buy 50 fishing poles and they take them down to this poor community and we will take them out and distribute them and all the people are standing there going, and trying to smile and say thank you, as they get their picture taken, but what they know is that they need nets, but nobody ever asked them, and they know how to fish very well. You don't need to teach them. They just haven't been able to afford the nets or the boats and instead they've got these poles and they are supposed to stand there looking happy, and I think that is even the way the U.S. tries to help around the world is so often without involving those people. And it's a power difference, you treat them like they are way down here when you don't involve them. When you really help somebody, you treat them as an equal and say, how can I help you? What is it that you need? And if they say, go buy drugs, you say no thank you, you know, you can always say no, or say give me a list of things, maybe I'll do some of them, I may not, you know, maybe I can't weed your garden but I could do, you know. But maybe all they need is somebody that will just work with the professional painter, and say, I'll be around to just make sure that the guys do a good job and that

that they charge the right pay. And she's got all the money and she's got all these things. Its amazing how much I think well-meaning people, I just want to write a little thing about, so if you really want to help, and find it in my own brain, if there is somebody that I really want to help and I will offer to, I have a little neighbor lady that's 91 and we drink wine together, we're good friends, and she'll say she needs something and I think oh no, no, no, but I'll also get this thing and you know. And then I'll think O.K., all you wrote. Ask if you want this, and she'll say, no, O.K. and then actually let it go, if she doesn't. You know.

J: Uh huh

Do: Well, you know.

J: I just want to thank you so much for your time. I know sometimes going through the memory lane, sometimes some people have a good appearance about it, and some people don't because it brings back all these other things.

Do: It's a great grief to me that I won't have other kids. That's very much. As I hit 50, I wish so much, and even at the divorce time I wanted so much to just go get pregnant, and raise a child by myself, but then I had HIV. And now that they can control HIV, its like its late and I'm still sick and anyway. That's a big grief.

J: I also wondered how you dealt with that, I didn't get into it, you know.

Do: There is too much. We could go for 3 days (laughs)...

J: Well, we don't want to do that now... but I was able to get the fact that you did give her up but now your reconnected and you are doing well in that area. And with your family too, it sounds like you, you know, they have been supportive of you and you have very good friends that are supportive down there in California and, I really just want to thank you so much for giving me this time to work with me on this and what I hope to do is after I transcribe this, I will send you a copy,

Do: O.K.

J: So that if at all there is anything there, that wasn't clear to you or if there is something that you feel like, no this is not what I wanted to say, and maybe the way I transcribed it, and you can put corrections there, and send it back to me, so before I put it in the main thing, it will be corrected by you.

Do: It sounds like a lot of work.

J: I know it is, but I have to do it. I want to do it. And so, I just want to say thank you, because you have really taken me on your journey and I appreciate it so much. I'm glad that you were able to make it, because it's a different voice... you know, after interviewing with other women, you have a different voice and every woman has her own voice.

Do: They are unique stories, aren't they?

J: Unique and special...so, I am glad to be a part of your story too, and to be in a position to be able to share your story and thankful that you were willing to do this with me.

Du: 39

J: Hi

Du: Hi

J: This is all confidential. Confidential in the sense that we are not going to use your name during this interview or any other time when this information is used.

Du: Uh huh.

J: And I'll just continue talking right now because we have already started talking and I'll just ask you for some demographic information. Like I said earlier, this is an interview about your experience of living with HIV/AIDS in a rural state... and looking at the issues that women that have HIV/AIDS deal with.

Du: Lot's of them...

J: Yeah, so that's what I want us to talk about... so people out there can know what the women with HIV are living with. So, I guess I will start by asking you when you were diagnosed and what the diagnosis has meant for you and in life..

Du: I was diagnosed in 1991. But, I pretty much already knew I had it.

J: You thought that you already had it?

Du: Yes, because my husband at the time, ex-husband now, he had a drug problem. Well, in our relationship it was fairly abusive, and women and children were to be seen and not heard. So, in 1990, I noticed that he kept taking these little pills. I thought it was some new street drug. And after seeing him take them for a couple of months, I started kind of getting worried, and asked him about them. Well that was just the wrong thing to do because I was told to mind my own F-ing business and keep my nose out of where it didn't belong. So I backed off and I was not the person you see here today. I got married at 15 years old; to a man that was 22 years older than me.

J: 22 years older than you.

Du: Right. So um, I was really a child. I didn't know any better. This went on and 3 or 4 months passed and he was still taking these little pills. And its really bothering me now.

J: And this was happening here in Montana?

Du: No. I was not in Montana. This was in California. So, one day I stole one of the pills, and I took it to the pharmacist, and I asked, do you know what this is? I was thinking it's a street drug, O.K., so but I asked, do you know what this is? The pharmacist says yes, where did you get it? No, never mind where I got it, just tell me what it is, will ya? That's AZT. I didn't have a clue what AZT was. So, I asked him what it was for. He looked at me like I was from another planet.

J: And how old were you then?

Du: I was ah, 27, yeah, 26, 27. And ah, so, I asked him, he says that's AZT. What's AZT? Well, ah, that's what people take when they are dying of AIDS. I was floored.

J: So, for the first time you are hearing this from the pharmacist.

Du: From the pharmacist. And this is what my husband has been taking for 6 months. That I know about.

J: And you had been married then for how long?

Du: I had been married for 12 years. So, I was, I don't know what I felt. I mean, I was just, this can't be happening. You know. And then I said, what in the world am I worried about, my God, are the kids O.K. I didn't care about me. I just, well if he has it, I have it, but are the kids O.K. How long has he had this?

J: and then, you had already heard about HIV, AIDS?

Du: Oh yeah, I had already lost friends, from this disease. I have always been, had a, I don't know why or how, but I have always had a connection, I don't have women friends, I never have had women friends, I'm just a Tomboy and all my women friends are gay men. If you will, I mean it's just the way it's always been, and I've lost friends, I'd already lost friends from AIDS. So, I kind of knew, but I didn't know. You know, I'd lost friends from it but I didn't know the details.

J: Because these were gay men that were dying from this, AIDS.

Du: Yes, and I didn't know the details. I knew my friends were dying, but I didn't want to know the details.

J: Because you didn't think maybe it applied to you as a woman.

D: Well, it didn't. At the time, it didn't apply to me. And, it shouldn't have applied to me anyway. Because I was in a no-risk category. I had been one man my whole life. I didn't do drugs, I didn't drink. I shouldn't have been at risk. So, I took the kids. I had them tested. They were fine. I didn't have myself tested at that time.

J: What made you hold back on yourself, do you think?

Du: Um, I had to make sure the kids were O.K. first, before I even dealt with myself, the mom thing. And they were fine. Then I just took it for granted that I had it. And, it took me a couple months to get the guts up to confront him. And, when I did, it was very, very ugly. Now I look back at it and say if I hadn't of run, one of us would have died that night.

J: Like right when you confronted him?

Du: Uh hum. Because it was extremely ugly and I ended up running for my life.

J: Did he admit or deny?

Du: Oh, he turned it around and made it sound like it was my fault for putting my nose in his business. I should have never even bothered doing that. It was not my business what pills he was taking or what they were for or anything.

J: Did he know that he could transmit the disease to you?

Du: Of course he did. He didn't care. And he didn't even care enough to tell me. He felt that he owned me. And he could do with me what he wanted. I can't believe I was ever in anything that twisted and sick, but, J: You were young then.

Du: I know. If I only knew now. But, so, I ran. I had \$100, my car keys. I did have a change of clothes in my trunk because of who I am. You know, I never know when I'm going to be dumped in the mud, or something off a colt, or whatever. And,

J: The relationship that you had with him?

Du: And, the relationship I had with him. But, it was always the excuse that a colt would dump me in the mud and I would have to change my clothes. But, I had a change of clothes, a car, \$100 in my pocket, and that was it.

J: Did you take the kids?

Du: Oh no, I tried that before. And, he hunted me down and it was horrible. It was, I mean, we don't have time to go into that. It was just horrible. He tortured me for a week, after I tried to take the kids. He told me the next time he would hunt me down to the ends of the earth and kill me. And, I believed him.

J: So, you were afraid.

Du: Oh, I was terrified. This man, I was 120 pounds, if that. And, he was 220 pounds. So, yeah, I was afraid of him, very afraid of him. But, the night I confronted him, I actually fought back. That's why I know one of us would have died if I hadn't run. Because, I wasn't taking it. I just, I snapped. That was it. This was the end.

J: It sounds like you had had it...

Du: I had had it. 12 years of his abuse and this final, as far as I was concerned, death sentence, which, I hadn't even tested, but I knew. So, I ran. I ran far away. Umm, see I had no place to take the kids. I was homeless. I didn't have a job, I didn't have any money, I was uneducated. What was I going to do? We always owned our own business. My husband and I owned our own business. So, I had no work history, or anything. You know that could be confirmed, or verified. So, I was, I had nothing to take the kids to, no place to go. They were in school, they had the horses, they had their dogs, I mean they had a life, and I couldn't see yanking them out of that security to go with me, where I had no idea where I was going, what I was doing, how long I would live, um, or how I would support me or them.

J: And how old were they at that time, when you left?

Du: 10 and 6.

J: 10 and 6.

Du: or 10 and 5. 10 and 5. 10 and 5. Yeah. Because they are 5 years apart. So, I left them there and uh, thinking that I would go find a place to live, get a job, get a place to bring my kids to and then fight my husband for them through the legal courts, where I would have a leg to stand on. It took me 4 months, I got a place to live two states away, um,

I had two jobs, and I felt that I had a home that I could bring my kids into. No matter how poor we were, I could at least feed my children. I had made some friends that probably wouldn't have been looked nicely upon in the community that I left, but I didn't really care. They were big. And took them with me for protection. I went down to confront my husband and get my things and the children and ah, he had sold everything. Everything in the home. Everything. There was nothing there. Moved, gone. No forwarding address, with the children. I haven't been able to find them since.

J: So, you don't even know whether he is still alive or not?

Du: No, Social Security won't help me. They won't tell me.

J: How about finding other family members? On your side or his side?

Du: He wouldn't let me have any contact with my side of the family, he kept me isolated.

J: Did you both come from California, originally?

Du: No. When I was growing up, we were gypsies, and my family, by the time I went to ninth grade, I can remember 14 different schools.

J: In California or here in Montana?

Du: Oh, all over the place. California, Nevada, Arizona, um, Oregon, Utah, I lived all over. So, it was nothing to just pick up and move.

J: How about his family?

Du: His family, his mother died, his sister divorced and remarried right before I left and I don't know her name anymore.

J: Her new name?

Du: No, her new name. His brother was killed in Viet Nam. And, I don't know where his father is, or if he is even still alive. So, I have no way to contact his family either.

J: It seems like when you were married for 12 years that he controlled you.

Du: Well, he kept in touch with his family, but he only had the sister, his mother and father. Um, his mother passed away right about a year and a half before I left him, and his sister remarried and I don't know her new name, so.

J: And I ask that because I'm just wondering whether that would be another route to find about your kids. . . .

Du: I tried. . .

J: So what has it been like, after you found out or you left and....what has your life been like living with HIV?

Du: Well, I found out when I was actually tested in 1991. And I found out I was positive in November of '91. After, I crawled back out of the bottle from not finding my kids. I really didn't want to live. And I went on about 6 or 8 months just drunk. I didn't want to feel the pain. And I was very angry. Extremely angry. So, I decided it wasn't healthy, me being drunk to find my children, so, I cleaned myself up, I got tested. I was positive. Actually, the first test I had, they said they didn't know, but I really think it was just all the alcohol in my system that just messed

up the test. You know, because I was just toasted. Um, but when I was sober enough to understand being tested, I went in and got tested and it came up positive.

J: This was something you expected?

Du: I expected it anyway, so it wasn't no big shock. I did find out, later on, while I was looking for my kids that my husband had been positive and known it since 1986.

J: and you guys got married in what year?

Du: '78.

J: '78. so he knew he was positive since 1986.

Du: uh huh. And I found the pills in '90. so that . . .

J: Uh!

Du: yeah, that he was a no-good SOB, but I knew that before that. But, I guess, in '91, I just kind of ignored it, because I already knew it, that I was positive. And, I wasn't sick. I didn't feel sick. I didn't look sick. So, I just did ignore it. Um, in February of '93, um, I came down with pneumonia. And it was pneumocystis pneumonia, and ended up in the hospital in Las Vegas, Nevada. I was there taking care of my father, because he had to have his... ah!... hip replacement. So, I was down there taking care of my Dad.

J: So, when you left him, you went and reconnected with your family?

Du: I reconnected with my dad, when Dad needed me at the time. I'd never been close to my mother. I went to my mother when I left my husband and she didn't believe what I was telling her, wanted to know who I had been fooling around with or what drugs I had been using, and pretty much disowned me when I wouldn't go back to my husband and beg him for forgiveness, for leaving him. I am not going there Mom! If you don't want me for a daughter, fine, I'm out of here. I'm not taking this crap, anymore. So, I have spoken to my mom twice since then, and it was in the last couple of years.

J: What was that like?

Du: Stressful. It was stressful. Because I just felt like she wanted to connect back with me. She made the effort...I wasn't making the effort. She's the one who turned her back on me. So, I wasn't going to hunt her down. Um, I already have a new family, that loves me. My friends, but, she made the effort to contact me, and I just felt like it was, well, I really do have a daughter, and since she's not dead yet, maybe she's not really going to die right away, so I better try and put up the appearance of being a good mom or something and try to connect back with her. I mean that's the feeling I got. It just, you know still wasn't real? I didn't feel the sincerity that she really cares, it was just for appearances.

J: So, you didn't feel the genuinenss in her contact with you.

Du: No, no, I felt like it was appearance that she was just trying to make it look like she cared for everybody else's um, what they saw. So, I still don't care to talk to her.

J: And what happened to your dad?

Du: My dad. . . my dad's my dad. My dad is, has a lot of problems. He's an alcoholic, um, he's a habitual gambler, and he lives in Las Vegas and won't move. Um, but my dad's my dad. My dad loves me. He's always going to love me. Um, I take care of my father, ah, well, what can I say. As long as I'm not laying in a hospital bed, his baby girl's not sick. There is no mention of sickness of AIDS, anything like that. He knows, but as long as he can sit and look at me, or talk to me, I'm not sick. It doesn't exist, and that's his way of dealing with it.

J: Uh!

Du: In '93, he had a real problem with me being in the hospital with Pneumocystis pneumonia. He doesn't do well with hospitals, anyway. When the doctors came in and asked me if I knew I had AIDS, and I said, I know I'm HIV positive, I've known it for a couple of years. No, no, no. You have AIDS. O.K., tell me, what's the big deal? Well, your Tcells are 35. they weren't really doing viral load then. But, and you are really sick. I'm in here, yeah, I'm sick. You know? It doesn't take a rocket scientist to figure that one out. Um, well no, what we're trying to say is if you have any friends and family, that you want to call together, um, we think that might be a good idea. They are telling me, I'm going to die.

J: How did that make you feel?

Du: oh, I was pissed. It made me mad. Who are they? They are not God. They are not the Creator. That's the only person that can say whether I am going to live or die. Besides, myself. I wasn't ready to go, and they weren't going to tell me I had to go. So, that just pissed me off. Like Hell. I'm not dying. You can't make me. I just laughed. It just made me mad and more determined. What do you know? Obviously, they were wrong.

J: Here you are....

Du: Here I am. And, it just made me much more determined. The only drugs that were available at that time were AZT and DDI and DDC, just became available. I can't tolerate AZT. It made me so anemic, I couldn't get out of bed. And DDI and DDC don't really work alone. Even then, they found that out right away.

J: You had to have AZT there.

Du: Well, they had to have something else and the AZT was the only thing available. So... and I can't tolerate it. So, I wasn't taking any meds and I didn't have very much for T cells left. So, I had to be careful. Um, I bounced out of it pretty good. I still, once I recovered from pneumonia and didn't feel sick, um, I had to go on SSI, which really bothered me?

J: How come?

Du: because I had never, I mean, I'd always worked two or three jobs to support myself and everybody around me too, I mean all my animals, I've always had animals, um, at the time I wasn't able to have my

horses, but I always had a dog or two, or even when I didn't have a home and lived in the car, you know . . .

J: Uh! . . .

Du: I still. But, uh, because, I couldn't work. I had to go on SSI and I couldn't work to be able to keep the medical, in case I had to go back into the hospital and stuff. And, it really bothered me. At the time, \$450 a month? I can sneeze \$450 a month. You know what I mean. That's nothing. You know, I can panhandle that on the corner if I needed to. And I was being limited to that. No more. No matter what. No more. You are not allowed.

J: Uh huh....

Du: that's what I mean. And its still that way, and it still pisses me off. Because now, its \$545 a month, and I'm not allowed to work. Well, I'm allowed to make \$80 a month. \$20 a week. Come on. You know? And \$545 a month? I have 4 dogs, 3 horses, a cat and me to take care of on \$545 a month.

J: And you have to pay rent?

Du: I have house payment. I have to take care of my animals. I have to take care of me. I have a \$25 a month Medicaid payment. I mean, my car. I have to keep gas in my car. I have to keep insurance on my car.

J: Uh!

Du: I have to maintain the car. Tell me how to do that on \$545 a month? It doesn't work. The math does not come out. So, we that refuse to give up our lifestyle, and our loves, moonlight. I take in colts in the summertime. I give riding lessons. I judge horse shows. And I trade it for my animal's food. Credit at the Vet, to pay my Vet bills, or leave me credit at the vet, things like that so I can, so I can keep my loves, because I can't afford it on \$545 a month. I'm still looking for my kids. I will do that forever. A friend of mine hired a private investigator, a private eye who couldn't even find them. So, I mean, we did find a file in Los Angeles, county for Child Protective Services. But, it is closed, sealed and red flagged.

J: So, you can't have access to it?

Du: You can't get access to it without a special attorney and going through the court system and I don't have the money to pay an attorney, and I won't live in Los Angeles county to get legal aid down there.

J: Oh,

Du: Which I would have to do. So, things are just kind of up in the air, as far as that goes. Um, living with this disease, it humbles you, it makes you dependent on the system. Um, the system sucks. I mean because you become helpless, when you don't want to be helpless. I know they are trying to help us, but it really isn't helping because its not letting us be our own person.

J: Yeah! . . .

Du: All the rules, its, it is smothering. You know. You can't do this, you can't do that. You can't live here, you can't live with that person.

You know, they have all these rules and you know, when you think you're going to die the rules don't mean crap, but if you want to live, you have to follow them? And it really sucks. Because, I want to work, I have always worked. I have never been on welfare, I've never collected unemployment, you know, I've always been there to help everybody else. I've never taken charity and going on Social Security has felt like I've had to take charity? Like I wasn't able to take care of myself anymore? And it really bothers me.

J: It is very expensive isn't it?

Du: And everybody says, oh, you know, you've earned it, you deserve it, its your right, and the only part that I think is my right is the medical coverage. I do believe that's my right.

J: Yes....

Du: Because I've done my part, I volunteer, I never ask for pay. I volunteer at the hospital, here, and I take care of friends that are sick and dying and I just lost one in January, I mean in July, to lung cancer.

And... ah, you know, I do my part that way.

J: Uh! . . .

Du: So, that makes me feel that I'm entitled to having my medical covered, but the Social Security crap, just doesn't fly with me. I just don't feel comfortable. Not making my own way.

J: that must be very difficult for you, as somebody that has been used to working for what you want and have . . .

Du: Yeah, I never got anything for nothing. I've always earned everything I got. And then, to get this piddly, piss poor amount, that is below poverty, you know, and be ordered that that is what you're allowed to live on. Why? I mean, I used to run a business and model, I used to make \$1,500 a day, modeling. And now I live on \$500 a month, one third of one day, I live on for a month. You do the math. There isn't none.

J: It sounds like your life changed a whole bunch, when HIV came along . . .

Du: Upside down.

J: How have you dealt with things in trying to survive?

Du: Anger

J: So, you have had a lot of anger it sounds like...

Du: A lot of anger.

J: Now, how have you dealt with that? I am asking you simply to find out how you deal with anger, with that mental anguish, how have you dealt with that over these years that you have lived with HIV?

Du: My animals.

J: Your animals.

Du: they help me. They keep me calm. When I get really upset, and angry, one of them will come and set their head in my lap or something or one of the horses will come and put their head over my shoulder and just you know, its kind of like they're saying, don't sweat the small

stuff. Let it go, its not worth it. And they are so calm, and they are so peaceful, and they don't get upset over the little stuff. You know the stuff you can't do anything about. And they are always there for me. No matter what.

J: Unconditionally.

Du: Unconditional, they're always there for me and that's what kept me sane and alive. Because, I have gone through a hysterectomy from cervical cancer, I've gone through an appendectomy where they had to take one of the ovaries that they left me after the hysterectomy, um, I went through menopause this year. I've been through toxoplasmosis, I've been through wasting, I've had three strokes, in 1996, I lost the use of the right side of my body. I couldn't speak. I drug my leg, I couldn't use my hand, I couldn't lift my arm above my shoulder. And my physical therapist is lying right at my feet, I refused to go to physical therapy.

J: So you have used . . .

Du: I've used my service dog. He has been my physical therapist, my best friend, my service dog, my savior, he's saved my life, that's the reason I haven't given up and died, because I don't have anybody to take care of him.

J: So, you feel you have to be alive...

Du: I have to be alive, there's nobody to take care of him like I would do it. So, I can't die.

J: Have you ever talked with someone, besides your friend, have you ever talked to someone professional about things that you have been going through, or anything like that?

Du: ah, just this summer.

J: What made you do that?

Du: I got shanghaied. I got railroaded. The Director of our local AIDS project and the new case manager at the clinic where I go, when I lost four people in like a month, and two of them were extremely close to me. One was a girlfriend of 27 years and the other was the man that I had been taking care of that had lung cancer for two years. I had been taking care of him for that time. He passed away and Snuff and I were the only ones by his bed. None of his family showed up and I was angry about that too. I didn't think that was right. I lost it. I did. I just came apart. I couldn't deal with it anymore. I had been neuropathy so bad and I was in so much pain, and I had just starting seeing a pain doctor, so I had some relief, but it wasn't very much yet, and then the four deaths, boom, boom, boom, boom. I just lost it. I just kind of looked for a rubber room, you know? Jay and Becky got together and Becky took me aside and talked to me and let me vent for awhile and cry on her shoulder and the next day, Jay called me and he says don't get mad a Becky but she called me and we have been talking and we would really appreciate it if you would do us this favor.

J: So, putting you on the spot....

Du: We would really like you to go see Ann if you would because Ann is part of our HIV positive focus group, but she is also a counselor.

J: Uh!

Du: Ann, her last name is just horrible to pronounce. She's a counselor, but she's part of our HIV focus group. We would just so appreciate it if you would just do us a favor and go talk to Ann and make us feel better, and I'm going, Jay, cut the crap, why don't you tell it like it is... get your little ass in and talk to Ann before you come apart, oh we're going to tie you up and drag you into see her. He goes, oh, you can read between the lines, can you? I go, yeah. This is a very polite order from my friends because you know, I'm losing it. Well, yeah. O.K., I can do that. You really think I need to. He goes, oh yeah. You can probably see it better than I can. Alright. So, I went in there, and I vented and talked to Ann and I guess I've seen her about four or five times. Since August.

J: How has that been?

Du: Its actually been pretty good. It does give me a place to vent where I get some feedback. I don't get a lot of feedback from the animals. I get some. Not necessarily a lot of feedback that is objective. To see things maybe through another human's eyes?

J: Your own self, through somebody else's eyes?

Du: uh huh.

J: And that has been helpful for you?

Du: It has.

J: Had you ever seen somebody before in your life, or this was the first.

Du: this was it.

J: this was the first time.

Du: This was it. Other than here.

J: Yeah.

Du: You know, here at the retreat. My first year here. Thank goodness you weren't here. Because, I was very angry. Very angry. It wasn't O.K. to cry. That was a weakness, as far as I was concerned. I was just a stone. Everything was just balled up inside me tight. By the end of the week, I learned its O.K. to cry. I must have went through two or three boxes of Kleenex. Felt so much better. I wouldn't miss this for the world.

J: So, it sounds likes this retreat is very helpful to you...

Du: Oh, its made a different person out of me. My therapy, instead of talking to somebody, my therapy, since I came to the first retreat I have been speaking to kids at Jr. Highs and High Schools about HIV....

J: And that has been helpful to you?

Du: Yeah, I have been doing AIDS education for the county I live in. and that's been just wonderful therapy.

J: How has the community welcomed you in there, as a woman living with HIV?

Du: you know, it hasn't, you've seen enough to know, if you don't like it, don't look. The kids accept me. The kids care. And the rest of the world, I don't give a flip. I don't care.

J: So, you are going to educate those kids anyway...

Du: yeah. I really don't care what their parents think or what they say, you know, I don't care. Because if I can get to the young people, we can change the attitudes. Talking to a bunch of grown-ups... its like talking the wall. They already have their opinions. I can't change them. Don't necessarily want to. I don't care what they think.

J: So, it sounds like it does helps you to go into the community and speak with the kids..

Du: It helps me a lot.

J: And you said that is your therapy?

Du: that is my therapy...connecting with the kids. If I can help one child, understand, stay safe, and maybe not make the same mistakes I made... its all worth it.

J: Does it make a difference when you speak to those kids whether they are boys or girls?

Du: Nope.

J: What is that experience like for you? Is it because you had a lot of your gay friends die from AIDS so you feel that talking to the girls is as easy as talking to the boys on this issue?

Du: On this issue, HIV doesn't care what sex you are. It doesn't care whether you are rich or poor, male or female, gay, straight, bi, it doesn't care. HIV is so indiscriminate. There is no discrimination, so if you give it half a chance, its there, its got ya. So, no it doesn't matter whether its girls or boys or anything, because HIV doesn't care, why should I?

J: What a good point for us to come towards the end of this interview. I have seen you here and I have observed you at the SPC meetings in Helena, and you seem so different, different in that you look very healthy, you look.....

Du: This place brings the best out in me.

J: You look very healthy, you look jovial. I've seen a big difference.

Du: the last time you saw me, I was in so much pain.

J: Uh!

Du: this is my happy place.

J: I never saw you talk a lot. But this time, you even sang last night.

Du: that's a first.

J: So, that was very impressive. Because it sounds like dealing with HIV is a very tough thing, and you are rising above it.

Du: It is tough. Especially when you really have nobody that you can count on.

J: But it sounds like you have turned things around for yourself..

Du: I have created a family around me.

J: A family around you... and now you are talking about Becky, talking about Jay, all those people.

Du: I have loving people around me.

J: You have opened yourself up to going to talk to someone. Talking to Ann. That is a big step for you. It looks like you are turning things around for yourself.

Du: I'm pulling out of it. I have been a loner. Because my whole life I never had anyone that I could count on to be there. Always me. The only one who has ever been there for me are my animals because I could take them with me. They were always there.

J: Good luck.

Du: I'm not going anywhere.

J: I totally appreciate your time. So, like I told you, I will send you a copy of this. Let me know if that is what you wanted to share.

M: 42

J: Hello! 'M.'

M: Hello!

J: Thank you for volunteering to participate in this interview.

M: It is my pleasure.

J: Well, like I told you earlier, we are going to be talking about your experiences of living with HIV...

M: Yes! I have a strong voice, and I am ready to talk about it...

J: Yes! You do have a strong voice M, and that is why I wanted to speak with you and hear about your experiences. So, what would you share about what your experience has been like since you were diagnosed with HIV...

M: Lots of things have changed. I have to say first and foremost has to do with compassion... um... I was a somewhat compassionate individual before HIV, but..... now.... I do have a very good understanding of differences... in people, diseases...

J: uh!

M: ... things of that nature... not to the point of prejudice or bigotry.... I've always been somewhat liberal... you know... and I have gained an awareness of myself and my health, and my body... um... definitely about my body and what's going on... um....

J: It sounds like you have noticed many changes about yourself....

M: Well, I'd have to say.... we all go through ... you know... we have different paths in our lives... we have different levels that we go through... you know... when you are an adolescent... when you come upon adulthood... you know... when you are in your twenties... you... you know... you are probably much older... well, it is natural to go through the stages when you don't think about retirement... you don't think about really settling down..

J: uh!

M: um... at thirty.... at thirty-two, for myself... being diagnosed... I really had to look at my behaviors... and why I chose my relationships that I was in because they were unhealthy for me... they were... um... abusive relationships... um... I was following a pattern... I thought I could change that individual... or change his alcohol habit or drug habit... um... or his violent behavior.... um... when in fact, I could only change myself... so it was just a matter of actually looking into the mirror... you know... it's been still an ongoing process... I mean... that's life... that's what life is all about... finding out new things about yourself... and.... trying to make it better...(pause).... because I believe you have to come back... and do it all over again...

J: uh!

M: ...So... um... at thirty-two as opposed to probably in your forties... is when actually... I think... you look at yourself on a whole and try to fix things... that's what I did in my early thirties...

J: um!...well, you are talking about 40s..um... so how long do you think you've had the virus?

M: ...I believe that... um... and my doctors want to believe that it's been since 1987....I moved to Wyoming....I came from big cities of Denver and Baltimore....we moved to a very rural area...moved with my childhood sweetheart... I hang out with him since I was a teenager....and he died a few years ago..... so.....

J: Um!...So, how has your health been?

M: My health in general has been pretty good... most of my problems have been from the medications... and I take Zoloft... once I've had a bout with... um... well... actually depression... for me it hasn't been a really severe problem... and I realize that depression comes at many points.....it doesn't just have to be... not wanting to see anybody... um... or hanging out in bed... you can feel it in other ways... such as... um... cleaning.....being obsessive about other issues in your life.....being very strung out.... for me it was one... so... um... you know... I dealt with that... like just 7yrs ago... and... I have never really gone into a severe depression state...

J: Uh!

M: All in all I have to say my life has been very healthy....it's pretty good... but you know... I work at it....I really do..

J: Now, with the depression.... do you look at it differently now compared to the time before you had HIV... or can you remember way back before you were HIV-positive having dealt with depression?

M: Never.... never did I even think it might be a sign of depression... no... no... no... I think it was different... I think HIV had a lot to do with it... it's always there every day even though you try to get away from it... um... not to think about it... for me.... I was a single parent of one daughter... so, it was... you know... it was more difficult to try to maintain sense among us in our house....but I did that because.... and always tried... at least we always strived for that....because that's the way I wanted to keep things... and that was my role in my family..

J: uh!

M:...I was the fix-upper and the caregiver in my family... so... um... you know... there were times... when you just wanted to forget about it... but things came in the mail because I was very active... for me... I dealt with HIV as an activist... taking on a lot of projects....and networking with other people around the world... getting involved in women's issues, especially in Africa and United States.. to... um... to try to make things better and to try to get medications and get women into drug study programs... um... and I spoke to congress one year... back in 1993, to try to open the doors....to gain access to medical trials for women...

J: uh!

M: Um... because the trials were out there... and still... it's still happening... the focus is more on males than it is females... so... I mean... the disease is different on many aspects... on males and females... so... um... so the mailing would come... the calls would come... and of course the meds side effects are ongoing... so, it's really hard to press yourself and say... okay... I'm not going to think about HIV today....

J: Uh!

M: ... so... my daughter at the time of my diagnosis was ten years old... so... for her... um... you know... that was... it was kinda of a battle because she would get very upset with me... if... you know... the phone would ring... or... if it had something to do with counseling somebody who'd just been diagnosed... or... um... another trip... because I traveled a lot at the time... the first five years I traveled a lot...

J: Uh!

M: Um... and... on anything to do with AIDS... activism... or um... issues surrounding the disease... um... was there... so... oh!... that was my way of dealing with it... that was the only way of empowering myself... and of course my daughter understands that now... but of course at ten... you don't really... you don't understand that... I mean... her world was... I was mom... and... and I was supposed to be there to take of her... and... and I did... I tried to maintain a balance... I thought it was good balance... you know... I guess I am finding out now that... maybe I'll find out later in life... in her life... maybe it wasn't quite such a good balance... so far... no complaint...

J: So far no complaints uh! So, what is she like now as a young woman?

M: She is a good girl... a young woman... she is twenty... she's almost twenty... a college student..

J: Talking about your daughter, how did you tell her about your diagnosis? Is it something she just found out from other people or were you able to sit down and talk to her about?

M: Well... I did sit down and talk with her... um... but it was only after it... it was about six weeks later... when I finally told her... um... my status... and... um... she'd already actually known about it because she had found some pills and pamphlets... and also... um... she heard me talking to my mother on the telephone... and... um... she held all that in... until I finally told her... and when I did tell her that she had to be tested... and this was prior to six weeks... the day I was diagnosed... very next day... the girl who was my health care from my county came in... for my status... I actually ... she asked if... um... I told her that I wanted my daughter to be tested... and of course she didn't believe it was necessary because there wasn't ... anyway, she said to me... in fact, that my daughter was not HIV-positive... but just for my own security... as a parent... as a mom... that's what I wanted... I mean, I wanted to... that was the first thing I thought of after being

diagnosed... that my partner... who... um... you know... had never really engaged in any at risk behaviors... um...

J: Uh!

M: And... um... for a very long time... um... there was a lot of guilt there... so... what I told her the next day when actually I was diagnosed... for her to be tested was that she was being tested for hepatitis... and I blamed it on the father, my ex-husband... see he wasn't in our lives... he wasn't paying support... so I blamed him... (laughs)... and actually, I feel a little bad about that because hepatitis is very... um... is not a very... um... gentle disease... and it's just as severe but not more in some cases of people who battle it as opposed to AIDS... you know...

J: Uh!

M: It's a... but... you know... I did think about those kinds of issues... I didn't think about limits when I told my 10yr old that... you know... you're going to be tested... I didn't want the shame... I felt so much shame....

J: So it sounds like you thought it would bring shame on you and you didn't want to deal with it at that particular time...

M: Exactly!... um... I didn't want her to blame mom... I didn't want to be the bad guy... you know... you already feel guilty enough... and ..um... you know you put your child through this...

J: Uh!

M: ... and at the time of the diagnosis, especially back in 1992... it's like... um... it's like... it feels like you could die... it's a death sentence... the truth is... it probably is... from the woman I spoke to in the past year... even being diagnosed in 2000... um... you know... you still kinda... you still think of it as a death sentence because everybody is different... and then what you want for yourself is knowledge about the medications... you know... that you can make it a manageable disease for some time... um... if you so choose... then that's possible, but first response is you are going to die....

J: Uh!

M: ...But actually we are not doing anything any different than anybody else because it's what it is... it's about death... everybody is gonna die...

J: You look very healthy... and I am just wondering what you have done over the years in trying to balance your life, physically and mentally... you seem to handle yourself so well when you are speaking to others in this group...

M: Thank you... well... um... I think HIV has definitely... um... made me stronger... it definitely has... um... I... um... you know... I wasn't really given confidence as a base as a child... what we are supposed to get for our foundation from our parents... um... I wasn't blessed with it yet... um... from any one of my parents...

J: Uh!

M: Well, I didn't get the... um... um... I didn't get the confidence... um... the tools to actually... in some ways and a lot of other ways which I recall there really wasn't confidence building structure there... in my background... so, it was something that just strived for on my own...

J: Uh!

M: Um... and I knew that I was a good trip of a whole person... and I think I just liked being confident... things that I had overcome in the past... I felt as though... um... you know... this was just another... another path... another obstacle that... um... my God had thrown at me... God gives us what we can handle... that's what my father taught me... I whole heartedly believe that now... um... I have to say, HIV has given me more confidence... yes!...um... I never really thought of it as courageous or anything... you know... to be open about my HIV status... talk about it, especially in rural area....

J: Uh!

M: I talk about my HIV status in the local newspapers... um... PSAs... on the radio... um... television interviews... um... going... you know... to places like Africa and Japan... speaking to ... um... political officials there... um... but... I've always had a voice... so that I've kinda been like a rebel... so... so... now I am a rebel with a cause...

J: That's what it sounds like...

M: Yeah!...I believe that HIV did build a lot of my confidence... really did... um... it's no question... um... I would have to say....

J: How you have handled your life sounds very interesting, especially your traveling to different countries and talking to all the different women from different backgrounds... that sounds very important... so, how do you compare their experiences of living with HIV and those of women dealing with HIV in rural America?

M: Well, we are very fortunate... um... when it comes to medications that's one thing... we have the dynamics, and we have the statistics of women living with HIV... and of women in battery relationships... or verbally... or physically abusive relationships... that of course is high risk behavior for the women in particular relationships... In South Africa... um... we know that this is not the way to be... In South Africa what I found is that it doesn't have anything to do with drugs or rock and roll or gay lifestyle... um... it has to do with strictly heterosexual transmission mainly... you know... and a lot of the women were just... um... there is good base in the neighborhood of very strong women... back in 1994 there were very strong women... and you know... but the ones with the strongest voice are the ones who help lead the others out... but it's very hard for them to do that because of their economic structure...

J: Uh!

M: We have the same dynamics here ... um... definitely, but... um... they don't have access to the medications... um... it's not something that's

talked about... I did meet young girls... um... who... it is considered... um... to have a virgin... if you have a virgin... or... you know... I don't know how to say this... um... sex with the young girls and older males is very prevalent over there... it is here too, but I... what I saw and what I learned for the ten days that I was there... um... was that it's very prominent there... and families actually strive for that... and they want their daughters to be with someone older because that brings in money... you know... he's got a job and...

J: Did you come across anything like if older men slept with the virgins they would get rid of their HIV?

M: Yeah! They slept with so many virgins... yes! We discussed that... in a way, there were some women that discussed that... that's exactly what it was... and they were from the Zulu tribes and Zimbabwe... what was amazing to me in Zimbabwe was that... um... here you had one of the ... um... you know... 1 in 12... and these were stats back then... 1 in 12 people was infected with HIV in Zimbabwe, but they had a great care facility, but no one talked about it... and most Zimbabweans had HIV as a problem...

J: And now it is a major problem....

M: Yes!...um... and now we know that... yeah! It is indeed a problem... and that was only 8yrs ago... things have really changed...

J: it seems that way....

M: Yes! It has... and my daughter is in college...

J: So, what's that like for you?... You, your family, and your community...

M: Um... I think because I was honest about things... and then... at the time for me... at the time of my diagnosis I think it was easier for me... and the reason I say that is because I was part of a volunteer organization... I worked with battered women at a battered women shelter... volunteered my time there... and I still do it...

J: Uh!

M: Um... and I was part of the Jaycees, which is an organization which helps out in the community... um... I also belong to a church, school functions that my daughter is involved in, things of that nature... so at the time of my diagnosis I was a non-drug user... and the key word being 'heterosexual'... that really made a difference... um... you know, unfortunately, that does make a difference... I think it's been easy for people in my community to ask me questions because I am the type of person that if you have something to say... um... I am going to go deep into it and ask trillion of questions of the people... if I see someone in the grocery store....

J: Uh!

M: ... and they are spouting out misinformation or something... I am going to be the first one to say... hey! Wait a minute... you know we can talk about this... let's talk about it... the truths... let's get rid of that

misinformation that you have about HIV...how it's spread and how it's not spread....

J: So you educate people as well....

M: Yeah!...I do educate people... and I am notum... and if I hear pssss! behind my back...if I hear...I am a confrontational type of person... so, I take things head on...

J: Uh!

M: So, I will ask... Is there a problem? Do we need to talk about something?...so, I think that's why my community has accepted me.... maybe because I have forced them to... (laughs)... I am here and I am not going away....

J: So it sounds like it's been a positive experience for you...

M: No... No... there has been a few examples... for me, little things like going in to shop for insurance for my daughter when she was 16...um... my insurance agent who had been for a few years... well, he knows all about my status... he's an older man... and... you know... I went to use the phone... and you could just tell he didn't want me to touch the phone... and that was 4years ago... and you know, his wife... she is an attorney... and we are acquaintances... but just obviously refuses to learn about it... I look at it this way, as a lot of things in life... most Americans will put their blinders on... and will not deal with it till it's on our door step... till it's in our face... so, I think maybe until it's our daughter, granddaughter... um... our own son... comes home and say guess what?... this is what I am dealing with now....

J: Uh!

M: ...then... it might be easy to get rid of those fears... not worry about touching the phone... um... and we find out the facts... he didn't want me to touch his phone, his pens or his pencils... you just know.... And as a woman living with HIV... people have dealt with it in different ways... there's um... in my community there is a sugar factory that runs year round, but mostly during harvest times... so from October to February, it's the largest employer in our community... base of our economic structure... with that, there is a girl that... um... was actually infected by the same man that I was... and she is... she had some sores on her back and her neck... to be specific... she works at this factory and she... you know... she is single and she's still sexually active....

J: Uh!

M: It is viewed that... you know... I've gotten calls in the middle of the night... um... that how horrible it is this person is... she got off work and now she is in the bar... which is so full, with a lot of people that work at the factory... they get off work... have a happy hour... and you know, relax with a couple of drinks and then go home... and go to work the next day... and this person that called me actually did convey to me that they had sexual relations with her two months prior, through this phone call that he made to me....

J: Uh!

M: And I just said... you know... they were very upset that she is out there in the bar... she's ... you know... working at coming to the bar after she gets off working... you know... she might be taking somebody home... um... you know... she's just sexually active... well, that just enraged me... it's like... first of all... if you know... even if I knew that she was HIV-positive, I wouldn't convey that information to you... second, though I talk about myself, other people don't... so, it's viewed that because I do... then all people or specific groups talk about it... no!... BS!... it doesn't work that way... you know, that's just the way I choose to deal with HIV... for her it's different...

J: Uh!

M: So... um... you know, I just put it out there like this... you know you need to treat the bar room as you gonna in an emergency room... treat everyone as if they were HIV-positive, then you don't have to worry about it... when I asked this person... yes!... okay!... so you tell me you had sexual relations a month ago, did you use protection? Well, hell, I don't remember... that was the answer that I got...

J: Uh!

M: So that right there tells me that... the spirit of the... they are telling me about how they feel about themselves... they were drunk and took someone home... the situation reminds me of 15yrs, when there were no medications... and there were a lot of people with HIV... remember the upstate New York incident?...

J: Yes!

M: ... I don't recall there being any allegations of sexual abuse, though... these were all willing participants... they just happened to be white middle class Upstate Suburban girls... and... um... so, maybe it got out and we got to hear of them because this lower economic based black kid comes up from the Bronx... from the city to infect the good little girls up there...

J: Uh!

M: There was no sexual abuse... they were all willing participants... being irresponsible... and that's the bottom line... but I don't think that we should have to wear a scarlet letter, I think we shouldn't have AIDS on our foreheads, we shouldn't be condemned or ostracized, I think everyone that I've met... and I've met a lot of people... and I've talked to a lot of people in the past eleven years about HIV... in fact, I can tell you that I've never met any one who wants to give it to someone else... no one wants to pass this on...

J: Uh!

M: ...and I don't think that I'm just being an optimist... um... I think that it's responsibility on everybody's part... and you'd have to live in a bubble now... I mean you'd have to live underground to not know about HIV... how it's transmitted... now it's up to the people... it's up to the individual now to play it safe... to be safe... and you can't put that responsibility on anybody...

J: Uh!

M: ...You know... someone with genital Warts... um... with Herpes Simplex Virus... someone with cancer... it's not expected to convey their status... why should it be any different? I like the laws in my state... um... it's confidential and I'd like to keep it that way... especially with medical records... you know, I've had situations... just a couple of years ago... I had a kidney failure, and they were going to do a test on me... and they injected a dye and I asked... the... my radiologist... he's such a great doctor, and he's very professional... I asked him to put on his gloves... although he knows about my HIV status, he has known for years... um... because he's performed other tests on me, this particular test didn't want to put his gloves on... and I said... you know, I really will feel more comfortable if you did... because as far as I know I have not infected anyone... and I damn sure don't want to start with someone in the medical community, so please put your gloves on...

J: Uh!

M: Well, when he stuck the needle in to perform the test, to put the dye in... to x-ray the kidney, there was blood everywhere... which has never really happened to me before... I am not a bleeder... and there was blood everywhere... I mean it was over my side... it was on the ceiling... it was on his tennis shoes... it was on the floor... and you know, you could just see the sigh of relief... I was like aren't you glad I told you to put your gloves on?

J: Uh!

M: What do I have to say to them? I got EMTs... literally screaming... very upset that they don't feel as though they should have to go to any life... um... life saving precautions with me... I mean... it should be their choice if they so choose to have to... and I just don't think that's right... first thing of all, you are in luck with such a profession to help people... it's my opinion... and I don't think you can pick and choose... that will be like saying... oh!... I am not gonna help that person because of the color of their skin or because of their religion... to me its like, what's the difference?... I carry around something that states my HIV status, and I have a vasperator, and I have a mask that prevents transmission of bodily fluids in the event that I would need CPR...

J: Uh!

M: ...and it just says please help to take the precautions to save my life... or please play it safe...

J: Well, it sounds like you are always prepared...

M: Well, yeah! Because I travel so much... so... and... um... though I am not much any more, but I have... so, that's a big issue...

J: So, what support groups do you have in your community?

M: I do not... I do not... I tried to get one started... the other people who are HIV-positive don't want to talk about it... they... you know... they so

choose not to talk about it...I do have a friend, though, a male friend...a very good friend in my community...actually I have....per capital my community is 12,000 the whole county...and out of that there are 10 cases just that we know of...that's pretty high...actually very high... we just lost one....my friend, the one that's positive, does not talk about it... he is very closeted about his HIV status....and who knows about everybody.....

J: Uh!

M: My friend and I travel to another state to go to a support group...He and I travel a 70 miles round trip once a month to this particular support group that I have been involved in for nine years now....

J: How helpful is the support group for you?

M: Um...it is very helpful....you know, I am able to talk about my issues... you know... what you go through on a day to day basis in relation to your health... um... you know you can talk about your problems with your colon....day to day inconveniences that you go through with HIV....andum....the fatigue, the tiredness... because no matter how much your family is....because my family is ..you know... is far away...they live on the East coast... so... um....it's my chosen family, my friends in my community, in my states...you know they are great, but they really don't want to hear about constantly from me....I can really let loose...I can actually talk about those issues, but it's frustrating to me on a day to day basis... and they understand.....

J: Uh!

M: ...so they suffer... and other times... you know... I am the only... um... I am in fact, right now... um... the only straight one....I have been the only heterosexual for a little over a year now in my support group...and there's quite a few of us...so, sometimes... you know, it's kinda like I... a lot of them don't really understand... but they do....it's a give and take thing....

J: And in your community... do you have mental health providers that work with you as an HIV-positive person?

M: Oh! No!...They don't know the first thing about HIV... my daughter went through....um... it was about three years into the disease... we both decided... she actually....she had said you know, I need to talk to somebody and deal with some of these issues... um... which made me feel good....um... and there wasn't anyone like that who was equipped in my community.... really... because they... um... really didn't know how to address the issue....

J: Uh!

M:and why I don't know because it's really not any different than...as far as some psychosocial issues...you are going through the same dynamics that you'd be going through with a parent problem with...you know...Leukemia or any other life threatening illness....but for some reason they weren't able to, as mental health workers, separate.....they couldn't put them all together.....so, I did finally

speak with a girl who was actually working on her dissertation....and she was a student....I talked to her on the telephone... and we had a great flow of communication going that lasted for about 20 minutes... and... um... and I realized that she was probably the person for my daughter... and she really did help her.....

J: Uh!

M: But I did have one....and this was actually a....um...was a college instructor in my community... and I was going to school at the time....I was checking out one the psychology classes... we developed a relationship....um... I told her my status... I conveyed my status to her....and she....um...you know... saw my daughter... they developed a great rapport... and... um... on a mental health level... as a counselor...

J: Uh!

M: ...for a child....and that was only because I sought her out... she said, I see grown up people, but I'll be more than happy to talk to your daughter about these things... you know... and so that was great!....It was so important to me for her to get her feelings out, to feel safe about things....so she would equipped to know how much time I have....so, I wanted her to be... you know... a strong individual.... I wanted her to be a strong woman with the right tools to succeed... and you know....um... make it on her own if she had to....because though my family is there... and I have lots of brothers and they can support my daughter... and though they would have been someone to take care of her, but maybe they can't do the best job like mom....so that was my goal....to see her graduate....it took baby steps.... I took baby steps... and took short term goals....

J: So, it sounds like you've had positive experience with mental health therapy...

M: ...And I think it is very important... I really do... um... I never thought that I would be a person who had any problems of depression....and now I take Zoloft... which is Prozac's sister....sister Prozac to....um... just kinda to keep adraft... to take care of....um....so I can stress about really big things as opposed to little things... and sometimes when you are dealing with that pink elephant in the room, which is HIV... you know you don't want to talk about it, but hen all of a sudden it's right there in your face... and you know... and it's....you know, plunging down the foundation of the house... you do have to talk about it because little things can develop into monumental things....and that was happening in my house....

J: Uh!

M: ...and that's why I sought out help....and talked to the college instructor friend....it's very important because you are very sheltered....you're very isolated... your family and friends, even though they try to understand, they are dealing with their own issues....maybe of losing you....and there are a couple people in my family who....you know....that's their characteristic... you know....they don't think

about... Oh! What's my sister going through? It's.... Oh! What is it doing to me?

J: Uh!

M:and that's okay!....I mean, I am not knocking it....it's just that... that's the way they deal with it....and... um... so....I can't voice my concerns to them...I can't get things off my chest....so, for my health it's very important....and to stay strong....I mean.....it would've been so easy to probably say to hell with it....to being diagnosed... I can tell you that I did... um....and I told my doctor this....um... when I first sought out care... six weeks after being diagnosed.... then I bought a ...it was like... um.....big piece of half a gram of cocaine... trying to light cocaine... you know... but I thought... well, you know, that I am gonna do something to try to forget... you know... at least it will numb me.....and of course I felt as though.....between the man that I'd chosen the relationship I'd chosen and my early years of sex, drugs, and rock and roll... specifically, drugs and rock and roll... it was like, well, of course I could drown into this....of course, I just flushed it....and I never thought about it again....

J: Uh!

M: Um... but it could have been so easy....I have talked to other people, women, men,....it's so easy to just do it....people that I've talked to that are my age... when I say to them....in my community....you know... have you been tested?.....they praise me for being so courageous, for coming out and looking healthy... and feeling healthy... and taking care of myself, and my life....and are in awe that I am still alive, and I am still doing well... they say, I really don't want to know, and even if I did I am not sure what I'd do....I probably wouldn't quit....um... and these are... you know... just... I mean... they are intelligent individuals... why they choose to make that decision I don't know... I can't really answer that....for me it just made me stronger....my basic goal was to take care of my daughter while I was with her... she was my responsibility... you know.....I wanted to be proud of her....I brought her to this planet, put her there....so it's my job to see her get through.....be raised into a....young... you know, individual... progressive, you know... made her into the society... that's what I did... an adaptive individual....

J: Uh! It sounds like you did a great job....

M: Yeah! I did... thanks!....I really do....I did my duty....

J: Thank you so much for your time M. You look health and your confidence is amazing.

M: There's good days and bad days... some days you have fun, and some days you don't....for me this is a weakness...my own personal thing is confidence....I hope mental health workers are also trained specifically in HIV work...the thing with HIV is you take on a whole different set of rules....I mean I have fought for stand by guardianship in my state... didn't have that before....

J: Uh!

M: When I did get ill, my...it was someone from DFS – Department of Family Services – who helped me before...but she was a friend of mine...but she said, you know...by law we can come in and take your daughter...and we could take your child from your possession...and she said because you are in the hospital, we need to make sure that her needs are being met...which is totally understandable, that's what that agency is there to do...I understand that...um...but, I really felt like that was such an unfair thing...so, it's like, well, so I need to find out what is wrong with the system...

J: Uh!

M: Stand by guardianship, what it was designed for is actually cancer, and then in the light of AIDS, it was for terminally ill parents...you go into the hospital and then conduct tests...you can't a marathon, it may take a while, but you know at least that your child is back in the home with you...and you can maintain a sense of normalcy...and get on with your life...you know...with as little interference as possible...that was a big issue for me...so, I made sure that the law was in place and that...um...you know, that I had my stand by guardians in place in the event that I got ill...

J: Uh!

M:...but that's the role of AIDS...it's not the same as other diseases, you don't go through radiation...you know...or you are not in remission...with AIDS it's an ongoing battle...one day you could be doing well, and then you are struck with an infection...the sickest that I have been in my life is when I accidentally got the polio vaccine to go to Africa...and it was a mistake of the nurse...my health care worker...it was the flu season, she was busy giving out immunizations and vaccines...

J: Uh!

M: ...and it was a mistake...boy!...I was sick...it plunged my immunity system...and I was in bad shape for six weeks...I had shingles...it was very...very bad...and you know, these things happen...and mental issues may come in...so my experiences of seeing a psychologist helped me a lot...but also it is important that if you are a woman...um...don't take a victim role...I don't, and neither does my daughter...so, I guess I chose to be in the relationship...you know...and now I have HIV...we didn't know in the beginning, so...um...it just...um...to even assume that kind of thing...if you are a woman you are a drug addict or you know...a sex worker or victim...you can't fill those slots...you can't...in fact, most Americans do that...we like to categorize everything...we like to label everything, and it is not necessary to do so. I don't know why we do, but we do.

J: Well, What a perfect way to end the interview M. Thank you so much for sharing your story with me...and I am certain that a lot of women will benefit from your it. Thank you for your time.

Re: 33

I am a 33-year old Native American woman living with HIV. I was born in Great falls, Montana. Adopted at nine months old and was raised in Texas. I graduated High School in 1987. My adopted families religion is Baptist, so the rules of the house were very restricted, I was not allowed to date, when I became old enough to. I never felt like I belonged with my adopted family. So the first guy I met that seemed interested in me I latched on because he listened to me. He was older than me. I was 18 and he was 28. I thought older people were wiser, boy did I find out different, I was very naïve. We dated for a year and half before we became intimate. He was my first love, and I was scared. We got married in March 1990. In June, of the following year, my husband and I were living at his grandma's house, because he was out of work and I only had a part-time job that time. One night, I had pain in my stomach and I was spotting, it wasn't like a period spotting. My husband took me to the University of Texas Medical Branch in Galveston to find out what was wrong with me. I had several doctors in the past tell me that I couldn't get pregnant because my hormones were not in balance; I had too many male hormones and not enough female hormones. When my husband and I had arrived at the hospital the doctor had asked me if I could be pregnant, I said no, because of what other doctors had once told me. I took a pregnancy test anyway, just in case. Being that it was a county hospital, the results of the urine test were taking forever. Finally, three hours later, a different doctor came in and told me the lab had still not performed the pregnancy test. So she left and came back with a Doppler machine, to my surprise, I was so far along in the pregnancy, a heartbeat was detected, I was pregnant. I was thrilled, so thrilled that I immediately threw my cigarettes and lighter away, because I did not want to hurt the baby anymore than I had already because I didn't know I was pregnant. Before I left the hospital, they had scheduled me for my first prenatal appointment later that month at the Lamar Health Clinic. My husband and I went together for my first appointment. When we arrived at the clinic, I was asked to fill out general paperwork. Thirty minutes later a woman had called me back, I thought it was the nurse to take me back to see the doctor, it wasn't, she was a case manager/social worker. My husband came back with me to talk to the case manager. She talked about different tests the clinic would be performing on me today, but one of the tests that the clinic would like to perform, needed signatures of consent, it was a test for HIV. She informed my husband and I what HIV was and how it is contracted. After she explained everything she asked my husband and I if we want to sign the form so they could perform the HIV test. I told her that I had only been with him and that I had never used IV drugs so I did not need to take the test. My husband then turned towards me and says, "Maybe we should." I

reluctantly signed the consent form. Two weeks later, four days after my 22nd birthday I had several appointments that day. The day was July 15, 1991. My first appointment was with WIC program and Food Stamps, usually these people who work for these places are not very friendly, but for some strange reason, this morning was different. Everyone was overly nice to me. After my WIC and Food Stamps appointment I had an appointment with the mid-wife at the clinic. I was sitting there in the patient room, the mid-wife came in and says to me most of your tests came out fine except for one, but we will talk about that later. She leaves, comes in again, examines me and leaves again. After about fifteen minutes, she comes back into the room again, and tells me the test for HIV was positive. She asked me if I knew what that meant. I didn't know exactly, but I knew it was terrible news. She told me I was too far along to get an abortion; I would have never considered such thing. I was shocked, scared, angry, and upset. I started to talk about how I was feeling and she proceeded to tell me that we don't have time for that right now; there are two people from the AIDS Coalition in Galveston to talk to you. From that moment on and for many years later, I figured that my feelings about being HIV-positive were not warranted. I then got dressed and went into the next room, I don't remember much about what they said, I was in a state of shock and disbelief that such a thing could happen. After the meeting, the woman drove me to my husband's place of work to let him know of my results. He had to come in later that evening to get his results, of course we knew his was positive because he's the one who gave it to me. When we went to get his results, the social worker talked to us about where do we go from here. I am 4½ months pregnant, there are no medicines I can take. He told us that our child had a 70% chance of not contracting HIV and 30% chance of contracting it. He then told us that I could not come to this clinic for my pregnancy care, but that I would need to go the University of Texas Medical Branch in Galveston and see a high-risk obstetrician. From then on I went to UTMB throughout my pregnancy. I also saw an AIDS Specialist to find out how my T-cell count was doing. One of the times during my pregnancy, I saw the AIDS Specialist, he told me I had 500 T-cells and that I would be luck if I saw my child turn three. I replied, "Are you God?" I never saw him again. I had enough worry about if my baby was okay, much less if my baby would have a mother at age three. Throughout my pregnancy, I prayed and hoped that my baby would be okay. I also prayed that I might have a C-section, because I was too scared to have my baby naturally. November 6th I had an appointment with my obstetrician, she scraped my uterine lining and told me that I would be having my baby soon. That afternoon I had back pains then in the evening I went to cook and got sick, I then started to have contractions. I went to the hospital around 9p.m. that night. The nurse came in and asked me if my water broke and took my blood pressure. I told her that my water has not broken yet. When she took my

blood pressure, it was high. She then looked at my chart and noted that my blood pressure has been high since I was 6 months along in the pregnancy. She asked me if I was aware of that, I said no I was not told about it. My water broke soon after the nurse had left. I had a few complications throughout the evening, I dilated to a nine and stopped. I pushed for two hours to see if I would dilate further, at about 2:30 that afternoon, a nurse went to approve for a C-section. Before I went in the operating room I was asked to sign a consent form to have my tubes tied. I had had two shots of Demerol and had been up all night. They insisted that I should not have any more children. I know I was positive, and I probably wouldn't have had another child, but they took that choice away from me when they made me sign the consent form. I signed it and then I was rolled to the operating room to have my C-section. I woke up from my C-section and found out that I had a beautiful baby girl. I went into recovery, I was running a high fever, it took a while before I left the recovery room. I didn't see my child until the following day. She was a healthy 7lb 21 inches long baby girl. I named her Natasha. My adopted family came to visit Natasha and I that day. They were not aware of my diagnosis, I had not told them. I did not need the extra stress through my pregnancy. I knew they would not react very well with that information. During one of my visits with my adopted parents, my mom had mentioned that there is a sign on the outside of my door that said 'Beware of Body Fluids and Blood.' My mom asked me why was this sign on my door, I knew why, but I was not ready to deal with that just then, so I played dumb. I informed all the nurses that they needed to close my chart and not to mention my status around my family. The nurses there at UTMB wore two pairs of gloves just take my temperature. I was in the hospital for 5 days, because I was still real sick. I had had fever and extreme Edema. I took Natasha home November 13, I did not tell my adopted family about my diagnosis and possibly my daughter's diagnosis until two months after she was born. I took Natasha to the Children's Hospital in Houston every three months to get her tested for HIV. When she was six months old I left her dad, and went into a Battered Women's Shelter. Natasha lived there for almost a year until I got on Section 8 Housing. When Natasha was a little over a year she was tested again for HIV. She had been testing positive from me, because she had not yet developed her own immune system. This time the lab ran another test where they set the blood to see if it grows HIV, it was positive. This meant she was infected. The doctor called me on the phone at the shelter that my daughter and I lived to tell me this. He also told me to bring my daughter in right away so they can test her again, I did. The next time the lab ran the same test second time it was negative. The doctor said that there must have been a mix up in the lab results. I took my daughter back four more times to be tested for HIV, and they all came out negative. I was so thankful that she had not contracted the virus from me. I don't know what I would have done if she was positive,

I do not think I could have handled it. God answered my prayers. My daughter and I moved out of the shelter into an apartment. I dealt with my diagnosis, but not very well. From 1991 till 1998, I had been planning my death. I was told I was going to die, a part of me believed it. I was placed on disability; I raised my daughter and waited to die. It wasn't till I moved to Montana to be with my biological family that I began to live. Really live. I have my sister to thank for that, she asked me what am I going to do with my life, sit around and wait to die as I had been, or get up and live the most of life. So I did. I started college in the fall of '99; I am soon to graduate in the spring of 2003. I am working towards an Associate's degree in Medical Administration Assistant. My daughter just turned 11, November 7; I plan on seeing her graduate high school, and maybe see her go to college. Life with HIV has its ups and downs. I take one day at a time, and try to live life to the fullest. I see things more clearly now, I really look at the beauty that is all around us. None of us are promised a lifetime on earth, and we got to do the best we can with the time we have left.

J: I guess I will explain why I am doing this interview. I am trying to get information from women who are living with HIV/AIDS... I am looking at the experiences of women living with HIV/AIDS in rural areas...

Pa: Ok... we can talk about that....

J: So, when did you find out that you were HIV positive?

Pa: April 4, 1994.

J: On April 4 of 1994?

Pa: In that poem last night... That was me... (laughs)

J: That poem really made everyone laugh.....you were so good...

Pa: Oh Yeah!... (laughs)....

J: So, how did you take the news about being HIV-positive?

Pa: Uh... Well, I didn't actually know, they had somebody from the Health Dept. come in and take the dad out of the house to get him to open up to it....and he wouldn't do it... so my doctor... my doctor gave a test behind his back... that's how I found out I had HIV...

J: You mean they took you in and did the test?

Pa: They took my blood and tested it for HIV without telling me what they were testing me for.

J: They took your blood?

Pa: Uh huh. Because they found out he had AIDS... they found out illegally, through other sources that he had AIDS... so he did an HIV test.

J: So, he had to get tested?

Pa: Yeah. The doctor did an HIV test on me and it came out positive.

J: So, when they were taking that blood, what was the reason for taking your blood?

Pa: Because he suspected my husband had given me the AIDS...

J: But they didn't talk to you about it?

Pa: No.

J: So, how did you react to that?

Pa: Well, I couldn't believe it... and it took me awhile... It took me about 8 months or so to figure it out, that he was lying about it. And when I left him the doctor said to me... (sigh)... that he had it for 14 years and he knew he had it.

J: He had it for 14 years while you were married?

Pa: No, we just lived together for a year and a half... and then I left him... and he died in 1995...

J: So, you left him after finding out about his status?

Pa: Yeah, I left him, before he left town. I think Michael Ray was about 8 months old, when I left him.

J: So, Michael is the little boy in the poem that died?

Pa: Yeah, the little boy. Yeah. He was a strong baby....

J: Uh huh

Pa: I learned a lot from him...

J: And then after that, what became of your life?

Pa: Uh...I moved in with my sister and brother-in-law... and basically every counselor and all these people from the Health Dept. just came to my aid... and one was my preacher and one was my AIDS counselor, one was... you know, a therapist... and they were all there... and I ended up with my own place... and taking care of my son...

J: Uh huh

Pa: ...until he died there... and then we moved. I had moved a couple of times but the place I live now, I've been there almost four years.

J: So, now it sounds like you have a stable life?

Pa: Yes I do. And it was pretty stressful when Michael Ray was alive because he was sick a lot and stuff... and I didn't know... and I didn't really know anything about AIDS... so... you know... so my first experience with someone that had AIDS was ah... I was working in a nursing home and this actor had been sent back to Montana...

J: Uh huh

Pa: ...and he had it, and he died of it... but, you know... I didn't think nothing of it, really...

J: Uh huh

Pa: ...but... um... but, Mike was very honest about his drug use and all of that. He just wasn't honest about the AIDS (laughs)... he never did admit to it...

J: So, it sounds like he was living in denial...

Pa: Yes he was in denial... he was really in denial... He was mad because he had it...

J: So where did he live before?

Pa: Oregon, and he moved to Montana...

J: Uh huh... So, how has HIV changed you?

Pa: (long silence)... I think since I got the disease that I'm stronger than ever before... I eat better (laughs)...

J: (laugh)... Oh! So you eat better now uh?

Pa: ...I take my meds. I rest, you know... um... when I first dealt with it, and I got my own place, my niece moved in with me, and She was 17...

J: Uh huh

Pa: ... and there were a lot of kids that came to my house... and um... I think that that really helped... with kids and having the kids around, you know... It was a little easier to deal with... they were great... I mean all of them...

J: Uh huh... so, did you talk to them about HIV?

Pa: Yeah!... and passed out condoms...

J: Uh huh...

Pa: ... lots of them....

J: ... and educating them?

Pa: Yeah.

J: What has been the challenge in having this disease?

Pa: My challenge?

J: Yes...

Pa: Well, I'd like to see it go away, but I know it won't... well, I'm not really sure if I understand what you mean...

J: I mean what challenging things have you experienced for having HIV?

Pa: I think the most challenging thing I have done, is taking care of my son... from birth to death...

J: Uh huh

Pa: Yea... well, there was one year, when he was two years old and that whole year he was healthy...

J: Uh huh

Pa: ...He did really good and stuff... but, the last year and the first year he was really sick...

J: uh huh...

Pa: ...but, that's when he started AZT... you know...

J: Uh huh...

Pa: ...they didn't have the cocktails out... they were there... they were just getting them out...

J: Uh huh... and what changed in your life?

Pa: I... ah... well, I never thought another man would have anything to do with me... and I have been going out with someone for five years... that I used to go out with probably over 10 years ago...

J: Uh huh...

Pa: ...And... ah... I think he has improved my life... He treats me really well... and we do a lot together, and spend a lot of weekends together and stuff...

J: Uh huh...

Pa: And he has his place and I have mine... We have our own lives (laughs)... and I like that... I like the space...

J: It seems that you have felt independent for the past few years.

Pa: Yeah, it's been a lot easier just being with one person, one person who understands... and his sister died of AIDS.

J: So his sister died of AIDS?

Pa: Yes...

J: So it sounds like it has been nice spending time with someone who has had a true experience about HIV?

Pa: And then the only other challenge I think I have right now is that I take care of my great niece, my sister's granddaughter... and she's got some problems, she was a preemie, and she's got delays, she is about a year behind...

J: Uh huh...

Pa: ...and ah... we just took her to Shriners... and ever since and she's got scoliosis and responded (not clear) as ever. She's just got a little more growth to come from her hip... I mean... you know...

J: Uh huh...

Pa: ... So, taking care of her has been my life since she's been born... Her mom went to work when she was six months old... and ah... I have babysat ever since.

J: So, you have been babysitting since she was a little girl?

Pa: Yea... Monday through Friday... (laughs)...

J: So, it sounds like this is helpful to you?

Pa: Yes, I think it's very good for me...

J: Uh huh...

Pa: ... because it was really hard when my boy was alive because he was so sick... and I think after that, taking care of a healthy baby is kind of nicer... you know, and I'm a little bit older... I can feel it...

J: But it sounds like it feels slightly different now for you.

Pa: Yeah, I have got a purpose... that's the way I feel about it... and she's a good girl.

J: So this keeps you going?

Pa: Yes, it does. It really brightened up my life.

J: In terms of relationships that you have had ah... it sounds like you have a very good relationship with your sister, I mean the one that you baby-sit for... now, what's your experience with other people besides your sister?

Pa: I've got a couple of friends, and they come over and visit and... ah... Irene's friends come over and visit a lot... a lot of kids come over and see me. They have through the years, ever since they got out of high school... to check and see how I'm doing and stuff... ah... I go to David's on week-ends... and that's about it...

J: That's about it... and how about in the community?

Pa: I walk a lot...

J: You walk a lot?

Pa: We walk to the store... we walk just about anywhere we have to go...

J: uh huh... it sounds like a good way to exercise...

Pa: Yea... I have had two back surgeries... and walking is my therapy on my second one...

J: Did that have anything to do with HIV?

Pa: No. I was born with it.

J: How about in your community as a woman of your age, living with HIV, what has your experience been like?

Pa: There is no other woman...

J: In your community?

Pa: Yes... As far as a woman goes... I don't know if there is anybody else... ah... the only other person I knew was a guy from Louisiana that had AIDS... and we just happened to meet and he had never opened up before...

J: Uh huh...

Pa: ... And he opened up to me...and he opened up to his son and we ended up really good friends... but, he moved back to Louisiana... and we don't really even have a support group in Helena...

J: There is no support group in Helena?

Pa: No... not that I know of... they have talked about it...

J: So how do you deal with that?

Pa: Um...I just stay positive... and ah...I tell people...

J: So, you do tell people about your status?

Pa: Yes...I'm very honest. Especially if they come to my home... pretty much people I meet, I've been very honest about it and I think the reason I do that is because Mike lied to me, you know...

J: Uh huh...

Pa: ..and it was a pretty big lie...I knew I had a virus, but I didn't know it was the biggest one... (laughs)... but, ah... yea... I think that putting on weight has helped me too....I feel better...

J: Uh huh...

Pa: ... when I was... before I converted to AIDS... I was always sick, when I was just HIV+...

J: Uh huh... very sick?

Pa: ... yeah, I was always sick, I was in and out of the hospital... and since I converted... the only time I have been in the hospital is when I converted, just to get me on the meds...

J: Uh huh...

Pa: ... and yea... I haven't been in the hospital since...

J: Uh huh... So, it sounds like you have been dealing with this with the support of your family...

Pa: Yeah, family and friends... I was born and raised in Helena... So I do know a lot of people in Helena.

J: So, how about your kids? How did they take this news?

Pa: Um... well, my daughter was mad at first and then she... she got to know a lot about AIDS and stuff... and, well she spoke at her graduation... speech about her mom... It was really cool...

J: How did you feel about that?

Pa: I felt very honored...

J: Uh huh...

Pa: ... My son... I haven't had his address, and they wouldn't let me tell him... they told him about... two years ago...

J: Who did? Who are they?

Pa: His dad and step-mom...

J: So they didn't want you to?

Pa: They didn't want him to know...

J: Uh huh...

Pa: Now I know he lives in Billings, but I'm not sure where at... I sent him a letter but I don't even know if he is at that address anymore... I will have to talk to his sister again...

J: Uh huh...

Pa: ...but, they lived in Minnesota... and my kids left because my daughter was raped... when she was very young... and ah... So, they lived with their dad's for... for a very long time...

J: So, was she raped in the home by somebody?

Pa: Uh huh, by a cousin... I pressed charges and everything on him... he got 30 days in the county jail... but see the thing is, he broke his parole so he ended up going back to prison... years later... so that was good...

J: So, did the father take the kids because you got AIDS?

Pa: I had the fathers take the kids... they have two different fathers... Laura lives in Sacramento, California, and Michael lives in Billings...

J: I see... So it sounds like you don't have a relationship with your son...

Pa: No. Not right now... someday, I hope that happens... you know...

J: Uh huh...

Pa: ...because I've got a good one with my daughter... you know...

J: It sounds like she's been supportive...

Pa: Yes, very supportive...

J: So, what is your life like now living with HIV... I mean... in comparison to the time when there were no cocktail drugs, and now when there are all these cocktail drugs... what is your life like?

Pa: It's pretty good, actually... I don't get really sick... you know... ah... the side affects are no fun, certainly... you know, but my health is... I think has improved...

J: Uh huh

Pa: ...I don't know, my count went down this year but... ah... they're keeping me on the same meds until November and if it still doesn't go up then they will change my meds. But other than that, I'm doing fine. I've weighed 130 for a year. I used to weigh 99 pounds.

J: You must be doing something right.

Pa: Yeah..sure... eating... (laughs)

J: Eating the right foods...

Pa: ...Or it just stays because you get older... I don't know...

J: Well, I don't know...

Pa: ... See, I have been thin all my life... so, I don't know... it was... and actually at that time I quit smoking cigarettes...

J: Uh huh

Pa: ... and... ah... I gained 20 pounds... quit October 19, my quitting date... and I will quit again...

J: oh, October 19?

Pa: uh huh, this month...

J: that's your birthday...

Pa: It's our neighbor's daughter's birthday and we do it that day because it's her birthday... and all three of us are doing it...

J: Uh huh...

Pa: ...my sister's already done it, though... She's on the patch... and I'm a real light smoker, my sister smokes a couple packs a day, and she has emphysema... so, she cannot smoke... In order to help her get off them I'm doing it again...

J: That's very supportive of you...

Pa: Uh huh.

J: Do you notice any difference in the way you have dealt with HIV before the drug and now that you are doing the drugs?

Pa: (silent for a while)... I don't know, everybody tells me I look good. Everyone I see tells me I look great... ah... I don't... I'm not as sick... Like I said, since I had HIV, it's weird... and I wasn't on meds till '96...

J: Uh huh...

Pa: ...I get tired of it... tired of having it, uh huh. A lot of people relate to me... you know, with my AIDS and stuff... ah... I don't know. I don't know if it has changed me as a person, but I feel stronger...

J: You feel stronger?

Pa: Uh huh

J: I guess I wanted to ask you one more time about this, in this process of dealing with this HIV, did you have to deal with any therapy, counselors, psychologists, and what was your experience?

Pa: Yeah, they took my son away from me when he was two months old... when they found out he had AIDS... and I basically jumped through hoops with social workers and therapists, involved with Healthy Families, Healthy Pregnancies... through which I met a guy named Greg B, and he ended up being my advocate...

J: Uh huh...

Pa: ... a very wonderful man... you know... ah... and I got Michael Ray back fast, but it was almost like a turned opportunity... I mean, I was under an eagle eye... That is to say they all had their eye on me... because Mike didn't take his meds and he didn't want anybody, even me and my son to take meds either. He didn't even take his meds for paranoia schizophrenia.

J: He was a paranoid schizophrenic?

Pa: Yea... he was mentally ill and it was my first experience... living, or being around somebody that was mentally ill... you know... I had never experienced that before...

J: Uh huh...

Pa: ... but, there was a couple of times I would see him take a pill and he called it "Superman Pill" and it more or less put him into a fit... like a zombie... you know... and he just got crazier and crazier...

J: So how about you, have you seen any counselor or social work for any experiences with the drugs?

Pa: Well, not really... ah... Pat T came back last year, and she's my AIDS counselor... and I heard she's back to work... so I'm thinking of

calling her up at the AIDS Project... to counsel me and I will start up again if she will have me as a client... she did last year, so...

J: Uh huh

Pa: She's back to work now... so... I just talked to Claudia about it this weekend...

J: Uh huh...

Pa: ...because I think it will help... you know... If anything it helps with the stress in my life... Like my sister is mentally ill, and she's on a lot of meds too... but we get along great... you know... I have learned a lot about her moods and everything...

J: So it sounds like your sister's illness is one of the stressors for you?

Pa: Uh huh... I'm like her caretaker... like a mom...

J: What are the other stressors in your life that since you have had HIV that had made you want maybe to go and talk to a counselor.

Pa: They suggested I did... because of the situation with Mike... from the very beginning...

J: Uh huh... but for you, personally, did you feel like you had reasons why you would want to besides the Mike issue... I mean other stressors in your life which have made you want to go and talk with someone?

Pa: Not really... No, I just thought I would call her up and see how she is doing and let her know how I'm doing, touch base with her... we see each other once a month...

J: Has that been helpful for you?

Pa: Yes... That's really helped me out a lot... I think so because I was raped as a young... you know, little girl... and there is a lot of issues... my dad drank... you know... and my mom gambled, but they were good parents, but they had their own addictions... you know... but, I think she was good for me... I just I would like to see how she is doing...

J: So all those issues came up for you when you were going to this Pat...

Pa: Uh yeah...

J: Was HIV the main issue or were you going to Pat just to deal with these other issues?

Pa: Yeah, deal with life basically, especially when the baby was alive... you know... the thing about him dying and then, learning how to deal with everything I guess...

J: Have you felt that sense of loss with the diagnosis of HIV at all?

Pa: I felt that Mike took something from me...

J: A sense of yourself?

Pa: My sister worries to death all the time that I'm going to die... and I keep telling her... I'm probably healthier than you are... It's like before you were sick you were going to die and now you're living... so what are you supposed to do?

J: Uh huh....

Pa: ... (laughs)... so I babysat...

J: It sounds like you really have done well... of course, the whole process of how you got this must have been traumatizing...

Pa: It was... It was...

J: Just having to deal with that must have been...

Pa: ... was very hard.

J: Very hard for you... but then it seems that you managed to get on top of it...

Pa: Uh huh....

J: ... and here you are today, this week-end, looking good...

Pa: (laughs loud)... yeah... I like you...

J: Very quiet... I noticed you in the group because you are very quiet... but it sounds like you are doing well healthwise...

Pa: Well, its this cold... and it hasn't been like this when I've come up here... I've had a cold this weekend when I come up here, you know... but... and everybody has been sick around me... I haven't caught nothing... I have been really fortunate... Knock on wood...

J: It seems like for your mental state, trying to work through this, you are also taking care of yourself...

Pa: Oh Yeah... I don't take it lightly... I will not do that to my family or to myself...

J: It sounds like you also have a good support system...

Pa: Uh huh... very much so...

J: Well, like I said at the beginning, the purpose of this is to have a voice of women who are living with HIV and how they dealing with everyday issues that maybe everybody else deals with too and they are also busy trying to take care of themselves just like everybody else...

Pa: Yeah... and life goes on just like everyone else... and what's typical of family, taking care of oneself, taking care of our children, and taking care of family in general...

J: ... and here you are someone that's HIV positive... and here, no one would have thought that somebody who was HIV-positive would have been doing all those things... but, you are doing that...

Pa: And you know, Pat, she pointed that out to me, that I am the family caregiver. She met my family... she met them all (laughs)...

J: So that sounds very impressive... and that is very important information for people to know... and just your experiences of how you've made something out of your life... meeting someone, your honesty, taking care of yourself and your family...

Pa: I feel very lucky.

J: Yeah. Not very many people can say that...

Pa: If you are meeting with a person, you better tell them what you got...

J: Your honesty is amazing... I think people have to learn to have that quality that you naturally seem to have...

Pa: Exactly.

J: Well, thank you so much for your time... Like I said, I'm going to make sure that I send a copy of the transcript to you for any type of corrections that you might have. This was great, and thank you for sharing your life with me...

Pa: (laughs)... You are very welcome, Joyce.

DD 57yrs

J: Hi

DD: Hi.

J: I'm so glad that you were willing to do this interview with me. Like I told you before, this is to learn more about women living with HIV, and you know, what their experiences are. So, I guess I will just go right into my first question...

DD: O.K.

J: What has been your experience, your life experience, um, in living with HIV?

DD: It's been really different experiences, because for number one, my age. I'm 57 years old...I'm a grandmother. And ah...

J: uh huh.

DD: Most people think of HIV is the fastest rising group is teenagers, which is true, they are still coming up in numbers....

J: uh huh.

DD: But the next fastest rising group is the elderly because the women of those days only had to think about getting pregnant.... We have another participant here that is 67 years old that got it from her husband.

J: uh huh..

DD: And the elderly are not aware of that this can happen to them.....

J: uh huh. So, what has been your experience in relation to family or the community?

DD: Well, I've been one of the lucky ones.....

J: uh huh.

DD: Most... a lot... I won't say most, but very many people with sexually transmitted disease like HIV or AIDS...

J: uh huh

DD: Ahh.....their family's have throw them away...

J: uh huh.

DD: They are ashamed and they don't want anybody to know and they throw them away. My family is not like that...

J: uh huh.

DD: Ah, my granddaughter was 8 years old when I was diagnosed... And, I remember when I was told. I don't remember making the phone call home to my mom....

J: uh huh.

DD: ...but, I know I did, because the next thing I remember in the doctor's office is seeing my daughter and my mother and my sister standing there... and I could see the doctor's mouth moving but I couldn't hear anything, it was like the ocean in my ears.

J: Everything stopped?

DD: Just everything stopped in time... and my family looked like I had been shot in a drive-by in front of them...

J: uh huh.

DD: Just total fear on their faces...

J: uh huh.

DD: But there was such an ocean of air rushing in my ears for some reason that... it did... it sounded like the ocean stopped... it was almost like I'd left my body because I was watching them talk and I was watching them cry but I couldn't hear any words...

J: uh huh.

DD: And I couldn't hear any tears, and I couldn't hear the sobbing, but I could see it. It was very strange....

J: It sounds like a very overwhelming moment...

DD: Yeah...

J: for everyone?

DD: Yeah, and I... I also had a post-traumatic stress disorder before HIV... so when I go on an emotional overload, I tend to detach and escape inside myself anyway... to feel safe...

J: Uh huh... do you want to say more about that?

DD: Well, people get PTSD in so many ways... mine, I happened to get mine while I was in the Navy... sudden death can cause PTSD, or rape, child molestation... young children witnessing violence between parents... there is many things that cause this...

J: uh huh.

DD: Mine happened to be because I was a hostage... And there was lots of bullets... and a man took a bullet through the neck to save me... and it sent me over the edge and I had it ever since...

J: uh huh.

DD: Um, so like epilepsy, you learn to live with it as best you can, just like you do HIV...

J: uh huh.

DD: I mean sometimes you're lucky and you get a warning, almost like an epileptic... you can feel attacks coming and you can isolate to your bedroom... and get to a safe place...

J: uh huh.

DD: And then other times... things that you don't expect with the mental health issue... with post-traumatic stress disorder... for example... one July, I was cooking hamburgers, had a bunch of friends over, we were making music... we are musicians... and for some reason the smell of the blood blacked me out... took them like 4 hours to bring me back around out of my trauma...

J: uh huh.

DD: And I'd never had that happen before so when I talked to my Vietnam Vet counselor, I said look it, I was having a happy time,

J: uh huh

DD: I said, we were barbequing and making music, I said there was no stress. How cans this happen to me?

J: uh huh.

DD: and she said it's called sensory triggers.

J: uh huh.

DD: Because there was a lot of blood involved in the shooting and for some reason the blood in the frying pan...

J: ... triggered that... uh huh.

DD: Uh huh... triggered that, somehow...

J: uh huh. Somehow. So, I want to go back to that moment when you said you were in the doctor's office and then you detached, um, before the moment you were told about your HIV status, how did you deal with your PTSD?

DD: Ahh... Oh, I had been going to counseling through a Vietnam Vet counselor for a lot of years... and I still don't always deal with it real well, but I've got tools that help me deal better...

J: O.K.

DD: It's just, it's not going to go away, and you can get tools to help deal for when you get overwhelmed by it...

J: uh huh.

DD: It just takes a lot to learn to use those tools, and not get caught up in the attack and try to use the tools at the same time is very difficult for awhile. It takes awhile to learn that.

J: uh huh. It takes awhile to learn that.

DD: Because it's hard to think logically when you're panicking.

J: uh huh.

DD: So, it's real hard to remember what your counselor says to do when you feel an attack coming and you're going oh no, I don't want this.

J: uh huh.

DD: And try to think of what to do at the same time...

J: uh huh.

DD: So, it, it took me about a year... I guess... working with my counselor to learn how to recognize the signs, and talking to my Vietnam veteran brothers.

J: uh huh, and so?

DD: Because they gave me coping skills... they'd say, when you feel your body tense up, and you feel your body is starting to react like you're in danger, but you're not, that is a sign...

J: that something is coming,

DD: Yeah, that something is coming. Use that to try to stop it, because you recognize it's coming, and they taught me how to pay attention to my breathing...

J: uh huh.

DD: ... and, they taught me things like, when, if it's real bad and I'm back in a situation, if I can think of it quick enough, put my guns away. Don't have them around me.

J: uh huh.

DD: Because, if I'm having flashbacks, I will be shooting at things that aren't there...

J: uh huh. So, everything comes back?

DD: Right, right. So, I've learned to do that, or if I feel an attack coming now, I'm smart enough that... ah... I've got a person that I can ask to come by if I am having a bad day...

J: uh huh. So you have people that you talk to?

DD: This is a day I need to have them by me... And I'll feel it, and I'll know it... and that's it... It doesn't stop me from having weapons, I'll have axes, and ball bats and everything else around my bed, but I won't have my guns...

J: uh huh. So, having HIV, do you feel like you PTSD has been... um, what is the right word to use, enhanced... or is there a difference at all?

DD: Oh! Yes! Definitely, definitely, especially the first couple of years...

J: uh huh.

DD: It... I was having attacks just like when I was first diagnosed. They were coming in the day; they were coming in the night... I couldn't sleep... I could be awake, it didn't matter... they would come anyway....

J: They would come anyway.

DD: And ah, that was a rough couple of years....

J: uh huh.

DD: But now, they don't come so often and...

J: What has stabilized things, you think?

DD: huh?

J: What has made things different for you?

DD: Ah, the same thing that causes PTSD... the detachment also helps me save myself some times... because, if I feel it coming, it's like, I'm not going to be in my body right now, I'm not going through this. And I just detach in my mind from the feelings, like the adrenaline and the shaking that starts and everything. I try to turn my mind off to that.... It feels very much like martial arts concentration...

J: uh huh.

DD: And that helps.

J: It helps. Now, as a woman, with HIV...

DD: uh huh.

J: Do you, do you feel discriminated against or, what can you say about that?

DD: Well, you really feel... I don't know if it is so much discrimination... as, you lose your self-worth to yourself... You feel dirty, you feel ashamed...

J: uh huh.

DD: Ah, at that time, when I was diagnosed, they were telling people you had 2 years to live, so, pay for your funeral and do what you want with the last 6 months...

J: uh huh.

DD: So, ah, I was supposed to be dead in '96... (laughs)...

J: How long have you lived with this?

DD: Almost 8 years.

J: Almost 8 years.

DD: And I'm 57.

J: uh huh. You look very healthy.

DD: Thank you. Thank you. And I think a lot of it is due to meditation and visualization...

J: uh huh.

DD: I think that really... and a positive attitude...

J: uh huh.

DD: I don't know if it's so much positive or stubbornness... because I just don't like to lose... period.

J: uh huh. Period.

DD: Period. Don't care what it is. So, ah... you know, and I won't ever let anybody say to me, you're dying of HIV, because I'll tell them, bullshit. No, I'm not. I'm living with HIV... I'll die when I'm damn well ready.

J: uh huh.

DD: And I'm not ready. You know... (laughs loudly)

J: You have a band...

DD: Yes... (continues to laugh)

J: And you have your daughter and your grandchild to take care of...

DD: I only took up bass guitar 2 years ago... Here I am 57 years old, I've got my first garage band... And we are having a great time making music... And one of my bass players, the 5-string bass player has HIV for 20 years, well AIDS now.

J: uh huh.

DD: And the other 3 are HIV negative folks that are friends of mine...

J: uh huh.

DD: And that's one place that your true friends and your other musician friends and stuff... that's one place HIV can't touch...

J: uh huh.

DD: ... is making music if you are really into music... music comes from the heart and from the soul...

J: uh huh.

DD: And that's just a place, I... I... we... that none of us allow, we don't allow the word HIV used in that music room...

J: uh huh.

DD: If they see I'm feeling sick, they're going man do you need to take a break? Because they know I kick them in the tail if they say are you HIV sick? No, I'm just not feeling good...

J: uh huh.

DD: I'm not HIV anything... I'm just not feeling good...

J: So then you relate with them normally, like you would have if you didn't have HIV.

DD: Right...

J: They sound like true friends...

DD: My true friends... I mean some of the friends that I had for over 30 years, as soon as I said this, because I didn't keep it a secret, I told everybody the same day...

J: uh huh.

DD: Ah, they did act like I was already dead, and I've never seen them since. And that was hard...

J: uh huh.

DD: People that I knew 20 to 30 years...

J: So, you lost friends?

DD: Uh huh... now I wasn't worth knowing...

J: uh huh.

DD: Because they were ashamed of me...

J: uh huh. How did that make you feel?

DD: Ah, it about drove me to the edge of my sanity...

J: uh huh.

DD: I just couldn't believe that 30 years of caring about a person could be thrown away that easy...

J: uh huh.

DD: And I really felt the pain of it so deep that I thought I was going to go insane for about a year...

J: uh huh.

DD: I felt like I was in this black hole, hanging on for my life but, I didn't want to hang on... I wanted to let go and just go crawl in a black hole and stay there...

J: uh huh.

DD: (after a long silence)... But, I couldn't do that... That would be against everything I taught my kids to live by... you know...

J: uh huh.

DD: ... Because I told them life does some really bad things to good people... and it's O.K. to be so afraid that you don't know what to do...

J: uh huh.

DD: But, it's never O.K. to be a coward...

J: uh huh.

DD: and there is a difference between a normal healthy fear, and being a coward.

J: uh huh.

DD: And ah, if I would fall into that hole, where I wanted to be so bad, it would have made the whole life a lie...

J: uh huh

DD: Because I'd a been taking the easy way out by falling into that pit and staying there where I didn't have to function...

J: uh huh... but you didn't...

DD: It would have been the coward's way out for me...

J: uh huh.

DD: And... I... there was no way... I walk my talk... There was no way that I could do that with the way I raised my kids to believe...

J: uh huh. So, it sounds like in your experience, after you got HIV, you did go through a rough period of trying to adjust... since this was such a new thing in your life...

DD: And you deal with adjusting all the time. I mean I still haven't dated since I've been diagnosed because I can't get over that feeling of being dirty and I have been 8 years without dating...

J: uh huh.

DD: Because, I don't... I feel like they're getting damaged goods... Still... Because I have HIV...

J: Because of the HIV...

DD: Right...

J: So, you still feel like you're damaged goods?

DD: Yeah...

J: And you feel like if you were with someone...

DD: That I might care about, that I could either expose them to it, or something... I... I would feel like I just took a gun and shot them, you know...

J: uh huh. So, is dating something that you would have wanted to do?

DD: Oh sure.

J: uh huh.

DD: Just too fearful to do it...

J: Just too fearful to do it... Humm... I

DD: I mean I don't know anybody, whether they're gay, straight like me or bi or whatever their sexual preferences... that chooses not to have a loving partner... I think it doesn't matter what your sexuality is... I think everybody, and I think that crosses all sexual lines, wants a loving partner... You know...

J: uh huh... So, how do you deal with that part of you as a woman, 57yrs old... who's having a good life at this point... and you are loved by your family and friends...

DD: uh huh...

J: And you also want someone in your life that you could love intimately... and yet that is not happening... so how do you take that?

DD: Well, I kind of take it, and well I appreciate those around me... all that I've got from all my friends, for one thing, and I've got a lot of guy friends, but also, I feel like if you are searching for something like that... well, I mean actively searching... maybe you shouldn't have been hurt quite like I was... but you know, actively thinking you need that to make you whole, then I think you already got a problem....

J: Uh huh..

DD: I mean, I already know I'm whole. I would love to have a partner, but it's not a need to feel whole because I don't have a partner...

J: That's good to hear...

DD: uh huh...

J: I heard you earlier talking about feeling out of place in this group... Could you say something more about that?

DD: Sure, Ah, most of my friends are men and ah... and being an outlaw by (**not clear**) ... with that kind of experience, and pretty solid guys... I totally understand the brotherhood and my position as a sister in the sisterhood there... I totally understand that... and, the loyalty... but, I don't know how to relate to women... in general... I'm not even sure I know how to talk to them...

J: uh huh.

DD: And here I was with 30 women living with HIV like me... and it was pretty intimidating... and because the first thing I thought was... man... who do I have to be, so I'm not me.

J: uh huh.

DD: And then it turned out, all I had to be was me and that was O.K., which really shocked me... because, like I said, I have no experience in friendships with women... the ones I've had were not good...

J: uh huh.

DD: So, um... there's really some great courageous women here...

J: uh huh.

DD: And, what I found really neat is they might not understand where I'm coming from, but they all accepted where I was coming from...

J: uh huh.

DD: And that was amazing to me... yeah...

J: I know there is still tonight and then tomorrow people leave... but what is your experience so far?

DD: It's been a really good one in growth, and it's been a good one to kind of... it's opened a little window for me that shows that we really can be sisters and women can be friends, and women can be strong together without that lack of trust that I have seen with women on the outside....

J: uh huh.

DD: You know, they either think you're after their boyfriend, your after their husband, or you're after some damn thing,

J: uh huh.

DD: And the play all these games with each other. And that's why I don't like it. Because it's like man, number one, I don't share, and number two, I don't go out with anybody that's attached and number three, what do you think of me if you think I would do that to you?

J: uh huh.

DD: So, I found most women on the outside, pretty insulting to my intelligence and pretty insulting to their own womanhood. And I just... it's not a place I'm comfortable...

J: uh huh. You are not going to go there.

DD: No. No. Because that all comes from insecurity of some kind, and I've got enough of my own demons... I don't need somebody to help me... (laughs loud)...

J: O.K... I have to ask you about this one more time... um, the way you talk about the counseling that you did, ah, before HIV, which was the

counseling that you experienced due to your being in the navy before and what ever happened to you then, and so you went to a counselor...

DD: Still do...

J: ...and still do... is it the same counselor you see for HIV related issues?

DD: Yeah... it's still... you see, she's going to be so proud of me when I go back and see my counselor. Do you know I have been going to my Vietnam Vet counselor out there for about 13 years and they still can't get me in group... I won't go unless they go one on one...

J: And they'll be so proud of you...

DD: And they'll be so proud that, not only did I walk into a group, but I walked into a group of women... They're going to go, what?

J: What happened to you?

DD: Yeah.

J: So, what I was getting at here is that after the HIV, you still have been going to see a counselor...

DD: Yes

J: uh huh.

DD: Yes.

J: So, what is your experience with counseling?

DD: Well, I've had both good and bad counselors. I've had some counselors that were God and decided they knew what was best for me and they were going to tell me how to put all of these little pieces together to live my life...

J: uh huh.

DD: And, I'm thinking no, you're talking about somebody's life in your family, but you don't know me, so I know you're not talking about mine...

J: uh huh.

DD: But, my counselor is great. She listens, I mean really listens, and then, like gives you a selection of possible solutions to help with whatever problem you are dealing with. Now if you are too lazy to get off your butt and pick a solution, and try it, that's not the counselors fault...

J: uh huh.

DD: That's your fault. Because some of those counselors stuff is very scary and there was lots of times that I didn't want to go there...

J: uh huh.

DD: But, I think that it helps you realize that you're not as crazy as you think you are...

J: uh huh.

DD: That basically, we all have mental health issues and we've got our little fears and insecurities and we've all had good and bad stuff happen to us, it's just that maybe not enough of us reach out for the counseling... It took me a long time...

J: Is counseling something that you would recommend for anyone dealing with HIV... um... women in particular?

DD: The way that I do that is through my public speaking...

J: uh huh.

DD: Because I go to Juvenile Hall and talk to the kids and I go out to the Women's Prison and talk to the women out there about what it's really like to live with this, and if you don't got it, and here I can give you a list why not... and I love doing that sort of thing... It helps me kind of work through my own stuff better too... And I tell my girls in person, you know, I'm not there to tell you to stay straight, I'm not there to tell you not to use drugs or booze, those are all your choices...

J: uh huh.

DD: What I am here about is to give you the nightmare of living with HIV... The straight down school... All I'm here to tell you is there's not anybody cute enough to have sex with that's worth your life... and there's ways not to become HIV positive...

J: uh huh.

DD: That's my only goal...

J: uh huh.

DD: And so the girls and I get along real pretty well, and they ask me lot's of questions...

J: That sounds good...

DD: One of my best girlfriends was a prostitute who was murdered behind her heroin addiction by Robert Yates... She was the one that was buried in his yard for two years... Melody Murphy was like a little sister to me... so these women are very important to me...

J: So, you knew that woman huh?

DD: She lived with me...

J: Uh huh...

DD: Her and her family and I and her big sister have been friends for over 30 years... And there were a lot of those girls still doing it... and if I can help one of them not go there, um, that's good enough...

J: If you were talking to women that were HIV positive, is counseling something that you would recommend to them?

DD: When they are ready and if they don't want like, they don't like the word counselor... a trusted friend...

J: A trusted friend...

DD: Just somebody that you can share your emotions with, because... when... believe me, the first two years of HIV, I don't remember...

J: uh huh.

DD: Hardly at all. I was walking... I was talking... I was functioning... I didn't go back to booze... I didn't go back to drugs, but that first two years from shock is a blank...

J: Uh huh

DD: I really couldn't tell you what I did from '94 to '96...

J: Uh huh...

DD: And it's really critical to have a friend you can share things with... and not worked out too big... I don't care if that friend is a priest, a rabbi, a girlfriend... it doesn't matter, someone... someone...

J: Someone to talk to...

DD: Uh huh... yeah, because there's times that you know, you wonder if you want to do the... yeah... there's times if you wonder if... man why don't I just suicide out?

J: uh huh

DD: There's times that you don't care and you want to go get reckless just because you don't care and then if you die by accident, then it's not your fault...

J: uh huh.

DD: I mean the emotional roller coaster the first couple of years is horrendous...

J: uh huh.

DD: And, and, they are all flooding so fast that you really need a safety valve, a friend, a counselor, a somebody...

J: uh huh.

DD: I was one of those that holed up and didn't believe in that. My counselor got worried and had a hospice worker sent to my door, her name K... And ah, she came to the door and she told me her name was K and she was from Hospice... Did I want to talk? And I said, lady how do I know if I want to talk... I don't even know if I give a fuck if I live or die.

J: uh huh.

DD: I said, come in if you want, it don't matter to me...

J: Uh huh.

DD: And we went up to my bedroom... she stayed... (laughs)... She's still my hospice worker...

J: Great...

DD: Yeah... and she's good for a lot of coping skills with the HIV issues and planning your own funeral and, how do you tell your children and what kind of service do you want. I mean nothing felt more weird than going and paying... and one, I resented it. I wanted another Harley. But, my granddaughter was only 8 and since we were all told I was supposed to die real soon...

J: uh huh

DD: My granddaughter wanted a place to take flowers. So, I bought a cemetery plot instead of the Harley.

Ra: 42

Ra: Hi Joyce...I am sorry!..(laughs because she kicks into my foot accidentally)...

J: It's O.K., it's O.K. Anyway, um, O.K., I can explain to you about this interview... I'm talking to women living with HIV/AIDS in rural areas...I am trying to look at the experiences of dealing with HIV/AIDS, as a woman...and issues that come up...

Ra: Oh...yeah, this is good...

J: So, I guess what I want to find out from you is, what has your experience been like since finding out about your HIV status?

Ra: Well, one of the things, it depends on if you're talking about when I first found out... I think I became more withdrawn at the time...I have been HIV positive for a very long time...

J: How long is that?

Ra: I was diagnosed 16 years ago, but I've had it for a total of 22 years...I was able to figure out how I got it...It was very easy...I got a phone call in 1986 from my mother and she told me that somebody in New York had AIDS...and it turned out to be a man I dated 6 years prior to that phone call.

J: uh huh.

Ra: So that's how I figured it out, because I already had been married to my husband for 2 years,

J: uh huh.

Ra: when I got the phone call, and he does not have HIV,

J: uh huh.

Ra: And I was with him 2 years before we even got married, so I know it was from that guy I was with before. It was easy to figure out. He was a hemophiliac, and I got it from unprotected sex. But to answer your question, at the beginning, I think I became very... um... withdrawn...

J: uh huh.

Ra: ...because I told my family, I told one friend and I didn't tell anybody else because I was afraid to share it with people because of the horrible stories I had heard...

J: uh huh.

Ra: Like people leaving people or shunning me or rejecting me...

J: uh huh.

Ra: ...but as the years went on... um... and watching TV programs that had to do with HIV, I kinda was feeling less worried about a bunch of talk shows about HIV... I would watch a talk show about HIV and see how the audience would treat the person on stage who has HIV, and that would let me figure out you know, I need to tell other people. It took me a very long time before I started telling... you know... people... and I had some bad experiences along the way,

J: uh huh.

Ra: Where people were afraid of me,
 J: uh huh...
 Ra: I told one girlfriend I thought would be very, very supportive, never heard from her again...
 J: How did you deal with that?
 Ra: It hurt, a lot. I remember calling her 6 months later and saying, I'm still alive...
 J: uh huh.
 Ra: She was very nervous on the phone, she went, oh oh, she didn't know what to say. It was like uh uh uh kinda thing.
 J: uh huh.
 Ra: Then I told another friend, who I absolutely thought would have a problem with it, but I was tired of lying to her, because every other Sunday I would have a support group and sometimes she would want to get together and I would have to say, I can't because of this or that, and that wasn't the truth, the truth was I had support group.
 J: uh huh.
 Ra: She didn't know I had HIV, so one day I got tired of it because I'm not a person who likes to lie, I don't, I'm not good at it and it just, it just doesn't sit right with who I am,
 J: uh huh
 Ra: And I just... I just decided... I... uh thought I would prepare her for it, and I said one of these days I want to sit down and talk with you... and woo, I started crying, I wasn't going to tell her at that point but...
 J: uh huh
 Ra: Now she want to know just what the hell was wrong with me, that I'm crying,
 J: What's wrong with you, yeah,
 Ra: So, I ended up telling her, and uh, she's been my friend ever since... so that's it... Sometimes you just don't know...
 J: uh huh.
 Ra: ... who's going to shun you, and who's not...
 J: uh huh.
 Ra: But now, I've gotten to a point where I don't even care...
 J: uh huh.
 Ra: And that's been the last year and a half... So, it's 2002 now, so... since somewhere around the year 2000, up until now, I've gotten to a point where it's O.K...
 J: uh huh
 Ra: Um... and I've been public speaking for a year now... I've talked to about 3 classes a month...
 J: uh huh,
 Ra: ...and I don't seem to be having any negative feedback from people... they even want to come up to me after classes and give me a hug... and they just feel so moved by the fact that I shared so much of myself with them...

J: uh huh

Ra: ... and I answered all their questions, and some of them are very intimate personal questions and I was happy to share it and I appreciate that...

J: uh huh.

Ra: So, I've gotten to a point where I went from being very withdrawn and very shy and isolated to feeling much more confident now, having a passion in life, which is public speaking... and I mean I wish I didn't have HIV, but, I still like public speaking. I found something now that makes me want to live and do something,

J: uh huh

Ra: I think it's real important to have a passion, and in fact, if I sing my song tonight, that's what it's about, passion and love...

J: uh huh.

Ra: ... and I want to share that with everybody, because I found that with the public speaking.

J: uh huh.

Ra: Ah... it did change my life in the way of my path in life...

J: uh huh.

Ra: I decided to change what I do in life because of the HIV... I have always been interested in health... especially, alternative medicine and naturopathic medicine...

J: uh huh.

Ra: I... I think even more so with the HIV... but, before the HIV I was interested in health... I was an aerobic instructor...

J: uh huh,

Ra: for many years in my late teens and early 20's...

J: Uh huh,

Ra: So I liked to stay healthy and looking good and eating right... and I was going to go in the direction, maybe later of being a naturopath,

J: uh huh

Ra: But then I decided... um... realistically, I just don't think it's a good idea. It's not conducive to having HIV... I would be around people who are sick...

J: I see...

Ra: So, I don't think it's a smart idea to expose myself to that...

J: So, that's why you were asking a lot of questions of that naturopath doctor... you had very good questions, and seemed to know exactly what you were talking about...

Ra: Well, thank you... um... yeah, that stuff... it's... it's interesting very much to me... I'm very much interested in alternative medicine because I like the idea of it... because with Western medicine, it usually just covers up the problem, it doesn't really get to the root of the problem and heals it in the core... it just, it's just a band-aid on it, a lot of time...

J: uh huh.

Ra: Like with different medicines, but When it comes to naturopathy, I love the idea that they find out what your body needs...

J: uh huh.

Ra: And if you give your body what it needs, it has the capacity to heal itself...

J: uh huh.

Ra: And I learned that healing doesn't always mean cure, that it can mean improvement.

J: uh huh.

Ra: And I had some back issues, in the past, and with naturopathy, it improved immensely...

J: uh huh.

Ra: I know how to control it...like, I have a skin condition that flares up... and I found out that by avoiding having too much wheat... certain foods, that I'm O.K., I can keep it at bay, but before I was taking something... I was using something the dermatologist had given me, and it ended up hurting me... and I had to fix what it screwed up...

J: uh huh.

Ra: And ah, I am such a fun of it now... I just love it... and even though I didn't go that direction of becoming a doctor... you know... me becoming a doctor of naturopath, still, I've decide... it's just as an interest of mine... and a hobby... to keep learning more...

J: uh huh. So, I am just wondering, because you do look physically very healthy...

Ra: Thank you.

J: And so, I was wondering how you deal with that because I noticed that with some people with their healing... there is struggle to keep physically strong...

Ra: Right.

J: and they are struggling to a healthy mental state...

Ra: A lot of people are depressed...

J: uh huh.

Ra: ...and...um...I'll tell you something, I'm not always happy... because I do have my down times... especially, um... it kind of goes from blood test to blood test. If my blood tests are great, I'm undetectable, I have good numbers, and T-Cell, I'm feeling relaxed... but if stuff starts to go array with my counts...

J: Uh huh.

Ra: ...like for example, for many years I was happy, pretty much...

J: uh huh.

Ra: Because my counts were staying great... and then fairly recently, maybe 6 months, 5 months ago... I wanted to change meds, and my doctor said it was time because one of my medications was making my joints ache... and I also had kidney stones removed twice,

J: uh huh.

Ra: So, we thought it was time to change... well, when I made the change, I went from undetectable to 400, which is not very high, but it still bummed me out, because I had been undetectable for 6 years...

J: uh huh.

Ra: And so...you know...I was scared, because I had this vision that oh it's at 400, does that mean it's going to keep going up, up, up, that it was going to continue to go up... it scared me...I was scared and... maybe I blew it out of proportion more than I should have...

J: uh huh.

Ra: So, we had to kind of experiment with finding the right combination so I could bring it back down and during that experimental stage I was like stressed and nervous and so it seems to, it seems like as long as my counts are good...

J: uh huh.

Ra: I think it affects my emotions...

J: uh huh.

Ra: But, if they're not, then I start getting stressed. And I think it also stems from, I just went through some very bad times um health wise, before the protease inhibitors...

J: uh huh

Ra: Just before, like just between '94 and '95,

J: uh huh

Ra: I started having problems with my health and with my HIV. And it first started with a very bad case of insomnia...

J: uh huh.

Ra: I could not get to sleep at all. And it was like nuts. And I started thinking about suicide. I would never do it, but I fantasized, and I even got to the book in the library that was pretty popular at that time, it's called Final Exit...

J: uh huh.

Ra: Have you heard of that?

J: I've heard of that, yeah.

Ra: It tells of all of these different ways that people can commit suicide. And it was weird, I wasn't planning on using it, but it really gave me, peace, to say oh, O.K., there's a way out if I have to do it...

J: uh huh, uh huh.

Ra: It sounds kind of morbid but it really did give me peace...

J: It gave you a sense of peace...

Ra: So I read that, I mean, I was still down, but it did give me some of that. Um, so I stated getting skinny and my face got really gaunt,

J: uh huh

Ra: And ah, so I was very depressed during that period too,

J: uh huh

Ra: And then when I went on the protease inhibitors and turned around pretty fast, I don't think I would be here if it wasn't for the protease inhibitors.

J: uh huh. So R, when you were going through that phase, did you ever talk to somebody?

Ra: I first started talking to someone um, it's pretty weird, like 4 years after my, well, I'm kind of going back in time, and maybe I am not answering that question directly...

J: uh huh.

Ra: I'll talk about this I didn't talk to anybody. I think I became isolated, very isolated, um, and I had already graduated from school and got my paralegal degree and now I was going backwards again because, of this illness, and ah, I have a case manager and so I go to her, yes, I went to see a psychologist,

J: uh huh.

Ra: yeah, and it helped somewhat. She really believes in psychoneuroimmunology, a big fancy word for visualization...

J: uh huh.

Ra: So, we did some of that, um, and it did help some, but for me what really helps was just to get on the meds and see the changes in my labs.

J: uh huh. Uh huh. So, it sounds like your health is determined by good lab results... which make you feel better about yourself...

Ra: Exactly. You got it to a T.

J: And so, from your sharing, it does sound like you are very happy and have very good support from your husband...

Ra: Yes, yes, I think we have this like amazing marriage. I mean its not like it doesn't wear on him some, it does, but, he wants to make sure that if he's going to be putting all this effort to bring me up, that he wants something to happen, and he has gotten a little bit frustrated when that doesn't happen, but a lot of times it does happen too...

J: uh huh.

Ra: And I have a few close friends. I'm not the kind of person that likes to have a lot of friends. I like to have a few close friends but I also like to be alone...

J: uh huh.

Ra: I like to, I have to be with people at least 3 times a week, or else I get really lonely, and depressed...

J: uh huh.

Ra: But if I'm with people every single day, I have to collect my thoughts, I have to think about what I have been doing, and... and that is why it is important for me to be alone sometimes...

J: uh huh, uh huh.

Ra: Just be alone... and be on the computer...

J: uh huh.

Ra: But I do um get support from the people that I know I've met people through support group and then what happens, I didn't really, but I remained friends with those people that I clicked with, that I liked the most... and_ we became friends outside the support group....

J: uh huh.

Ra: I still have those people that that I talk to as well...

J: How did the support groups help you, or did they?

Ra: In the beginning, in the early days...

J: uh huh.

Ra: 1986, well, actually, I didn't do support groups for like the first 4 years, after dx because I was so ignorant about, I had no idea about support groups, I didn't know they existed.

J: uh huh.

Ra: I was 26 when I was diagnosed. And I guess I was a very young 26, I had never heard of those things...

J: uh huh.

Ra: But it took my husband quitting smoking for me to find support groups. It sounds weird, but I'll tell you why that happened. Because he was trying to quit cigarettes, he was starting to freak out. He couldn't, emotionally, I don't know, I've never been a smoker, but it was hard for him to handle not smoking...

J: uh huh.

Ra: And he was at work one day, and he just started crying, bawling... Not smoking also exacerbated his feelings about me having HIV. And he was crying about me having HIV and his not smoking was making it worse. So, when he couldn't stop crying, he was at work one day and somebody said you gotta get a support group... That's not like him at all. He's a marine, but he's not the crybaby type. So, they got my doctor, whose his doctor too to sit with him and um, talk, also said, we have something for you here at work, uh, I don't know if it's Human Resources, but they have some kind of free um therapists...

J: uh huh.

Ra: Yeah, and so they went and talked to him and he opened up, because he had been keeping it a secret too. He didn't tell anybody at work about me because..the job, they might think he has it too, and he doesn't. And they said, how long have you been dealing with this? And he said for years. Do you know a man named so & so, and he said no. He's a case manager and you should really talk to him and so should your wife, and so we ended up eventually talking to him, and he told us about the support groups...

J: uh huh.

Ra: So, he became like my counselor, cuz he was like a counselor/case manager. He was wonderful...

J: uh huh.

Ra: And ah, I had forgot if I got off track but... did I answer your question?

J: Oh yes_ because I wondered if having somebody like a therapist has been helpful for you... and also whether support groups have been helpful to you... that's what I have leading to...

Ra: You wanted to know how the support groups helped me.

J: uh huh.

Ra: So, in the early days, they were good, there were two different types of support groups. Actually they were the same. But I was at one and in those days there wasn't protease inhibitors.

J: uh huh.

Ra: So, it was actually, I would leave more depressed from the support group when I left there, than when I went there...

J: uh huh.

Ra: Because people were dying and you could see how sick they looked. And everyone was just talking about how sick they were...

J: uh huh.

Ra: And it was just a bummer, and I didn't find that supportive, because they weren't supporting me, they were just talking about I have this and I have this and I have, I mean it was just...

J: They were dying.

Ra: Yeah, so I mean, what's supportive about that? And I think they became more supportive, oh yeah, and then I joined another group and they just, all of them died in two years.

J: That must have been very hard for you...

Ra: There is actually one person left from there, a woman, the rest were all men and they all died in 2 years. So that wasn't a supportive group. There wasn't a facilitator in that group.

J: uh huh.

Ra: We would meet at each other's homes. We traded every other week at each other's house. And we kind of prided ourselves on not having a facilitator, that we were independent, and could do it ourselves. Big mistake. Because as we were dying, I mean, I wasn't dying, but they were dying, and we needed somebody there to help us work out feelings all these funerals that we were going to and there was no one. I mean we would sit there and we would look at each other and who's next? who is the sickest one here, who's going to die...it was horrible...it was just horrible...

J: Uh huh

Ra: And now, and the protease inhibitors came, and I was telling you about this earlier, but I want to capture it on tape, because I joined another group and all of us were feeling well and we decided to have a group that wasn't like a typical support group...

J: uh huh.

Ra: But we would talk about this book, and we would work on each chapter, and we would discuss how we could help ourselves to nutrition, with supplements, um, positive thinking, so it was a very, very constructive kind of group because that's what the book was about.

J: What is the book?

Ra: The book is called Healing HIV by Building your Immune System., by Dr. John Kaiser.

J: O.K. That's good.

Ra: And he's an MD and he believes in integrated medicine and that's taking medications as well as alternative medicine as well...

J: uh huh.

Ra: In other words, combining the two, which makes a lot of sense to me...

J: uh huh. That helped a lot.

Ra: Oh it helped a lot. I mean when we weren't doing the book, we would have a speaker who would talk to us about different health modes, like Chi Gong, which is supposed to be very helpful a lot, heal the body...

J: uh huh.

Ra: We even had a therapist there so she could help us do art therapy and I loved that. I mean that was the support group I would have thought of going to...

J: Are you still doing that?

Ra: No, it just started to faze out and people weren't coming. It wasn't because it was a boring group. I think maybe people just got lazy and got involved in their own lives...

J: Uh huh

Ra: Yeah, it wasn't because we weren't getting along. And I've remained friends with those people outside of the group...

J: How has the rest of the family handled your situation?

Ra: Um, my whole family is very supportive... My mom's afraid to drink from the same glass of water...

J: Oh, really?

Ra: But that doesn't bother me. I don't care about that. Because I know she loves me very much. She gives me hugs and a kiss on the cheek and my families great. Unfortunately they all live in California. So, the only family I have where I'm at is my husband and his mom and his aunt. And that's it...

J: And how are they?

Ra: Fantastic. No problem at all...

J: uh huh.

Ra: Now he has a sister whose husband did not want his children to come visit us, I mean they live in Canada, so my mother-in-law could not see her own grandchildren anymore because of me. Because he was ignorant, he didn't know anything about HIV and so he was afraid for them to come visit us...

J: Being ignorant is very sad...

Ra: Yeah, I felt bad because that's her grandkids. I didn't know, I felt helpless about the whole situation, and frustrated and...

J: And now things are better?

Ra: the grandkids talk to her through the phone now. I don't think they would have a problem coming to visit at this point. I haven't talked to the husband. I don't know how he feels like. He never calls us and visa versa...

J: yeah,

Ra: But the wife is um, my husband's sister. She talks to us. And we talk on the phone. But she was angry for a long time, because, not at me, but at George and his mom because I wasn't supposed to find out how the husband felt about the grandkids and...

J: uh huh.

Ra: Actually my husband wasn't supposed to know either. She had told her mom and her mom told us, and so that's the kind of family they are, is when they get angry, they don't talk to each other for years...

J: oh,

Ra: It's terrible. Actually, I'm the one who brought them back together...

J: uh huh.

Ra: I called her one day and left a message and said you know your mother's really sick and I don't want to wait until she's dead to tell you to give her a phone call...

J: uh huh.

Ra: Cuz then you will be angry with me and say why didn't you tell me she was sick?

J: uh huh.

Ra: So, after that things worked out... so...

J: How about in your community. How have people handled your situation?

Ra: Well,

J: _____

Ra: Well, when I'm going to my public speaking, I have absolutely no problem.

J: uh huh.

Ra: People are seeking me out. I mean just recently the YWCA was asking some people do you know someone who has HIV, a woman, because we have a women's spoke forum going on...

J: uh huh.

Ra: We've got a series of seminars...

J: uh huh.

Ra: And the want it to be about HIV these people said oh, R, you know R. You know, people knew me. So word of mouth...

J: uh huh.

Ra: I haven't done it yet, it actually going to be a fairly soon, I remember it's 14th_ at the YWCA, talking to a bunch of women...

J: uh huh.

Ra: So, it seems like they want to learn about it...

J: uh huh.

Ra: It's a good thing. They are not trying to sweep it under the carpet...

J: It sounds like in your experience, having HIV has not been too detrimental to your life. Would that be accurate or?

Ra: Umm, it just depends on what period you're talking about...

J: Yes you are right...

Ra: In the early days it was really bad '94 and '95 was bad... then things started to pick up again...

J: Uh huh. So then in the cocktail drug era things got much better for you....

Ra: Much, much.

J: So that your feelings, in terms of how feel about your health have been better...

Ra: Absolutely. Absolutely.

J: Uh huh. Uh huh.

Ra: But of course at the same time, sometimes I think about what do I want to do? Because my husband would like me to go back to work...

J: Uh huh.

Ra: And I'm a little bit fearful about going back fulltime, because I've gotten so used to being on disability. I've been on disability for 7 years now and I'm kind afraid to let go of it?

J: Uh huh.

Ra: Because I heard its much harder to get disability and if I want to get back on it, it will be a little bit harder to get it back....

J: Uh huh.

Ra: So, I'm thinking part time instead, and do a little extra work, and he said that's O.K.

J: Uh huh.

Ra: So, that makes it easier that he's agreeable...

J: You have less challenges now?

Ra: Yes.

J: After the Protease Inhibitors...

Ra: Definitely.

J: And you do sound mentally strong...

Ra: Definitely.

J: That's really good...

Ra: One of the things that keep me strong mentally, is not being in the dark about my disease...

J: Uh huh.

Ra: I always try to educate myself, and trying to find out what medicines are coming out in the future...

J: Uh huh.

Ra: Things like this give me hope. In fact I even started a little Hope Notebook. And I've already put a couple of things in it. One of the was there is something called Human Growth Hormone, I don't know if you've heard of it?

J: I have heard of that.

Ra: What they found in this study is, it was a short term study, a small group of people, that it increased the size of their thymus, and the thymus is the part that makes the T-cells,

J: Uh huh. Uh huh.

Ra: And so it grew significantly and it also produced more T-cells. I cut out of class because they are going to conduct a bigger study... and... And then... What else did I put in there? So, that one gave me some hope....

J: Uh huh.

Ra: And then there was another study that came out. I can't remember now. But, if I, if I keep looking at things and seeing what I can do to help myself, knowing what's coming out, then that also gives me strength. I'm on what's called a list serve, have you ever heard of a list serve, a mailing list?

J: Oh a list serve... I am on some, actually, for HIV prevention....

Ra: Sometimes people refer to them as mailing lists.

J: Mailing lists. List Serve, yeah.

Ra: I'm on one about PI's, protease inhibitors, another one is called the lipid list, it's for people who have Lipodystrophy...

J: Really, uh huh.

Ra: Do you know how they work? Or I could tell you how they work if you don't know exactly how they work..

J: I do know, but you can go ahead and talk about your experience...

Ra: I Correspond. And you can see all these people's letters and you can decide who you might want to reply to, everybody, like 100's of people, letters. And if you have a question, you can write a letter, like for instance you could ask, I've been having some trouble with Crixivan I notice I'm not sleeping well. Does anybody else have that problem?

J: Uh huh.

Ra: And then somebody might respond to that and tell me, they might even tell me what they did for that...

J: Uh huh... so you are networking with others...

Ra: And they also share articles that have read, studies that are out or coming out. So I think networking, that's the word, is incredible...

J: That's what it sounds like...

Ra: It's incredible. It's helping me stay strong. I think it's important to talk to a lot of people going through the same thing...

J: Uh huh.

Ra: And ah, people who are, like minded that, want to learn and to help themselves. So we share different websites and recent articles....

J: It almost sounds like a support group...

Ra: It is, it is. Definitely.

J: Uh, is there any mental health worker in your community that you visit with at all?

Ra: Uh, I haven't been lately, but I just haven't found the need.

J: O.K.

Ra: I've been O.K.

J: Would you suggest to someone who is dealing with HIV and they are in that crisis mode to see a mental health therapist?

Ra: Definitely. I think mental health, just see a psychologist, or some kind of counseling. I mean definitely. I mean, I have done that. For real. Whenever I was in a terrible crisis.

J: Yes.

Ra: I think many times I made use of a counselor. The first time was near the time I was diagnosed, and I was dealing with anger towards my father because he wasn't the greatest dad growing up. And I felt that in order to really get help and to take care of myself, I have to get rid of these angry feelings...

J: Uh huh.

Ra: And so I went there, not about the HIV, but about the angry feelings...

J: Uh huh.

Ra: It just took a matter of four visits, you are supposed to have 8...

J: Uh huh.

Ra: And I feel I am more, and now I realize why he was the way he was and...

J: Uh huh

Ra: and what I did as a follower, because I talked to him and I said you know what, I believed in you for along time because I was afraid, and I am not anymore...

J: Uh huh. Uh huh.

Ra: And fortunately, he was willing to have a decent conversation about it and it really helped me a lot...

J: Uh huh. And then, one more question about counseling and then we can end our interview.... Was the understanding of HIV by the counselor in your sessions an important factor?

Ra: Um, I'm trying to think. Was the fact that I had HIV important to our conversations?

J: No, to their understanding of HIV... their knowledge about HIV?

Ra: Oh, HIV,

J: Was that an issue?

Ra: When I came to talk to the counselor about my father, the HIV wasn't an issue whatsoever...

J: uh huh.

Ra: I mean I explained to her, like I did you, that I wanted to get rid of some of the feelings because I need to start taking care of myself...

J: uh huh.

Ra: Oh, not that I wasn't taking care of myself, but I knew that that would be a better way, to take care of myself by getting rid of all the trash in my head.

J: uh huh.

Ra: So that was an issue in that case, but when it came to my fears about HIV,

J: uh huh.

Ra: then I would see a counselor regarding that issue, that you know, I'm afraid, I've got this disease, all my friends are dying, then we'd discuss that. And she worked with me, this was a woman who works with people who have HIV...

J: So she had knowledge about HIV,

Ra: Lot's of knowledge, in fact she was the one who taught me psychoneuroimmunology, oops, I better, should I say that again?

J: Oh no, it's okay...

Ra:Um, O.K. It only mattered when I talked to a woman who works with people who have HIV. She in fact this woman is like an angel...

J: uh huh.

Ra: She started an organization and she has all these different kinds of classes for people with HIV to help with the feelings...

J: uh huh

Ra: And, it seems like her main thing is psychoneuroimmunology and so she would teach me how to use visualization to help me um, because she believed that you could actually raise your T-cells with your mind, so, I guess in that case, it was an issue....

J: Uh huh, uh huh, O.K. It sounds like your experience with living with HIV has been hard, and yet also brought you very positive things in your life?

Ra: uh huh...yes

J: and at this point in your life, you do look and sound very health...

Ra: Thank you.

J: I really want to thank you for your time...

Ra: You're very welcome...

J: I appreciate your time because I realize that it is a big deal for you to talk about all this...

Ra: I am used to it now, but you're very welcome.

J: Well, I appreciate this... so what I am going to do is transcribe this and then I will send you a copy to read it and let me know if I left out anything that was important to you or if I didn't state something like you wanted it to be...

Ra: O.K. But you know what? You don't have to do that stuff. I don't even want to see the film of the guy that made me, you know, put me on TV...

J: O.K. I just wanted to make sure that it you knew that you will have access to transcript...

Ra: It doesn't matter to me.

J: So, this is going to be a part of my dissertation.

Ra: I just hope it helps you.

J: I think it helps women out there too because the more information out there, the better...

Ra: Well, if you have any other questions...

J: Yeah, and if I have any other questions?

Ra: Like even later...

J: uh huh, and can I email you and call you?

Ra: Yes, absolutely. I can give you all that information if you'd like...

J: Yeah, because I do have that list of names, you know?

Ra: Oh yeah, that's right, so you've got it...

J: So, I can do that?

Ra: Yeah. Uh huh.

J: Thank you so much.

Ra: You're welcome.

J: Good luck.