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UNIVERSITY OF SAN DIEGO

Hahn School of Nursing and Health Sciences

DOCTOR OF PHILOSOPHY IN NURSING

TITLE OF DISSERTATION

AN ETHNOGRAPHY STUDY OF HIV POSITIVE MIDLIFE BLACK WOMEN

by

Charlotte Stoudmire

A dissertation presented to the

FACULTY OF HAHN SCHOOL OF NURSING AND HEALTH SCIENCES

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requirements for the degree

DOCTOR OF PHILOSOPHY IN NURSING

May/2008

Dissertation Committee

Dr. Jane Georges, Chairperson

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Abstract

Black women, ages 45 and older, are disproportionately affected by the HIV/AIDS epidemic. In 2001, Black women comprised 11% of all older women in the United States; however, they accounted for more than 50% of AIDS cases and more than 65% of HIV cases (Winningham et al., 2004).

The literature review reflected little research specifically looking at the reason(s) for the increase in HIV in Black women, ages 45 to 60. Furthermore, few research studies focused on HIV patient health beliefs and their experiences in living with HIV.

This study was conducted with an ethnography research method coupled with the American Black feminist theory. The primary purpose of this qualitative study was to examine the reason(s) why the HIV rate is growing at an alarming pace for Black women ages 45 to 60 years old. The research instruments consisted of a demographic form and a six-question interview guide that formed the basis of 60 – 90 minute interviews meeting the research criteria.

Demographic information was collected from a self-administered survey that included age, employment status, income, education level, date of infection, source of infection, date treatment started, whether the participant was currently in treatment or not in treatment, and the reasons for that treatment decision.

This was a non-random sample of convenience. This researcher chose not to conduct a random sample because of the parameters of the inclusion and exclusion criteria. The participants consisted of 22 HIV-positive midlife Black women between the ages of 45 and 60 years old who self-selected to participate in the research study;

however, two of the participants declined to have their interviews included in the results. Therefore, 20 participant-encounters were included.

IRB approval was obtained from the University of San Diego. The participants signed an informed consent that insured their confidentiality. The researcher analyzed the qualitative information by hand coding the data because the ethnic, feminist, and culture elements might lead to misinterpretation if qualitative-analysis software was used

Black women, ages 45 to 60 years offered significant reasons why they were infected with the HIV virus (e.g., lack of education about HIV, media influences, aging, unprotected sex , the onset of drug use after age 40). The findings from this study remain pertinent in all nursing research and advance nursing's utilizing of the American Black feminist theory.

Finally, the findings may also facilitate further research into the reason(s) for the increase in HIV infections in Black midlife women. In addition, this study may further the body of research which leads to changes in the delivery and policies of health care.

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Dedication

“Believe in yourself! Have faith in your abilities! Without a humble but reasonable confidence in your own power you cannot be successful or happy.”

Norman Vincent Peale

God’s grace and favor along with this wisdom from Norman Vincent Peale kept me focused through the past 3 years of my journey.

To all HIV-positive Black women, God is whispering in your ear that he loves you unconditionally. You are *women of worth* and new creatures in God’s love. Thank you for sharing your lived experiences that have enriched the world’s knowledge about living with HIV.

To my parents, Dorothy Ann and William Stoudmire who now have seat next to God in heaven, you empowered me at an early age to reach for the impossible and to appreciate what an education could do for me and others. They coached me, dried my tears of frustration, and supported and loved me unconditionally.

To my siblings whom I love dearly, Yvonne, Michael, and Donald Stoudmire, you listened and encouraged me when I needed a friend. You traveled long distances to help me celebrate my professional successes over the years.

To my daughter and friend, Cassandra L. Taylor , you are my joy, my strength, my inspiration. I love you. To my two grandchildren, Blair Taylor and Akili Thomas, if *Granny* can do this, so can you. We shared moments of love which I would never trade for anything else in the world.

Finally to my friend, Rita Callahan, AKA: Thelma. My daughter fondly named us Thelma and Louise, AKA: Charlotte, because of our spiritual journey, dedication to

nursing education, community service, and professional connection. We have supported each other everyday in some way throughout this educational journey. We used our love for God and sense of humor as the underpinnings of our friendship.

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I am extremely grateful to Dr. Jane Georges, chairperson of my dissertation committee and mentor. I met this gentle and brilliant woman when she and Dr. Cynthia Connelly, committee member, interviewed me for the PhD program. I felt a spiritual connection with Dr. Georges. Both she and Dr. Connelly have proven to be inspirational for me. Their ability to teach and inspire students to excel are the tools of excellent educators.

Thank you Dr. Georges for the Thursday meetings where I could discuss anything with you, then cry about it, and finally be joyful and motivated to continue on!

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Third, an appreciation for my lifelong friends, Delores Cleveland, Yvonne Grant, Rhonda and John Phillips, Karen Primus, Violet Anderson, Ruth Shannon, and Pat Glaster who did not think I had lost my mind when I decided to return to school to pursue my Ph.D. in Nursing. They remained supportive and encouraging throughout my journey.

This educational voyage has been the most delightful one I have had in many years and the blessings I received will never be forgotten. Finally, I give honor to God because, without his love, I would not have obtained my Ph.D. in Nursing.

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CHAPTER 1

Introduction

An estimated 1,000,00 people are currently living with HIV in the United States, with approximately 40,000 new infections occurring each year. Seventy percent of new infections occur in men while only 30% occur in women. When viewing HIV demographics by race, 54% of new infections arise in African Americans and within African Americans, 64% of new infections inflict African American women. For women, 75% of new infections are heterosexually transmitted. One-half of all new infections in the United States occur in people 25 years of age or younger (Until There's a Cure Foundation, 2006).

Background and Significance

By the end of 2002, the Centers for Disease Control and Prevention (CDC; 2003) estimated that between 1,039,000 and 1,185,000 people in the United States were living with HIV/AIDS. Of those infected, between 24% and 27% remained undiagnosed and unaware of their HIV infection. During that same year, the estimated number of deaths resulting from AIDS was 18,017, including 83 children under the age of 13.

In the United States, 65 million people currently live with an incurable, sexually transmitted disease (STD; Centers for Disease Control & Prevention, 2003). In addition, 15 million are infected with one or more STDs each year.

When studying trends over several decades, multiple research studies demonstrated a direct correlation between STDs and HIV. Effective prevention and treatment could drastically decrease the number of people becoming infected with HIV. In 2002, 28% of all human immunodeficiency virus/acquired immunodeficiency syndrome (HIV/AIDS) cases involved women in the United States; approximately 69% of those cases involved non-Hispanic Black women. Heterosexual transmission was the most commonly reported mode of HIV transmission among women. Black women comprised a growing proportion of people newly infected with HIV. By 2002, the HIV infection rate for Black women in California was 14 times higher than that of white women (Centers for Disease Control & Prevention, 2003).

Youth Age 13 – 19

By 2002, Black teens (age 13 through 19) comprised 66% of AIDS cases in this age group although they represented only 15% of the teenage population. White teens comprised 11% of AIDS cases and accounted for 63% of the teenage population. Black youth encompassed the largest single group of young people infected with HIV. As of 2001, they account for 56% of all HIV infections ever reported among young people aged 13 – 24 years (Centers for Disease Control and Prevention, 2003).

In addition, Youth Advocates for Youth (2006) reported that young Black women aged 15 – 24 were at heightened risk of HIV and other STDs. The reasons were complex and included poverty, discrimination, inadequate access to health care, disproportionate rates of incarceration, distrust of the government, and sexual risk-taking that was largely affected by poverty and lack of opportunity. In order to address the heightened risk for HIV that these young women faced, society should have directly confronted racism and

discrimination as well as empowered young Black women and their communities to lead the struggle to end HIV.

Women Age 45 – 60 Years

Black women age 45 and older were disproportionately affected by the HIV epidemic as well. Despite that Black women make up only 11% of all older women in the United States in 2001, they accounted for more than 50% of AIDS cases and more than 65% of HIV cases among older women (Winningham et al., 2004).

The number of cases is expected to increase as people of all ages infected with HIV/AIDS survive longer due to triple-combination drug therapy and other treatment advances. Between 1991 and 1996, AIDS cases in the over-50 population rose more than twice as fast as those among younger adults (National Association on HIV Over Fifty, 2007).

Older individuals with HIV or AIDS were usually invisible, isolated, and ignored. Despite myths and stereotypes, many seniors were sexually active and some were drug users. Therefore, their behaviors might put them at risk for HIV infection. The rate of HIV infection in seniors, but not AIDS, is especially difficult to determine because older people have not been routinely tested (National Association on HIV Over Fifty, 2007).

Older persons were typically first diagnosed with HIV during the late stages of infection and often became ill with AIDS-related complications, dying sooner than their younger counterparts do; these deaths could be attributed to original misdiagnoses and immune systems that naturally weakened with age (National Association on HIV Over Fifty, 2007).

HIV/AIDS educational campaigns and programs have not been targeted towards older individuals, as evidenced by the lack of a wrinkled face on a prevention poster. Seniors were unlikely to consistently use condoms during sex because of a generational mindset and unfamiliarity with HIV/STD prevention methods (National Association on HIV Over Fifty, 2007).

Special Considerations for Older Women

For older women, there were special considerations, including menopause, decreased need for condom use as birth control, and normal aging changes (e.g., decrease in vaginal lubrication, thinning vaginal walls) that increased risks during unprotected sexual intercourse (National Association on HIV Over Fifty, 2007). In addition, older people with HIV/AIDS faced a double stigma: ageism and infection of a sexually- or IV drug- transmitted disease.

While men who had sex with men formed the largest group of AIDS cases in the over-50 population, the number of cases in women infected heterosexually had been rising at a higher rate and continues to comprise a greater percentage of those entering into their 60s and beyond. HIV-infected seniors, sensitive to cultural attitudes that assumed elderly people had lived their lives, became fatalistic about the possibility of dying from AIDS (National Association on HIV Over Fifty, 2007).

Older individuals might confront social and professional biases regarding the allocation of limited health care services and resources available to the AIDS community (e.g., whether spending money the elderly implied the best use of precious resources). Because the aging process itself lowered energy levels and resulted in restrictions in social routines that could cause emotional/psychological problems, an older adult

infected with HIV might feel additional losses and could endure further severe depression. Seniors often have been less likely to find support and comfort among family and friends and, because they were traditionally not comfortable in support groups, they might be less inclined to join them (National Association on HIV Over Fifty, 2007).

Power Relationships

Various living conditions influence the context within which low-income Black women engage in a diverse range of high-risk behaviors that increase their risk for HIV infection. Gentry, Elifson, and Sterk (2005) conducted a 2-year ethnographic study from a Black feminist perspective on two groups of women, including street women and house women, to explore the affect of living conditions on the high-risk behaviors that increase their risk of HIV infections. The study defined street women as those who were the absolute homeless, the rooming housed, and hustling homeless. House women included women who were family housed, the heads of household, and the steady-partner housed. The results revealed that various living arrangements placed women at risk in different ways and suggested that low-income Black women were at high risk for HIV infection, a group often considered homogeneous and having within-group needs that must be addressed in HIV prevention research.

Additional studies examining women's abilities to negotiate safer sex behaviors have been the focus of HIV risk reduction research. An ecological framework that located sexual behavior within the context of gender relations became a common theme. Researchers suggested that women might be at a disadvantage when initiating protective sexual behavior because of gender- and cultural-based imbalances in heterosexual, interpersonal relationships.

Another research study (Ketchen, 2007) considered two aspects of intimate-relationship power: relationship control (e.g., partner controls what I wear) and decision-making dominance (e.g., who usually decides when to have sex). Decision-making dominance was divided into three subscales (i.e., male dominant, female dominant, mutual). For relationship control, there was an inverse correlation between undesirable life changes and more control on the part of a woman.

Fatalism

Black women continue to hold misconceptions and fears regarding HIV/AIDS and their sexuality. A lack of insurance, an inability to pay for insurance, transportation issues, childcare needs, and problems navigating health care and hospital systems all represent challenges. In addition, a sense of fear, fatalism, silence, a lack of trust in modern medical professionals, and beliefs in folk medicine significantly influence many Black people (Angel Network, 2003).

Of concern is the concept of fatalism, defined as “the view that we are powerless to do anything other than what we actually do . . . [to] not have things so organized that it is possible for us to do things which affect what beliefs we have” (Rice, 2006, p. 4) and its relationship to Black women’s beliefs about HIV/AIDS. The literature supported common beliefs among Black and Hispanic women that they have HIV because they committed a sin, thus they deserve the punishment, and death is inevitable. Furthermore, this fatalistic belief can hinder their ability to make reasonable decisions about health care and women might not seek preventive care and follow through with treatment recommendations (Powe, Daniels & Finnie, 2005). This research project will attempt to address these areas of concern.

Race, Gender, and Beliefs about HIV/AIDS

The HIV dilemma for Black people, aged 13-39 years, supported the need for further investigation as to why HIV has increased in Black people, ages 45-60 years over the past decade. As indicated by SDHHSPC (2006), educational and culturally sensitive services have not always been available. Furthermore, the provided services did not focus on Black women between the ages of 45-60 years. In addition, a physical assessment of Black women in this age group as benign might contribute to misdiagnoses and a rise in those becoming newly infected.

A lack of interest in HIV testing more likely affected older women despite that more than one-half of these women have participated in risk factors exposing them to HIV at some time in their life. In addition, Black women were unclear about what was expected of them for their health care needs. They looked towards their health providers to guide them as needed. When that did not occur, many were not assertive or were ashamed to ask for HIV testing (Akers, Bernstein, Henderson, Doyle, & Corbie-Smith, 2007).

According to Grant (2005), single Black women and their physicians shared many of the same concepts about midlife sexuality and women in their 40s and 50s. Most women believed that they were at-risk for HIV, whereas most physicians considered their younger patients, ages 15 to 29, to be at-risk and believed the risk declined with a patient's advancing age and gender. This research project may identify that physicians also may need education to focus on HIV in midlife women.

Black American Feminist Theory

Contemporary Black American feminists have identified central themes in Black feminism evidenced in a struggle that has continued in the U.S. for over a century. These themes included, (a) the presentation of an alternative social construct for not only the present time, but the future, based on the experiences of African American women; (b) a commitment to fight against race and gender inequality across the boundaries of class, age, sexual orientation, and ethnicity; (c) a recognition of the struggles of Black women; (d) the promotion of Black female empowerment through voice, visibility, and self definition; and (e) a belief in the interdependence of thought and action. As Black women became cognizant of the multiple-systemic forces of oppression, they pursued collective actions towards social change, transforming society and themselves through their own agency and self-determination (Barlee, 1994).

Nursing has begun to recognize the need to be more culturally sensitive, explore these unknown concepts and theory, and apply them to their research and practice. Many important issues pertaining to health care and the Black patient have been ignored when observed through a white-only lens.

Barlee (1994) addressed this concern and related that, despite the presence of Black feminist literature, the growing body of nursing literature based on feminism and the feminist approach to research remained narrowly focused on white feminist concerns. By ignoring the realities of Black women, nursing reproduced the errors of previous white feminists. Barlee demonstrated the relevance of the Black feminist approach to nursing by applying it in conjunction with general feminist research principles and anthropological theory in research concerning the experiences of low-income Black

women with dysphoria and depression. The findings of his study suggested that a combination approach more clearly illuminated how context affected dysphoria in poor Black women.

One Woman's Story

A typical HIV-positive midlife Black woman would be best illustrated through the following example. Mar is a 47-year-old Black woman with two children, ages 12 and 17. She resides in low income housing in Southeast San Diego. To support her family, she works for minimum wage as a receptionist for a nonprofit organization. She is HIV positive.

Mar's story began when she befriended a deacon in her church. After dating for 10 months, he proposed to her. She believed she was finally getting what she had prayed for – a husband. She related, “I have been alone for five and half years. I needed help, both financially and emotionally, to raise my kids” (Personal Communication, Mar Moon, November 15, 2006).

Mar continued, “I went to a women's workshop at my church which was on marriage. Some of the content of the workshop's content was on intimacy, sexually-transmitted diseases and HIV/AIDS. I was shocked when I heard the presenter discuss some of the physical symptoms of the diseases. I was experiencing some of the symptoms” (Personal Communication, Mar Moon, November 15, 2006).

Mar took the advice of the presenter and was tested for HIV. She soon discovered that she was HIV positive. She is now faced with a grave dilemma and has many unanswered questions. However, the biggest disappointment was learning that she has a

life-threatening disease because her husband was unfaithful. Mar's story, and other women in similar circumstances drive the need for further research.

Necessary Actions

Specific programs must be implemented for older adults who need to be informed about the transmission and prevention of HIV. Outreach should include workshops and training devoted to basic HIV/AIDS information, *safe* sexual and drug-using practices, testing, and negotiation skills all tailored to the older population. Health care and service providers on all levels should be educated on HIV-risk behaviors and symptoms of HIV infection; they need to conduct thorough sex and drug-use risk assessments with their older clients/patients (National Association on HIV Over Fifty, 2007).

Programs are needed that focus on teaching health care and service providers, including the prevention of misdiagnoses, testing technologies, treatments, support groups, case management, and the importance of being actively involved in the health and well-being of older clients/patients (National Association on HIV Over Fifty, 2007).

In addition, successful media and social marketing campaigns may raise awareness of HIV/AIDS in older people and reinforce the need for educational programs, while promoting respect and validation for those who are elderly (National Association on HIV Over Fifty, 2007). For example, California as a state and San Diego as a county differ from other locations in the United States. The proportion of HIV-positive people is smaller both in women and in Blacks. In California, 2.1% HIV cases involve women under the age of 29; however, 13.1% involve women age 50 years or older (County of San Diego Health and Human Services Agency [CSDHHSA], 2006). As a result, experts speculate on the root 'cause(s) for increasing rates, but little information on this specific

age group is available. Prevalence rates are unclear but believed to be higher than previously expected.

Furthermore, a recent research study conducted in Pittsburgh, PA, documented an increase in the portion of AIDS cases diagnosed each year involving people most likely infected between 30 and 50 years of age. HIV prevalence data suggested that the age group of those 20-44 years of age, followed by those over 44 years of age, constituted the predominant pool of infected persons thus serving as the main potential source of new HIV infections (Allegheny County, 2005).

Statement of Problem

In 2002, the leading cause of death for African-American women aged 24-35 years was HIV/AIDS. Of the 123,405 women inflicted with HIV/AIDS, 64% were African-American (Centers for Disease Control and Prevention, 2006). The increase in African-American women being diagnosed with HIV translated into additional needs for services in San Diego County.

A survey conducted by the SDHHSPC (2006) determined the needs of people living in San Diego who were diagnosed with HIV. The survey included questions designed to gauge an individual's level of knowledge about how the disease was transmitted. One significant survey finding was that 32% of participants did not inform their sexual partners that they were HIV positive.

The County of San Diego estimated that, of 508 reported HIV cases, 129 cases involved African-American women (CSDHHS, 2006). Because of this survey, specific needs were identified by the SDHHSPC (2006), including inclusive and coordinated services, such as culturally sensitive education, case management, and resources that

were lacking in many communities. In addition, the needs of the participant's entire family should be assessed in order to adequately support the participant.

The primary target population was the Black female community with a secondary target encompassing all women of low-socioeconomic status. Presently, many Black women are the primary heads of their household and they worry about being unable to provide care for their families. Added to this is the financial cost of treating HIV/AIDS, the lack of medical insurance that makes testing difficult, a clear diagnosis, and a lack of access to pertinent medical services. Therefore, it is not surprising that many choose to put off a visit to the doctor until it is unavoidable.

Statistics Given on the San Diego Census Report

The total population of Southeast San Diego is 9,347: 36.8% Black, 28.6% Hispanic, 19.5% White, and 8.7% Asian. More than 30% of the families live in poverty. Female head of households in the area total 853 (40.8% of all households). The median household income in Southeast San Diego County is \$23,845 compared to \$47,067 in San Diego County (San Diego County Census Report, 2000).

Most of the female heads of households include two to four children and are raised by a single parent with limited cash flow. Financial constraints are responsible for limited access to health care. However, if a woman involves herself in a relationship or risky behaviors to obtain financial support, she could compromise her own lifestyle, health, and the health of her children.

Gaps in the Literature

Little research has been conducted specifically looking at the reason(s) for increased HIV in Black women aged 45 – 60 years. In addition, many research studies

predicted the likelihood of Black women respondents engaging in safer sex behaviors, but acknowledged this as a partial component of the problem (Sediacek, 2006).

Furthermore, a few research studies have focused on HIV patient health beliefs and their experiences living with HIV, but more research is needed on the issues of health care providers concerning time constraints and biases on aging and sexuality, all of which hinder Black women patients' prognoses (Grant, 2005). In addition, more research is needed in seniors' sexual and drug-using behaviors as it affects HIV disease progression and treatment for those age 50 and over (National Association on HIV Over Fifty, 2007).

This researcher believes that there is a significant relationship between HIV-positive Black women and their male counterparts that may contribute to the risky behaviors of Black women. The health disparities Black people face further complicate the ultimate health of HIV-positive Black women.

These questions demand answers that only further research can provide. This research study will uncover some of the answers through experiences of the participants that will provide pieces of this puzzle that will enhance the strengths of nursing research.

Purpose of the Study

The purpose of this research study is to explore the factors that contribute to the increase of HIV in Black women ages 45-60.

Research Design

The Ethnography Research Design approach, coupled with the Black American Feminist Theory, is appropriate for the proposed population.

Specific Aims

This research study will explore and describe the lived experiences and power relationships between Black women, their men, and pertinent mediating social factors.

Significance of Research on Society, Academia, and Industry

This research study's findings will increase the body of knowledge involving the relationships between Black women (ages 45 – 60 years) and men. It will also provide some preventive strategies for decreasing the incidents of HIV/AIDS in Black women in this age group. In addition, this study will reduce negative societal dialogue concerning HIV-positive Black women. Finally, the findings of this research study may provide a basis for further research to improve compliance with recommended treatment of Black women infected with HIV.

Nursing Research

The following lists the purpose of this research as it relates to nursing.

- To increase the use of the feminist grounded theory by future nurse researchers. In addition, the feminist ethnography exemplifies the paradigm of qualitative nursing research (Yi and Yin, 2004).
- To increase the body of nursing science and can aid nurses in becoming leaders in preventive health care policies and programs for women 45 – 60 years of age by providing innovative health education and support for this age group.
- To help nurses make a positive difference in winning the war on HIV by realizing the influence of culture on illness and wellness and the importance of utilizing patients' strengths when planning care. This can be accomplished by providing

voices to women and by insisting on quality assessments for those presenting with the signs and symptoms of HIV/AIDS, regardless of age.

Conclusion

The success of HIV-positive Black women 45 – 60 years of age and health care providers requires a proactive approach towards treatment recommendations and compliance. Changes may occur for different reasons and may be motivated by either external or internal factors. Subsequently, HIV-positive Black women who understand their illness, pursue health care, and receive and comply with valuable treatment recommendations will enjoy improved health.

Furthermore, learning more about this integrated set of implications will serve as an explanation for this phenomenon influencing recommended treatment compliance of Black women who are HIV positive. These recommendations will also give nurses a correct balance of preventive tools (e.g., health care, education) to facilitate a reduction of risky behavior and pre-mature death for Black women.

CHAPTER 2

Literature Review

A brief review of the historical development of the HIV virus will provide the foundation of the literature review. The research in the files of the professional literature will provide an understanding of the HIV-positive Black women's struggle with the illness, societal attitudes, and mediating social support as it relates to their health care-seeking behaviors.

In 1992, the World Health Organization (WHO) estimated that as many as 10 million people around the world were infected with HIV and 40 million would be infected by the end of the 20th century. This staggering prediction reflected the general consensus that, without the immediate and proper interventions, the epidemic would spread rapidly and vastly through sexual transmission (Institute of Medicine, 1994).

Background and Significance

At the end of 2003, the CDC (2002) estimated between 1,039,000 and 1,185,000 of all persons in the United States were living with HIV/AIDS; 24% - 27% of those were undiagnosed and unaware of their HIV infection. That same year, the estimated number of deaths of persons with AIDS was 18,017; 17,934 adults and adolescents, 83 children under the age of 13.

In addition, an estimated 65 million people in the United States were living with an incurable STD. Approximately 15 million people became infected with one or more

STDs each year. Research showed a direct correlation between STDs and HIV. Effective prevention and treatment could drastically decrease the number of newly infected people with HIV (CDC, 2003).

In 2003, women constituted 28% of all HIV/AIDS cases in the United States; approximately 69% of those cases were among non-Hispanic Black women. At that time, the HIV-infection rate for Black women in California was 14 times higher than that for White women (CDC, 2003).

Of the 123,405 women living with HIV/AIDS in 2006, 64% were Black women (CDC, 2006). The increase in Black women diagnosed with HIV translated into an additional need for services in San Diego County. The SDHHSPC (2006) conducted a survey to determine the needs of San Diegans diagnosed with HIV and developed questions designed to gauge the level of knowledge on transmitting the disease. The survey found that 32% of participants did not inform their sexual partners that they were HIV positive (SDHHSPC, 2006). In 2002, the leading cause of death for Black women 24 – 35 years of age was HIV/AIDS (CDC, 2006).

HIV-positive Women Ages 45 – 60 Years

The steady increase in HIV infections in Black women appeared compounded due to the increase of Black women 45 – 60 years of age. Research studies were scarce on this age group.

One research study examined the number of AIDS cases diagnosed each year. These cases were probably infected between the ages of 19 and 29 and their numbers have been increasing. A consistent observation across the country was of those who were between 40 and 60 years old at the time of AIDS diagnosis; this assumes a 10 year

incubation period. HIV prevalence data suggested that the age group 20 to 44 year olds, followed by those older than 44 years old) constituted the predominant pool of infected persons who were thus the main potential sources of new HIV infections ((Alleghany County, 2005).

Furthermore, Black women aged 50 years and older were disproportionately affected by the HIV/AIDS epidemic. In 2001, Black women comprised 11% of all older women in the United States; however, they accounted for more than 50% of AIDS cases among older women and more than 65% of HIV cases among older women. (Winningham et al., 2004).

The number of cases of HIV/AIDS for all women has also been growing over the past few years. Heterosexual transmission has become the most commonly reported mode of HIV transmission among women. Black women make up a growing portion of newly reported HIV infections. The rise in the number of cases in women of color, age 50 years and older has been especially steep. These statistical trends should concern women who re-enter the dating scene after divorce, separation, or widowhood. Most were infected with the virus through sex with infected partners. Many others obtained HIV through shared needles. Because women typically live longer than men and because of the rising divorce rate, many widowed, divorced, and separated women return to dating (National Association on HIV over Fifty, 2007).

Like older men, many older women might be at risk because they did not know how HIV/AIDS spread. Women who no longer worried about getting pregnant might be less likely to use a condom and to practice safe sex. More women have been widowed at an age when they were still active sexually. Despite myths and stereotypes, many seniors

have been sexually active as well as some drug users; therefore, their behaviors could put them at risk for HIV infection. In addition, vaginal dryness and thinning often occurred as women aged; when that happened, sexual activity could lead to small cuts and tears that raised the risk for HIV/AIDS (National Association on HIV over Fifty, 2007).

Multiple Partners

Research associated a higher number of lifetime sexual partners with increased risk of HIV infection. Among sexually experienced female teens in 2003, 16% of Blacks reported four or more lifetime sex partners as compared to 11% of Latinas and 10% of Whites (CDC, 2005).

The Older Male Partner

Young women might be at a higher risk of HIV when an older male was their sex partner. Compared to adolescent males, older male partners might present a greater risk of HIV infection because they were more likely than adolescent males to (a) have had multiple partners and varied sexual and drug use experience, (b) have concurrent sexual partners, or (c) already be infected with Chlamydia or other STDs. In addition, power inequality and age differences played a role in the relationship dynamics between the adolescent female and her older male partner. Research indicated that, compared to older women, a younger female trusting the experience and caring of the older male might be less able to negotiate condom use, might rely more on her partner for sexual health information, and/or might allow her partner to make sexual health decisions that were not in her own best interests (CDC, 2005).

Grant (2005) explored differing cultural models of midlife female sexuality by recently single women from a displaced homemaker program in north Florida and

primary care physicians in the same community. Clinical communication research suggested that patients and physicians might differ in their perceptions to such a degree that effective health communication was hampered.

The study considered how 44 midlife women conceptualize sexuality and sexual health for themselves and other women their age, compared to how 31 physicians conceptualized sexuality and sexual health for older women patients. These sexual health conceptualizations included a focus on HIV/AIDS knowledge, risk perceptions, and their ideas about discussing sexual health in clinical contexts (Grant, 2005).

Furthermore, Grant (2005) discussed African-American and Euro-American women between the ages of 45 and 68 who completed demographic surveys, health care encounter vignette-based interviews, and one of three cultural consensus modeling techniques (i.e., free list, pile sort, rating procedures). Attending and resident physicians, mostly from a family practice clinic, completed a similar interview format. Results reflected that the recently single women and the physicians shared many of the same concepts about the sexuality of women in their 40s and 50s with a few notable exceptions. Primarily, most women believed that they were at-risk for HIV but most physicians considered their younger patients to be at-risk, with the risk declining as the patients advanced in age. Women believed that physicians should discuss sexual health issues with older patients just as they would with the younger generation. They desired a clinical atmosphere conducive to discussing such sensitive topics. Physicians believed that speaking to older patients about sexual issues was an excellent idea, but lacked time with each patient making it very difficult.

Mediating Social Support Factors

A recent study published in the *Journal of Multicultural Nursing and Health* (JMNH; Hurst, Montgomery, Davis, Killion, & Baker, 2005) examined the relationship between social support and its impact on the ability of HIV-positive Black women to perform self-care practices in a descriptive correlational, longitudinal design. A sample of 62 women between the ages of 19 and 60 completed the Norbeck Social Support questionnaire, the Denyes Self Care Agency Instrument, and the Hurst Demographic Questionnaire. Bivariate statistics and Pearson product moment correlations were used to analyze the data. The results noted that the highest positive correlations were in women who perceived themselves as healthy and performed self-care practices. It was important to address the women's attitude towards their illness along with their experience in coping with the stress of their illness. According to Bova (2001), focusing on the cognitive appraisal model of stress and coping was useful for building knowledge on adjustment to chronic illness among HIV infected women. Interventions aimed at refraining negative appraisals had the potential to affect adjustment.

Socioeconomic Factors

The growing incidence of low-income Black women living with HIV provoked psychological distress that compounded adjustment difficulties and increased barriers to health care. Annual income levels were low with 87% of participants earning less than \$10,000; 84% of the participants were African-American (Catz, Gore-Felton, & McClure, 2002). These researchers assessed the levels of the Black women's depression, stress, and anxiety symptoms and found them to be elevated. Few women demonstrated active coping skills and they perceived fewer social supports. Furthermore, young Black women

15 to 24 years old were at a heightened risk of HIV and other STDs. The reasons were complex and included poverty, discrimination, inadequate access to health care, disproportionate rates of incarceration, distrust of the government, and sexual risk-taking. Sexual risk-taking, itself, was largely affected by poverty and lack of opportunity. In order to address the heightened risk for HIV that these young women faced, society ought to directly confront racism and discrimination and must empower young Black women and their communities to lead the struggle to end HIV (CDC, 2005).

According to the San Diego County Census Report (2000),

The total population of Southeast San Diego County is 9,347; 36.8% Black, 28.6% Hispanic, 19.5% White and 8.7% Asian. More than 30% of the families live in poverty. Female householders in the area total 853 (40.8% [of all households]). The median household income in Southeast San Diego County is \$23,845 in comparison to \$47,067 in San Diego County (para.2).

Most of those households had two-to-four children being raised by a single parent with a limited cash flow. Financial constraints were responsible for limited access or no access to health care, perhaps contributing to involvement in relationships to obtain financial support and other risky behaviors that might compromise their health and lifestyle.

Consequently, various living conditions influenced the context within which low-income African-American women engaged in a diverse range of high-risk behavior resulting in an increased risk for HIV infection. Gentry et al (2005) conducted a 2-year ethnographic study exploring the affect that the context of living conditions had on those high-risk behaviors that increased their risk of HIV infections through the lens of the Black feminist perspective in two groups of women, street women and house women.

Street women included women who were the absolute homeless, the rooming housed, and the hustling homeless. House women included women who were family housed, heads of household, and steady-partner housed. Results revealed that the various living arrangements placed women at risk in different ways and suggested that low-income African-American women were at high risk for HIV infection; a group often considered homogeneous and having *within group needs* that must be addressed in HIV prevention research.

Additional studies laid the groundwork for present research addressing the disparities of HIV transmission among women of color. Perhaps the most notable was Wingood and DiClemente's (1998) and Younge's (2005) Theory of Gender and Power (TGP), which was used as the theoretical framework for the development of a proposed model in the current study. The goal of the TGP and the current study was to examine how interpersonal power influenced HIV-protective behavior among low-income African-American women while accounting for culture and cognitive-behavioral factors.

This study had two primary purposes. The first purpose was to contribute to the literature on the HIV-related behaviors, attitudes, and beliefs of low-income, African-American women. The second purpose of this study was to propose an integrated model of HIV protective behavior, incorporating both the traditional and contemporary ecological models of health behavior (Younge, 2005).

While only some of the hypotheses were supported in the proposed model, analyses suggested that the model should be investigated further. The hypothesized relationships between variables might need to be further conceptualized with relevant populations. These data provided important new insights into low-income African-

American women's risk for HIV infection, especially the factors that were relevant to women's interpersonal relationships (Younge, 2005).

Health, Illness, and Disease

The World Health Organization (WHO) (1948), in the “preamble to its charter, announced that health is a state of complete physical, mental, and social well-being and not merely the absence of disease or infirmity” (p.100). Although the WHO made a blanket definition of health, the question of how to define health remained as it created a multifaceted definition that included health, illness, and disease. Societal attitudes and the environment influenced the health, illness, and disease definitions.

According to WHO (2003) AIDS affected South Africa more than any other country; more than 5 million of its 45 million people have been infected. HIV/AIDS has corroded an already fragile social fabric as it left a throng of orphans in its wake. In November 2003, United Nations officials reported that AIDS killed more than 3 million people worldwide. Another 5 million were infected with HIV, the virus that ‘caused AIDS (para.2).

Many of South Africans lived in unhealthy environments (e.g., no clean water for drinking or bathing, cold damp housing, poor or no lighting, limited food supplies, garbage in the streets, rodents in houses, no indoor toilets/showers, cramped living spaces). Compounding these problems was no access to health care.

A definition of health that is specific to health issues rather than globally including illness and disease has been needed. On a trip to South Africa, this researcher posed the question, “How would one define health? Should health be defined by previous experiences with health problems, cultural, societal influences, and/or traditional

beliefs?” Overall, the answers included, “Who cares, everyone is dying of HIV/AIDS here,” “Can you do something?” “Being healthy means not having HIV/AIDS,” “I need money to buy medication,” and “The government does not help us” (Multiple personal communications, April 1, 2006 –April 14, 2006 with South Africans). Their answers were simple because not having HIV/AIDS would be the ultimate goal. People experienced other diseases (e.g., diabetes, cancer, hypertension); however, these diseases were not killing their neighbors at such an alarming rate.

According to Lupton (1994) defined the onset of illness, especially if severe, as one that “constitutes a threat to the integrity of the body and self- identity, and requires a status change from well person to patient regardless of the type of culture an individual lives in, the dysfunction of the body represented in illness disturbs the harmony between the physical, social and moral being”(p.134).

In contrast, a diagnosis of HIV/AIDS placed the person in jeopardy spirituality, morally, and socially in South African. The pending death cost and took more than controlling the time between diagnosis and death supported by Lupton’s statements. Lupton discussed an important aspect of disease and illness that shed some light on the dilemma, *the Myth* in South Africa. (Lupton,1994)

Further more Lupton (1994) points out in most cases; God is perceived the cause for the person to experience a disease or illness. However, for people with HIV/AIDS, it is their lifestyle and sources of infection is because of their lifestyles and behavior such as substance abuse homosexual activities, prostitution, or innocent victims who have been infected through no *fault* of their own such as recipients of blood transfusions, children born to women with HIV infections or heterosexual women who simply *fell for the*

wrong man without knowing that they were injecting drug users or bisexuals. In summary, the definitions of health, illness, and disease have been influenced by a person's previous experiences with health problems, cultural, societal influences, and/or traditional beliefs. In South Africa, health, illness, and disease were only defined by whether the person had HIV/AIDS.

Health Care Seeking Behaviors

Failure to seek health care contributed to the mortality and morbidity of African-Americans. They experienced the highest morbidity and mortality rates of all American racial and ethnic groups, yet were reported to utilize health care less often than non-minority Caucasians. Understanding reasons for low utilization of health care had promise for reducing these health disparities.

Andersen's Behavioral Model of predisposing, enabling, and need factors that influence health care utilization was used to investigate group differences in self-care, health responsibility, provider problems, geographic access, and appointment availability in low-income African-American and Caucasian elders (Aroian, Vander, Peters, & Tate, 2002). This study examined whether these variables differentially predicted health care after accounting for health status, age, gender, financial comfort, and education. Compared to Caucasians, African-Americans reported significantly more problems with providers, geographic access, and appointment availability, as well as greater personal health responsibility, but they did not differ in the degree to which they utilized health care or were engaged in self-care. Health status and level of self-care were significant predictors of health care utilization for African-Americans, while health status and age were significant predictors for Caucasians.

Study findings suggested that health disparity among African-Americans stemmed more from problems with health care and how it was delivered rather than from the amount of health care that was being utilized. As health care providers, nurses needed to respond to African-American's dissatisfaction with their providers and promote policies to improve geographic access and appointment availability for low-income African-American elders (Aroian et al., 2002).

In addition to such disparities in health, Blacks also report suffering from disparities in the care they receive. A 1999 study found that 80% of Blacks believed they received different medical treatment and had different care options due to their race. Findings from a 2001 study by The Kaiser Family Foundation's National Survey of Physicians corroborated Black patients' sentiments. The study first examined physicians' perceptions of disparities in medical care. Of the White physicians interviewed, 77% believed that disparities in how people were treated within the health care system "'rarely' or 'never' happen based on factors such as income, fluency in English, educational status, or racial or ethnic background" (p.3). In the same survey, 8 out of 10 Black physicians reported that the "health care system at least 'somewhat often' treats people unfairly based on various characteristics, with differences that are particularly striking with regard to race and ethnicity (Williams & Johnson, 2002, p.4).

It has been suggested in the discussion about the disparity of health treatment Blacks receive that health providers must encourage HIV-prevention efforts including the use of rapid testing, and they must offer care in the communities where care was needed (Strothers. Lewis, Hood, Butcher, 2004). In addition, that care must be provided by people who were knowledgeable about and sensitive to the populations that was being

treating. To ensure that their patients were receiving appropriate care, clinicians should seek consultations, when appropriate, from physicians in other specialties with experience in HIV/AIDS including cardiology, endocrinology, and obstetrics/gynecology.

African-American women have continued to experience disparities in health status when compared to their European-American counterparts, yet often their unique perspectives were not presented in the nursing literature. Ebron-Shamble (2005) discussed various theoretical frameworks arising from Black women's thoughts and reality that could be used to enhance and expand transcultural nursing knowledge. Historical, socio-cultural, and literary perspectives were used to illuminate the realities of African-American women's lives. Selected frameworks arising from these realities recognized the impact of race, class, and gender on the lives of African-American women and had the potential to guide nursing research and practices.

According to the National Alliance of State and Territorial AIDS Directors (2005), early public health responses were not geared toward the African-American community; therefore, education and resources were not targeting this population. HIV in this population was spreading and families were segregating. Few health and human service programs provided services specifically geared toward African-American women with HIV and there was an outcry for resources and services for this population.

A qualitative study conducted by Rajabiun et al. (2007) investigated the process of engagement in HIV medical care from the perspective of people living with HIV/AIDS (PLWHA). In-depth interviews were conducted with 76 participants in six cities. All participants were considered underserved because of histories of substance use, mental illness, incarceration, homelessness, or cultural barriers to the traditional health

care system. A semi-structured interview guide elicited narratives related to health care and the role of program interventions in facilitating access to care. Data analysis revealed that participants cycled in and out of care, a process that was influenced by (a) their level of acceptance of being diagnosed with HIV, (b) their ability to cope with substance use, mental illness, and stigma, (c) their health care provider relationships, (d) the presence of external support systems, and (e) their ability to overcome practical barriers to care.

Rajabiun, et al (2007) further discussed how outreach interventions played a role in connecting participants to care by dispelling myths and improving knowledge about HIV, facilitating access to HIV care and treatment, providing support, and reducing the barriers to care. The findings suggested that outreach programs could interrupt this cyclical process and foster sustained, regular HIV care for underserved PLWHA by conducting client-centered risk assessments to identify and reduce sources of instability and improve the quality of provider relationships, implementing strategies that promote healthy practices, creating a network of support services in the community, and supporting adherence.

Theory Development

To answer these questions and further understand this phenomena; theory development will be critical. According to Meleis (1997)

Knowledge breeds knowledge; the more knowledge we need, the more we are stimulated and challenged to further develop an understanding of the phenomena. Theory development in nursing is enhanced by the wealth of theoretical knowledge we already have. The theories developed by nurse scholars provide an impetus for further refinement and development. They lead to an agreed upon set

of concepts and are central to nursing and point to phenomena of interest to nursing. (p. 65)

According to Im (2005), nursing theory changed towards epistemic pluralism in theoretical and philosophical thinking. In the 1950s, under the tremendous influences of logical positivism, grand theories were developed and used to answer questions on the nature, passion, and goals of nursing and nursing scholars. Theorists believed in the unity of nursing knowledge; however, over the last 60 years, theorists argued the validity of nursing theory and developed many other definitions and steps to theory development. As an example, Nolan, Lundh, and Tishelman (1998) suggested nursing benefits from having their patient care grounded in nursing theory which promotes quality dialogue between health care providers and professional growth.

Nursing Research and Theory

This section will explore whether the role of nurses in the delivery of health care differs with opportunities for treating a pandemic disease in diverse locations, including undeveloped countries (e.g., South Africa). In addition, this section will seek to understand if health care providers' practices contribute to the health disparities of HIV-positive Black women and whether these health practices and their patients' access to health care 'cause new problems for nursing care.

In 2005, this researcher suggested to colleagues this unique dilemma in health care delivery should be addressed in a nursing theory:

It would fall under the category of a Situation-specific theory, Chinn and Kramer (2004) defined the Situation-specific theory that focuses on specific nursing phenomena, that reflect clinical practices, and that are limited to specific

populations or to particular fields of practice. It is different from the other theories because it can incorporate diversities and complexities in nursing phenomenon, consider sociopolitical, cultural, and historical context of nursing encounters, and be easily applicable to nursing practice (p.138).

Chinn and Kramer (2004) pointed out the choice of a particular approach depended on one's purpose for developing theory, what one already knew or assumed to be true, and one's underlying philosophic ideas about the nature of nursing knowledge. If one began with an entirely new idea about something with little existing research, the form of the theory one constructed might categorize concepts into a relational taxonomy that essentially describes those ideas. If Chinn was correct, then the string of empiric concepts developed from the experiences of Black women would lead to the examination of the HIV/AIDS epidemic from a cultural aspect versus traditional treatment models. That would help to explain the subtle intricacies of culture, society, locus of control, and practices influencing South Africans infected with HIV/AIDS.

Nursing could be the leader in preventive health care polices and programs for women ages 30 – 60 by providing innovative and preventive health education and support. Nurses, being the voice of women demanding quality assessments when presenting signs and symptoms of HIV/AIDS, could accomplish this.

An Historical Look at Black American Feminist Approach to Nursing Research

Barnes(2008) discussed the history of the Black American Feminisms dates back to the early nineteen century which profiles African-American women like Maria Stewart,

Anna Julia Cooper and Sojourner Truth were the risk takers. They were involved in protests against slavery and believed Black women had rights also. Although these women did not meet the white profile as a feminist, they were very active in the political movement against slavery and sexist. It was hard not to admire these women for their strength, personal power and visionary statements.

In addition, Barnes (2008) points out the movements of antislavery and women's rights of the nineteenth century was the foundation of the Black women's rights movement in the 1960s and presently. Black women have fought through out history to have a voice independently of white women. Their issues are not quite the same . As the researcher reviewed the literature and compared it to the struggle many Black women have endured the white woman's struggle did not lend itself to life threatening issues such as what was experienced by the Black woman. Black women were *fighting for their lives and the lives of their family*.

Further more the Black American Feminisms, (n.d.) discussed the complexity of the terms to describe Black feminism demonstrate the dimensions of Black American women's demand for social, economic and political equality. However the terms support the desire for a compatible and progressive vision of social justice based on the historical and ongoing struggles against the race and gender is shared .

Despite the presence of a body of Black feminist literature, the growing body of nursing literature on feminism and the feminist approach to research remained narrowly focused on White feminist concerns. By essentially ignoring the realities of Black women, nursing reproduced the errors of previous White feminists. Barlee (1994) demonstrated the relevance of the Black feminist approach to nursing by applying it in conjunction with

general feminist research principles and anthropological theory in research concerned with low-income Black women's experiences with dysphoria and depression. The findings of the research suggested that a combination approach more clearly illuminated how context affected dysphoria in poor Black women.

Yi and Yin (2004) described feminism and proposed the integration of a feminist method into qualitative nursing methodology in order to expand the body of nursing knowledge. The method of the worldview of feminism included philosophy, epistemology, and methodology. A feminist grounded theory and feminist ethnography were suggested as a way of strengthening nursing research methodology using literature review. The results were four diverse philosophical perspectives of feminism: liberal feminism, radical feminism, Marxist feminism, and social feminism. In addition, epistemological perspectives, including feminist empiricism, feminist standpoint, and postmodern feminism, were explained and were related to the methodology and methods of feminism. Yi and Yin suggested that the incorporation of feminist approaches within nursing was a valuable attempt to expand the body of nursing knowledge and to enhance the quality of nursing care services by rectifying male-oriented knowledge and by empowering women in the care of other people. Specific feminist research issues relevant to nursing research included inherent themes in feminist research, feminist research methodology, gender stereotypes, and nursing research gender-based stereotypes. These studies had potential benefits in nursing research when feminist research issues were used. Most formal models of nursing, and thus most nursing research based on these models, ignored gender issues. They ignored part of the social reality of nursing and might provide distorted images of nursing. A feminist approach to nursing research could

enhance the reality-based gender issues relevant to nursing specifically, health care generally, and contribute towards rendering effective health care within a multidisciplinary health care context (Ehlers, 1999).

Women's mental health has been linked to oppression and to oppressive practices in health care. Feminist approaches to health care delivery and research have been suggested as a remedy for the subtle and overt oppression faced by women. Many nurses have used feminist principles to conduct and report their research and to critique existing studies. Though nursing authors have identified useful feminist guides for conducting and reporting research, few examples of the practice of feminist critiques of research have been available in the nursing literature. This analysis synthesized and adapted feminist principles from nursing literature and presented a feminist model to review selected nursing research reports of women with HIV. A convenience sample of eight articles from nursing journals were examined for statements or implications that the authors (a) perceived the purposes of the study as benefiting women, (b) demonstrated an awareness of the structures and policies that oppressed women, (c) were sensitive to issues of diversity, (d) were committed to social change, and (e) recognized the female participants' strengths. The selected articles were found to meet many of the feminist criteria, although these principles were not always explicitly addressed in the articles (Bunting, 1997).

Fatalism

Little, if any, systematic research has been conducted to reveal how adult African-American women and males who were infected with HIV knew and felt about the epidemic; how they obtained the information they had; and how they saw themselves in

the context of both HIV/AIDS and society. The absence of such knowledge left a great gap in the development of programs for an ethnic group that has been affected and infected to a greater proportion than any other group.

Harper (1998) conducted a research study that was designed to assess the educational needs of African-American males. For most of the men in the study, their optimal and actual knowledge levels were closely related but they did not practice their HIV/AIDS knowledge consistently because they allowed personal and cultural barriers (e.g., fear, denial, isolation, low self-esteem, fatalism, lack of trust in medical professionals) to interfere with their use of HIV/AIDS knowledge. Therefore, programs were still needed to help adult African-American males make better use of their knowledge of HIV/AIDS improve their quality of life.

While fatalism has been well documented and perceptions effect health behavior, there existed a paucity of research as to men's perceptions of free prostate cancer screening. Additionally, the concept of fatalism prevalent among the socio-economically disadvantaged had not been investigated in combination with perceived benefits and a dependent measure of freedom (Tingen-Smith, 1995).

Research examining the degree to which perceptions of fatalism influenced breast cancer screening in culturally and ethnically diverse population groups was scant. Spurlock and Cullins (2006) described the outcomes of a study undertaken to examine relationships between perceptions of cancer fatalism and breast cancer screening in African-American women. Findings supported the postulation that fatalism negatively influenced health-promoting practices (e.g., breast cancer screening). Contrary to prior though, research findings revealed that age was observed to be inversely associated with

cancer fatalism. This research study could serve as one of the key bridges for nurses to play an active role in assisting patients with the diagnosis of HIV and cancer.

Nurses have enjoyed a key position in enhancing knowledge, correcting misperceptions, and allaying fears related to breast cancer. However, little attention was given to these psychosocial issues in nursing texts and the extent to which they were covered within nursing curricula was unclear.

A study guided by the Powe Fatalism Model compared perceptions about breast cancer and sources of cancer information among a random sample ($n = 158$) of nursing and non-nursing female students ($M = 24$ years old). Data were collected using the Breast Cancer Perceptions and Knowledge Survey and a demographic questionnaire. A significant number of myths and misperceptions related to breast cancer were prevalent within both groups. Few nursing students reported obtaining information on common perceptions about cancer from their coursework. More research was needed to understand how the nursing students' perceptions about breast cancer influenced their ability to provide patient care across the cancer continuum (Powe, Underwood, Canales, & Finnie, 2005).

This study was symbolic of the voices and experiences HIV-positive Black women shared with this researcher. "When I heard I had HIV.I thought I was going to die the next day." "People die within a few years when they get HIV?" "I did not want to die but what could I do to stop death from coming?" (B. C, S. D. and F. I., personal communications, November 5, 2007). Nurses needed to be sensitive to the voices and to consider how best to deliver care to the HIV-positive Black women.

Because of the settings in which they work, nurses have been in a key position to significantly enhance knowledge, allay fears, dispel myths, correct misperceptions about chronic illnesses, and encourage adoption of healthy behaviors. However, the role that nurses could play depended on their own knowledge, beliefs, and perceptions. Their educational preparation, their training after graduation, and their lived experiences shaped nurses' knowledge, beliefs, and perceptions (Galaychuk, 2000).

Power Relationships

Sharp and Stitzinger's (2003) study expanded research done on power and satisfaction in romantic relationships. They hypothesized that those with less power would also be less satisfied. Using data from 54 college students, the reported level of power and satisfaction in their relationships was examined. One finding was an inverse correlation between power and satisfaction. They also discovered that longer relationships correlated with less satisfaction. While the findings did not support the research hypothesis, useful information from this study could guide future study of relationships.

Sharp & Stitzinger (2003) described power as control over one's partner and having decision-making ability. Both males and females agreed on this definition. Most described their relationships as egalitarian, claiming that in a true loving relationship, power should not exist. Men and women had different views on what made them feel powerful and decision-making duties were often delegated in accordance with typical gender role divisions in labor. This study did not, however, focus on relationship satisfaction to perceived power.

Mixed findings have been discovered related to satisfaction and power in relationships. Therefore, this phenomenon should be an important topic to study in order to gain more knowledge on the connection between these two variables. Based on the previous research, one might hypothesized that the partner with the least amount of power in the romantic relationship would be the least satisfied in that relationship and those who reported the highest equality in power would be more satisfied with their relationship than those in unequal power relationships (Sharp & Stitizinger, 2003)

Kyomugisha's (2003) study examined another aspect of power relationships. The study surveyed 201 women attending a sexually transmitted disease (STD) clinic in Milwaukee, WI. The women in the study engaged in risky sexual behavior, had a sexually transmitted disease, and therefore were considered to be at high risk of sexually transmitted HIV. The results of the survey showed that the women (a) acknowledged relational patterns that favored men, (b) perceived themselves as having power in general but not in sexual relations, (c) had a negative attitude to condoms, and (d) did not use condoms. These findings suggested that HIV risk-reduction interventions for African-Americans at risk for HIV were unlikely to be successful unless they educated women about relational dynamics and empowered them in their own self-interest despite negative cultural, demographic and socio-economic pressures.

Burney (1995) discussed codependent, dysfunctional relationships where participants exhibited the dynamics that were a normal consequence of relationships between people raised in an emotionally dishonest and repressive, shame-based culture. As soon as one met another who would help repeat the patterns of abuse, abandonment, betrayal, and/or deprivation, the more inviting the person. Codependents had radar

systems that 'caused one to be attracted to the people who were the most untrustworthy, unavailable, smothering, abusive, or whatever was needed to continue the cycle.

What the Literature Reported

The overview of the literature did not support this researcher's concept ethnology of Black feminist theory in the construct of HIV-positive Black women 45 – 60 years of age. Nor was there a wide body of research in the literature that discussed fatalism in Black women with HIV. However, the literature did discuss Black women-men relationships, power relationships, the Black feminist approach, and health disparities. Furthermore, as the rate of HIV infection grew for Black women, the body of research addressing mediating social supports, social-economic issues, health care, and needs remained insufficient. Few empirical research studies were primarily qualitative or quantitative. Therefore, a mixed methodology may be the method for future research.

CHAPTER 3

Methodology

The primary aim of this research study was to examine multidimensional, interconnected assumptions and beliefs based on the many themes that surfaced during the interviews with HIV-positive midlife Black women. This study combined ethnography research method with the Black American feminist theory as a mechanism that examined older Black females lived experiences with HIV.

The steady increase in HIV infections in Black women is compounded in part with an increase in women 45 – 60 years of age. There is a dearth of research on this age group. One research study examined the number of AIDS cases diagnosed each year. A consistent observation across the country was of those who were ages 40-60 at the time of AIDS diagnosis (assuming there was a + 10 year incubation period). HIV prevalence data suggests that the age group 20- 44 years (followed by >45 yrs) constitutes the predominant pool of infected persons who are thus the main potential sources of new HIV infections (Alleghany County, 2005).

Furthermore, Black women age 50 and older are disproportionately affected by the HIV/AIDS epidemic. In 2001, Black women comprised 11% of all older women in the United States; however, they accounted for more than 50% of AIDS cases among older women and more than 65% of HIV cases among older women (Winningham et al., 2004).

Research Question

What factors contribute to the increase of HIV in Black women ages 45 – 60 years?

Overview of the Qualitative Research Study

According to Creswell (2002), “a qualitative study is reflective of the participants’ views of a central phenomenon and the researcher’s deeper understanding of it” (p.149). Qualitative research relies heavily on actual data collection to look for emerging themes through open-ended participant questions. Although a literature review is necessary in qualitative research, it does not play the central, leading role in driving the research that it does in quantitative research. Qualitative research relies heavily on actual data collection to look for emerging themes through the use of open-ended participant questions. *Present* data collection leads the research process in qualitative research.

“The design for qualitative research is often emergent and depends on what the researcher learns as the study unfolds” (Polit, Beck, & Hungler, 2001, p. 207). The research is limited to content analysis, which is the process of organizing and integrating narrative information according to emerging themes and concepts

Ethnography Research Method

Ethnography literally means a *portrait of a people*. An ethnography is a written description of a particular culture, the customs, beliefs, and behavior, based on information collected through fieldwork (Harris & Johnson, 2000).

Ethnography is a social science research method relying heavily on up-close, personal experience and possible participation, not just observation, by researchers trained in the art of ethnography. These ethnographers often work in multidisciplinary

teams. The ethnographic focal point may include intensive language and culture learning, intensive study of a single field or domain, and a blend of historical, observational, and interview methods. Typical ethnographic research employs three kinds of data collection (i.e., interviews, observation, documents). This in turn produces three kinds of data (i.e., quotations, descriptions, excerpts of documents) resulting in one product (i.e., narrative description). This narrative often includes charts, diagrams, and additional artifacts that help to tell *the story*. Ethnographic methods can give shape to new constructs or paradigms and new variables for further empirical testing in the field or through traditional, quantitative social science methods (Harris & Johnson, 2000).

Black American Feminist Theory

The paper by Ehlers (1999) suggested that incorporation of feminist approaches within nursing was a valuable attempt to expand the body of nursing knowledge and to enhance the quality of nursing care services by rectifying male-oriented knowledge and by empowering women in the care of other people as well as themselves. Ehlers discussed specific feminist research issues that could be relevant to nursing research. This included inherent themes in feminist research, feminist research methodology, gender stereotypes, and nursing research gender-based stereotypes. These studies revealed potential benefits in nursing research when feminist research issues were used. Most formal models of nursing, and thus most nursing research based on these models, ignored gender issues. As a result, they ignored part of the social reality of nursing and might have distorted images of nursing. A feminist approach to nursing research could enhance the reality-based gender issues relevant to nursing specifically, health care generally, and

contribute towards rendering effective health care within a multidisciplinary health care context.

Sample and Sampling Method

This ethnographic study was a non-random convenience sampling as the researcher was not able to conduct a random sampling because of parameters of the inclusion and exclusion criteria discussed below. The participants consisted of 22 HIV-positive midlife Black women between the ages of 45 – 60 years who self-selected to participate in the research study. Two of the participants declined to have their interviews included in the final results of the data collection; therefore, 20 participants interviews were included.

Inclusion and Exclusion Criteria

This researcher chose San Diego County as the region of study. According to the data retrieved from San Diego County's database, there were 232 reported cases of HIV (San Diego County, 2007). The researcher believed that conducting research in other areas of California would not be representative of the San Diego County region for the following reasons:

1. Los Angeles and San Francisco population is not reflective of the lifestyles and culture of Southeast San Diego.
2. The societal views and attitudes towards people with HIV may be different.

HIV-positive midlife Black women were between 45 and 60 years of age, as this represented over 40% of San Diegans with HIV (CSDHSA, 2006). All socio-economic levels were served as the HIV virus affected individuals in all financial levels.

To be included in the study, participants had to be HIV-positive midlife Black women who lived in and/or were born in the United States, who could read at a minimum of an 5th grade level, and who could speak English. Non HIV-positive Black women who were between the ages of 18 and 44 were excluded in the study and younger than 18 were excluded also. Non-HIV positive women are excluded. The age exclusion reflected the current demographic information on age groups and represented 70% of the women who contract HIV (CSDHHSA, 2006). No youth under the age of 18 was considered because parental consent as well as participant assent would need to be obtained to participate in the research study.

Participants had locations and social environments in common and this was exhibited throughout the interviews. When the women shared their stories, there were common threads, including the clinic and support groups they attended. Many of the women had the same health care providers.

Recruitment

The participants consisted of 22 HIV-positive midlife Black women who self selected to participate in the research study by answering recruitment flyers that were posted in clinics and at the African-American World HIV/Aids conference in December, 2007. The researcher set up an appointment with the participants, either in their homes or in a small secluded room in one of their churches. The locations provided the participants privacy to fill out the self-reporting questionnaires and sign informed consent. Barriers included the participant's literacy, time, space, environment limitation, transportation, money, and cultural factors.

Data Collection Tools

Interviews, which consisted of five open ended questions and one question that asked the participants if they wanted to add any other information after the initial interview, were completed along with a demographic questionnaire given to the participants.

Demographic Questionnaire.

From the demographic questionnaire (see Appendix A), descriptive statistics were used to convey average age, marital status, income, education level, date of diagnosis, entry into treatment, dates not in treatment, reason for discontinuing treatment, and reasons for resuming treatment. The results of the demographic information were analyzed to confirm that this was a representative sample.

Interview Guide/General Statement

Describe your experience living with HIV.

1. What influences your decision to have protected or unprotected sex?
2. Describe a conversation you have had with potential sexual partner(s) about sexually transmitted diseases and HIV?
3. Please tell me how you take care of your health?
4. Please describe how your health care needs are met?
5. Is there anything else you would like to share with me before we end the interview?

Procedures for Data Analysis

Advantages

Narrative logic. A narrative of the data collected can be seen in Chapter 4. The data analysis of the content of the interviews was written verbatim to not misinterpret the true meanings and themes in the data collected. In addition, a descriptive narrative of their stories may also be seen in Chapter 4. Chensil (1995) stated the data are arranged with an eye for storytelling. Researchers plot out the data in a fashion that allows them to transition from one exemplar to another just as narrators arrange details in order to best relate the particulars of the story.

Computer coding of data. This researcher decided not to use the Computer Assisted Qualitative Data Analysis Software (CAQDAS) as a subfield of expertise. This type of software package provides a computerized analysis of qualitative data instead of performing the coding by hand (Lee & Fielding, 1991). The reasons for completing the coding by hand was to encapsulate the ethnic, feminist, and cultural overtones in the interviews that may have been misinterpreted by the software thus producing false themes. Reliability was ensured by facilitating a focus group who validated what the participants reported.

Ethnography is one of the most widely used of all the qualitative research methods. The underlying logic of coding and searching for coded segments differs little, if any, from that of manual techniques. There is no great conceptual advantage over the indexing of typed or even manuscript notes and transcripts, or of marking them physically with code words or colored inks. In practice, the computer can add many advantages. The speed and comprehensiveness of searches is an undoubted benefit. The

computer does not search the data file until it comes up with the first example that will illustrate an argument or will it stop after it has found just one or a couple of apposite quotes or vignettes. The software has an additional merit that marks an advance on the practical value of manual coding and searching: it can cope with multiple and overlapping codes and it can conduct multiple searches using more than one code word simultaneously (Genzuk, 2003).

This researcher chose to utilize data coding as a means of analysis. Cooper and Schindler (2002) defined coding as follows.

Coding involves assigning themes to answers so the responses can be grouped into a limited number of classes or categories. Coding helps the researcher to reduce several thousand replies to a few categories containing the critical information needed for analysis. (p. 456)

The three coding phases used by the consultants were open coding, axial coding, and selective coding.

Open coding. Open coding is most closely associated with grounded theory approach to qualitative research. Strauss and Corbin (1990) described open coding as a process of:

- Breaking down data into discrete parts.
- Examining these parts closely and comparing them for similarities and differences.
- Asking questions about the phenomena that are suggested by comparing and contrasting work. (p. 62)

Straus & Corbin (1990) reported that “process of breaking data down involves selecting an observation, a sentence, or a phrase from field notes, taking it apart, and giving a name to each discrete incident, idea, or event. This name stands for or represents a phenomenon” (p. 63). For this study, each item was compared to others and similar items were assigned the same label. The aim of open coding was to develop conceptual categories, to describe subcategories, and to explain phenomena observed during a field-based research study.

To conduct the first phase of the content analysis, this researcher developed a color-coded table that coded the responses per question of each HIV-positive midlife Black woman who participated in the survey. Similar words and concepts were later narrowed into themes and finally attached to a conceptual framework. This researcher was able to understand the data conceptually as well as descriptively.

In the coding of data, three different raters were used independently to assure the accuracy of coding and inter-coder reliability. Burns and Grove (2001) noted that “inter-coder reliability is the degree of consistency between multiple individuals who are coding data” (p. 801).

Axial coding. Neuman (2003) described axial coding as the point in which the researcher “focuses on the initial coded themes more than on the data. He or she moves toward organizing ideas or themes and identifies the axis of key concepts in analysis” (p. 444). Once the researcher attaches coding labels to data, general groups of similar concepts typically emerge. In developing categories from the codes, this researcher was successful in bringing large amounts of data under the umbrella of *higher-order* organizers to keep the numbers manageable. Searching out the relationships between

these higher-order organizers ultimately enabled this researcher to describe, explain, and interpret these data.

To continue the content analysis, this researcher inquired about the *who, what, which, where, why, and how* questions of data previously coded. This researcher gathered all of the conceptual codes referring to a focused category and coded them as new categories. This categorization process yielded higher level themes under which all the initial conceptual codes were accommodated. Coffey and Atkinson (1996) asserted “the process of ‘formalizing’ or deciding upon a theme involves identifying its chief attributes or properties” (p. 13). The second phase did produce categories for action planning. Completion of the axial coding phase led to Phase 3, selective coding.

Selective coding. In selective coding, a conceptual framework took place from the interrelationships of the themes that occurred during axial coding. According to Creswell (2002), this theory provides an abstract explanation for the process being studied in the research.

This researcher did review the selected data collected in the axial coding phase and determined the central phenomena. From this analysis, this researcher developed a conceptual framework that encompassed all of the central phenomena themes.

Qualitative data analysis and interpretation is based heavily on the coded connections, common aspects, and linkages among the data. In order to classify data into categories, it was necessary to think about the meaning of the categories. To aid interpretation, it was important to make explicit the conceptual bases or understandings of the categories and what made one category differ from another. Interpretation of data required both conceptual and integrative thinking and involved identifying and

abstracting important understandings from the detail and complexity of the data. As a result, the information generated supported a deeper understanding of the source of issues that affected HIV-positive midlife Black women in San Diego County.

Disadvantages

The role of the researcher. While researcher bias and subjectivity are commonly understood as inevitable and important by most qualitative researchers, the beginners in qualitative research are generally not comfortable with the idea of research that is not value-neutral. It regards awareness of one's "biases, blind spots, and cognitive limitations as high a priority as theoretical knowledge" (Mehra, 2002, p 2). The idea is to keep the two voices separate, emic (insiders' voice, participants' voice) and etic (outsider's voice, researcher's voice), as much as possible and decide whose voice will be the predominant voice in the text. By nature, the etic voice may be hidden but is always present by way the text is organized, how the data are presented, what quotes are used, and what data are ignored. If interested in the emic voice being the predominant voice to tell the story, then it is important to keep out personal judgments and interpretations as much as possible.

This researcher used emic voices through out the fourth and fifth chapters to emphasize important phrases in the development of the participants' stories. The interviews are unedited to capture the participants' true meanings, cultural, ethnic, and Black American feminist underpinnings.

Protection of Human Participants

According to the National Cancer Institute Human Subjects Protection (n.d.):

The researcher conducting the study has the primary responsibility to ensure that participants in research are fully informed of their rights and properly protected.

The researcher is specifically responsible for ensuring that the study is properly designed, scientifically sound, and yields valid results. The participants meet selection and eligibility requirements. The study is approved by the IRB and conducted according to the protocol. The informed consent is appropriately obtained. The protocol changes and adverse events are reported to the appropriate boards and authorities. The rights and welfare of participants are monitored throughout the trial. Finally, all members of the research team are qualified and trained in research methods and human participant protections. (p. 6).

Informed Consent

A copy of the informed consent form may be found in Appendix C.

Potential Risks of the Study

The potential risks for the participants included loss of confidentiality, revealing their HIV diagnosis to others, and questionnaire results. At the beginning of each interview, the researcher informed the participants that their involvement was voluntary and that they could refuse or cancel their participation at anytime without any monetary or other risks.

One participant ended the interview prematurely because the content of what she was sharing made her cry and 'caused her to relive the initial shock of hearing her diagnosis. Two additional participants completed the interviews but later phoned the

researcher and requested the content of their interviews not be published or shared with anyone else. Those requests were honored by this researcher.

Secondly, this researcher protected the three previously mentioned areas by providing an Informed Consent. No personal information was revealed; this was accomplished by blind identification (e.g., assigning a code number). The questionnaire and demographic results, along with the Informed Content, were locked in fireproof cabinet where no unauthorized person could gain access. In addition, individual data were reported via blind coded interviews transcripts of the aggregated data was disseminated of the scientific research.

Potential Benefits of the Study

Although there was no direct benefit to the participants, this research might help other HIV-positive midlife Black women practice preventive measures and be highly motivated to comply with treatment recommendations.

Conclusion

This research study focused on HIV-positive midlife Black women who resided in San Diego County. All participants were a reflection of the objectives of the ethnography research method combined with the Black American feminist theory; therefore, their selection was nonbiased and non-power-based. The research study reached out to HIV-positive midlife Black women by collaborating with the participants in the research study to understand their experiences and the factors that contributed to them being infected with the HIV virus.

This researcher believes that education can create social change and positive outcomes. With knowledge comes power and choice. The findings of this research study

has provided some insight into the actual influences on HIV-positive midlife Black women's compliance with treatment recommendations. The findings have generated a need for further research in this area.

CHAPTER 4

Results

*Breaking the Walls of Silence: Interview Transcripts***W001****Age: 54****Marital Status: Single****Education level: High School graduate****Income: \$18,000 per year On State Disability****Date of Initial Diagnosis: 9/1997****Infected by: "Unprotected sex"****Health Insurance: Medicare/Medical****Date Entered treatment for the first time: 11/1997****Currently in treatment: Yes****Discontinued treatment: No*****Describe your experience living with HIV.***

Kind of horrible at first. It was kind of horrible, but now it's easier.

First, I was scared I was going to die and then I didn't tell anybody for 5 years, but now I am more comfortable with it. I am still afraid to tell others that I have it. You know other people.

When you did reveal that you had HIV, you spoke to mostly family and friend?

No. I didn't tell my family for 5 years. I didn't tell them. I kept it a secret.

When you did reveal that you had HIV, you spoke to mostly family and friends. But when you decided to reveal that you had HIV, were your family and friends the first ones you told?

Well, I told my brother first and I told him not to tell no body. Then I told my family because I didn't want my family to treat me in a different way. You know, different like they were scared of me or anything like that.

Since that time, has your family been supportive?

Yes. My family treated, yeah, very supportive.

They were very supportive, which I was thinking they wouldn't be, but they are.

What is it that you think is the core reason why you have continued to be hopeful and positive even though you are living with a chronic disease?

I think there will be a cure for it. I guess I'll just have to learn to take my medication and live on. People are not dying from it no more.

Do you practice safe sex?

No. I don't have sex at all.

Is there a spiritual component to why you think you are so positive living within this chronic illness?

I pray to God.

Are you active in your church?

I go to church once in a while. I used to go every Sunday. I don't go that much no more.

Once in a while I'll go.

Is there a reason why you don't go as often?

Sometimes I don't feel like it. I know I got to change that.

A lot of times I am not sure what church is all about and how to worship but in my heart I believe. It doesn't necessarily mean sitting on a church pew but God want us to worship with other people.

I'm wondering, do you have a small sector or group that you have a tendency to talk about your spiritual needs and talk about how good God has been to you.

I go to groups and stuff, but I don't tell the people how good God has been to me. God saved my life you know I was sick 1990 I got sick and I was in a comma for a month. I lost a lot of weight.

Is this when they discovered you had HIV?

No. I used to work at the hospital. I would always donate blood there and so the last time they told me that I had been exposed to someone that had AIDS.

The Red Cross told me. It was very dramatic when I found out.

I used to give it all the time. You know, at my job I would give it all the time And then the last time I donated which I worked on my job for 13 years the last time I gave it they contacted me down at the Red Cross I needed to come down to the Red Cross. They couldn't tell me over the phone. I needed to come down and I went . I thought I was going to die when they told me.

I thought I was going to die right then.

Why?

Because at the time with HIV people thought it was a death sentence.

There is more treatment modalities people are changing their lifestyle and living a lot longer. I know people who were diagnosed 26 years ago.

Really

Yes, they are still living their lives and out there witnessing and helping other people who are getting newly diagnosed so there a mission there. So what influences your decision to have protected or unprotected sex? Well you told me already and basically you decided not to have sex or the fact that you have HIV you know you can practice safe sex, but what Influences you not to have sex at all?

I don't have a boyfriend. And I'm told that if I have a boyfriend ... I can't tell a guy that I am HIV either. As far as I meet a guy. I don't have the nerve to tell a guy. Because I think when I tell them they will run away and he wouldn't want to be with me no more.

If you did meet a man and you didn't tell him you had HIV. How would get him to practice safe sex with you?

Oh. He'd have to have safe sex with me

So you're strong enough and able to say to him "We can't have sex unless you use a condom."

Yes

Describe a conversation you had with a potential sexual partner about sexually transmitted diseases and HIV. Have you ever had that conversation?

No, I haven't.

Could you tell me how you take care of your health? How do you stay healthy?

I take my medication. I take my medication every day. I eat the right foods and stuff. The doctor tells me I should have the surgery for obesity. He says I'm obese.

You're obese? What do you weight right now?

I weight 306. When I tell people I weight 306 they don't believe it. 'cause I am tall with it. I have height.

Do you exercise?

No. I'm going to start exercising. I am going to start walking. When I walk sometimes I get tired. Like what happened with my niece this weekend when we went to the mall. We went to the mall and we had to walk a long way 'cause we couldn't part in the parking lot of the mall. We had to park on the street.

You know if you started out by walking 15 minutes a day for three of four days week an then over a period of a couple of weeks increase that to a half an hour. And if you just walked a half an hour 5 days a week and you are already dong the rest which is taking your medicine, eating correctly, and a positive attitude the weight will come off.

It will?

Yes. In addition, drink water. It will keep your system flushed which helps with weight lost. Could you please describe how your health care needs are met?

They're met fine

Are you comfortable with the care your health care provider is providing?

Yeah, but everything is not related to HIV. When my doctor feels that every time I say something it is related to HIV, but I don't feel it should be related to HIV. Do you know what I mean?

I am not sure. They relate everything you say to HIV.

But I don't relate everything to having HIV!

Can you give me an example?

Like one time I had this cold or something. I had a cold. So I went to the doctor, but I had changed doctor. My friend told me I should go to another doctor and I told the doctor then that my ear was bothering me and I went to another doctor and she told me that I had an ear infection and gave medicine for it when the other doctor said I didn't have anything wrong with me.

Good example thank you.

Is there anything else you would like to share with me before we end this interview?

My private area is getting bigger you know. My private area was getting bigger so I went to the doctor and they said that it is nothing wrong with me. They say I am just fat down there but it s getting bigger and bigger. Why is it getting bigger and bigger?

Have to spoken with your doctor about this problem?

Yes, but it seems like it's getting bigger and bigger though.

You need to see a doctor.

I used to have a butt, but I don't have a *butt* no more it's all in my stomach. The fat is under my arms. You know where my bra is, the weight hangs under my arms. My chest got bigger, but under arms it is hard to fit a bra because it all fits tight. The weight is like loose and it is hanging over.

You need a bigger bra. If you lost the weight you would be able to wear your bra comfortably.

It would?

Yes it would

But wouldn't it hang though

Yes. Have you had children?

Yes.

Well did you notice that everything went back to the right place except the stomach?

Yes.

Now I when I go to the doctor and the doctor even... 'cause I didn't think it was normal everything getting bigger and the doctor wanted to check me and everything and she asked, "Would you like an ultrasound?" I said Okay

She said, "it's just probably fat. Then I got the Ultra sound and they said I had cyst, little cyst on my ovaries. The doctor said this was why I was getting bigger down there.

W002

Age: 59 years old

Marital Status: Single

Education level: High School graduate

Income: \$18,000 per year On State Disability

Date of Initial Diagnosis: 1992

Infected by: IV drug use.

Health Insurance: Medicare/Medical

Date Entered treatment for the first time: 1993

Currently in treatment: Yes 15 years

Discontinued treatment: "Yes briefly for 2 months when I was told I had AIDS"

Describe your experience living with HIV.

Initially, I thought, I could not have HIV I was 41 years old. It only happens to teenagers.

Am I going to die? I can not tell anyone because I am ashamed. I should have known better.

Living with HIV has been like going undercover for the past 14 years. Until recently I had not told my family or friends. I finally told them when I was told I had AIDS. I was surprised as to their reaction. My mother was sad for a very long time and did not have much say until one day I attended a support group which was mixed with HIV-positive people, family members who had a family member who had HIV and heterosexual people that were not positive for HIV.

I was surprised to see my brother, sister, and mother walk in to join the group. It was interesting watching their reactions to what was being shared and hearing their questions and comments. That was the day I started to live again.

I stopped wearing a scarf tied around my head all the time and changed my outlook on life.

I have regretted shutting my family and friends out of my life for so long. Also not having children. I had three abortions. I guess I was smart enough to know I did not want to raise a child in my dysfunctional world and/or possibility infect the child with HIV.

I guess I have been in denial for 15 years.

What influences your decision to have protected or unprotected sex?

Yes, I have had the conversation with men about protected or unprotected sex and HIV but it did not make much difference for them. They just wanted to have sex and so did I. It doesn't matter what I want anyway. It never has. Because men feel women are hungry for affection and women outnumber men so they use their power to get you to do *anything to keep a man*. But now I will not stand to be disrespected anymore. I tell men that so if I lose them, then it happens early in the relationship rather than later."

Describe a conversation you have had with potential sexual partner(s) about sexually transmitted diseases and HIV?

I was very lonely most of the time. So when I got a chance to have sex I did! I didn't feel like a woman anymore just a tool for a man to use

So I did not talk much about sexually transmitted diseases or HIV. I was scared to talk about it because then the guy may decide not to have sex with me.

In the past I had sex for drugs and felt no real comfort in it.

I want to be in a relationship now that is loving. I want to teach a man how to really love me. I want to trust someone again. Will I have unprotected sex I am not sure.

Please tell me how you take care of your health?

Every day can be a struggle especially the way I was handling my HIV.

I take care of my health by going to the support groups, taking my medication and keeping my doctors appointments.

Please describe how your health care needs are met?

In the past I had problems with the doctor not spending enough time to talk to me about how I was feeling but now since I go to a clinic that specializes in HIV patients it is much better.

Is there anything else you would like to share with me before we end the interview?

Living with HIV had knocked the quality out of my life, however I am now learning to think and live differently with HIV/AIDS. We need more women services and education about HIV.

W003

Age: 58 years old

Marital Status: Married

Education level: High School graduate

Income: \$ 20,000 per year On SSI

Date of Initial Diagnosis: 1997

Infected by: Husband who was a deacon in the church and led a double lifestyle.

Health Insurance: Medicare/Medical

Date Entered treatment for the first time: 1997

Currently in treatment: Yes

Discontinued treatment: Yes for short periods because "I felt I was going to die"

"When I had a HIV infected child" "No support services for Women"

Describe your experience living with HIV.

As a woman I describe it as something that's affirming for me now because I can take care of myself, but I also describe as a disease that has a lot of stigma and if you're not strong you may give up. It's a disease that I've grown with.

When you first discovered that you had HIV positive about 10 some years ago.

What was your first reaction then?

That I would die. How could this happen I'm not gay. It just doesn't happen to whites. It not in my community, being from Kalamazoo, Mich.

Very religious community

Yes. And they weren't, back then, doing burials for people who had AIDS

Your husband was in the church with you.

My husband was in the ministry

You were infected by him?

Yeah. I didn't know he had an alternative life style. He liked men.

You told me initially that you had a child that was infected also.

Yes. I did.

Was the first pregnancy from this marriage?

I have twins. She was one of the twins that was infected

Is the child still living?

Yes she is. And she has an infected daughter which I am raising. A 10-year old.

So you remarried how long after you divorced from the first husband?

I married my husband in my teens and I stayed married until he died in '93. I didn't marry again until 3 years ago.

Did he die of AIDS?

Yes. He died of full-blown AIDS.

It must have been very difficult for you raising your children alone.

Yes it was.

Does your second husband know you have AIDS?

He has the virus.

He has the virus also? Do you practice safe sex?

Sometimes

What influences your decision to have protected or unprotected sex?

Because we have an understanding and we trust each other. But I have learned enough since then to know that you should be aware.

Describe a conversation you have had with your partner about sexually transmitted diseases and HIV. And the fact that both of you are infected you probably have had this conversation.

I had to educate him more because even though he was infected in 97, his knowledge of HIV was not as strong as mine. He was different. I had to educate him and teach him on taking his medicine care and how you go to the doctor and everything like that. He was kind of like indoctrinated on it because I speak on television and at churches so he knows that well.

He knows I'm on the HIV commission so that was one way he had to know.

Wonderful. Please tell me how you take care of your health.

I deal with acupuncture. I deal with herbs. I take my regular HIV meds. I do reading. I travel when I have time. And if there is something that is too negative in my life, I release it because I don't have time for that.

Good for you.

Tell me how your health care needs are met.

No I don't because they understand that I am very outspoken. I've been with a program since 94 so they know my needs. They know what I need. They know if I don't like I'm going to tell you. So I'm very outspoken and they know that. I control my health.

What do you think is the one thing that keeps you going?

My faith in God and knowing that there are other women out there that need to be educated. Knowing that even though I have the virus and it's almost into my 26th year; I'm okay with who I am.

I am infected but I am still that beautiful queen that can still give. I don't carry a label.

My name is _____. It's not age. It's not paperwork it's just someone who knows who she is and I'm accepting who I am. And I don't deal in darkness. I tell people I am infected and I speak out and educate a lot. And I guess working as a substance abuse counselor helps too.

Yes. And taking care of my grandbaby and giving hope to my husband.

Wonderful

You inspired me just by talking. I like the part about that you see yourself as a beautiful queen.

At this point is there more you wish to share before we end this interview?

That more women need to be reached especially Black women. Because there are more Black women that may have been infected in the 90s and the 2000s and they don't have the education of understanding the virus or even not knowing how to advocate. Some of them fall in the cracks of not having that knowledge that they need. And I think do not know how to navigate their care, because I think they need to know how to navigate their care as a Black woman. And they also need to know about relationships. 'cause a lot of Black women feel that when you get HIV you have to settle for anything. No you don't. And women have to learn to love themselves as a Black woman with this disease. A lot of Black women feel guilt they feel okay no one is going to want me. They have that

esteemed blocked. So I think they need to say that they're alright and get therapy also. A lot of times Black women don't get therapy.

Not only do they need to get therapy. If they say they are seeking treatment or they want to talk it out. They say "Ah girl go talk to your girlfriends. Talk to your mother. Talk to your grandmother. A lot of times talking to someone that away from the situations, that has an objective perspective can help shed some light. Maybe it was something you already knew, you just needed someone to articulate it for you. I know you know what I'm talking about. And I think one of the issues for Black women is intimacy. We don't talk a lot about it, yet we have been accused by society for being quite open about our intimate feelings and areas of trust and love and relationships, but actually we're quite closed.

How is it you managed to get the strength to enter into another relationship?

First of all I had to love myself and go through self forgiveness and repair my brokenness of the disease. Then I had to set boundaries of what I was going to allow in a relationship and what I was not going to allow. There had to be a repairing of myself and then I also had to look at what I was willing to go into a relationship with someone who was positive sloe. There was that aspect. And was they person ready to deal with someone whose as public about what I have. They had to be accepting of what I believed in. But they also had to be willing to take care of their own health. I will guide you. I will help you, but in the end you will have to take care of your health. I demand it. If I am taking care of my health you're going to do it. I don't have time for excuses. I don't have time to hear "I'm going to die". No. You're going to die if you want to die, but if you want to live, you live. I don't believe in secrets. Because a lot of people grow up with secrets and little things we

were told we can't do in our life when we grow up. I didn't believe in those secrets, believed I'd have to be honest. That's how I came to the relationship and there was a period of watching him and know what he believed in too.

And knowing that he had to be whole too. And if he wasn't totally whole that he better work on it until you come to me. 'Cause I didn't have time to take baggage. I didn't have time to take a bunch of regrets. And he had to be honest in his diagnosis. You have secrets on how you got this disease. You have to tell me. Then I will decide if I will deal with it or not. So I have to have that honesty and I have to know that before I even marry you that though you have this disease you will go to the doctor and get checked for other STDs.

'Cause I'm not carrying anything you have. So it's those things that I had to be sure of.

This has been a positive appointment for me. And I want to thank you so much.

Because a lot of women don't have that kind of strength. You are correct; more education and more advocacy, more information and demonstration around how to access your health care is needed.

Women between the ages of 45 and 60 women are increasing in numbers in new cases. Can you tell me why?

They don't think that . . . A good example is this. If you get a senior person that is 50 or 60 or 70 even. She will say Honey, I'm married I'm too old to catch this disease. My husband and I have been having sex for years. It just can't happen. There is that denial of, one, that they can't get that disease.

Especially in the senior community. Child you can't come to me with a test. I'm too old. I'm old enough to be your mamma.

There is also the understanding of thinking that I have been with that partner long enough whatever he tells me, it's okay.

There is also the fear of what your family is going to say when they find out that you have the disease. Or sometimes they are afraid of carrying the label. How am I going to date? How and I going to tell people of what I have. So it's that fear. It's also that naïveness of the young ladies. Thinking that if they mess with the men in the penitentiaries. The thug issue. They said I like thugs, but they aren't looking at the fact that he's been in the penitentiary and has had sex with men.

Yes. Even though it might not have been something he willingly engaged in he has had sex and could be infected.

The partner doesn't have to come out and tell me 'cause that's his right. So things like that . . . Young ladies are not asking about what they did in the penitentiary. And having that fear. It's that big fear of I don't have to ask him. He's home. He's too much of a muscular man. He doesn't have the attitude of a homosexual. Then there are also the mixed messages from their mom. You get somebody or if you don't get somebody you're not whole. You can't be single by yourself. You need that man to make your life. So a lot of young ladies fall into that trap of 'I can't be by myself'. I can't even be my best friend unless I have someone to complete me. And then we have the fear of the mother that's wanting someone to help raise their children, when they could do it themselves if they had that confidence. We just sometimes as women don't have the confidence that it takes. It's just the fear of I can't be accepted I can't be by myself. I just can't do it I'm not a woman if I don't have a partner. Sometimes women will accept anything for a partner.

As long as he can hold me. As long as he's there. That means I might be able to take abuse. I can take him going out on me as long as he's mine.

W004

Age: 56 years old

Martial Status: Engaged

Education level: High School graduate

Income: \$ 16,200.00 per year On SSI

Date of Initial Diagnosis: February 1995

Infected by: "I had unprotected sex while using drugs."

Health Insurance: Medical

Date Entered treatment for the first time: 1996

Currently in treatment: Yes 12 years

Discontinued treatment: Yes for short periods because "I felt I was going to die"

"When I had a HIV infected child" "No support services for Women"

Describe your experience living with HIV.

In the beginning it was like being in Hell which I never been there. It was depressing, sad, *why me*. Everybody else who had it has died. A whole bunch of negative things. But today I'm okay with it.

How did you get through the last 16 years being okay with it?

It took me going to church and believing what the Lord would say through my pastor to tell me about it.

Your spiritual beliefs gave you the positive outlook on life.

Yes.

You're engaged. Are you engaged to someone that is HIV infected?

No.

Are they aware that you are HIV positive?

Yes

What influences your decision to have protected or unprotected sex?

By showing us that the Lord said I was healed and every time I go to the Dr. my test have been undetected in my viral load.

With your fiancé do you engage in unprotected sex?

Yes

How long have you been in this relationship?

Since September 3rd of this year.

Have you ever been married before.? Do you have children?

I've never married before. I have two children. One is 32 and 33 a boy and a girl.

In the process of being spiritual and becoming more positive with your disease have you found it difficult with your family or friends once they found out you were HIV positive?

No. My children don't feel bad. I protect them. Because everybody still don't have enough knowledge of the disease. They believe in touching or being around somebody you can catch it. Only because of my children and they're not comfortable yet with it. They are out in the world so they know what they hear and so. So because of them I'm careful. You know.

How were you infected? Do you know?

Unprotected sex. And I was using drugs. Not anything with needles but just to have it be noted and having unprotected sex.

So drugs influenced your decision?

Yes.

Have you ever had a conversation with a potential partner or with your partner now about sexually transmitted diseases and HIV?

All the time

Could you just tell me a little bit about how that conversation goes?

I used to go with him when I was younger. And we reunited as friends on the 1st. Then September the 3rd he invited to me to his moms house for Labor Day We wanted to have sex and I asked him if wanted to use a condom. He didn't want to and I wound up saying okay and I slept with him the first time, but before I slept with him again I made sure he knew why I asked him to use one. He told me that he'd prayed and asked God to give him a wife and he believed God wouldn't give him anybody that would be infected. We don't even discuss it today.

You're blessed

Yes, I'm blessed. The master has told me this. I push my beliefs on him that I believed in the Lord Jesus Christ and I go to church on a regular basis. I didn't push that on him because for whatever reason I was humble when I saw him again. It was like we had never been apart and a week later he asked me to marry him. And I can't get rid of him. It's no peaches and cream 'cause we fuss like anybody else, but we do have unconditional love for one another and I know it is unconditional because he goes with

me. He goes to the doctor with me. He goes to Chemo with me and he does everything with me. We keep it between my family (which is my kids) and him. We don't take anything outside the house about my health.

Matter of fact when you called last Sunday we were in church. We had just gotten out of church and I taped the answering machine and called you.

I was just talking to _____ today. She asked me "Did you do yours?" I said "No. I am going to call her 'cause I know she should of got my consent form.

How do you take care of your health?

I have one more day of smoking. I made a commitment that I would quit smoking. I don't rest enough. It's nothing that I'm doing 'cause I don't do anything. I do herbs and acupuncture. But as far as the rest . . . I believe . . . I don't believe. I know that the Lord is taking care of me because all through my addiction I wasn't a bad person. I just didn't know how to love myself. I hurt my family because you know drugs 'cause you to hurt people. Some things loaded or unloaded I just didn't do. It didn't feel right with my heart. I do believe in the spiritual person higher than myself keeping me. I stand tall behind that. No matter whether I'm get sick or not I will always believe 'cause all going to get hit. Trials, test or tribulations it is what you truly believe in. I believe in medications. Don't get me wrong. If I have to go back on them after my chemo I will go back on them. But I'm doing only because my doctor asked me to with my chemo. I am. I am okay.

What are you getting Chemo for?

I was diagnosed with cancer. I was listening to a doctor today. They were on TBN. They said sugar. Cancer eats through the sugar 'cause that's what it likes. So it made me think maybe . . . You know I know I am a sugar addict.

Do you have diabetes?

No. Thank God I don't need anything else. But after tomorrow... So far today I think I only ate two pieces of sweets.

You are going to stop smoking and decrease you sugar intake.

Yes and start back exercising.

How long have you had the lymphoma?

I found out this summer. June or July of this year.

What kind of symptoms were you having?

I had a big knot under my arm. No symptom. A knot under my arm. I went to have a mammogram and it showed up.

No they told me to go the women's breast cancer treatment place and the doctor there drained some of the fluid out of it. And when the pathology report came back it diagnosed it as _____.

I know. I'm a nurse too. That's why I started asking you more questions about the chemo.

How long was the knot there?

The knot had to have been there since last year, but then it started growing I didn't think nothing of it.

I'm glad you received timely treatment.

I've gone through two chemo and I have them every 3 weeks.

How are you feeling?

I feel great. I have not symptoms. No nothing. The only thing I noticed was that one side of my mouth was darker and my thumb. But other than that. Nothing.

Good. That's normal. I'm glad things are working out for you.

When you are getting your health care, do you find that your provider meets your needs?

She's great. I see Dr. I've been seeing her since 1996. And I'm still with her.

Wonderful. That's somebody that really knows you.

Yeah. She's more than a doctor. She is a friend. She spends time with you. She listens to what you want to say about it then and she will go along with you till your next visit and she if she says it don't work... That's what I like 'cause I say let me work this. I'm not going to run on in here every three weeks, I mean three months unless I'm sick and its always been like that between me and her. I'm getting better with it 'cause now with the Hodgkin's I try to keep her informed of everything, but every time I go she spend and hour with me and sometimes I think, Lord I don't want an hour with her today. Matter of fact I went to see her the day before Christmas and I knew that was going to be an in and out. It was an hour. I love her though. Not only as a doctor she is my friend. I can talk to her. I never hid anything from her.

Good. Because I believe part of the problem is when you have a chronic illness your relationship with your health care providers is very important 'cause you want them to be able to hear you. You know your body better than they do so you want them to hear you when you say things aren't working right for you. So I am glad to hear you say that you have a very supportive relationship with your health care provider. In this whole continuum of your healthy living with a chronic illness. Can you describe to me the best time you've had during this illness and the worst time you've had during this illness?

The best time I've had is getting engaged with someone that truly wants me. That's the best time I've had. The worst time is when I found out. When you really first find out that you have a chronic disease that is when all of the fear comes. But once you wake up every morning and find out that you need someone greater than yourself. It gets easy. That was the worst time.

Finding out. Even with the lymphoma. I had to tell myself. Fool if he heals you once He'll heal you again. I'm okay with it.

Is there anything that you would like to share with me before we end this interview?

I am a human being. I am not a perfect person. I still sometimes have issues, but I thank God for my life today. I truly do.

Actually I have heard from a number of the women I spoke with talk about who they are and not being identified by the fact that they are HIV positive. I believe that is extremely important. I believe this how the healing takes place.

The Bible tells us we have what we say. I will not say that I don't have it. I will tell people that I've been diagnosed with it and I have the symptoms, but I don't have the disease of it.

You have to have some spirituality going on in your life. Because if you don't you're not going to make it. Maybe you will make it, but you won't have... I am peaceful. In everything in my life I am so peaceful. Even though I have to fuss cuss and everything I'm still peaceful. It's a peace I have inside. I mean that's only because of Grace and Mercy. I learned that I accept me for who I am. Ugly, no I am not. I accept me today. I love myself. If no one else loves me, I've learned how to buy me nice gifts.

I learned from going through it. Certain people in your family you can't tell. When I first told my family (not my children) but some of the others in my family they would get mad at me. They told me I would die and that was good for you. When I say close I mean close, but it was never my children.

Sister, mother, they could be so cruel with their words to you. So cruel. You know I went through a lot of verbal abuse when I told my family. They didn't have to treat me different because they said enough words to kill me.

So it's a lot that you go through. Yeah I went through a lot. But today I care nothing about them. I put them in God's hands because if they knew better they'd do better.

I think part of that is having that spiritual core in your life, is that you have the ability to forgive them for those words. Because those words come from ignorance. But people don't understand just how powerful words are. The Bible tells you that.

If you keep speaking death on me you will reap what you sow.

That's right

My mom used to throw that stuff in my face, but now she is spiting up and throwing up and the doctors can't find anything wrong with her. And I want to tell her "You reap what you sow", but the Lord said "Just shut your mouth."

Pray for her healing. Then you pray for the forgiveness.

A lot of times people say things because they are so afraid and they say things out of ignorance. Not so much out of cruelty but out of fear.

W005

Age: 58 years old

Martial Status: Single

Education level: Associate degree in music

Income: \$ 16,000 per year

Date of Initial Diagnosis: 1996

Infected by: "I was raped" "I was getting high on crack with this guy"

Health Insurance: Medical

Date Entered treatment for the first time: 1996

Currently in treatment: Yes for the past 11 years

Discontinued treatment: Yes because I had no money or transportation.

Describe your experience living with HIV.

It's up and down. I have my good days and my bad days.

What's a good day for you?

A good day for me is when every thing is just working normal for me. Even with the side affects I can get up and get around. Do my thing you know.

My bad days are when I'm sick and down and out and with the diarrhea I can't do anything. I'm frustrated, my appointments aren't kept. You know reschedules. I am stressing. Then I have days where I can just sit up and wish that somebody had a cure and I could just not have it no more.

And then I also heard that there is a cure for it, but you have to have money for it and I don't think that's fair. You know because there are people out there. Not just me. I am not just looking for an out for me. I'm looking for other Black people too. They don't

have the money to pay for that and I don't think that's fair. You are just playing with people's minds.

I know. I went through it because you know I been had it for eleven years and I know when I first started I was in and out of the hospital with pneumonia. My T-cells was like 5. I just stayed sick, you know and I didn't understand that. You know, it was just that ACT. This is my second medication I'm on. The first one I was taken more pills. But it's not just the medication itself. It's like I appreciate the people that go out and do the walks. I wish I could do the walk. A couple of miles or something for that, but I don't know if I would because I'm still closed closet with mine.

And also it's a thing where I hear them giving money and donating money to get more medication. Sometimes, I don't know if it's me, I really hear that.

Where's the cure at? Where's the money that is going for the cure. They got this place at _____ where they're working on cures and advanced stuff where people don't have to do this and that. _____ school for Cancer. Why can't they do that for us. And I thank God that I'm still here, but you don't you don't have nothing for us to try. You know as far as a cure.

I can't imagine how you feel. Because there is no cure, it's symptom management.

Another thing. I know a lot of people that died. People I went to school with died. People that I knew of died and even just people out here and when they first found out...some killed themselves. Suicide. They just couldn't take it no more.

What keeps me going is strength and will and God. I pray before I get up in the morning. I pray before I go to bed. I thank him for that day and that I was able to wake up another day. I'm bless you know. I'm fighting for my life basically. I've been through a lot. I've

been through a procedure where I had a cyst on my spine. They did the procedure and I went to home care and I went from a wheelchair to a walker to a cane. They told my sister and my daughter that I would never walk again. Every time I got ready. I told myself "I'm getting up out of here" and I would pray to God before I went from one to the next. Like from the walker to the cane I would walk the halls and say a prayer and ask God to walk with me. My strength and His will. It keeps me going because there were times when I wanted to end it too. You know I didn't think I could go on any further. When I first heard about it, people were dropping like flies. When I got it I was scared I thought "well I'm going too." I was scared. But then I got more into it being my self and they have these medicines now. I can live, but I still think about even though these medicines have helped me people are still dying due to complications. I hope that I don't have complication, but the reason why my doctor is doing the CAT scan is because I'm losing weight. And just like my legs you can see the veins in my legs. So it s like what is going on with me. He has done a CAT on my chest and my stomach, but everything has been coming up normal. That has given me hope. But what is normal if I'm losing all of this weight. What is normal?

The side affect of your medicine could be the reason. How did you get infected?

I was raped. Sex! I don't know if I can say this, but I am a recovering heroine addict. I've been clean for 6 years. So I don't know. I used to use intravenous drugs and smoke crack. I don't know if it was from that or form the guy I was getting high with. But I know its him. He died a long time ago. He just kept using.

No one has the right to violate you. And even with the social culture at that time, no one has the right to violate you.

Are you in a relationship now or not in a relationship with someone?

I was. Kinda still. We were supposed to get married. I called it off. But we still see each other. He still wants me, but he is messing around with other women and I called him on it. We were having sex. He is HIV symptomatic. Which I thought was a good thing (not that he had it) but when I had to tell him when we got to that point where I felt the relationship was going further. I did tell him, but it was difficult.

Baby began to cry.

W006

Age: 60 years old

Marital Status: Divorced

Education level: High School graduate

Income: \$ 20,000 per year On SSI

Initial Diagnosis. February 1996

Infected by: "A man I had unprotected sex with who was HIV positive and had not informed me."

Enter Treatment for the first time: March 1996

Health Insurance: Medical

Currently in Treatment: Yes

Discontinued treatment June of 2006

Reason: "I needed a break"

Resumed treatment: June 10, 2007

Reason for resuming treatment: “My T-Cells were very low. I was tired all the time”

Describe your experience living with HIV.

Wow. It's terrible. It's all the secrecy, denial from people. Stuff like that. You are always trying to keep this person from finding out, that person from finding out. You have a tendency to withdraw a lot. You don't socialize as much and having the fear of people finding out. That's me that's my opinion. Otherwise when I go to the groups I feel safe there. I feel comfortable. So I go to a lot of support groups. With me its like having a double life. This side knows about it and the other side doesn't know about. Then I get to listening to some of my friends that criticize it. I said well you know. I had one friend that lived next door to me. I had known her for 40 years and she was telling me about this guy who made sweet potato pies and she said “well you know he has HIV and I couldn't eat it. I just couldn't eat it.” So I'm thinking to myself. So when I cook you come down here and eat my food, but if I told you about me, what are you going to do. You not going to speak to me no more? You're not going to come to my house any more. Basically that is the life you live.

I find it interesting how when you are living a life like that how mean people can be.

So that hasn't changed at all. The problems you have had with coping with your friends and family. That hasn't changed over the last 15 years even with the increased awareness of HIV?

Not with the ones that I'm associated with. I have a couple close friends I told and they are cool with it, but the rest of them don't know. I have two friends that I told and they didn't change with me and I feel comfortable with them.

How were you infected and was it someone that you knew?

Yes. It was from someone I was messing around with. He said he was an ex-drug addict. But evidently he got it while he was using IV drugs. But he's dead now.

How long ago did he die?

Oh about 4 or 5 years ago.

You said you were divorced. In this time frame were you divorced?

I was divorced

Do you have any children?

Yes. I have 4.

Are any of your children HIV positive?

No. They were all grown when I got infected. My baby is 35. I have been infected for 21 years.

Are you presently in a relationship with anyone?

Not at the moment.

How long has it been?

I had one a couple years ago off and on.

Did you practice safe sex at the time?

Yes.

Did you tell him?

Yes. That was one of the two.

Was he infected?

No

When you talked to this past partner how did he respond to the fact that you wanted to practice safe sex?

I'd told him before we had sex. I saw where it was going so I called and made reservations at a motel. So I met him at the motel and stuff. I told him I was HIV positive. He didn't say nothing. He just started hugging on me. So nothing changed.

Can you tell me how you take care of your health?

Well I stay busy a lot and I take my meds. I try to keep a positive attitude. That is basically it.

Do you attribute your ability to in the last 21 years to stay focused or stay positive to your spiritual beliefs or support?

What keeps you going?

Hope. I think. I think there is a combination of it and the support groups. I went to church yesterday, but I hadn't been in a few months before yesterday. But I would go to the support groups so that was basically what kept me going.

Do you find that when you are seeking health care that your health care providers are reasonable?

Yes. I only had one doctor and that was back in 1994. And I have a _____ because I have a shrinking bladder and when he found out he wouldn't give me the test and stuff that he was supposed to. Then the doctor that did my back surgery talked to him. We have been getting along ever since.

Is there anything else you'd like to share before we end this interview?

Not that I can think of. I just wish folks would stop being stupid and accept this like they accept everything else.

Like they accept diabetics and cancer. You tell them that you are diabetic or that you have cancer and they don't frown on you. But then you tell them that you are HIV positive then they want to turn the other way. People just need to stop being ignorant. That's the bottom line. They are just ignorant and they need more education and more knowledge and accept people that are.

Having it for 21 years, how active have you been in trying to educate them about HIV?

I just try to tell them about the condom and have safe sex 'cause I don't get to much into the point blank about HIV or whatever. I just tell them you have HIV and AIDS and all the different diseases you can get. So if your are going to have sex, you better use protection. I don't never get just point blank.

So what about your children. Do they know?

No.

None of your husbands know?

Both of my husbands are dead.

One was in Alabama and I left him. My other husband was out here and he died of cancer. Weren't together when he died any way.

You have not told your children. What do your children think when you go back and forth to the doctor? Do you live alone? Your children don't ask you questions about your illness?

No. I stay busy and as long as I stay busy, they don't worry about me.

How many grandchildren do you have?

21 grand kids and 2 great grand. The grand kids keep me busy.

I should think they would.

They keep me going a lot. Even though sometimes I get mad and put them out. I always let them come back in.

They are good support. They don't know but they are good support.

You need that.

They can say so many things and do so many things. That even after they are gone you think about them and you can't let them see you laugh, but when they are gone you are still laughing and that keep you up.

I think it is great that you have that support system and it's remarkable that you have not had to reveal your illness to your family. And the fact that God has blessed you to live with the chronic illness and you seem to be in pretty good shape.

I've never had any aches or problems yet.

I may have a lot of other problems because I was born with transversalitis which is like MS on the nerves, but I have never had any HIV related problems.

You'd don't have cancer or anything like that.

No. A lot of my friends in my support group they have it and I have been blessed. Every time they check mine always comes out negative.

W007

Age: 47

Marital Status: Divorced

Education level: Associate degree in Science: Substance abuse counselor

Income: \$ 18,000 per year On SSI

Initial Diagnosis. 6/1989

Infected by: "From a blood transfusion because I was bleeding a lot. The doctor told me I had cervical cancer and needed a hysterectomy."

Enter Treatment for the first time: 1995

Health Insurance: Medical/Medicare

Currently in Treatment: No Was in treatment for 8 years

Discontinued treatment 2000

Reason: "It was not working for me"

Resumed treatment: No

Reason for resuming treatment: Did not resume.

Describe your experience living with HIV

That could be a very long answer or a short one. From onset it was very difficult dealing with the fact that here's my life being turned upside down just when I'm trying to get it in order. Then after coming to the place where this is what this is there's no getting out of it'. I began to learn all I could about it. I was going to all kinds of seminars, conferences, talking to all different kinds of people. Just trying to get a gist of what this was that I was dealing with in a real kind of way. Not just what was written in the books, but in the life experience kind of way. And what I found is that it really is manageable. You know that it's not totally a death sentence. That people perform quite well after adjusting and then I started dealing with it in a societal kind of way and I found that people were very

rejectional. That they would be combative if pushed. Then I tried dealing with it in the working world and I found that to be challenging as well because, of course, not every day is a good day and that's with anybody but its more so with those who have a compromised immune system. And it was hard with all the stress and the pressure. The hours, the long hours... The competition became monotonous and I found myself losing T-cells, getting sick more often. And so my doctor said, "No more working world for you girl. You've got to go." And so I went back to school and thought that if I got into another field that it would be much better, but it wasn't.

What field were you in initially?

Initially I was in Security. Private security. Corporate security. It was hell. I got into school to be a counselor. So I started doing Psychology and got an Associate degree in that. I started doing pre-post counseling. I got into phlebotomy. I got into medical assisting, all of these things just trying to find my way. And even though it all comes to a place that helps me in the long run to where I am now. At the time I didn't see the benefit. I got really frustrated. I left California and I went to Georgia and I got married, of course, I am divorced today. The marriage life was not what I thought it would be. My husband wanted this stay at home, in the kitchen kind of wife and was more of an independent go getter kind of person. He had a lot of things that he didn't discuss with me. Very private and shut off and I wasn't in cahoots what he was doing so I didn't feel like that was for me either. I walked away from that and came back out here and went back to school. I got back into lecturing and talking about HIV. It seemed to pick up. People seemed very interested in what I had to say after all. I had run the whole gamete of finding out things. So I just started giving it back to those who didn't know a damn thing. To them I wan an

encyclopedia. And the fact that I had such a real story that I could relate to them it was much niche. I was in a support group one day and a woman was there. Her grand daughter had died and she had no one to turn to. There was no group for her. And I was like wait a minute. There must be something we can do for her.

So I'm driving down the street and I am praying to God. I know you have me here for a reason. I tried killing myself but you wouldn't let me die so what is my person. You have me here for a reason. I need to know what that is. Then I looked up and there was a sign. It was some people that were dancing in water and it was some thing about enrichment. And I thought. Ah there it is. It is about time that we enrich our lives. There is enough information about prevention and intervention, but as a people we where not getting it. It just was not getting through to us. And I know that I am kind of a hardcore person. I know I've been through the ghettos and have had some rough living. And I've also had some good living. I've been on top too. And the life I've been on both sides.

How were you infected?

Through a blood transfusion in '86. I had cervical cancer. I went into the hospital. I had lost 90% of my blood supply. I was dying. This was 1986 when they hadn't started testing the blood yet and this was right at that time because it was July of 86 that the government mandated that all donated blood be tested, but I guess I got caught in that little trap right there. They didn't test the blood they gave me. Obviously. I was given 10 liters of blood.

How old were you?

I was 23. Just a baby.

I didn't even know what kind of surgery they were doing. All I could do was call my dad and tell him that they were doing surgery.

He said "Baby just have surgery and get home. That was his concern just get back home. My dad said do whatever you have to do just send me home. And afterwards I found out that I had had a hysterectomy. They took my uterus. You know when they kept saying uterine surgery. I didn't know what a uterine was. What the hell is a uterus.

You were married for how many years?

I was married for 4 years.

Was he infected?

No.

Did he know you were infected?

Yes.

Did you practice safe sex?

Sometimes.

He never expressed any concerns of getting infected?

In the beginning, we talked and he follow-up and got his own information. He learned about HIV and the risks. We were as safe as we could be. But there is nothing that is 100% other than abstinence or masturbation.

How do you take care of yourself now that you are not in treatment?

I take a lot of natural remedies. I eat right. I sleep right. I stay out of stressful situations. I do herbs. I do acupuncture. I do cleansing. Whatever it takes.

When you were in the health care system. Did you find that your providers were user friendly? That they were respectful? Did they treat you differently because you had HIV.

No. All of my doctors specialized in HIV.

What influences your decision to have protected or unprotected sex?

You said "Sometime you did and sometimes you didn't." What influences that?

Comfortability with my partner. That they understand the risk that we're taking and understood the knowledge.

I agree with you. I agree that your journey is to educate and 'cause you to have a different comfort zone with your diagnosis. I liked your flier it was tremendous. It was colorful. It was upbeat and supportive.

That's the whole key. It is upbeat. It's not a glum lot anymore.

It doesn't have to be. How do you take care of your health?

Actually I have been doing a lot of natural remedies. It works better.

Is there anything before you and I finish this interview that you would like to tell other people out there.

If I would add anything it would be dealing in the comfortability zone. HIV is not something you run from it is something you run to. Because when you understand it you run the hell away from it.

Understanding is power. When you understand something... Your mom can tell you all day long that the stove is hot. But until you touch it you don't know how hot it is. So I tell people to get in the books. Talk to people. Get to know them. It's okay to be my friend. It's okay to talk to me about personal things. Talk to me about pussy and dick.

That's what they understand. That is your vagina. That is your penis. No matter how much you try to run from it. Every time you look in the mirror there it is. So understand what it is and how to use it.

Girl you are powerful. That is what we need out here.

W008

Age: 54

Marital Status: Married

Education level: Bachelors in Business Administration

Income: \$ 42,000 per year

Initial Diagnosis. 1999

Infected by: "I had an affair and did not use a condom"

Enter Treatment for the first time: 2000

Health Insurance: United Health care

Currently in Treatment: Yes 7 years

Discontinued treatment : No

Reason: N/A

Resumed treatment: N/A

Reason for resuming treatment: N/A

Describe your experience living with HIV.

How do I live with HIV.? I don't. Who does? You can't tell your family and friends because at my age I should have known better than to unprotected sex with a man who was not my husband.

I finally told my husband who I have been married to for 19 years. So I would not infect him. We split up for a while but still did not tell the family and friends why.

What influences your decision to have protected or unprotected sex?

We use a condom now because I don't want him to get HIV. But we don't have sex very often anymore. I think it is because he still is hurt and afraid of getting HIV. He gets tested frequently.

I can barely talk to you about it. It hurts. I may start crying. What keeps going around in my head everyday is how I could be so stupid. I am scared of being alone. My husband may leave me. I cannot work anymore. I used to be a real estate broker but get too tired easily to keep up the pace of the job demands.

I have frequent mood swings, problems with pain in my legs and appetite. We used to go roller skating with our children. I do not go with them anymore. I do not sleep well.

I wish it will go away.

Please tell me how you take care of your health?

I recently joined a support group for women only because my doctor kept bugging me to go. I like it. I can talk freely about my feelings, concerns and get my questions answered.

I take my medicine and try to eat right and exercise but it doesn't always work for me.

Especially when I feeling depressed and angry. I think I am angry most of the time.

Counseling does not help and my husband refuses to go.

Please describe how your health care needs are met?

I guess I get my health needs met. At first I was not honest with my doctor and would frequently cancel appointments.

Is there anything else you would like to share with me before we end the interview?

No.

W009

Age: 50

Marital Status: Single

Education level: Culinary school: Chef

Income: \$ 19,000.00 per year On SSI

Initial Diagnosis. 2001

Infected by: "Had sex with a man who had HIV.I did not know. We did not use a condom"

Enter Treatment for the first time: 2/3/2003

Health Insurance: Yes Medi-cal

Currently in Treatment: Yes 5 years

Discontinued treatment No

Reason: N/A

Resumed treatment: N/A

Reason for resuming treatment: N/A

Describe what is it like living with HIV?

Living with HIV is an everyday struggle. It is survival. It is an understanding of who you are and what you want to do in life. That is what it is for me. 'cause you don't know who you are going to run into on the streets. I'm not a street person. I'm very much a loner. And the individual inside is a peace of mind. So it could be a hurting thing because you have feeling. Like in the past some one could call you AIDS when you were HIV positive. It's a survival trip.

What got you to that point?

The point of survival? It is relating to myself. I have anger. I could be an angry person and I could curse you out. I could kill with my own words. So I do counseling. I go to church. And I listen to a lot of people. And I learned how to accept me as me.

Who do you find are your biggest supporters?

Have you told anyone else besides your support group or family members that you have HIV?

Everyone in my life knows I have HIV. I have over 100 friends I have been to over hundred funerals. My husband is in the penitentiary my brother is in the penitentiary. Most of the guys I know in the past are in the pen. I have letters that I write to people in jail. Everyone that I know.

Having that type of support really keeps you anchored.

I don't have to go around anyone not knowing or bringing up the subject or wondering if they drink a beer or smoke a cigarette after me. I didn't dawn on me. I'm coming from _____ I am in a community where I'm a project person. The kids can be very cruel.

They will say things like “I can’t touch you or I will get it.” They get that from their parents. It is that ignorance that will take you down.

How do you support other people?

I have male friends. I listen to their advice they give me because if they can change me then I can change them. It’s a give and take situation. Not one sided.

Are you in a relationship right now?

Yes.

Are you practicing safe sex?

I have never practiced sex. Safe sex is no sex. I was celibate for about two years. I married my husband while he was in jail until 2003. It took him two years to get out. But I was in a relationship for 27 years when I first encountered this disease in 2003. I’ve never in my life used a rubber. And I have never passed on my HIV to anyone and I have had only three outside relationships.

Is he infected?

No. My husband is not affected and the man that I am with today is not.

When you had this conversation with them what was their reaction to the fact that you were HIV positive?

It wasn’t about their reaction, because if you start at the beginning of the relationship letting the person know it’s not about sex. I’m not the type of person that wanted sex anyway. It was a mind thing a one-on-one thing. So being alive with this illness I come out first and say, “Look, I don’t use rubbers I don’t do this and I’m HIV positive. Then explain it to them and I take it down ever step that I am taking you through it. And they come back thinking that is an honest way to break it to me and they will show me their

experience with it and break it down to me and what their knowledge was with it. They involve themselves in it to know where I'm coming from with it.

What I'm hearing is you educate your partners. You are open and honest with them.

You meet them where they're at and you bring them up to the level of HIV

education that they need to be in order to be in a relationship with you. Is that what I'm hearing?

Yes. You can't even have a friendship, male or female. When you are a type of female that is attracted to men anyway the first thing that women think they have on their mind is sex. You should start the relationship off by telling the truth about what it is. Then you won't have to run into the fog. It's an open situation. They knew if they want to stay with you, learn to be your friend and find out what your faults are and what your goodness is, what you want to do in life. It's a long-term goal.

You made a decision to have unprotected sex. What influenced the decision?

I have never used a condom in my life. I've never even taken a rubber out of a package.

Why? With all the media and all the educations surrounding HIV and other diseases.

I'm very over protective with my body. I just don't lay down with anyone.

Very selective

Yes.

How do you take care of you health?

When it comes to my eating. I have an eating disorder. I get tired of chewing. I'm anemic and I don't have any sense of smell. I am very particular about what I eat. I don't enjoy most cooked vegetables. I wouldn't eat corn unless it was on the cob unless there was

something wrong with the corn. I was around most of my men and my common-law husband used to cook. So he prepared my meals and he took care of me tirelessly and in home care worked. I'm trying to get that back... I listen to what my instincts want and what my body wants. If my body doesn't want the medicine. I don't take the medicine. The beginning of this HIV the AZT took me from 105lbs to 79lbs because I didn't know the AZT was eating me alive. I started to faint and my knees got weak and so I went to the doctor. He put me in the hospital and gave me a blood transfusion and they released me within four to five days. Another month later I was back in the hospital.

What the doctor was doing was still giving me the AZT. When he asked me if I was anemic. I said "Yeah". Well your white blood cells are eating up all of your red blood cells. This last time I went in he sat me down right there and they put a blood _____ in me. That got me to not liking the medicine from 1993 when I first got this. I've been aware of what goes in my body as far as the medicine. I take care of it alone. I have the spiritual belief in Jesus. I healed by the blood of Jesus.

So your belief is healed by the blood. It's common among the women I've been interviewing. It is who you are inside and what you believe and where you put your faith. A positive attitude really makes a difference.

I'm not a good reader, but I listen and watch TV _____. You know they say meditate on the word. I pick up my Bible. I don't play with God. I go to Bible Study Tuesdays and Thursdays. I'm having a problem in the Lord wit the church. The church is gossipy and their not taking me down that way. Satan is not the one that is destroying it. You allow Satan into your life. He will not on the door but you don't have to answer it. He will go to and forth but Jesus is here all the time. You pick up your cross and carry it

and you let your spirit man, the inner man , not the carnal man, rule over everything. He died for all of us. Doctors can't cure the common cold. They don't want us taking over-the-counter medicine. So I live on it and how my body affects me.

That is an important. I am finding out through my interviews that this is a flag. A number of women talked about really being in touch with their own bodies and that translates into you deciding what you will put in your own bodies. I have talked to women who say they actually are not taking medication. But they have received their medicine in support groups, through spiritual faith, their family members as their treatment, but not necessary taking medicine.

That's their way. Everybody is an individual and the medication doesn't affect everybody the same way. There are people on drugs and alcohol and that is their choice. They used to give me Tylenol 3 for pain. They give out marijuana to the patients and I would take some marijuana and a piece of Tylenol and smash it together and roll and smoke it. They would say, "What is that?" I call it a primo. And what is the cigarette for? I'm putting it in here with this weed and the Tylenol. I have to take it, but I get to decide how. Then when it comes to alcohol. There is certain alcohol I can't take. It will make my body feel good. My interaction where my anger can be provoked, but I will have a beer. The brewing part of the beer gives my body the energy that it needs. It's a way... 'cause if you abuse anything it will mess you up.

You are right.

Everything they give us is a drug.

I'm a nurse and I hadn't thought about it like that because a lot of research is done not necessarily on African-Americans, but on White people. I used to be a research

nurse and the medications were given to White males, not necessarily White women. But then it is used in treatment for all cultures. You're right it doesn't all work on us.

Then the size of the pill is deep because I am claustrophobic. I am claustrophobic in my throat. If the pill is too big for me to swallow then I am not going to swallow it. And if they give you too many pills to take you don't want to take them. When it comes to my medicine, I have 3 different HIV medicines and a weight gain pill. I will take the 3 in the morning with the gaining weight pill and I take one in the evening with the gaining weight pill. When my mouth doesn't want to swallow it, I'm not going to take it.

Between this month and December I haven't been taking my medicine on a daily basis.

Which I had because being diagnosed with AIDS is hurting on you when you know you are not detectable and you go and you get a blood test and your viral count is undetectable and your T-cell count is up higher than it's ever been like over 500.

Because I used to be down to 200 or 300. And then you are diagnosed with AIDS

because it's not being explained to you. It takes your mind off of why you want to take the medicine every day to make it all go away. Then you get the lowest dose you can get.

Once AIDS is on your record it can't be erased. And that happened last year in November.

Well it was August, but I didn't get the paperwork until November.

I'm undetectable with over 60,000 of this stuff. I am symptomatic HIV with 60,000 of this stuff inside of my body most of my life. And then you give me AIDS diagnosis because you went back over my records 5 years ago. Why wasn't it told to me then?

But then I wasn't thinking about my medicine. I didn't care about my illness. Now that I put it on the table and made it first in my life and made sure I wake up to take the pill and

to do what the doctor say do then you give me a bad diagnosis. I took my self-esteem off of it. I lived in faith for it. The doctors aren't there for me.

So getting that news three month ago and now this is a whole new dimension. You have been living with it for 5 years? You were living with it for that long and in the last three months they have actually shattered that safe feeling you had.

The trust I built up. Shattered. This is the most I've been in the counseling and into the treatments with the other women. This was the year that I've done it and it was a day-to-day basis. I had something planned at Oasis everyday to keep me from going back into my past. I was on drugs and smoking and drinking and everything. And to shatter my dreams like that, it doesn't stop me from going forward, but it put a hold on my medicine. I don't have to go to the doctor to get my medicine. The pharmacy delivers it. I just don't want to take it no more.

Well, I believe the support from your family, faith and knowing your own body will be the determining factors that will help you make the decision to go back and stay on your medication regimen or never do it again. I think, just from hearing you, those are the three factors Now it sounds as if you are in that waiting period; the place of decision making. I wish you the best on your final decision.

I got them and I pulled them out two nights ago, right before I went to the support group last night. I put them all together, my Monday through Sunday, but its up to me to do it. If I have the strength to pick it up I will start it and it will be on a day to day basis and I won't stop. I'm just building me up for it. It hurts.

I cannot imagine where you're at. I am a psych nurse. I have been doing psych and counseling for 25 years and part of my psych counseling has been with HIV patients.

I've never been able to understand or even imagine what that type of diagnosis feels like. We treated the depression around the HIV diagnosis. I think I remember you saying you don't sleep well.

I have insomnia.

Yeah and it's hard to function when you don't sleep well either. People who don't have a diagnosis of any chronic illness that have difficulty sleeping. It is a 'must fix' thing with physicians.

When it comes to that. It has nothing to do with the HIV and my doctor knows I have a sleeping problem. Where in the past they would give me volume #10 pill. One pill would knock me out forever. Then they thought because people sell the drug in the street and I'm taking the drug because of my sleeping so they put me on ambient. That was about last year. Now when I want my medicine goes out. My medicine gets delivered from the pharmacy. But if it don't come with my sleeping pills I call up the doctor and ask her where my sleeping pills are, she says she doesn't want me to get addicted to the ambient. That doesn't have anything to do with me. I need sleeping pills to go to sleep. My eyes will be closed and my mind will be wide open. That's why I leave the TV on all night. So I can hear something. So when you wake up the next hour and your eyes are wide open and your mind is wide open you wonder what happened. You take something to go to sleep and you get at least a good four hours rest. And then if you wake up, you take another one, you take another one. You are not getting addicted to the drug.

You're not getting healthy REM sleep. It helps the body recharge. It is called R.E.M. sleep. And you know what. You need to read up on it. If you have access to the internet. Read up on it. It is called Rapid Eye Movement sleep. There are levels of

sleep. If you can't get to sleep in the first 45 minutes to an hour. That's called difficulty falling asleep.

I called the pharmacy. They will go over the doctor when it comes to my sleeping pills. I called them the night before and I told them I got my medicine, but my sleeping pills didn't come. They say "Wait a minute baby. Let me look it up in the computer. We don't have it ordered for you, but we'll send it out tonight." I am glad I didn't have to go through the doctor because if I had to go through her she will say. No I am not going to sign it, but later on that day she will sign it. She's trying to play a game. I don't know why a doctor would play a game with what you know your body wants.

You know what I think it is.

She may not think you really understand. This is an example of the patient knowing their body and knowing what they need. You may be depressed.

I recommend you talk with your doctor again about your difficulty sleeping.

That's why I leave the TV on. So I have something to look at. Sometimes I will turn to a religious station so I can hear them. I just don't take it lightly. My dad calls me every morning between 7 and 7:30 because he bought me a coffeemaker. He wants to know if I've had my coffee. If I miss him I call him and wake him up. He the helper. It comes from all things. He knows I'm up at that time of the morning.

They are getting us prepared for this 'Strength for the Journey' at my church in June. I have a lot on my plate. I'm going back to school in. I went to Jail last year, January 30th and I got out March. That sent me back a step. That's what started me to want to be around the kinds of people I was with yesterday. Most of us are in the same women's group. Then we met new faces last night so we started a whole new thing ourselves and it

empowered me to start on a whole new direction and seek new influences in my life.

That's how you get more people.

Is there anything else you would like to share with me before we end this interview?

No. I'm good.

Well, I want to thank you for your time.

W010

Age: 57

Marital Status: Married

Education level: High School graduate

Income: \$ 20,000 per year On SSI

Initial Diagnosis. 1989

Infected by: "I was molested by my father when I was 7 years old. Later my mother found out he was HIV positive when I was 23 years old"

Enter Treatment for the first time: "I do not remember"

Health Insurance: Medi-cal

Currently in Treatment: No

Discontinued treatment "I am asymptotic"

Reason: N/A

Resumed treatment: N/A

Reason for resuming treatment: N/A

Describe your experience living with HIV.

At first I was scared. So I got educated on it and every thing. Then about 8 years ago I was able to talk to people about it. I became more comfortable and relaxed.

So you've told your family and friends?

Yes . My family and friends knew about it since I was a young adult.

How did you get the virus?

I was molested by my father. He had it.

How old were you?

From ages 7-12

What keeps you going through all of this?

Really my kids. Different people. Friends and family. You know how you live a sheltered life for so long and you close yourself in. I didn't really want to socialize with anybody because I was scared. You know how they were going to react. They people that didn't know. I was scared to be around them because I was scared of how they would react when they found out.

What keeps me going is my children because they know about it. I have three sons and a daughter. My oldest son is 27 my second son is 25 my other son is 15 and my daughter's 8. My oldest three boys are educated on it and support me. And my partner...everyone helps support me. And my mom she supported me , but I lost her on the 16 of March 2006. So after that it really started taking a toll on me. Dealing with her death and other issues I was going through and it was all of a sudden. The day after her funeral something hit me and it said "No. You have to maintain. Do what you need to do. You keep going" I try not to get depressed. I keep going everyday. I got kid I have to take to school. I have

to cook, clean my house. I don't give up. I just stay busy. You know. Pray and I go to support groups. You know I have people there for me now.

I heard you saying that for you main things that keep you going 1st it's family. Your faith and then your friends. The support groups you go to. With your partner. Do you practice safe sex?

Then no. When I had my kids. No. But now I don't even bother with it. For the last 6 years I have not engaged in sex.

Prior to the 6 years would you have a conversation with someone about using a condom or not?

Yes, Yes. Yes. They would have to. I wouldn't tell them why because I was ashamed. I wouldn't tell them why but I would demand it. It wasn't happening.

When you had that conversation with that partner?

Did any of them give you a really hard time and you made a decision just not to deal with them?

No. With males? No. You know how you talk to someone and you tell them I just can't do it unless you have a condom. So basically there was no argument. It was either "Yes, I wear it or that's okay and I would go on about my business.

Did you have conversations about sexual diseases with other men?

With other partners? No. You know men. They ain't worried about all that. That conversation would never come up because they're too busy trying to have sex.

How do you take care of your health?

I go every 90 day to the doctor I goes to 5P 21. Every 6 months I'm in a study called Y study. What they do is a full physical and pap on me. They do everything. I might get out

of here and walk sometime and pick my daughter up. But other than that... That's just about how I take care of myself.

I eat. I do eat, but I have been trying to cut back on my foods for the last couple of years 'cause they told me that I had high cholesterol and high blood pressure. So what I do is back up off the greasy foods. I may boil or bake my foods. I don't do too much frying no more. They wanted me to stop with the rice and gravy but I am sorry I can't do that. I love it. I eat more greens. Every now and then I will eat a salad. I would say once a month I will eat a salad. I like tomatoes. I will cut up tomatoes and put salad dressing on that. But I eat a lot of greens.

It sounds like you are trying to eat healthier. In addition, your attitude is so positive which contributes to your state of health.

Have you ever had health care service problems from a health care providers?

Never. That is one thing I can say. Out of the clinics I go to I have never had any problems.

You receive health care from health care providers who specialized in treating people with HIV.

Yes. This is what this clinic is: 5P21. It is only for people with HIV and AIDS.

How long do you think the clinic has been there?

They have been there for at least 17 years.

Are your children infected?

None of them

Is there anything else you'd like to share with me before we end the interview?

No that's it.

W011

Age: 60

Marital Status: Widow

Education level: Bachelors in Arts: School teacher

Income: \$ 20,000 per year On SSI

Initial Diagnosis. 2000

Infected by: " I had sex and did not use a rubber"

Enter Treatment for the first time: 2001

Health Insurance: Medicare/Medi-cal

Currently in Treatment: Yes

Discontinued treatment No

Reason: N/A

Resumed treatment: N/A

Reason for resuming treatment: N/A

This participant would not reveal on tape she was HIV positive.

"I do not want anything on tape because I am too ashamed." You know how people talk. What could I say; I am too old to catch this disease. I thought it would not happen to me." I have three family members who have it. I personally don't have it but I need to be in a support group that helps them. I want to learn more about it. Especially with the symptoms they have. They have the mood swings and there taking medication that gives them adverse affects and we're really not knowing what to do. And so any help or information I can get to help me with them would be good. I have one friend that passed

and so it made it difficult. And at that time we didn't have the information and we didn't have the resources that we needed.

So this is why I wanted to get more information on it. To help my family members. I really appreciate it. It enlightened me especially with the other women and the experiences they were talking about. It really helped me and I feel real good about them and myself. 'cause its like I took a step forward with help for my relatives. And then I understand that you could have it for years and don't know. Even with the test. Its good for us as women to get education in these things. As well as many other things. It empowers us and it is something that we need more of.

What did you find out about HIV from talking with and/or listening to family members?

Not using condoms and sleeping around is the biggest 'cause. We've sat and talked among ourselves in my family and talked about how you could get it through transfusions. It's not ether or just another aspect of it.

Author Ashe had contracted it. It is something the doctors are working on to come up with the technology to deal with it better. The information we can give them is input so they can help us. Because every person's incident isn't individual.

Because the way people can get affected could come from any variable or multiple areas so it's important that people are provided with the information of how they can get infected.

Knowledge is the key. At one time it was a 'hush hush' thing. You didn't want to acknowledge it or say anything about it. If you or your family member or friend had it

there was that denial and then they shunned away from you. So we're doing a lot better, but we could still do better as coming together and speaking on this.

Do you have conversations with your partner about sexually transmitted diseases and HIV?

Most definitely.

How do you take care of your own health?

Better. Always getting yourself tested. Then being with your partner. You always have protected sex. Then with dealing with everyday friends it becomes a conversation. Its not something you shy away from. You bring it out in the open. But you know it is a funny thing. Once you break the ice and start talking about it. You would be surprised how some will come up to you and want to talk to you and you can be a motivational person and encourage them to go get tested. Then you pray for yourself and them.

What would you tell a young person about sexually transmitted diseases and HIV?

First of all the golden rule is this regarding sex. You ask for them to be abstinent but this is not something that is really practiced. So you move on to the next phase and you tell them without a doubt. Protection. Protection. Protection. You drum it in to them. Because even just one time. Its all in the course of learning sexual habits.

The people in your family that are infected. Can you tell me how they got infected?

One nephew he had been with a partner and by them being together for five years his partner I believe got it first and then he got it. Then I had another family member, a niece. She had been gang raped. Traumatic and one trauma piled on top of another trauma. See what I'm saying. You have to get hold of those emotions and just pull them out.

I am somebody. This is not my fault, but if I am at this junction in my life I must take the responsibility for it and to see what I can do to make sure it doesn't happen to someone else. To break the cycle.

Is there anything else you wish to share with me during our interview?

I really liked talking with you. It was just like medicine. Because people need to be able to talk.

W012

Age: 52

Marital Status: Divorced

Education level: High School graduate: Certified nursing assistant

Income: \$ 16,000 per year On SSI

Initial Diagnosis. 2003

Infected by: "I used Heroin IV drugs and dirty needles"

Enter Treatment for the first time: 2003

Health Insurance: No

Currently in Treatment: Yes

Discontinued treatment Yes

Reason: No money.....No transportation

Resumed treatment: Yes

Reason for resuming treatment: "My T-cells were low .They put me in a program at a clinic that gives me health care for free"

Describe your experience living with HIV?

At first it was really difficult accept it and everything and after time went by 'cause *it takes time to get out of denial*. After time went by I was going to the doctor and saw other people there and they have helped me a whole lot. They have a women's support group. Every Thursday we get together and we have lunch and talk. The on Wednesdays I go to a heterosexual meeting there. We talk in the morning . Then once a month we have this thing called a rendezvous. And at the rendezvous different speakers come in to talk to us about different illnesses and diseases our disease. They talk about our diseases and tell us about different parts of our bodies. Like neuropathy, that's in our legs. I'm learning about my problem. Once you learn about your problem you can make yourself more comfortable living with it. If you don't know nothing about it, you won't care about it and you will do nothing to help yourself.

If you want to help yourself, you will find out all about it. That is why you need to get into a support group to help you on it. That is my life now. I've stopped doing a lot of wrong activities so now I look forward to going to my meetings. When I a done with my meetings come on home and I try to relax. And that's my day. I love it because there are so many benefits that they have for me. For instance its like going out to lunch. Then we have these raffles. We win gift cards and different little items. They make it so that you want to come. Because you know a lot of people aren't going to participate in something if they aren't gaining anything. They know how to make you come. They treat you so good. That's my life. I spend about four to five hours there and when I come home I am ready to relax and eat and watch and then I go to bed. I go there twice a week, sometimes more. It all depends. With me I'm 52 now so I can't do what I used to do. And with the

illness it doesn't allow you to do all that. You can be active but when you get settled in age you can't do it any more. I am glad I have something to do because I would just sit up in this house. And now that I have something to do I go faithfully. When you like something you go to it. If you have a job that you like you will go to it. Right now I am having difficulty that for years I wasn't having, but now the neuropathy with me getting older and the illness. I can't be on my legs that long. This week I got out Wednesday, Thursday and Friday so today I don't want to do nothing. Tomorrow I won't do nothing. My legs are kind of hurting now, but I've learned to live with the pain. The pain is not that bad though. I've been going through it for so long and I don't want to take a pain pill every few hours 'cause I would be hooked on them, so I have gotten used to it.

I am learning to deal with the pain.

Are you in a relationship with someone right now?

No. I don't have no husband. I'm single and I don't have a boyfriend. I have one or two men friends that I talk to but no relationship. But when I do want to have an intimate relationship it is like one every few months. That's how I am. I am not hung up on the sexual thing with a person. I can't say I'm passed that 'cause some women have to have it every night or every week. If I can get something good for 1 month then I am good for the next couple of months.

When you do engage in sex; do you engage in protected or unprotected sex?

That's the problem a lot of men don't want to use condoms, but me I'm not doing nothing without it. I didn't get mine through sex. But however I got it, I don't want to pass it on to anyone else. Then by me already having it I don't want it to get worse by dealing with anybody else. Usually when people have a lot of unprotected sex they end up with

Hepatitis or VD. Or they have other problems. People don't always just have the HIV virus. You don't know that if you meet a man who is positive just like you. That doesn't mean he is responsible or doesn't have other problems.

I have had experience where when it came to the nitty gritty he didn't want to use it. I told him nothing's happening. With men sometimes they don't care. But I have to have it. If I don't I'm not doing anything.

Yeah. I got my virus through needles.

What drug were you using?

Heroin.

How long were you using heroin?

Five or 6 years.

How long have you been clean?

Three years.

Good for you!

That's why I stopped running around in the "streets". Because when you run the streets you'll wear yourself out. When I started to working on getting clean I found out about the _____ and then I had somewhere to go to change my whole surrounding up people.

Like a young lady I met. She don't smoke, or use drugs or anything like that and I had to ask her myself and (she is a Christian). I asked her, why do you want to be with me? I am an ex-drug addict, but she made me feel good 'cause she said. That's in your past. She would give a person a chance. I haven't had a friend like her in almost 20 years. My whole life has changed due to _____.

I advise it to anybody. They get people houses and Section 8 and it don't take long either. Because part of the problem being HIV positive is people can't work and if they don't immediately get some type of assistance they do lose a lot.

I've been on my own since I was 18, but my mom always encouraged me to pay my bills. She said "You get your money order. You pay your rent, you pay your light bill." And right today I do that. By her doing that to me all those year that helped me pay up the bills. It is a since of habit. I live alone. My kids are grown and I love it.

How many children do you have?

Four.

Have any of them been infected?

No.

When were you infected?

In 2003.

Have you ever had a conversation with a potential partner about STIs or STDs or HIV?

I never asked another guy about the STDs but as far as the virus I have. If I want to do anything I deal with a person from the past that knows me. Because up at the meetings. A lot of people meet at the meetings. Sometimes we will go to different meetings and they will meet different people, but I'm just feeling different about me. Until I can find me a working man... I don't need a crack addict or dope dealer. I'm not looking for a man. If he comes around, he comes around. I don't know what stage I'm in but I have had some problems with men. I am not bisexual or anything like that. I just don't want another addict. I don't want a bum. I am just happy to live by myself. Then its hard to find a guy

with my status. I don't work I don't know if they will come. But God will send me someone and if he doesn't, He doesn't.

You're at peace where you are with your life right now. I hear that in your voice.

You're okay.

I'm okay. I am really okay. I am just as happy. I would like to be more comfortable inside. You know when you get older you want new everything? I am on \$220 a month. I can't afford to buy new stuff. My stuff I've had for years and years and you know women want to change up stuff every 15 years. I just deal with what I have and if I ever get the chance to do over my bedroom or something. I would be really content. Till I get it I'm working on it some kind of way. Something going to give 'cause I think about it all the time.

They say that as long as you stay faithful and know that miracle will happen. Expect it and it will happen for you. So you keep the faith. And the Bible also says be comfortable where you are at. And the things will come to you because you are not anxious or angry or stressed . You're at peace there and even though you want something a little bit better that's okay. At least you're at peace now at your station.

I don't really care for visitors really. I am a little set in my ways.

If you don't call and you come over without telling me I will not answer the door.

Shouldn't nobody be knocking at my door. You know when the kids come by they call me. I don't have company really. I see people when I go out, but as far as company I don't really care for company. If I happen to have it it is for a special reason. You know how some people do sometimes. I'm not into that.

You don't let all that drama in the door.

Yeah. They know I don't allow it so they don't even come. If you put your rules out and your foot down it won't even happen.

How do you take care of your health? You seem to be pretty knowledgeable with your meds. How do you do it?

Right now I lay down more than I sit up, but anyway. This stuff 'causes you to to have a bad appetite. In my experience it is a phase with the appetite. Once you get one. I don't want to let mines no more. I try to eat healthy food. I constantly eat 'cause I don't want to lose it. 'Cause when you lose your appetite and you don't eat you start looking bad. Some people they look sick. You know. But as long as you eat and rest. I rest. I get mine.

That is important. Resting helps promote healing along with a positive outlook.

I eat food. I go to the doctor and take my medicine. To me eating, taking medicine and resting is important.

How do you get your health care needs met. Do you have problems getting your needs met when something is bothering you?

No because I'm a good talker and that's what they teach us in those meetings too. In the beginning you just listen to the doctor and what he tells you, but now I tell the doctor what I want him to do. What is hurting me and why is this like this. I ask the questions now. Then as far as the medicine is concerned, they deliver it to your home. The provided care is good, but I'd like them to be a bit more interested in my health. I think when they have so many patients they lose interest in some of them. They seem to don't have time to listen. So you have to make sure they make the time by asking questions.

You would prefer a little more talk time?

I go once a month to see them. Just a little more time to talk.

Is there anything else you would like to share with me before we end this interview?

Not really, but if you have anymore surveys don't hesitate to call me.

W013

Age: 50

Marital Status: Divorced

Education level: 11th grade

Income: \$ 15,600.00 per year On SSI

Initial Diagnosis. 3/2007

Infected by: "I had a Blood transfusion " Further questioning : "I did IV drugs for 10 years."

Enter Treatment for the first time: 8/2007

Health Insurance: None up until 12/2007

Currently in Treatment: Yes

Discontinued treatment Yes

Reason: No health insurance

Resumed treatment: 12/2007

Reason for resuming treatment: Low T-cells and got Medi-cal

Describe your experience in living with HIV.

I was kind of down and first, but then when after I got to living with it and going to different groups and stuff I was more able to deal with it as far as telling family members and stuff.

What keeps you going?

What keeps me going is my heavenly Father along with my parents and my god son and my great nephew.

Are you in a relationship with someone?

No. Not at this time.

When you were did you ever have conversations about unprotected sex?

I was engaged to be married. My fiancé died. He had cancer. The questions did come up.

Did you practice safe sex?

As a matter of fact there was not anything going on until we were married. There was no decision one way or the other because you were waiting until you got married.

But you had that conversation. He knew you were HIV infected?

Yes.

Was he infected?

Yes

Was he infected before you?

No.

How did you get infected?

IV drugs.

Can you tell me how you take care of your health?

Going to the doctor and keeping appointments. Taking meds and that's basically what I do to take care of myself.

Did you have any problems taking your meds when you first began or any time since them?

Yes I did.

Did you stop taking them for any period of time?

No. I never stopped taking my meds.

I told the doctors and then they just changed my medications when the side effects became so bothersome.

How do you get your health care needs met? Do you find that the doctors are providing adequate health care services?

With me they are supportive. Sometime sit seems like they keep asking me to go get this checked and that checked. But at times I don't want to do it right then. They stay on me. So for me they help me out pretty much.

What do you think is the core reason as to why you stay as positive as you do? Is there anything else besides your family and the support group?

I think it's my church life. My belief and my Lord and Savior.

Do you find the conversation with men about unprotected sex difficult?

I would say yes, because the subject about sex and protection just never came up.

The subject of unprotected sex never came up by you or them?

It was more or less a conversation of can we do something rather than are we going to use protection The conversation really focused on whether or not you were actually engaging in sexual activity rather than whether or not to use a condom.

Is there anything else you wish to share with me before we finish this interview? Is anything coming to mind?

Right now nothing is coming to mind. But maybe later on.

You have answered all of my questions. Thank you.

W014

Age: 56

Marital Status: Divorced

Education level: Business degree

Income: \$ 20,000 per year On SSI

Initial Diagnosis. 1999

Infected by: "My husband was on the down-low"

Enter Treatment for the first time: 1999

Health Insurance: Medicare/Medical

Currently in Treatment: Yes

Discontinued treatment Yes in 2000

Reason: "The medicine made me feel sicker than I was" I switched to using herbs and vitamins.

Resumed treatment: Yes

Reason for resuming treatment: My T-cells were low.

Describe your experience living with HIV.

Horrible! Lonely! Every time I think of it I get sick to my stomach. I wonder how I could have been so desperate for a husband that I did not see the signs nor heed the warnings from a few of my friends.

I was in the church, faithfully went every Sunday and involved in the church activities and committees. Now that is not part of my life because I have HIV. I was ashamed to go back. I know my church doesn't support people with HIV. They look down on adultery, gay men and women and people with HIV/AIDS. They believe everyone who has HIV has a drug history, are prostitutes, and/or other "ungodly" lifestyles. But I have gotten over this. I speak a lot to groups about HIV so that other people who have it will not be afraid to go to church."

I had been praying for a husband for a long time. I met one of the youth pastors. We started dating and in less than six months we were married. I thought I was going to happy forever.

About year and ½ into the marriage I caught my husband in bed with another man. I surprised him at a church conference where he was speaking. I did not attend but decided to surprise him about 2 days before the conference. The conference was in New Orleans and I had gone to college there. I had not been back since I have graduated from college. I thought we could extend our time in New Orleans and have a mini vacation.

My husband was stressed out because of his job and church responsibilities so a short get-away was needed. What's the term. Oh yeah *on the down-low*.

I can and will not relive that moment! Because it hurts like when I first found out I was HIV positive! How do you face your church, family and friends with this!

I turned around and left the room. I have not spoken to my ex-husband since that day. I was destroyed. I went through 9 months of severe depression and lost 55 lbs. I thought I wanted to die but God saved me. God lifted me up and gave me the desire to go on.

What influences your decision to have protected or unprotected sex?

Why would that matter now?

It matters because many people who are HIV positive do not practice safe sex and infect others with the HIV virus.

Oh.

Describe a conversation you have had with potential sexual partner(s) about sexually transmitted diseases and HIV.

I not sure if my ex-husband and I ever had a conversation about using a condom or STDS/HIV. We were in love. I trusted him. After he was a youth pastor in the church and up standing man in the community.

Please tell me how you take care of your health?

As I told you before I take my medication now but in the past I quit taking it because it made me sick. I tried every herb and vitamin on the market. I still use some herbs and vitamins. I exercise and eat right. I pray a lot. I attend support groups which I consider treatment.

Please describe how your health care needs are met?

The Clinic I go to have very sensitive doctors and nurses who work there. I have not had any problems with getting care. However, I think the doctors could take a little more time listening to my complaints.

Is there anything else you would like to share with me before we end the interview?

More education about HIV. Men need to be honest with the women in their lives about their sexual activities. Men need to attend support groups where they have a voice and it is safe.

W015

Age: 58

Marital Status: Widow

Education level: Radiology technician

Income: \$26,400 per year, late husband's estate

Initial Diagnosis. 1998

Infected by: "Unprotected sex with my boyfriend"

Enter Treatment for the first time: 1999

Health Insurance: Medicare/Medical

Currently in Treatment: Yes 8 years

Discontinued treatment : No

Reason: N/A

Resumed treatment: N/A

Reason for resuming treatment: N/A

Describe your experience living with HIV.

I thought I was going to die right in the doctor's office. I always get tested frequently because I was a call girl for an escort service. There was a mistake! I went home and cried! Then called my boyfriend and asked him if he loved me.

When he got home from work I asked him if he ever got tested for HIV. He said no. I told him I had just found out I had it. I accused him of giving it to me. I just could not understand why he would do something like that to me. I thought he loved me.

I thought another man I can not trust. I will never be happy.

I met him about 5 1/2 months after my husband died I was so lonely. My friends and family urged me to get out more. I was depressed. I only worked part-time when my husband was alive so I had plenty of free time on my hands to be depressed.

My marriage had times where it was rocky .My husband had several affairs during the marriage and one affair resulted in him fathering a son which occurred about a year before he was killed in an auto accident.

My husband used to beat me up often. I tolerated it. After he died I did some grief counseling where I discovered I was molested by my mother's two boyfriends from the ages of 9-15 years old. My mother did not believe me when I told her. I married the first man who paid me some attention to get out of that horrible house. My mother always chose her boyfriends over me.

Since finding out I have HIV I decided I was not going to continue being a victim. So now I speak at support groups. It has really helped me heal from years of pain.

Sorry I can't talk about this anymore.

W016**Age 59****Marital Status: single****Education level: High School graduate****Income: \$ 18,000 per year On SSI****Initial Diagnosis. 4/15/1995****Infected by: "The father of my two youngest children during sex. We did not use a condom"****Enter Treatment for the first time: 1995****Health Insurance: Medicare/Medical****Currently in Treatment: Yes 12 years****Discontinued treatment Yes briefly.****Reason: "Got tired of all the medication"****Resumed treatment: 6 1/2 months later****Reason for resuming treatment: "None. I just decided I needed to."*****Describe your experiences with living with HIV.***

Just a lot of major changes in the way you live. I have to watch what I eat more carefully. I am acquiring other ailments because of HIV. I'm sick a lot. Not bad. I catch every little cold. Not major but it is a nuisance. It interferes with everyday life. Then there is the pill situation. I have to take this pill at this time and that pill at that time. I think it is just the way I have to live.

Did you have to stop working?

Yes.

How long after your diagnosis did you have to stop working?

About three years I guess.

Have you talked about protected and unprotected sex with your partner?

Yes with a counselor. Men never wanted to really discuss using a condom. You know they just wanted to have sex.

Have you talked to a potential partner about the STDs and HIV?

No I haven't Mainly because it is not a normal topic I would discuss with a man.

Are you seeing anyone?

Yes

How were you infected?

My youngest two kid's father gave it to me

Is he still living?

He was diagnosed in 1998. Yes he is still living.

How many children do you have?

I have four.

What prompted you to have unprotected sex with him?

Because I was in love and I didn't think that it was a risk. He wasn't having sex with anyone else.

Did you know that he was HIV positive?

No. And he still hasn't told me that he is, but I know that he is because he went to prison right before I was tested.

My youngest daughter has it also.

When I went to tell him about it he wasn't surprised. I feel he had to have known because he went to prison and when you go to prison they test you for all of the STDs. So he had to have known he had it. If he hadn't had it there would have been a reaching. It also triggered things that I had seen but didn't pay attention to. It made me think about this guy and how we used to go over his house all the time. It was how he treated him. It just made me realize that he and this guy were having a relationship. And that's why I believe he hasn't told me because he would have to tell me the whole situation.

Your daughter, is she symptomatic?

No. She is non-detectable

How is she coping with it?

She is very strong little girl. I was telling you that when I finally went to talk with her about she was very positive. She said I don't really like its changed my life much. I do sports and it doesn't affect me in school. I interact with boys. I don't think it will be a problem when I find the right man because I wouldn't think about having sex before marriage anyway. She is very positive.

God bless me in a major way with her because she is a very intelligent and understanding child. She looks at things like an adult. Not like a kid. That helps a lot.

Do you practice safe sex now?

No. He refuses to use a condom and he knows that I'm HIV positive. He feels that we are soul mates and that if we go we will go together. He's been tested twice and he is negative.

How do you take care of your health anything besides meds?

I try to avoid catching colds. I used to walk around without a coat. I started covering up when it starts getting cooler. Carrying an umbrella in the rainy season. Also watching what I eat. I have started adding a lot of fresh garlic to my food because I heard that it really helps the immune system.

My dad was in herbs and things and so I picked up a few things. I use raw onion because that is supposed to help clean things. Then I just try to stay out of situations where I might get sick.

What else keeps you going during this chronic illness?

My mother's prayers have a lot to do with it. I was raised in a holiness church. My faith is not as it used to be, but my mother prays for me. I draw my strength from her faith. It is so strong. I have seen my entire life how her prayers worked for her. I have strength in her prayers. I think that's the biggest thing. That and I promised my dad that I wouldn't give up.

Do you find that when interface with your health providers are they user friendly?

Yes. I have been with the same clinic since I was diagnosed in 98. They have a very wonderful staff there. They very friendly and they make sure the patients are comfortable. My thing was I just didn't want anyone acting like they were afraid to touch me. But I've never experienced nothing like that.

There was a lady that would come by the recovering home and educate us on how to protect yourself and how to keep from contracting the virus. She was the reason why I went and got tested. They even have clean IV needles.

They need to have more education. I think they need to start in middle school

Is there anything else before we end this interview that you want to share with me?

Educate kids at a younger age about HIV and unprotected sex and about men being on the down low. I think schools should educate boys about men being on the down low. I remember when the article about the guy who came up with the term down low and advised that all men be honest with themselves so that they could be honest with their mates. He didn't consider himself to be gay until his wife walked in on him and another man.

He lost his family and wife for a period of time. He should have been honest with her. He should have been up front. He said that if he couldn't admit to himself that he was bisexual, how was he going to admit it to himself?

Something has to be said about these men to young guys so that it doesn't spread. Even with all of the coming out business if people are able to be truthful about their sexual orientation they will be a lot more honest. I think if they could find a way to do something about that I think it would help a lot. We need to educate our children.

W017

Age 50:

Marital Status: single

Education level: Chef: attended four years of culinary school

Income: \$ 19,000 per year On SSI

Initial Diagnosis: January 2007

Infected by: "I did not use a condom with an ex-boyfriend"

Enter Treatment for the first time: August/2007

Health Insurance: Medicare/Medical

Currently in Treatment: Yes less than a year

Discontinued treatment No

Reason: N/A

Resumed treatment: N/A

Reason for resuming treatment: N/A

Describe your experience right now living with HIV?

I've been going to the doctor. Getting all the information about HIV. Getting all the tests, all kinds of shots.. I guess I feel a little sad and hurt sometimes about it. It didn't have to happen but I deal with it.

What keeps you going?

I enjoy life. I have a lot to do. I'm on a mission. I still have a lot of things I want to do and things to look forward to. That's what keeps me going.

Do you have a spiritual leader?

I don't really go to support groups. That was just the second time I've been to some time of support group. I rarely go to church, but I'm spiritual. I grew up in a Baptist and Methodist church and I do believe in God. And I go to church periodically but I don't go to church all the time.

What influences your decision to have protected or unprotected sex?

I usually use a condom initially in the relationship but when we have gotten close we stopped using protection.

Tell me how you got infected.

This person I was dating for 4 month infected me. I believe he knew he had it but he didn't tell me. You know. We used protection in the beginning, but after the months went by we stopped. You know you kind of get more comfortable.

Were you able to confront him about that?

Yes just recently I confronted him because he kept showing up at my house unannounced. I asked him from the beginning. Even when I first met him if he had a test done and he said yes he had one done recently. Then I asked him more recently if he had another one done and he said "Yes" and I told him I wanted him to come over and bring me the results because I wanted to see what it said, but he hasn't done that yet. And he probably won't.

Does it concern you he has moved on and didn't tell you?

The reason I would like to know whether he did or not (which I believe he is the one). Hopefully he's not going around spreading it to other people. That is my main concern. I hope he's not going around giving it to other women because then I would have to report him.

Are you in a relationship now?

Yes

The relationship has been going on how long?

I've been knowing _____ for a year and a half.

Do you practice safe sex with him?

Definitely.

Describe a conversation you have had with potential sexual partner(s) about sexually transmitted diseases and HIV?

Yes. Well I found out in July of last year and as soon as I found out I called him and told him that I had tested positive. He freaked out. And I guess he had to deal with it on his own terms. He is still a little uncomfortable, but we still have a good relationship.

So the conversation you had with him. You told him what was going on with you.

Yes.

That's good because you never know. Now that he knows; do you have conversations around the subject of HIV. Is he seeking more education?

You know he hasn't asked me. I think he may have investigated some on his own, but he told me to tell him everything. He's so busy. He just recently got one of his first books released. He had it published before. But he just got it published again. He has been promoting that and he has a second one coming out in July. He is just very busy. He says if there is any information I can give it to him. I believe that he goes on line and answers questions he has.

If he's smart enough to write a book then he's definitely has done some research.

This is not something you talk about on a daily basis. Why should we discuss it on a daily basis?

We'll discuss it. When we have sex we have to make sure everything is okay. And so we discuss it too. Especially about that part.

I think as you make that adjustment in this year of learning about yourself and about the illness. You can't let it consume your life. I can't think about it 24/7 and discuss it all the time because I can't focus on that. I have been unemployed for quite a while and I just

got a new job. They hired me on Friday so I go to work on Monday. So I've got a new job and I've got to concentrate on this now because I need a job and I need to work. So I've got to focus my energy but I'm always focused on my HIV myself, taking care of myself and doing what I got to do. I just don't live it, breath it and think about it every minute of the day.

What do you to take care of your health?

I eat pretty good anyways. I went to culinary school for four years so I'm a good cook. I try to eat healthy and not eat a lot of junk. Take my vitamins and tame my medication (of what I do take). I have to take thyroid medicine and high blood pressure pills so my blood pressure is no tot bad. But when you are stressed and everything it doesn't help. I take my medicine and I exercise. I take other stuff to build my immunity up. There is no more that I think I can do. I can't let it consume me. It's not even in the picture for me.

When you interface with your health care providers, do you find that you are getting the kind of quality care that you expected?

Oh. Yes. You know I have Dr. _____. She is one of the best Doctors and they run every test possible. Give you every shot. They give you a shot of Hep A, B, everything. They even did a genotype on me to see if I needed to take medication, that I could take any type of medication. And I can take any type of medication if I had to. So they do everything possible to make sure that you get the right care. They're very good.

In the short time that you've been diagnosed with this, what else do you think is needed in or around HIV education? Do you think there are any gaps?

Yes. You know, Black folks. They just don't get educated. They won't take an AIDS test. They won't take one. I have asked a few people about taking one and they have said "I

don't need to take one. Why should I take one." That's their attitude. The first thing is that they need to be educated to take a test frequently, but I think the major thing is that they don't get tested. At least Black people don't.

They don't?

And I think a few of them know they have it and they constantly have unprotected sex anyway. You might have a point. That's why it's spreading so rapidly.

Part of that is a lack of education, but there is also a lack use of condoms and other preventative measures.

I know because I listen to Michael Baize talk show. I was listening to him in the car and he actually had a talk show about AIDS. You know a lot of people were calling in and saying that they knew people who knew they had it and still won't do anything about it. Spreading it around. They know the person has it and they know the person that's doing it. And then a lot of them won't get tested.

Yeah I don't know what it is.

Even my best friend said "I don't want to know"

I hear that frequently. If I do get tested. Can you get it by getting tested? You know those kind of questions. Blacks need more education on HIV.

I know many people own HIV and it's not theirs. You have to live with it like you have to live with diabetes or cancer. You have to live with these things but they are not you.

I am not going to let it own me and take over my life. Well that's something I just can't let happen.

Thank you for your time.

W018**Age 49****Marital Status: single****Education level: High School graduate: Personal Trainer****Income: \$ 16,000 per year On SSI****Initial Diagnosis: March/2004****Infected by: "I was raped"****Enter Treatment for the first time: March /2004****Health Insurance: Medical****Currently in Treatment: Yes****Discontinued treatment Yes skipped several times****Reason: "I do not like taking medicine"****Resumed treatment: Yes****Reason for resuming treatment: "I realized I would die if I did not take my medicine"*****Describe to me your experience living with HIV.***

It is like a constant reminder. I get depressed a lot. I try to overlook it and tell myself that everything will be alright. I try to look at the positive side of it. I hate the medication.

What are they treating you with?

I take Chubat, red tap and Norver

Do you have children?

One girl. She's grown.

Is she affected?

No.

How do you live day to day? What's a day like for you?

Sometimes bad days, sometimes good days. Sometimes I'm just lonely.

What's a bad day for you?

When I think about what happened to me. When I think about getting HIV. How would anyone ever accept me.

Would you like to be in a relationship with someone?

Yeah. I do but I'm not in a relationship with anyone right now. Part of that has to do with the anger around the rape and partly the HIV _____. I am afraid that if I'm in a relationship with someone and I tell them. How are they going to respond? How would they treat me?

That does make a difference when you start to pursue other relationships out there.

Have you told your family members or friends?

The participant ended the interview at this time. It made her very uncomfortable to talk about the problems with the rape, feeling lonely and having HIV. She says that she feels extremely isolated and has not spent a lot of time interfacing with a lot of people. She experiences depression and made a decision to go back on her meds because she wanted to live and knew it was risky not being on medication. She feels she's too young to be in this situation, but did not want to continue forward with the interview.

W019**Age 56****Marital Status: Single****Education level: Bachelors in Art: Music major****Income: \$ 21,000 per year On SSI****Initial Diagnosis: 1996****Infected by: " Ex-boy friend who used IV drugs****Enter Treatment for the first time: early 1997****Health Insurance: Medicare/Medical****Currently in Treatment: Yes 10 years****Discontinued treatment Yes for 6 months****Reason: "I started dating a man, then moved in with him for about 6 months. I did not him to know I took so many medications.****Resumed treatment: Yes****Reason for resuming treatment: Low T-cells.*****Describe your experience living with HIV.***

Just devastated. It is the same for me every time I have to talk about it. The terror from finding out in the beginning comes upon me every time I have to discuss it.

The initial shock is not like hearing anything else in your life. There is this total disbelief.

Then what runs through your mind is 'How am going to deal with this and how am I going to keep this secret. I spent a good part of my first year with this sickness

developing all kinds of clever plans on how to not tell people. I was in a relationship with this guy where I hadn't gotten to the point of having sex. But we were moving towards it

quickly. I made the decision not to tell him so that he wouldn't reject me. So I was in that relationship for two years. He asked me to get tested, but I already knew that I was infected with HIV. He revealed to me that he had gotten tested and he now was infected with HIV. So I was probing him to see who he thought was a partner that might have given this to him. He said " You know, when I was in prison I was gang raped about 4 year ago and that is a result of me contracting HIV" And it was such a relief for me because I hoped that maybe that is where he did get it. And that he had it when they first started having sex and that I may not be the person that gave him the disease. So they continued with the relationship. I still haven't told him.

I find that real interesting.

My thought is 'what he doesn't know won't hurt him.' He's very conscious that he has a disease and now that he knows it he wears a condom. Which he really doesn't need to do but I still don't reveal that I have it also.

What influences your decision to have protected or unprotected sex?

We didn't have the discussion of having unprotected sex prior to that part of the relationship. But we did have it after he revealed the he was infected with HIV and we use condoms now.

Describe a conversation you have had with potential sexual partner(s) about sexually transmitted diseases and HIV?

Conversation around STDs and HIV came after he revealed he was HIV infected, but not in the beginning of the relationship.

Please tell me how you take care of your health?

How I takes care of my health by watching him. He eats healthy. He exercises and he has positive attitude. They talked about moving in together, but there is no way I could hide all of the medicines I am is taking from him and because he's infected he would know instantly. I chose not to live with him. But I takes his lead. I have lost about 30 pounds since I have been dating him. Because he exercises, I exercises like running and walks with him. I feels better because I am taking better care of myself. But I used to be in such a funk about being infected with HIV that I didn't eat right, or take care of myself. I was avoiding my family and friends. Actually having him in my life has made it better. I have been going to support groups with him, but talking in the meetings as his support person. Therefore I haven't revealed my illness.

I am not sure how long I am going to be able to keep that up or how long the relationship with the two of them will last but right now I am enjoying being with him.

Are you receiving the health care services you expected from your health care providers?

I am not had any problems with my doctors.. The problem was me. I stopped my treatment for 6 months. I hated taking the medicine. Swallowing all of that stuff and choking on that stuff most of the time, then feeling nauseous all the time it took up my whole day. The whole ritual of having to lie down so I couldn't go to work so I ended up being fired from my job. It was just a mess. I am not working so I do not have health insurance. I finally got into a clinic and they changed my meds around so it doesn't require having to take all of those meds at this point.

Is there anything else you would like you share with me before we end the interview?

More education for the Black population. More women services because it is limited where I live at or the clinic is in a bad area and people see you and say “Ahhhhh. She’s going to this clinic. She must have HIV”. So I walks around in fear all the time, hoping that no one discovers my real problem. I prefers going to a clinic that normal people goes to. I do not go to clinics just specializes in HIV because I wants to keep it a secret as long as possible.

W020

Age 55

Marital Status: Single

Education level: High School graduate: Florist

Income: \$ 18,000 per year On SSI

Initial Diagnosis: 2005

Infected by: “I dated a guy who had been in prison and was raped by several of the inmates. He did not reveal he was HIV positive”

Enter Treatment for the first time: 2005

Health Insurance: Medicare/Medical

Currently in Treatment: Yes 2 ½ years

Discontinued treatment No

Reason: N/A

Resumed treatment: N/A

Reason for resuming treatment: N/A

Describe your experience living with HIV.

When I found out. It crushed me. He was loving and I had just come out of an abusive relationship that I had been in a relationship with for four years. I have never been married, but have been in some long-term relationships with men.

I was lonely. I lived with the guy for four years and dated him for two years prior to that. So a total of about six years we were in this relationship and he decided that he was going to go off with someone he felt looked better than me.

Men have all the reasons they can think of for cheating on you and mistreating you.

Actually, I felt it was a blessing because every time he didn't like what went on in his life I was beaten up. So for a long time I didn't have enough courage to seek professional help. So him leaving the relationship actually freed me and saved my life.

Then eight months later I met this guy who didn't reveal a lot about his past until 8 or 9 months into the relationship. He share that he had been in prison and had been out for a year, but never revealed that he had been raped by inmates in prison or that he was HIV positive. We went together for about a year or year and a half. Then there was a community health fair I went with some friends. I got tested for HIV. There I was informed I was positive.

I can still remember the bitter taste in my mouth when I was told. I had vomited up bile and that I was going to pass out. The lady was trying to be supportive but I couldn't hear her clearly anymore. It was like listening to the teacher in the Charlie Brown cartoons. I couldn't take it in. I could not believe that I was infected with HIV.

What influences your decision to have protected or unprotected sex?

I don't know. I sit here with you now and I was not able to have that discussion about unprotected sex. I had been a relationship where I had unprotected sex for six years and being out of the dating field for that long, I was not prepared to have that talk.

Describe a conversation you have had with potential sexual partner(s) about sexually transmitted diseases and HIV?

I wasn't sure what to say and asking him if he would get tested and me getting tested wasn't even my mind and I don't know if it crossed his mind at the time to have the discussion. I confronted my boyfriend and he, to this day, acts as if I may have gotten it from a prior boyfriend. So I contacted my previous boyfriend and asked him to get tested and he did and it came back negative. At this point present boyfriend reveals to her that he had been gang raped in prison and that he was HIV positive, but thought that now that she was positive that they could continue their relationship.

I almost went and bought a gun to kill him. What do you do when someone gives you a death sentence and does it in such a flippant way? What do you do. If it wasn't for the fact that I went to church and had a friend that went through a horrific relationship with her children's father and leaned on the Lord to get her strength back because she was contemplating suicide. That spiritual connection with the friend helped me get over the fact that I wanted to take revenge over this guy. I wanted to hurt for what he had done to me.

The violation and mistrust was bad enough, but then he had the nerve to walk away from me and started dating someone else.

I sometimes wonder if he has ever told anyone else that he is HIV positive. He may be out there infecting more and more women.

Please tell me how you take care of your health?

I take my medication. I don't know how to do anything different. I try to eat right and walk, but there are days when I can't believe that this has happened to me. I just can't believe it. I am extremely lonely and I don't know how not to be lonely and I don't want to get close to anyone because I've got this disease and I don't know if I want to reveal it to everybody. My spiritual friend knows about it, but I don't know. I guess I take care of my health by secretive which probably creates more stress. What am I supposed to do? Everyday is like hearing it again. I hate to see the advertising. I remember looking at the advertising all around me before and I thought it was something that was cured.

It's not cured. It is symptom managed, but not cured.

I'm learning that now. I'm going to support groups and getting more involved and finding what this disease is and what it does. That is the reason I'm taking them. I don't know if I want to know more about it. I just know that I have it.

Is your health care provider meeting your need?

I haven't had it long enough to have a lot of experience with it. I haven't been bounced around from one provider to another or anything like and I don't have anything to compare it with, but I am comfortable with my clinic. The more I learn about myself the more I am able to ask my doctor for what I need.

Is there anything else you would like to share with me before we end the interview?

What is needed out there.....

I would like to have detectors or tracking devices that says "bing, this guy has HIV". Something that would alert someone that was interested in getting in a relationship with somebody that would let them know that that person was HIV infected. Men would be a

lot more honest about their sexual activity and men need to wear a condom and women need to wear a condom to invest in your own lives. I can say that now in hind sight because I didn't say or do any of that, but now I know that is what I should have been doing.

This is not a place you want to be. This is not something you want to grow up with, go to bed with, think about, live with on a daily basis. It just isn't. I get sad every time I think about it and when I get around people that are HIV positive and their up and being positive about their life and picking up the pieces. Some of them are going back to work and all these different things. I know I can do these things. I work part time now. I know I can do these things, but it just drags me down and recently the doctor put me on a low dose of something for depression.

Focus Group

Initially seven women joined the group then five minutes later another woman and two men joined the group. The group consisted of six HIV Black midlife women, two family members who have loved ones who are HIV positive and one Black man who is HIV positive and one Black man not HIV positive. Age range was 49-56 years old. Total of ten in the focus group. The following are the questions and the answers of the focus group.

1. Is it true that the reason why most African American (Black) women become affected with the HIV disease because they are engaged in a relationship with a man and because they want to feel safe and they want to feel loved, they engage in unprotected sex.

“I think that is because they want to be loved and they feel that they need to be loved that they forgo that protection. That if the man loves you too you forgo that safe guard. You forgo that safe guard even though you should protect yourself.”

In order to solidify that relationship do you find that the biggest issue is being able to trust somebody.

“I don’t. Because certain people got to understand you and know you for who you are. They understand the illness that you safeguard within yourself.”

Some of the other participants talked about their relationships or wanted to be in a relationship with someone simply because they wanted to be loved and they wanted to love but after being infected when they started to rethink that relationship and about that exposure and most of them said it became a trust issue. With the secret of being infected with HIV in their next relationship they would inform the partner or they didn’t, but it became an issue of trust for them. Could they tell their partner?

“That is what it becomes. After it happens to the person initially there is a betrayal of their trust. They aren’t honest on how they contracted it in the beginning. So it makes it a little more difficult. But in their self they have to...”

“I have to automatically tell. If I plan on being intimate with them I have to tell them because that was the way that I was infected. The person that did this to me to this day has not admitted it to me. So I refuse to put anybody else in that position. Because that’s playing with a person’s health.”

“Also the person that I date now, I was dating when it happened because I was also seeing someone else. They gave it to me and I know he did have it but he didn’t say anything. So I told this person that I’m seeing now that I contracted the HIV because I

trust him but I didn't know how he was going to react. Just freak out and say I'm through with you or whatever. But my trust in him was that he knew as who I was. That was really encouraging. I felt that he would be able to deal with that which he did."

"And the thing about it with me was that I was already in another relationship when I found out. So now I have to go and tell this man. I was scared to death.

But once you bring it up in the open and talk about it then they want to know more about the illness in you."

"I had a friend when he first heard about the illness in 93 he asked me how was I infect. It took me a long time to figure out what the question was. He asked me and I cried and life went on".

"Yes life goes on. And you take on that responsibility, when the other person infected you, you take on that responsibility so that any other relationship that you have it becomes that bond between the two of you."

"And then they say you can use rubbers. What is safe sex? Rubbers can bust. Exactly. It's the trust within each other."

"You just the other day my partner told me he cared about me. He said, "You know I trust you with my life. You have to know that because I know your situation and us staying together. So you know I'm putting my life in your hands. So I guess that's where the trust comes from."

"So it sounds like twenty or twenty-five years ago. To be diagnosed with HIV was a death sentence and now they say it is not."

2. So what kind of things have you done since you were diagnosed with HIV to improve the quality of your life?

“Taking my meds.”

“I recently found out last year and I tried to get educated. I knew instantly that the meds that they have now will keep you going for a long time if you know what to do. So I was never worried about it. I never thought about dying. That’s out of the question. But what I did. I went to see doctors and I started changing my diet. I eat good anyway. I ‘m a cook what can I say. I tried to eat a little more healthy, exercise and try to get into better shape and be mentally charged and ready. And that’s all I can do.”

“I say educate yourself once you find out that you have something. Educating yourself to the best of your ability. Then educate the ones dear and near to you. SO then that way they can kind of understand what you’re feeling. They can be like a support group for you.”

“I’ve been HIV positive for 19 years. No medication. I am one of those long-term progressers. I was molested by my uncle. So that’s how I contracted it. It’s a trip because I go to the doctor every three months and nothing changes. My viral load is undetectable and my CT count is 857 so... “

“I have not been on medicine. Within the last month I have stopped taking my medicine. My viral load is undetectable and my CT count is ... I had 1200 and I was symptomatic. It will take your focus off of what you should be doing. You don’t see the doctor for three months and they offer you some medication because you are on medical”.

“I’ll tell you like this... If they offered me some medicine I wouldn’t take. I would to different meeting with different doctors who would come in and they would tell you that a lot of those medications would tear up your liver. So why would I take something to help mess me up? I’m fine just the way I am.”

“We go to these women’s groups and we hear these stories and stuff and those who have never taken any medicine are more healthy than we are on a daily basis”

“I’m going to tell you when take medication. For my children. When I was pregnant. I took the AZT for my children. My oldest son is 16 my second one is 15. I have a 12 year old and a 10 year old. All of them are negative.”

“When I had my youngest two kids. Well with my youngest. My baby girl. I didn’t know I had it . I hadn’t been diagnosed with it. Her father gave it to me. This is the reason why I know he had it because my baby had it. I didn’t know. I was on drugs and my baby was placed with his mother. Thank God for her. When I found out was when I went to get myself cleaned up. They offered the pretest and I took the pretest and I found out I was positive. When I go to tell them about me being positive they tell me that my baby is positive. Now they have been knowing all of this time but none of them were concerned enough about me to tell me so I could get help for myself. And I was two steps from dying. My daughter is 14. She is perfect. She doesn’t have to take any meds. I wish I’d known because maybe there was something I could do to prevent her from having to go through that.”

“I’ve never had a problem towards myself with having it because I believe it happened because it should have happened. So that is one issue that I never had to deal with. The one issue that did bother me was that I gave it to my baby. And I’d had serious resentment towards him and his family. And I pray to God that I can let that go because it kept me from being around my kids. It kept me in relapsing because I needed to medicate myself because I can’t handle that. But what really got me passed that was when I sat down and talked to my daughter because I didn’t know how she was going to feel about

me giving this to her. And when I came and sat down and talked to her she said “Momma I was waiting for you to feel comfortable enough to come talk to me about this.”

And I have tears in my eyes because my baby is such a loving understanding person. She said “I have no problem with that momma. I know you didn’t do it on purpose. It wasn’t nothing that you tried to do. I was just wondering when you were going to feel comfortable enough to come talk to me. I’m fine as long as you’re fine.”

After that I was able to forgive all of them. I’ve never mentioned to them the anger I had for them, but at that moment I was able to just release it. And I have been able to stay clean since then. That was my hold. That helped me get back on my recovery. That was five years ago. But like I said. As far as myself. It doesn’t bother me. Once talked to my kids and got them passed that scared stage. Mom’s not going to die. Mom plans on being here until they find a cure for this. I will do what I had to do. My last issue was with my baby girl. I thank God that we worked that out and I have been clean for five years. Now I can consistently take my meds like I’m supposed to. I used to fall off. Take a week ‘cause I sunk into a depression and just didn’t care and then I would get back on them. But once I got that resolved with her I have been so much better. So much happier. That was a burden lifted off of you.”

3. *How do you go in and out of being in treatment? What are the reasons why?*

“We go through a mourning period learning the diagnosis. Then we get in the treatment then for some reason we stop going to the doctor. We stop taking our medication”.

“Because I was diagnosed as AIDS about three months ago. I am undetectable. I am at the best health I’ve ever been. I’ve taking my medicine for a whole year. And when I had 60,000 of the viral load inside of me I was undetectable. If you go up under 200 you are

diagnosed as AIDS. You can have 200 T-Cells in one viral load and you still don't have to be at full blown AIDS. I had 199 and I missed one and I was blown. But I had 16,000 of this virus inside of me and I was symptomatic. When I cleared all the virus out they went back to 10 to 15 years and found that one time that I wasn't and they threw it on my last diagnosis".

"That was years ago. They just went through my past files and just brought it up to me. That messes up my insurance because I'm thinking I'm HIV not AIDS".

So which one are you?

"I was misdiagnosed with AIDS years ago. I am diagnosed with AIDS now, but they didn't tell me that six years ago. They just told me that seven months ago.

It messes up my insurance because it has the question 'Do you have the AIDS Virus'. It changes the medical"

How do you feel?

"It tore me from wanting to take that medicine. Then it's a trust issue.

Then your doctor and they want to give you sleeping pills. You don't have to see you doctor to get your medicine because of medical. They will deliver it to your home. But when you want the sleeping pills because you have insomnia. Oh you can't have that, so you have to find another way to get your sleeping pills, but without him you can not get a full prescription. So now I have to go to another doctor and tell them that my medicine was delivered on the tenth, but they didn't give me my sleeping pills. So now I am going over the doctor's head. If your going to judge me, you keep me up at night because that's my sleep".

“I learned the tough way that you really can get complications if you don't take care of your health. When I was first diagnosed with HIV I stuck to my diet and took all my medication and did everything that I was supposed to do. Then I got angry and rebelled. I stopped taking my medication, I stopped going to see my doctor, I would make fake excuses for not seeing the doctor, how did I know that they would know that I made them up when they checked my T- cell levels? I rebelled for many years. I knew it all and could preach to any body how they should avoid risky behaviors and care for themselves but I didn't practice what I preached”.

“I eat healthy now and take my medications, I keep my clinic appointments and tell my doctor what really going on with me. My key point is that it's never too late to start taking care of yourself. I thought my life was over... It's just beginning”

4. Do you find that your interaction with your health care providers is real supportive.

Do you get your needs met?

“Sometimes they don't take your heartbeat or check your chest to see what in there and they want if you are feeling okay. Yes its just verbal contact. No hands on contact.”

“I've never had any problems with those doctors.”

“Well I'm blessed because I don't have insurance. I'm on ADAP I have very good doctors. I go in there she checks my eyes, my ears, my nose, my throat. She checks everything. She keeps me regular on all of my pap smears. On my mammograms she makes sure that I have everything I need. I just told her that my eyes were starting to mess with me because I have diabetes also. I have these reading glasses. I can read with them, but I'm having trouble seeing with them. Now she sent me to the eye doctor. She

sends me to the dentist. If I have a fungus she sends me to the podiatrist. I get the best of care. I get my medicine to my house.”

“I had stopped taking my medicine ‘cause of the side effects. I can only take it so long then I need to take a break. After a while the side affects stop.”

“I know that’s why I stop taking my medicine. I think I might have had the side effect a month maybe a month and half after I first stopped taking the medicine and they changed my medicine because I was so taking so many pills. I told the doctor that that was what ‘caused me to stop taking them because I was sick of taking so many pills. I was just living my life to take pills. This pill at this time and this pill at this time. So now I just have one pill once a day. Because I have so many other health issues. I have high blood pressure, and I have diabetes, and I take mental health pills. I take pill for depression and insomnia.”

“You take so many at the same time how do they figure out where they are going. Its like the pills are going in your system and you are really thinking inside your mind. Now where is this pill going?”

“I’m not taking any more pills. I refuse. I won’t even take an aspirin for a headache. I’ve been taking so many pills for so long. I had a clock with the little beeper thing to remind me to take them. It was like..... This is not living. I’m just living to take a pill. You know this is just ridiculous. No I am not taking them no more. So I went back to my doctor and told him I think I have had it with my medicine cabinet and I haven’t taken it since. I’m since and tired of taken pills.”

“You have to speak up for yourself. You are the main person that has to interact with your doctor and let the doctor know. The doctors are still in school themselves. If you say

something to the doctor and he's paying attention and he make a notation. He takes is with him and they get together and discuss these things."

What keeps you going?

"Having responsibilities is what keeps me going. Family and support"

"Having faith. A lot of love. Trust. Having a lot of people and those people trust you keeps me going. See I recently lost my mother in 2006. That was my jacket. She was my jacket. And it was real hard and its still hard 'cause I sit by the phone waiting for that phone to ring. I know she would never come up 'cause she didn't like climbing the stairs in my apartment, but I'm still waiting for that phone to ring, but I know she's there and she is also keeping me going".

You've got your guardian angle.

"That's about the same with me and her, but with me it is my father. I lost my father. He was the reason why I started get myself together and stopped using drugs. He said Baby I wan to make sure that you can take care of yourself before I leave here. And when he said that something just told me that my daddy is going away. And I got myself together and I was clean for a year and a half before he passed. And I relapsed for a minute but then I thought. But them it was like I could hear him in my head saying "_____ what did I tell you." And I got back straight."

"So the memory of my daddy and the presence of my daddy and my kids and my grand kids. They give me a reason to want to stay healthy and stay here. Especially my grand babies. I watch them while my daughter goes to work. That is what keeps me. That love."

"What keeps me going 1st and foremost my heavenly God that gives me the will and courage and strength to keep on pressing and this HIV is on the back burner to me. I have

another issue that comes before HIV and that's my dialysis. That's what I deal with first and my HIV is second and my godson. He keeps me going. And also my parents and grand baby. I want to be around to see them grow up."

"What keeps me going is I like life. I enjoy having a good time and just doing what I'm doing. I have a lot of stuff that I'm still going to do. So that keeps me going everyday. I just like being here."

"To hear from your father every morning. That's a blessing. I wonder if I am drinking coffee the same time He is. He bought me a coffee pot for my birthday. It was January 6 and you only get like two or three little cups. My parents say "What was the purpose of that coffee pot" I said, "My daddy bought it for me." What I say is "Cause He wanted me to drink out of it. He didn't want no body else to have none."

The 'Down Low' Syndrome

Most of the men in this group spoke up and talked about the image of the Black man. He was strong and takes care of his family. When he had those tendencies the Black culture is not real accepting of that and he can not be involved in that activity and be out with it. In other words he cannot say that he is bisexual. Most of the time they are in relationships with women and prefer to be in relationships with women either married or date them. But for their extra curricular activity to be with a man and feel that is just a part of who they are and it should not be primary in their relationships or at their jobs or any place that they interface with their family or community.

Men realize that other men that are on the down low have a hard time socializing with them because they feel like they are being groomed by that man that is on the 'down low'. The man in the focus group that was HIV said in his activity of being on the 'down low'

looked for men that were strong with muscles. He was not attracted to men that were blatantly feminine or gay. The stereotypical gay guy might be attracted to him but he would not engage in sexual activity with him.

The one that was heterosexual said it was a fine line. He said what raised the hairs on the back of his neck was when a man paid him a little bit more attention to him than a regular man would. He said sometime they want to fix his shirt or a lot of rubbing on his back or they keep sending him drinks. That is just a little bit too much and big warning signals for him that even though this is a strong looking man that seems like he is looked up to “a pillar in the community” type he starts to get uncomfortable ‘cause he can actually feel the vibes.

5. Why is the use of condoms while you are not in a committed relationship and knowing that your partner has also had numerous sexual encounters still not something Black men prefer not to do? In addition, why to Black women allow Black men not to use a condom?

Some said they just never used condoms period. They didn’t use them in the beginning of the relationship or in the middle of one. They just did not believe in using condoms and that was just the way it was. A number of the members felt that for women it was a way of showing a man that they trusted them and they really wanted to be closer to them and they really wanted to be in a relationship. It was in hopes that in permitting them not to use a condom it would insure that that relationship would grown and the men would be committed to them.

“The men said that is just a myth. They just preferred not using them. There was not rhyme or reason. They aren’t that conscious about the risk of HIV.”

7. Knowing that your partner had HIV why wouldn't you practice safe sex?

“If I am in a relationship and feel that if we are supposed to be together then we are supposed to be together and we can die together. My girlfriend is HIV infected and I don't use condoms.”

“The condom us is over rated. You have to buy the right one and you have to use them in a certain amount of time. Sometimes when you are in the heat of the moment it not the time to stop to put on a condom. There are a lot of variable that take place in the decision making to use a condom. The biggest one is that men don't want to wear a condom.”

There was one woman that said “No wrap. No sex.” If you didn't wrap your weenie then there would be no sex. She said she basically refused to engage in sexual activities unless he agrees to put on a condom. She said that sometime it has broken the mood. Some guys have said “You don't really love me.” Or laying a guilt trip on her and she says she just stands her ground or she doesn't have sex. When she was younger she used to go for that and that is part of the reason why she is HIV positive. Because she allowed men to talk her out of using a condom and making that demand and expecting it, she sees that as an onslaught to her self-esteem as a woman. If you don't want to protect both of us (what you do with your body is your business) but don't you respect me as woman because I'm asking you to do this? This is me so why would you not want to put on a condom. It's not a great big thing. It's not like you can't stop for a minute and put a condom on. She said she buys her own condoms and has men use those. She is basically in a relationship with a guy who is HIV positive now and they go in and out whether or not they are going to use a condom. She says it's still risky because he could have another strain of HIV or another type of sexually transmitted disease and I could get that. But we have been

together for the last three years so I have kind of backed off on my demand of his use of a condom. Maybe it is because we are both in this together. There aren't too many potential partners out there so when we find each other we cling to each other because we want to be normal. We want to get married. We want to have children and protect ourselves. This woman has four children and the youngest is 7 and the oldest is 19. She has been infected for the last 7 years."

8. *How are you getting health care needs met?*

"I do not look like a gay man and sometimes has problems with health care practitioners giving me the eye when I tells them I am HIV positive."

"I am in a HIV program and feels a little bit more comfortable talking about my illness especially when I go to support groups that are mixed. I understand how women feel in being infected. I infected my wife and a girlfriend. Also I understand for how gay men perceive my role as a man on the *down low*. Right now I am not actively involved in a relationship with anyone, male or female. I am just rebounding from the last two years of being HIV infected."

9. *What do you have to live for?*

Many shared that self, loving life, family, enjoying life and doing what makes them happy.

10. *Are you a woman of worth?*

"I am so glad to be alive and enjoying life. I have been diagnosed with HIV over 10 years and I take all the medication. I was raped in my early twenties and somewhere in my other relationships someone gave me HIV. Now I have beautiful children that are not affected and yes, I feel like a woman of worth. I've managed to live a pretty normal life

with this illness. You can't see it on me that I have HIV. You can see that I eat well. I 'm a little over weight, but it hasn't turned into a disease that has kept me from living a normal life."

"I really know I am a woman of worth because dying has not entered my mind. I am thinking of about living because I know I am a woman of worth."

One woman who had recently got a job as housekeeper and loves cooking and its been a hard climb since her diagnosis to get a job and she feels that right now being gainfully employed has really boosted her self esteem. Her boyfriend is very supportive and had supported her financially and emotionally through the time of unemployment.

"My fiancé and I became engaged. I was reluctant at first but my fiancé makes me laugh, smile and he just makes me happy. I told him a year ago about my diagnosis that I am HIV positive and he said he it didn't matter because he loves me. I had a child at a young age and they are HIV positive. And now that she is older and a teenager we discuss more of the affects of HIV. She is more accepting."

"It was difficult realizing that Ii was the direct 'cause for my child having HIV."

"I met my husband, early on the relationship I was so ashamed I would dress unbecomingly. I would wear long dresses and such. He told me I was a young woman, why was I dressing in such a manner. And that was a point that allowed them to get to the next level. We have been together for this long because we do the things that any other couple does. We are loving and caring. We do a lot of activities. He is real supportive, but we do not practice safe sex even though he knows I have HIV."

11. What's the difference between love and lust?

“One time in my life I was party goer. I’d party here and there, looking for love. Just lusting everywhere I went just having a good time. Then I realized I wanted someone who really cared about me so I started looking for someone to love me for me. I wasted so much time at that time. Now I have a person in my life that cares about me and I’ve told him that I am HIV positive. Finally, even with this disease of HIV, I finally found love.”

“I met this guy and we talked for about a week. After that week he said he just wanted to get to bed. He just wanted me and at that point I had to tell him I was HIV positive. He got mad and never called again. That was lust not love. Since then I have met a man and this time it is love. We talk and we discuss things and we have a beautiful relationship. We do things together.”

“It is not always about sex. I have someone in my life that is truly a joy. I always thought that most men just wanted to use me, but when we found each I have found a compatible person. We go on outings and the movies and talk walks on the beach. We hold hands and hold each other and the intimacy is love for me. I was up front in letting my companion know that I was HIV positive.”

Breaking the Walls of Silence: An Analysis

HIV-Positive Midlife Black Women's Characteristics

The participants were HIV-positive Black women between the ages of 45 and 60 years old. The average age of the participants was 44 years, the youngest 47 years old and the oldest 60 years old. The average number of years the women had HIV was 15.5. The range was as low as 1 year and as high as 34 years. Most occurrences of infection were between 5 and 12 years.

The majority of the women were single, three were married, four divorced, two widowed, and one was engaged. There were 15 women who have at least two children, one had three children, two had four children, and three have no children. There were two female children infected with HIV, ages 14 and 29 years; one of the children was a twin. In addition, the 29 year-old who is HIV positive now has a 10 year-old daughter who is also HIV positive.

The majority of participants were high school graduates, except three completed entry-level training with certificates, three earned associate degrees, and three held bachelors degrees. The average annual income was \$16,200 and the lowest was \$16,500 and the highest was \$42,000. Most of the participants received social security disability; however, many of the women earned above the poverty line salaries because their vocational training and degrees were completed before being affected by the HIV virus.

The incidences of exposure to the HIV virus included 12 participants willingly having unprotected, two were raped, one molested, one via a blood transfusion, and four from abusing IV drugs. Of interest, four women had unprotected sex with a HIV infected

male that did not reveal he was infected. The average age of the infected women was 44.3 years old.

Finally, three women practiced safe sex at the time of the interview. The reasons for not practicing safe sex were male partners refusing to use condoms, in a monogamous relationship, practiced abstinence, and desired to be normal.

Study Description

The participants were recruited by placing flyers on various organizations bulletin boards within the community. Participants who had already been interviewed referred other HIV-positive midlife Black women. A total of 22 women were interviewed; however, two women who were not aware they were HIV positive for years because they were asymptomatic and two of the women later requested their interviews not be shared. Two women had difficulty completing the interview because of the pain it 'caused them to speak about HIV. The final count was 20 participants. Eighteen of the 20 interviews were conducted in the participants' home. One interview was conducted in the participant's church office and the other in her sister's house in the family room.

The researcher discussed the details of the research study twice, once in a preliminary telephone interview, done to confirm the prospective participant met the research protocol, and again with an explanation about the informed consent process. Just prior to the beginning of the interview, participants were reminded that the interview would be tape recorded. In addition, the researcher obtained the signed informed consent form, gave the participant a copy, and assured confidentiality.

The interviews were a collection of the lived experiences of HIV-positive midlife Black women. The six interview questions explored their lives, decisions about

protection and sex, relationships, and their health practices. Many of women used the interviews to answer not only the interview questions but to expand on their life stories and beliefs. In addition, they shared their disappointments and triumphs. The researcher believes that in order to gain an understanding of the different dimensional concepts from the interview data; the interviews had to be presented in their natural form to address the cultural and feminist aspects.

The stories were meant to show people that HIV is multifactorial, while in the past it was viewed as a death sentence. However, HIV could be a positive entity if these women had the right attitude. The right attitude was not what most HIV-positive midlife Black women had in the beginning!

The Interview Results: The Voices

Life-Changing Event

Black women still hold misconceptions and fears regarding HIV/AIDS and their sexuality. The following are excerpts from the interviews.

Psalm 23: 4. “Yes, though I walk the (deep, sunless) valley of the shadow of death, I will fear or dread no evil, for you are with me” (The Bible, King James Version).

The shadow is God’s forever presence for the joy in the life of HIV-positive Black Women ages 45 to 60 years old. This belief is shared by many of the women. They reported their faith helped them to begin the healing process by breaking the walls of silence and speaking the truths about their lived experiences.

W001 “First, I was scared I was going to die and then I didn’t tell anybody for 5 years, but now I am more comfortable with it. I am still afraid to tell others that I have it.”

W002 “Initially, I thought, I could not have HIV. I was 41 years old. It only happens to teenagers. Am I going to die? I cannot tell anyone because I am ashamed. I should have known better.”

W003 “It was horrible! How could this happen. I’m not gay. Married women do not get HIV. How did this happen to me?”

W004 “In the beginning it was like being in Hell, which I never been there. It was depressing, sad, ‘why me.’ A whole bunch of negative things.”

W008 “How do I live with HIV? I don’t. Who does? You can’t tell your family and friends because at my age I should have known better than to unprotected sex with a man who was not my husband.”

W020 “I can still remember the bitter taste in my mouth when I was told. I had vomited up bile and that I was going to pass out. The lady was trying to be supportive but I couldn’t hear her clearly anymore. It was like listening to the teacher in the Charlie Brown cartoons. I couldn’t take it in. I could not believe that I was infected with HIV.”

The Secrecy

The secrecy component is riddled with the issues of denial, shame, fear, low self-esteem, guilt, anger, loneliness, depression, and berating of self. *I should have known better*. These issues are the underpinnings for contracting HIV/AIDS via unprotected sex and IV drug use.

W001 “No. I didn’t tell my family for 5 years. I didn’t tell them. I kept it a secret. Well, I told my brother first and I told him not to tell no body. Then I told my family because I didn’t want my family to treat me in a different way. You know, different like they were scared of me or anything like that.”

W002 “Living with HIV has been like going undercover for the past 14 years. Until recently I had not told my family or friends. I finally told them when I was told I had AIDS.”

W006 “It’s all the secrecy, denial from people. Stuff like that. You are always trying to keep this person from finding out, that person from finding out. You have a tendency to withdraw a lot. You don’t socialize as much and having the fear of people finding out.”

W018 “The initial shock is not like hearing anything else in your life. There is this total disbelief. Then what runs through your mind is ‘How am going to deal with this and how am I going to keep this secret. She spent a good part of her first year with this sickness developing all kinds of clever plans on how to not tell people. She was in a relationship with this guy where she hadn’t gotten to the point of having sex. But they were moving towards it quickly. She made the decision not to tell her so that he wouldn’t reject her.”

Defeating Denial

Denial can be a valuable tool, a good way to cope with negative feelings about HIV, especially when one is first diagnosed or when one feels that the disease out of control. However, denial becomes a problem when denial is the *only* way of coping. Instead of a temporary tool, it becomes a permanent way of life. The response to all HIV aggravations becomes *I will not think about HIV anymore*. This means trouble. When individuals turn their back on HIV, their long-term health will be endangered.

W003 “They don’t think that . . . A good example is this. If you get a senior person that is 50 or 60 or 70 even. She will say Honey, I’m married I’m too old to catch this disease. My husband and I have been having sex for years. It just can’t happen. There is that denial of, one, that they can’t get that disease. Especially in the senior community. Child

you can't come to me with a test. I'm too old. I'm old enough to be your mamma. There is also the understanding of thinking that I have been with that partner long enough whatever he tells me, its okay.

“There is also the fear of what your family is going to say when they find out that you have the disease. Or sometimes they are afraid of carrying the label. How am I going to date? How and I going to tell people of what I have. So it's that fear.”

Decision Tree

Some of participants revealed they *never* used condoms. They did not use them in the beginning of the relationship or in the middle of one. They did not believe in using condoms and that was that. The focus group believed that, for women, it was a way of showing a man that they trusted him, they truly wanted to be closer to him, and they really wanted to be in a relationship. It was in hopes that, by allowing them not to use a condom, the relationship would grow and the men would be committed to them.

Focus group. The men said that condom use was a myth. They preferred not to use them, without rhyme or reason. They were not that conscious about the risk of HIV.

W002 “Yes I have had the conversation with men about protected or unprotected sex and HIV but it did not make much difference for them. They just wanted to have sex and so did.”

W007 “Comfort ability with my partner. That they understand the risk that we're taking and understood the knowledge.”

W008 “We use a condom now because I don't want him to get HIV. But we don't have sex very often anymore. I think it is because he still is hurt and afraid of getting HIV. He gets tested frequently.”

W009 “I have never practiced sex. Safe sex is no sex. I was celibate for about 2 years. I married my husband while he was in jail in 2003. It took him 2 years to get out. But I was in a relationship for 27 years when I first encountered this disease in ‘93. I’ve never in my life used a rubber. And I have never passed on my HIV to anyone and I have had only three outside relationships.”

W010 “I have never worn a condom in my life. I’ve never even taken a rubber out of a package”

W013 “As a matter of fact there was not anything going on until we were married. There was no decision one way or the other because we were waiting until we got married.”

Power Relationships

Ketchen (2007) discussed a number of studies examining women's abilities to negotiate safer sex behaviors, a subject that has been the focus in HIV risk-reduction fields. An ecological framework, locating sexual behavior within the context of gender relations, is becoming a common study. Researchers have suggested that women may be at a disadvantage when initiating protective sexual behavior because of gender and culture-based imbalances in heterosexual, interpersonal relationships.

In addition, Ketchen (2007) considered two aspects of intimate relationship power, relationship control (e.g., Partner controls what I wear) and decision-making dominance (e.g., Who usually decides when to have sex?). Decision-making dominance was divided into three subscales (i.e., male dominant, female dominant and mutual). For relationship control, fewer undesirable life changes were associated with more control.

Furthermore, the following excerpts from the interviews supported these assumptions. This researcher found that men might be the power source in the relationships of younger women, although older women told their stories of control in their relationships riddled with loneliness, desperation, lost of long-term relations through divorce and death that made them vulnerable. Older women could be infantile in their approach to dating again.

W003 “It’s that big fear of I don’t have to ask him. He’s home. He’s too much of a muscular man. He doesn’t have the attitude of a homosexual. Then there are also the mixed messages from their moms. You get somebody or if you don’t get somebody you’re not whole. You can’t be single by yourself. You need that man to make your life good. We just sometimes as women don’t have the confidence that it takes. It’s just the fear of I can’t be accepted I can’t be by myself. I just can’t do it I’m not a woman if I don’t have a partner. Sometimes women will accept anything for a partner.”

W009 “It wasn’t about their reaction, because if you start at the beginning of the relationship letting the person know it’s not about sex. I’m not the type of person that wanted sex anyway. It was a mind thing a one-on-one thing. So being alive with this illness I come out first and say, “Look, I don’t use rubbers I don’t do this and I’m HIV positive. Then explain it to them and I take it down ever step that I am taking you through it. And they come back thinking that is an honest way to break it to me and they will show me their experience with it and break it down to me and what their knowledge was with it. They involve themselves in it to know where I’m coming from with it.”

W012 “That’s the problem a lot of men don’t want to use condoms, but me I’m not doing nothing without it. I didn’t get mine through sex. But however, I got it ; I don’t want to

pass it on to anyone else. Then by me already having it I don't want it to get worse by dealing with anybody else."

"Usually when people have a lot of unprotected sex they end up with Hepatitis or VD. Or they have other problems. People don't always just have the HIV virus. You don't know that if you meet a man who is positive just like you. That doesn't mean he is responsible or doesn't have other problems."

"I have had experience where when it came to the nitty gritty he didn't want to use it. I told him nothing's happening. With men sometimes they don't care. But I have to have it. If I don't I'm not doing anything."

Focus group There was one woman that said "No wrap, no sex. If you didn't wrap your weenie then there would be no sex." She said she refused to engage in sexual activities unless he agreed to put on a condom. She said that sometimes it has broken the mood. Some men said "You don't really love me." When men would attempt to lay guilt on her, she replied that she just stood her ground and she does not have sex. When she was younger, she used to go submit to the guilt and that was part of the reason she contracted HIV. Because she allowed men to talk her out of using a condom, making that demand, and expecting it, she recognized that was an onslaught to her self-esteem as a woman. "If you don't want to protect both of us (what you do with your body is your business) but don't you respect me as woman because I'm asking you to do this?"

The Betrayal

Focus Group "After it happens to the person initially, there is a betrayal of their trust. They aren't honest on how they contracted it in the beginning. So it makes it a little more

difficult. Women who do not reveal they have HIV are guilty as the men who infected them.”

“I have to tell automatically tell. If I plan on being intimate with them I have to tell them because that was the way that I was infected. The person that did this to me to this day has not admitted it to me. So I refuse to put anybody else in that position. Because that’s playing with a person’s health.”

W017 “No. And he still hasn’t told me that he is, but I know that he is because he went to prison right before I was tested. My youngest daughter has it also. When I went to tell him about it he wasn’t surprised. I feel he had to have known because he went to prison and when you go to prison they test you for all of the STDs. So he had to have known he had it.”

W018 “Even when I first met him if he had a test done and he said yes he had one done recently. Then I asked him more recently if he had another one done and he said ‘Yes’ and I told him I wanted him to come over and bring me the results because I wanted to see what it said, but he hasn’t done that yet. And he probably won’t.”

W020 “The violation and mistrust was bad enough, but then he had the nerve to walk away from me and started dating someone else. I sometimes wonder if he has ever told anyone else that he is HIV positive. He may be out there infecting more and more women.”

The Down-Low Syndrome.

The men in the focus group spoke up and discussed the image of the Black man; someone strong who takes care of his family. When he had *those* (i.e., homosexual) tendencies, the Black culture was not accepting; he could not be involved in that activity

and be out with it. In other words, he could not say that he was bisexual. Most of the time, they were in relationships with women and preferred to be in relationships with women, either married to them or to date them. Their extra curricular activity, to be with a man and believe it was is just a part of who they were, should not be primary in their relationships, at their jobs, or any place where he or she interfaced with family or community.

Focus group “Men realize that other men that are on the ‘down low’ have a hard time socializing with them because they feel like they are being groomed by that man that is on the *down low*.”

W014 “About year and a half into the marriage I caught my husband in bed with another man. I surprised him at a church conference where he was speaking. I did not attend but decided to surprise him about 2 days before the conference. The conference was in New Orleans and I had gone to college there. I had not been back since I have graduated from college. I thought we could extend our time in New Orleans and have a mini vacation. My husband was stressed out because of his job and church responsibilities so a short get-away was needed. What’s the term? Oh yeah on the *down-low*. I can and will not relive that moment! Because it hurts like when I first found out I was HIV positive! How do you face your church, family and friends with this?”

Focus group: “I do not look like a gay man and sometimes has problems with health care practitioners giving me the eye when I tells them I am HIV positive.”

“He infected his wife and a girlfriend. He also gets a feel for how gay men perceive his role as a man on the *down low*. Right now he is not actively involved in a relationship

with anyone, male or female. He is just rebounding from the last 2 years of the diagnosis of being HIV infected.”

Giving Up the Guilt

HIV-positive midlife Black women believed they were bad people because they developed HIV. Many times the exposure to the HIV virus was not their fault. The guilt was overwhelming when the HIV virus was passed onto their children. Guilt is common when living with HIV and not useful. Because of guilt, people often established tough, sometimes impossible, rules about how to manage HIV *I must never have sex again. No one will ever love me again.* Since one can never be perfect, rules like these made the participants feel like failures, leading to feelings of depression for many of them.

Depression

Depression, a serious problem, can be more severe when one is HIV positive. About 80% of the participants revealed depressive symptoms (e.g., poor sleep, isolation, low mood, low libido, increased guilty feelings, lack of enjoyment in daily activities). If they were depressed, it manifested itself in their ability to management their medication regime thus affecting T-Cell levels and other related medical problems. Depression became a vicious circle.

W005 “Another thing. I know a lot of people that died. People I went to school with died. People that I knew of died and even just people out here and when they first found out...some killed themselves. Suicide. They just couldn’t take it no more.”

W008 “I have frequent mood swings, problems with pain in my legs and appetite. We used to go roller skating with our children. I do not go with them anymore. I do not sleep well. I wish it will go away.”

Health and Health Care

Living well with HIV took emotional and spiritual strength because of the life-threatening nature of the disease. HIV was more than just a simple matter of eating right and taking medications. Staying strong, emotionally and spirituality, was key to keeping stress and T- cells levels optimal. Unfortunately, people with HIV and their doctors often neglected these aspects of the disease. At some point in time, participants were overwhelmed by the thought of keeping track of their medications, clinic appointments, adjusting their lifestyles, and everything else that went with having HIV. Nevertheless, they learned the consequences if they did not comply.

Focus Group: “I learned the tough way that you really can get complications if you don't take care of your health. When I was first diagnosed with HIV I stuck to my diet and took all my medication and did everything that I was supposed to do. Then I got angry and rebelled. I stopped taking my medication, I stopped going to see my doctor, I would make fake excuses for not seeing the doctor, and how did I know that they would know that I made them up when they checked my T- cell levels?”

“I rebelled for many years. I knew it all and could preach to any body how they should avoid risky behaviors and care for themselves but I didn't practice what I preached'. I eat healthy now and take my medications; I keep my clinic appointments and tell my doctor what really going on with me. My key point is that it's never too late to start taking care of yourself. I thought my life was over . . . It's just beginning!”

Angel Network (2003) addressed the lack of insurance, inability to pay for insurance, transportation, childcare needs, and problems navigating health care and hospital systems as challenges. In addition, a sense of fear, fatalism, silence, a lack of

trust in modern medical professionals, and beliefs in folk medicine were significant influences among many Black people.

The difference in health disparities for Black women were not as looming in this population because of the HIV initiatives (e.g., Ryan White initiative) that provided health care through specialized clinics. The clinics were staffed with HIV-trained health care providers. However, the health service complaints had a different voice; many of the participants shared that within HIV health care, the health disparities with health care providers related to all the participants' complaints to HIV. This interrupted the quality delivery of care because the participant believed their real needs were not being met (e.g., sleeping difficulties, skin rashes, blurred vision, minor aches and pains, female complaints). Many of the participants expressed a need for more talk time with the health provider and an increased sensitivity to their female complaints.

For older women, there were special considerations of menopause, decreased need for condom use as birth control, and normal aging changes (e.g., decrease in vaginal lubrication, thinning vaginal walls that increased risks during unprotected sexual intercourse) that should be considered (National Association on HIV Over Fifty, 2007). In addition, this researcher discovered through the interview process a serious issue: Women stating that their health care providers were not taking good care of them, that they wanted to be in touch with their own bodies because that translated into them deciding what they would put in their bodies.

This researcher spoke with women who reported that they were not taking their medication. However, they received their *medicine/treatment* in other ways (e.g., support groups, spiritual faith, friends' and family members' support).

Health Care Disparities

W001 "My private area is getting bigger you know. My private area was getting bigger so I went to the doctor and they said that it is nothing wrong with me. They say I am just fat down there but it s getting bigger and bigger" The doctor finally did an x-ray. They found I had a huge cyst. It was cancer."

W006 "Yes. I only had one doctor and that was back in 1994. And I have a _____ because I have a tiny bladder and when he found out he wouldn't give me the test and stuff that he was supposed to. Then the doctor that did my back surgery talked to him. We have been getting along ever since."

W008 "I guess I get my health needs met. At first I was not honest with my doctor and would frequently cancel appointments."

W009 "When it comes to that. It has nothing to do with the HIV and my doctor knows I have a sleeping problem. Where in the past they would give me volume #10 pill. One pill would knock me out forever. Then they thought because people sell the drug in the street and I'm taking the drug because of my sleeping so they put me on ambient. That was about last year. Now when I want my medicine goes out. My medicine gets delivered from the pharmacy. But if it don't come with my sleeping pills I call up the doctor and ask her where my sleeping pills are, she says she doesn't want me to get addicted to the ambient. That doesn't have anything to do with me. I need sleeping pills to go to sleep. *Everything they give us is a drug.*"

WO12 "The care is good, but I'd like them to be a bit more interested in my health. I think when they have so many patients they lose interest in some of them. They seem to

don't have time to listen. So you have to make sure they make the time by asking questions.”

Spiritual Health

W004 “You have to have some spirituality going on in your life. Because if you don't you're not going to make it. Maybe you will make it, but you won't have... I am peaceful. In everything in my life I am so peaceful. Even though I have to fuss cuss and everything I'm still peaceful. It's a peace I have inside. I mean that's only because of Grace and Mercy. I learned that I accept me for who I am. I accept me today. I love myself. If no one else loves me, I've learned how to buy me nice gifts. I think part of that is having that spiritual core in your life, is that you have the ability to forgive them for those words. Because those words come from ignorance. But people don't understand just how powerful words are. The Bible tells you that. If you keep speaking death on me you will reap what you sow.”

W008 “What keeps me going is strength and will and God. I pray before I get up in the morning. I pray before I go to bed. I thank him for that day and that I was able to wake up another day. I'm bless you know. I'm fighting for my life basically.”

W014 “I was in the church, faithfully went every Sunday and involved in the church activities and committees. Now that is not part of my life because I have HIV. I was ashamed to go back. I know my church doesn't support people with HIV. They look down on adultery, gay men and women and people with HIV/AIDS. They believe everyone who has HIV has a drug history, are prostitutes, and/or other *ungodly* lifestyles.” But I have gotten over this. I speak a lot to groups about HIV so that other people who have it will not be afraid to go to church.

Burnout

W009 “Everything they give you is a pill. Then the size of the pill is deep because I am claustrophobic. I am claustrophobic in my throat. If the pill is too big for me to swallow then I am not going to swallow it. And if they give you too many pills to take you don’t want to take them. When it comes to my medicine, I have 3 different HIV medicines and a weight gain pill. I will take the 3 in the morning with the gaining weight pill and I take one in the evening with the gaining weight pill. When my mouth doesn’t want to swallow it, I’m not going to take it. Between this month and December I haven’t been taking my medicine on a daily basis.”

W016 “It interferes with everyday life. Then there is the pill situation. I have to take this pill at this time and that pill at that time. I think it is just the way I have to live.”

Education

The HIV-positive midlife Black women and the focus group expressed a need for more educational opportunities, women services, and mixed support groups. Their concerns centered on the media’s false picture about HIV/AIDS being a curable disease when it was not. This contributed to people not taking the risk factors seriously and the increase in newly infected cases each year.

Self-Education

W007 “I began to learn all I could about it. I was going to all kinds of seminars, conferences, talking to all different kinds of people. Just trying to get a gist of what this was that I was dealing with in a real kind of way. Not just what was written in the books,

but in the life experience kind of way. And what I found is that it really is manageable. You know that it's not totally a death sentence."

A Call for More Education

Focus group "There should be a lot more HIV educational opportunities for Black people. It is not okay to practice unsafe sex, whether you are in a committed relationship or not. Especially with a diagnosis of HIV."

"We need more men and women together in mixed groups, heterosexuals, family and friends that have people that are HIV positive, more men in these groups to talk about HIV/ AIDS to have an on-going dialogue the impact it has on family, work relationships and etc."

"We need to talk about how the HIV initiatives out here that are trying to provide the medical support for HIV and really trying to provide a normalcy for people that have contracted HIV."

W002 "We need more women services and education about HIV."

W003 "That more women need to be reached especially Black women. Because there are more Black women that may have been infected in the 90s and the 2000s and they don't have the education of understanding the virus or even not knowing how to advocate. Some of them fall in the cracks of not having that knowledge that they need. And I think do not know how to navigate their care, because I think they need to know how to navigate their care as a Black woman. And they also need to know about relationships. 'cause a lot of Black women feel that when you get HIV you have to settle for anything. No you don't. And women have to learn to love themselves as a Black woman with this disease. A lot of Black women feel guilt they feel okay no one is going to want me. They

have that esteemed blocked. So I think they need to say that they're alright and get therapy also. A lot of times Black women don't get therapy."

W014 "More education about HIV. Men need to be honest with the women in their lives about their sexual activities. Men need to attend support groups where they have a voice and it is safe."

W016 "There was a lady that would come by the recovering home and educate us on how to protect yourself and how to keep from contracting the virus. She was the reason why I went and got tested. They even have clean IV needles. They need to have more education. I think they need to start in middle school. Educate kids at a younger age about HIV and unprotected sex and about men being on the down low. I think schools should educate boys about men being on the down low. I remember when the article about the guy who came up with the term down low and advised that all men be honest with themselves so that they could be honest with their mates. He didn't consider himself to be gay until his wife walked in on him and another man."

Educating Others

W003 "I had to educate him more because even though he was infected in '97, his knowledge of HIV was not as strong as mine. He was different. I had to educate him and teach him on taking his medicine care and how you go to the doctor and everything like that. He was kind of like indoctrinated on it because I speak on television and at churches so he knows that well."

Conclusion

HIV-positive midlife Black women experienced all the stages of grief: denial, anger, and acceptance. They found importance in *having faith in God*. They all *decided to*

have positive attitudes about their lives. However, the treatments made them sick and they would stop the medication for a while. Interestingly, several of the women had cancer in conjunction with HIV, another difficulty to coping. Many resumed their treatment because of low-T-cells and other reasons. One of the determining factors was they learned more about HIV and made a conscious decision to live a healthy lifestyle. Furthermore, the women had similar issues around understanding safe sex methods. Some contributed their decisions to low self-esteem, loneliness, and men who would not comply with their wishes. Many of them revealed their responsibility and preferences in the decision-making, which was not to use condoms.

Families and friends had been supportive of the women, which proved to be a contributing factor to their healthy lifestyles. However, many of the women expressed a need for more education opportunities and women's services.

Integrated through out the interviews were the following strategies for success: faith in God, forgiveness, family and friends, positive attitude, support groups, the value of self, medication, acknowledgment of having HIV/AIDS, eating well, exercise, herbs, acupuncture, removal from stressful situations, taking a stance for determining protected sex decisions, and self-education. HIV-positive midlife Black women embraced their lives and lived for the present, not for the future. This made life livable.

CHAPTER 5

Discussion and Conclusion

This study examined the lived experiences of HIV-positive midlife Black women. The analysis of the qualitative, tape-recorded, semi-structured interviews results exposed many threaded and connected themes in their responses to five open-ended questions, with one additional question that solicited their opinion on any other issues they felt comfortable sharing. The narrative descriptions with phenomenological overtones supported the ethnographic study and American Black Feminist Theory.

The women participants went to considerable lengths to share their stories of discovery, pain, shame, guilt, and secrecy. This researcher believes, because of the cultural and gender connection with the participants, the women revealed more of their lives. As such, this researcher could interpret many of the gestures, body language, and meanings of certain issues shared in the interviews. Several of the women expressed their gratitude for having a researcher who could truly understand them and could tell their stories.

The foundation research question was, What factors contribute to the increase of HIV in Black women ages 45-60? The five focused interview questions were constructed and used to answer the research question. The first interview question opened the door to dialogue with the researcher about their initial reaction to hearing the diagnosis of HIV, further exploring the women's lived experiences. The second question assessed their decision-making process in having unprotected or protected sex. The third question

addressed the content of their communication with their partners about sexually-transmitted diseases and the influence on their sexual decisions. The fourth question examined how the women took care of their health and the fifth question spoke to the quality of health care they received and their relationship with their health providers. The final question was designed for women to share their opinions on any issue.

This chapter will discuss major themes that emerged from the content gathered in each interview question. In addition, this chapter will provide an open window into the daily lives of these women. Finally, the chapter will address the limitations and implications of this study.

The following discourse describes similar episodes of the participants' daily lives using their voices and enabling the reader to understand their lived experiences.

A Day in Our Lives

“Its summer and the last amusement park we went to was a visit to our clinic doctor and support groups for social support. We think a lunch date occurs when we schedule our medical appointments around the clinic cafeteria specials. We call our pharmacist more than our friends. Our beds are unmade, dirty dishes sit on the counter, piles of laundry could be mistaken for Mount Rushmore, cars haven't been washed since the last president, and we use our unopened mail as beverage coasters. Our T- cell levels are higher than we wish, we've put on some weight we can't seem to lose, and we don't exercise as much as we wish we would. We know what to do but we wonder why we aren't doing it.”

“Some days we cannot get out of bed. Why? Chronic fatigue, painful legs, sleepless nights, crying spells, overwhelming loneliness, increased feelings of guilt and

shame. Living with HIV makes it harder to escape depression. It becomes a vicious circle. In addition, sometimes we end up in the hospital with complications of HIV. After a couple weeks of being in the hospital and having tests done we finally get to go home.”

“Sometimes we screen our calls to avoid answering the question, ‘So how are you and what have you been doing?’ Does anyone really want to hear that you feel tired, overwhelmed, anxious, afraid, and sometimes sad? We wonder if we are a burden and worry about our desirability when we can’t shake our guilt, shame, anger, frustration, and inertia. So what do we do about it? We go to our support groups. First we gather around a table and connect with kindred souls who speak our language and share our experiences. Under the compassionate guidance of an identified leader we take weekly self-assessments for our depression and anxiety. We are introduced to the concepts of cognitive behavior therapy to understand our negative cycle of thoughts and feelings. We learn how to identify the distortions in our own thinking patterns and we create a new, more helpful approach.”

“Then something amazing begins to happen as hopefulness returns to our lives. A new friend may be made among the people who understand us, maybe it gets easier to exercise a little, or perhaps T- cell counts start to improve. We don’t feel quite so alone, and when we leave each support group session we feel uplifted by the understanding and encouragement we received. Maybe we laughed at ourselves for the first time in quite awhile. We can now feel our pain, shame, and guilt but still appreciate the details of someone’s triumphs for our salvation. Then we knew we were getting the hang of it!”

“Remember when Dorothy asked Glenda how to begin her journey to Oz? Glenda said it’s always best to start at the beginning. The momentum for change in our lives

began the moment we decided to become more conscious of the things we wanted and could improve. Sometimes success is as simple as being involved in life.”

“Even though not every day is perfect, we are learning to live with HIV and relearning how to live and fit it into our lives. This may sound like a sad story so far, but its not . . . it's a blessing in disguise. We have learned so much through our illnesses. Education is key. Its not as hard as we thought it would be. We have learned what is important in life. Not to take small things for granted. In addition, we have learned how important family is... and so much more.” (The combined voices of the HIV-positive midlife women, personal communication, December 16, 2007-January 25, 2008).

Social, Psychological, Cultural, and Economic Stressors

Social, psychological, cultural, and economic stressors are highly correlated with HIV among midlife HIV-positive Black women. The ‘causes are historical trauma, destabilization of families, and economic disadvantages. Bird (2002) related that the loss of culture had been the primary ‘cause of many Black persons’ existing social problems, especially those associated with substance abuse and HIV. The methods to measure the Black person’s cultural beliefs and values had not been well developed.

In addition, Barlee (1994) discussed that contemporary Black American feminists identified central themes in Black feminism evidenced in a struggle that has continued in the United States for over a century. These included (a) the presentation of an alternative social construct for not only the present time but the future based on the experiences of African American women; (b) a commitment to fight against race and gender inequality across the boundaries of class, age, sexual orientation, and ethnicity; (c) a recognition of the struggles of Black women; (d) the promotion of Black female empowerment through

voice, visibility, and self definition; and (e) a belief in the interdependence of thought and action. As Black women become cognizant of the multiple systemic forces of oppression, they have pursued collective actions towards social change, transforming society and themselves through their own agency and self-determination.

Furthermore, Barlee (1994) related that despite the presence of Black feminist literature, the growing body of nursing literature, based on feminism and the feminist approach to research, remained narrowly focused on White feminist concerns. By essentially ignoring the realities of Black women, nursing reproduced the errors of previous White feminists. Barlee demonstrated the relevance of the Black feminist approach to nursing by applying it in conjunction with general feminist research principles and anthropological theory in research concerning the experiences of low-income Black women with dysphonia and depression. The findings suggested that a combination approach more clearly illuminated how context affected dysphoria in poor Black women.

Black American Feminists Theory

Many of the women discussed situations, circumstances and relationships in their lives they have struggled with in regards to their identity as a woman. The term feminist does not strike a familiar cord with them in its context. You may not see their names in the literature as famous Black American Feminists. However their lives are examples of their ability to overcome sexist and racial discrimination, social economic and political inequality by simply living their lives. Some of the women found their voices.

W002: “Yes, I have had the conversation with men about protected or unprotected sex and HIV but it did not make much difference for them. They just wanted to have sex and so did I.

It doesn't matter what I want anyway. It never has. Because Black men feel Black women are hungry for affection and women outnumber men so they use their power to get you to do *anything to keep a man*.

I was very lonely most of the time. So when I got a chance to have sex I did! I didn't feel like a woman anymore just a tool for a man to use.

But now I will not stand to be disrespected anymore. I tell men that so if I lose them, then it happens early in the relationship rather than later.”

W003: “No I don't because they understand that I am very outspoken. I've been with a program since 94 so they know my needs. They know what I need. They know if I don't like I'm going to tell you. So I'm very outspoken and they know that. I control my health I am infected but I am still that beautiful queen that can still give. I don't carry a label. My name is _____. It's not age. It's not paperwork it's just someone who knows who she is and I'm accepting who I am. And I don't deal in darkness. I tell people I am infected and I speak out and educate a lot. And I guess working as a substance abuse counselor helps too.”

“And they also need to know about relationships. 'cause a lot of Black women feel that when you get HIV you have to settle for anything. No you don't. And women have to learn to love themselves as a Black woman with this disease.”

W007 “I began to learn all I could about it. I was going to all kinds of seminars, conferences, talking to all different kinds of people. Just trying to get a gist of what this

was that I was dealing with in a real kind of way. Not just what was written in the books, but in the life experience kind of way. And what I found is that it really is manageable. You know that it's not totally a death sentence."

W014 "I was in the church, faithfully went every Sunday and involved in the church activities and committees. Now that is not part of my life because I have HIV. I was ashamed to go back. I know my church doesn't support people with HIV. They look down on adultery, gay men and women and people with HIV/AIDS. They believe everyone who has HIV has a drug history, are prostitutes, and/or other *ungodly* lifestyles. But I have gotten over this. I speak a lot to groups about HIV so that other people who have it will not be afraid to go to church."

Interview Guide/General Statement

Interview Question #1: Describe your experience living with HIV.

Powe et al. (2005) discussed how the literature supported the common beliefs among Black and Hispanic women who believed they had HIV because they committed a sin, thus they deserved the punishment and death was inevitable. Additionally, all the women stated a combination of the following, "HIV diagnosis was a shock." "I thought I was going to die that moment." "I could not get my breath." "This could not be happening to me." "Married women do not get HIV." "I wanted to buy a gun and kill him. Maybe kill myself too." All the women initially viewed HIV as a death sentence and then progressed to suicidal ideation, suicide attempts, and finally homicidal ideation. The next phrases included denial, anger, shame, guilt, secrecy, and finally acceptance. It was a

roller coaster event for the women, many of whom turned towards their religious roots and faith to negotiate the ordeal.

Interview Question # 2: What influences your decision to have protected or unprotected sex?

The incidence of women infected heterosexually has been rising and continue to comprise a greater percentage of those ages 60 years and older. HIV-infected seniors are sensitive to cultural attitudes that assume, that people who are elderly have lived their lives, so it does not matter if they die from AIDS (National Association on HIV Over Fifty, 2007). However, the women presented a contrasting phenomenon. In the interviews, many discussed their role in the decision-making about having unprotected sex or protected sex. Some of the women found their voices and were determined not to engage in unsafe sex practices. Apparently, women had more power than they exercised in their relationships.

Condom use was minimal. Men did not value wearing a condom as a high priority. For some women, too, it never was a high priority and now it is not as well. The conversation around protected and unprotected sex was limited and did not happen as frequently as it should between Black men and women. Self-esteem, self-image, and power were the underpinnings of the limited use of condoms.

Interview Question # 3: Describe a conversation you have had with potential sexual partner(s) about sexually transmitted diseases and HIV?

This communication usually occurred after the diagnosis of HIV and generated because of the need to discover if their partner infected them and why. If the conversation occurred before sex, it usually centered on the HIV diagnosis and a new relationship with a man. The women wanted to know the men's HIV status and/or not share their diagnosis. In addition, the women wanted to know if the men had other STIs that would 'cause them additional medical problems.

Interview Question #4: Please tell me how you take care of your health?

The medicine the women prefer taking was the social support they received from family and friends and contributed to their sense of wellness. The women shared their appreciation for the power of their families and friends in their lives. Additionally, the women stated HIV was easier to live with when one had a support system. Loneliness was harder to cope with and could lead to depression and/or suicidal ideation. The women described meaningful ways how loved ones supported them (e.g., family members joined them for healthy meals each night, good friends shared their anger and disappointment with a report of high T-cells levels, their spouse offered to do the grocery shopping, their neighbor agreed to take a brisk walk with them). The women stated committed and honest relationships, love, respect, and cultural beliefs were the cornerstones for their healing.

Many of the women stated they were taking their medicine, eating healthier, exercising, attending support groups, and keeping their doctor's appointments. Although two of the women also had cancer, they reported their ability to cope with the diagnosis

of cancer was better initially than was the diagnosis of HIV. The women contributed that their faith in God was the most important healing element in their lives.

Interview Question # 5: Please describe how your health care needs are met?

The new initiatives centering around HIV opened the doors for free and improved health care. Women shared that they episodically did not have medical insurance. They obtained free health care treatment approximately 1 year after being infected. They had jobs and health insurance prior to being infected with HIV, but soon lost their jobs and health insurance.

Many economical reasons kept them from seeking treatment. When they finally were assigned to a free clinic and/or other programs for HIV-positive people, they found relief in being on a medication regime and maintain a healthy life cycle. Support groups were instrumental in their recovery as well.

Many of the women stated they were satisfied with their health providers because they specialize in HIV treatment. These specialized clinics and health providers made a difference in the quality of their health care.

Men on the down low. A focus group member shared his experience with health providers. "When you reveal to them that you have HIV then there seems to be a kind of tension between the health provider and the patient. I am concerned about how health care providers perceive men on the Down Low. I do not look like a gay man and sometimes have problems with health care practitioners giving me the eye when I tell them I am HIV positive."

Furthermore, several of the women decided to end treatment altogether and practice integrated health techniques (e.g., herbs, massage, meditation). Most women

were pleased with their integrative health care provider. Many contributed their satisfaction to improved health services for HIV patients, self-education about HIV, and long-term relationship with those health providers. However, Powe et al. (2005) advised that a fatalistic belief could hinder their ability to make reasonable decisions about health care. The women might not seek preventive care and follow through with treatment recommendations.

As indicated by SDHHSPC (2006), educational and other culturally sensitive services were not always available. Furthermore, the services that were provided did not focus on Black women between the ages of 45 and 60 years. In addition, a physical assessment of Black women in this age group was benign and might contribute to misdiagnoses and a rise in those becoming newly infected.

Akers et al. (2007) discussed the lack of interest in HIV testing was more likely to affect older women, despite that more than one-half of the women in this group participated in risk factors that exposed them to HIV during their lifetime. Additionally, Black women were unclear about what was expected of them as far their health care needs. They looked towards their health providers to supply the guidance they needed. When that did not occur, many were not assertive and/or were ashamed to request a test for HIV.

Grant (2005) stated single Black women and their physicians shared many of the same concepts about midlife sexuality and women in their 40s and 50s. Most women believed they were at-risk for HIV, whereas most physicians considered their younger patients, ages 15 to 29 years, to be the most at-risk and that the risk declined with the

patient's advanced age and gender. In addition, the women were seen as complainers and not taken seriously.

Health disparities. Bird (2002) discussed disparities and dispossession as twin concepts. Most people could not imagine the massive dispossession that removed Black people from their ancestral lands and the genocide and cultural eradication that followed. Furthermore, the family unit was disrespected. Black women were made to work in the *big house*, Black men in the fields, and their children taken away to become slaves for people whom they did not know. Sadly, many never saw their children again. Additionally, Bird reported that dispossession was at the root of Black people's health disparities. This researcher acknowledges the silence in the data collected that may keep the reader ignorant of the seriousness of the health disparities problem.

Older people with HIV/AIDS faced a double stigma: ageism and infection of a sexually- or IV drug- transmitted disease. Older individuals could confront social and professional biases regarding the allocation of limited health care services and resources available to the AIDS community. Because the aging process itself lowered energy levels and resulted in restrictions to social routines that could 'cause emotional and psychological problems, the older adult infected with HIV might feel additional losses and endure an increased severity of depression. Seniors often were less likely to find support and comfort among family and friends and, because they traditionally were not comfortable in support groups, they might be less likely to join them (National Association on HIV Over Fifty, 2007).

Ross (2001) discussed that the limited data on racial and ethnic minority health could make it difficult for agencies to identify health disparities and justify the need for

special initiatives. In addition, accessing health care was an issue that appeared repeatedly in the literature, research, and studies that examined lowered health status in minority populations.

Interview Question # 6: Is there anything else you would like to share with me before we end the interview?

Many of the women shared their limitations, including low health literacy, poverty, unemployment, media influences, age, lack of a relationships, and health disparities. They expressed their concerns about their limited income, which prevented them from having a better quality of life. In addition, the women expressed a need for more educational opportunities and women services. According to these women, targeted areas should include prevention, early diagnosis and treatment, and more culturally sensitive health providers and researchers.

Another area of concern was the access to health care for other health problems not related to HIV. The women stated it could be difficult to get care because some providers were shortsighted when it came to assessing their other medical needs. The health provider bundled all their health complaints under HIV. This prolonged the turnaround time for receiving treatment. One women stated having cancer was better than HIV because her other health problems were not ignored and got treated timely.

Limitations

Method

Ethnography means trying to understand behavior and culture by going into the community and talking to people wherever they are and doing whatever they do. It means entering someone's world for a small space of time. With ethnography, the researcher

explores the intimate parts of the participants' world. Coupled with the American Black feminist theory, ethnography supported the findings of this research study. This researcher found it was helpful in understanding the concepts of both ethnography and American Black feminist theory. The marriage between the two entities brought forth a complex but caring foundation for the analysis of the data collected. The women were comfortable sharing with this researcher because of the similarity in culture and gender. Furthermore, the women who had difficulty sharing their stories did not hold the researcher's behavior accountable but the awakening of the pain, sadness, betrayal, and secrecy as the 'cause.

Homogeneity

Homogeneity was present in this study because all the women were Black, midlife, and living with HIV in southeast San Diego. The two most important similarities were their faith in God and an appreciation for family and friends' support that contributed to their sense of wellness. However, the differences between the women were education, marital and economic status, and number of children. In the midlife age range, 45 to 60 years old, many of the women had established careers only to have lost them due to their incapacity to work in their chosen careers.

Researcher Bias

There was a potential for this researcher's biases to spring forth because of the ethnic, cultural, and gender identifiers with the women in the research study. This could have compromised the content of the data reported, but the researcher had an earnest need to obtain a clear picture as to why Black women in this age group have increasing numbers of newly infected HIV cases and the need to stop the spread of HIV.

Researcher as an Instrument

This researcher did not conduct the study with any preconceived notions simply because of the urgency to get the authentic stories of the HIV-positive midlife Black women told. Listening as a concerned and passionate advocate for the truth enabled the women to share their stories with the confidence that their stories would be accurately. Furthermore, Miles & Huberman (1994) wrote that the researcher could not be viewed as a voyeur, spy, or pest if he or she was to be effective in data collection.

Reliability and Validity

Davies (1999) discussed validity in its relationship to the truth and/or correctness of the findings. The collection of data through self-reports could have altered validity in this research study. In addition, Morse, Swanson and Kuzel, (2001) wrote that “truth is also subjective and multiple truths can exist simultaneously “(p. 269). These Black women gave reports of the actual lived experiences with HIV. In order to increase truthfulness, a rapport of trust and a comfortable working relationship was developed during the initial telephone conversation and upon first meeting for the interviews. The women were encouraged to speak freely about their experiences living with HIV. Their truthful reports helped the researcher to help other Black women.

Reliability cannot be assured by repeating this qualitative study (Davies, 1999); however, this study’s effort toward that end meant accurately interpreting the data. Initially, this researcher planned to utilize qualitative software to analyze the data collected in the interviews, but chose not to because of potential misinterpretation due to cultural and feminists’ undertones. Therefore, the researcher conducted a focus group consisting of other HIV-positive Black women, HIV-positive men and non-HIV-positive

family members and men. Interestingly, their answers correlated with the responses this researcher received from the 20 interviewed participants. Themes were the same: shock, denial, guilt, shame, betrayal, secrecy, condom use, communication on STIs and HIV, health care issues, compliance with treatment recommendations, relationships, and God being central in their struggle.

Research and Clinical Implications

Research Implication

This study explored the lived experiences of HIV-positive midlife Black women with six different findings:

1. Women after their diagnosis were not practicing safe sex. These women shared the need to feel normal and loved. They avoided, in some cases, to share their diagnosis because they feared losing a relationship. They explained that need to be normal, loved, and fear of losing a relationship were the three foundation elements for their decision. In addition, the women engaged in unsafe sex because they believed it could not happen to them and that the HIV was cured. They explained that the media portrayed people living and not dying with HIV in United States. Conversely, several women shared their decision to have safe sex even at risk in losing the affection of their partners. The women did not want to infect anyone because they were infected through heterosexual contact. In other words, they wanted to build a solid trusting relationship without guilt and fear.
2. HIV-positive women had HIV-positive children in a time and place where that could have been prevented. Two of the women in the study had HIV-positive children and one family had three generations of females infected with HIV.

3. The onset of substance abuse after the age of 45. Several of the women reported they starting using drugs in middle age. Four of the participants were infected through IV drug use and influenced their inability to make reasonable decisions about their health.
4. Economic status did not correlate with the nationally-reported statistics for women infected with HIV or in this age group. Many of the women completed high school, had additional training and/or degrees, and had careers prior to being infected with the HIV virus. Their social behaviors did correlate with the basic social behaviors of HIV infected women of all ages.
5. Men who are on the down low had problems convincing health providers to take their health care issues seriously.
6. . In spite of the diagnosis of HIV, these women were leading purposeful, positive lives and exemplifying the humility of the spirit. It was as if they carried a banner, titled *education and prevention*, to help rid the world of HIV/AIDS.

Clinical Implications

The women in this study experienced communication problems with the health care providers. Several of the women believed they were seen but not heard by their health care providers. They believed their other health problems were sometimes ignored if they were not HIV related. In addition, the women were seen as complainers and not taken seriously as well as questionable gynecological treatment by their health practitioners. As an example, because these women were aging; many changes occurred in their reproductive organs that were not related to HIV. One of the women reported a cyst growing in her vaginal area. Her physician informed her she was just getting fat.

Through her persistence, the physician finally ordered an x-ray that revealed a large cancerous tumor.

Programs are needed that focus on teaching health care and service providers in areas such as the prevention of misdiagnoses, testing technologies, treatments, support groups, case management, and the importance of being actively involved in the health and well-being of older clients/patients (National Association on HIV Over Fifty, 2007).

Nursing Research

One purpose of this research study was to increase awareness in and use of the American Black feminist theory by future nurse researchers. Yi and Yin (2004) stated that feminist ethnography exemplified the paradigm of qualitative nursing research.

Another purpose of this study was to increase the body of nursing science to aid nurses in becoming leaders in preventive health care policies. This study provides insight into programs for women, ages 45 to 60, through innovative health education and support for this age group.

Finally, this study encourages nurses to may make a positive difference in eradicating HIV by realizing the influence of culture on illness and wellness. Nurses should recognize the importance of using their patients' strengths when planning care. In part, nurses can accomplished this goal by advocating and implementing quality health assessments for the women.

Final Reflections

This study was an episode in the long educational journey for a researcher who had many experiences working with HIV patients over the past 15 years. She started as nurse research clinician on a behavioral health research unit with newly diagnosed HIV

patients, worked in intensive community outreach for preventive health care education, and continues as a health care consultant providing health care education and program development. Many questions about HIV and Black women arose from those experiences. In 2004, this researcher discovered through community contacts with HIV-positive people that there were more women in the midlife range becoming infected with HIV. This created the groundwork for this research study's question.

The process of writing the dissertation was a convincing tool for this researcher because it validated the gaps in the literature addressing the problem of midlife Black women becoming HIV infected as well as this researcher's need to answer the research question.

This researcher was skeptical of finding enough participants to meet the sample requirements. She shared some of the identifiers with the participants (e.g., race, gender, age, education, marital status) but was not HIV positive but did not understand why the incidence of HIV was increasing in this age group. There was an underpinning of doubt that the assertions of this researcher might not be causative factors.

The recruitment methods reaped 22 participants because the recruitment methods. A flyer was placed on several clinics' bulletin boards and the researcher experienced a successful poster presentation at a conference. In addition, the researcher spoke at the African American World AIDS Conference in December, 2007. The women were grateful to have a platform to share their stories.

Despite an unsteady start, this research has been one of discovery, validation, triumph, and tears. The researcher believes this study will open the door for future

research that will integrate the Black American feminist theory and ethnography into learning more about Black women.

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APPENDIX A

Demographic Questionnaire

All information is kept confidential as explained to you in the Informed Consent. There are no right or wrong answer. Please answer the questions to the best of your ability to do so.

Thank you in advance for participating in this research study.

1. Are you between the ages of (circle one)
 45-47 48-50 51-53 54-56 57-59 60
2. Martial Status Married ___ Single ___ Divorced ___ Separated ___
3. Education level _____
4. Annual income _____
- 5 Date of initial diagnosis _____
- 6 Do you have health insurance? ? Yes ___ No ___ If yes what type? Check one that applies to you.
 Medi-cal ___ Medicare ___ SSD ___ Private health care insurance ___
- 7 Date you entered treatment for the first time _____
- 8 Are you currently in treatment? Yes ___ No ___ If yes how many? Years _____
 Months ___ Weeks _____.
- 9 Have you ever discontinued your treatment ? Yes ___ No ___ If yes are any of the following items the reason(s) Circle as many that apply
 - a. No childcare
 - b. No health insurance
 - c. No money
 - d. Lack of support from spouse/significant other.
 - e. Lack of support from family
 - f. Lack of support from friends
 - g. No transportation
 - h. Relationship with health provider
 - i. No access to healthcare

APPENDIX B
Interview Guide/General Statement

- 1. Describe your experience living with HIV.*
- 2. What influences your decision to have protected or unprotected sex?*
- 3. Describe a conversation you have had with potential sexual partner(s) about sexually transmitted diseases and HIV?*
- 4. Please tell me how you take care of your health?*
- 5. Please describe how your healthcare needs are met?*
- 6. Is there anything else you would like to share with me before we end the interview?*

APPENDIX C

Informed Consent Form. Participants to fill out the Self- administered demographic questionnaire and individual interview: for the Research Study: Titled HIV Positive Black Women in Southeast San Diego

INFORMED CONSENT TO BE PARTICIPANT IN A DOCTORAL STUDENT'S RESEARCH STUDY

A. Purpose and Background

Charlotte Stoudmire, MSN, RN is a doctoral student in nursing at the University of San Diego, is conducting a research study for her dissertation topic: HIV positive black women in Southeast San Diego utilizing self administered demographic questionnaire and interviews. The researcher is hoping to find out with the participation of HIV positive black women what factors such as their social and family issues, health beliefs and other related health practices which would impact their ability to seek healthcare.

B. Procedures

If I agree to participate in this educational research study, the following will occur:

1. I will be given a chance to ask questions about this the research study and self-administer questionnaires before I am asked to sign this consent form.
2. I complete the self-administered questionnaire and interview in at a place which is convenient to me. The process will take about 60 minutes. If I get tired, bored, uncomfortable, or for any other reason, I can ask to be terminated or complete the questionnaire and interview on a different occasion.
3. There will be no audio-recording or video taping made of the Informed Consent conversation or you filling out the questionnaire..
4. In the self- administered questionnaires, I will be asked questions about my health and/or my perspectives on my support systems.
5. The interview will be audio-recorded.

C. Risks and Discomforts

1. If some questions make me feel uncomfortable, I am free to stop the filling out the questionnaire at any time. Also, I can decline to answer any question.
2. To maintain my privacy in this research study, questionnaire results records will be kept confidential as possible.
3. Should I reveal information about child abuse or intent to hurt myself or others, however, the researcher would be obligated to report this information as nurses are mandatory reporters.
4. No handwritten notes of your answers on the questionnaires will be made. The answer will under go special research data collection software called SPSS and Computer Assisted Qualitative Data Analysis Software (CAQDAS)which will enter and analyses the blind data produce the findings. A code will be assigned to you. It will be on your questionnaire and interview records. Neither my name nor any identifying information will appear on the questionnaire and interview. The questionnaire and interview findings records will be kept in the locked files

of the researcher. Only the researcher, Dissertation Committee Chair Dr. Jane Georges, co-chair Dr. Cynthia Connelly and committee member Dr. Wilma Wooten involved in the researcher study will see the findings records.

5. At the completion of the research study, the student will shred and destroy all questionnaire and interview records.
6. Charlotte Stoudmire, doctoral student and Dr. Jane Georges will keep information about me as confidential as possible, but complete confidentiality cannot be absolutely guaranteed.
7. I understand that there is no agreement, written or verbal, beyond that expressed in this consent form.
8. I will be given a copy of this consent form.
9. There may be a risk that participating in the research study may make me feel tired. Sometimes people feel anxious or sad when after filling questionnaires which sensitive questions are asked about their health, health beliefs and health practices. If I would like to talk to someone about my feelings, I can call the San Diego Mental Health Hotline at 1-800-479-3339. Also, I can stop filling out the questionnaires at any time you feel tired or for any other reason.

D. Benefits

There will be no direct benefit to me from participating in this research study. The anticipated benefit of this research study is that doctoral student who is mentored by Dr. Jane Georges for her dissertation will gain knowledge on qualitative methods of research.

E. Questions

I have talked with the student about this research study and I have had my questions answered. If I have further questions I can call Dr. Jane Georges, at the Hahn School of Nursing and Health Science at 619-260-7481; I may also call Dr. Patricia Roth at 619-260-4548.

I, the undersigned, understand the above explanations and on that basis, I give my consent to my voluntary participation in this educational assignment.

Signature of Interviewee

Date

Location (San Diego, CA)

Signature of Person Obtaining Consent

Date

Witness

Date

APPENDIX D

You have just completed several self-administered demographic questionnaire and the interview regarding your experience with living with HIV. For example: your support systems, health attitudes, and of health attitudes on health, and compliance with treatment recommendations.

I am attempting to determine whether HIV positive black women ages 45-60 can benefit from additional health services and educational information to help them live a healthier lifestyle..

I will have the results of this study by May of 2008. Please call me or E-mail me at the below address if you would like to receive a written copy of the results. You may also contact me before then if you have any other questions regarding this study.

Studies involving health may raise concerns about your own physical or mental health. If you are experiencing any concerns or anxiety over issues raised in this study, the following agencies are available to you for your support:

Council of HIV/AIDs 000-000-0000

Mental Health 000-000-0000

Charlotte Stoudmire

Doctoral Student

University of San Diego

Phone 619-567-0000

E-mail address: jamaa@cox.net

Thank You for Participating in this Study!