Living With HIV Disease: A Phenomenological Study of a Group of Older Black/African American Women

by

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Abstract

LIVING WITH HIV DISEASE: A PHENOMENOLOGICAL STUDY OF A GROUP OF OLDER BLACK/AFRICAN AMERICAN WOMEN

by

Judith C James-Borga

Adviser: Professor Keville Frederickson

Black/African American women are disproportionately affected by human immunodeficiency virus (HIV) disease. The purpose of this study was to gain an in-depth understanding of the experiences of a group of lower socioeconomic, older Black/African American women, who were living with HIV disease. A purposive sample of ten participants was obtained and data was collected through unstructured interviews. Using the phenomenological stance of Merleau Ponty, and guided by van Manen's methodological processes, seven essential themes emerged: transcending adversity and becoming; using knowledge as empowerment; dealing with HIV stigma; concealing and revealing; tending to their emotional life; and caring for others while they themselves were being cared for. The meaning of living with HIV disease is a dynamic interrelated patterning process of these essential themes. The findings support Pamela Reed's theory of Self-Transcendence. Implications for nursing include: the urgent need for a paradigm shift that acknowledge the strengths of older Black/African American women; the need for the integration of sexual assessment and education on risk reduction and medication adherence into routine healthcare encounters; and for further research to expand the data base on strategies that older Black/African American women use to overcome diversity and live with HIV disease.

Key Words: HIV; older Black/African American women; self-transcendence.

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Dedication

These 4.5 years have been an amazing journey that I could not have accomplished on my own accord. I am grateful to my God for giving me the health, strength, and guidance to pursue and achieve this endeavor. I am so humbled by this experience and will forever be grateful for all who contributed to my success in this life-changing undertaking. I thank my family for allowing me the time and the space to pursue this venture.

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Table of Contents

List of Tables

List of Figures

Chapter I

AIM OF THE STUDY

The United States will become a place where new HIV infections are rare, and when they do occur, every person, regardless of age, gender, race/ethnicity, sexual orientation, gender identity or socio-economic circumstance, will have unfettered access to high quality, life-extending care, free from stigma and discrimination.

Obama, 2010, p. vii

In July 2010 the White House released the National HIV/AIDS Strategy, the first national comprehensive plan for addressing human immunodeficiency virus (HIV) disease in the United States. The national vision included provision of high-quality HIV care free from stigma and discrimination. The Federal Implementation Plan for the national strategy acknowledged that the quest to change the public's attitude toward persons with HIV disease presented one of the greatest ongoing challenges to implementation (White House Office of National AIDS Policy, 2010). However, if stigma and discrimination are to be addressed, attitudes about people with HIV disease need to change.

This stigma is experienced both internally, as a result of personal guilt and shame, and externally, from the social networks of the infected individuals (Emlet, 2006a; Lee, Kochman, & Sikkema, 2002; Wolitski, Pals, Kidder, Courtenay-Quick, & Holtgrave, 2009). It is not surprising then, that persons with HIV disease perceive stigma not only from the general public, but also from nurses and other health care providers. This often translates into significant barriers to quality health care (Payne Foster & Gaskins, 2009; Yannessa, Reece & Basta, 2008). While knowledge alone does not change behavior (Fishbein & Ajzen, 1975), researchers have indicated that knowledge gained through specific targeted educational strategies that emphasize understanding has been found to dispel myths and has a positive influence on providers' attitudes, practice patterns, and interaction with persons with HIV disease (Stanton & Johnson, 2000). This study seeks to understand what the experience of living with HIV disease is like for older Black/African American women. The purpose is—through the women's description of their experiences—to uncover the essence of what living with HIV disease is for them. It was anticipated that the knowledge generated from this study will provide new insights for nursing care, practice, and education.

This chapter begins by identifying the phenomena of concern, HIV disease in older Black/African American women. An overview of the context and background of the problem is provided. The justification for the study is given. This is followed by the researcher's assumptions and biases. The chapter concludes with a discussion on the research approach and the relevance of the study to nursing.

Background

It has now been three decades since the identification of the virus that causes HIV disease. In the early years, as researchers urgently attempted to understand the infectious processes, much emphasis was placed on the medical and biological issues, such as the transmission, disease progression, risk factors, and treatment associated with HIV infection (J. D. Ruiz & Molitor, 1998; Tortu et al., 2000). Similarly, there has been an overwhelming emphasis on specific high-risk subpopulations such as gay men, adolescents, injection drug users, sex workers, and mothers and their infants. Meanwhile, the older adult population, and specifically older women, a group who has consistently been present in the HIV population (Centers for Disease Control [CDC], 1998a, 2008), was not always viewed as a population of concern and has received considerably less attention in the literature (Linsk, 2000).

Black/African Americans are disproportionately affected by HIV/AIDS. They represent 13.6% of the United States population (United States Census Bureau, yet they account for 44%

of the persons living with HIV disease and 48% of the persons with a new HIV diagnosis in 2010 (CDC, 2010). Of the women with a new diagnosis of HIV/AIDS in 2008, 67% were Black/African American. This rate of infection for Black/African American women is second only to that of Black/African American men (CDC, 2010). The rate of new infections for Black/African American women is 20 times the rate of that for Caucasian women. The focus of most HIV research within the Black/African American community, like in other racial groups, has been on high-risk populations such as injection drug users (IDU), men who have sex with men (MSM), and women of childbearing age. As the cohort of elderly Black/African American women who were infected at an earlier age grows, and the number of new infections in women 50 and older increases, the need to understand the experiences of these women becomes critical.

Emerging reports from the CDC indicate that the incidence of HIV disease in persons age 50 and older is growing. In 2008, there were an estimated 682,668 persons living with HIV disease in the United States and its five dependent areas. Of this number, 108,696 were age 50 and older. In 2009, there were an estimated 42,011 new cases of HIV disease diagnosed and persons over age 50 accounted for 15% these new infection (CDC, 2010). It is estimated that by the year 2015, persons ages 50 and older will account for 50% of those living with HIV disease. This increase is attributed to two main factors: the effectiveness of highly active antiretroviral therapy (HAART) and the growing rate of new infections. The discovery and successful use of HAART has made it possible for many persons with HIV disease to live longer, thus changing the trajectory of the disease from an acute life threatening illness to a chronic disease (CDC, 2008; Halligan, Halligan, Jeske, & Koh, 2009). This longevity has resulted in persons who were diagnosed in their earlier years now aging into the population of persons age 50 and older. The second factor contributing to this increase is the escalation in the number of new infection in this age group (CDC, 2010). This increase in the incidence of new infections has been credited to some of the following reasons:

1. Midlife and older persons are reported to be less knowledgeable about HIV/AIDS.
2. Midlife and older persons often do not perceive themselves to be at risk for HIV/AIDS.
3. Midlife and older persons often report the inconsistent use of condoms.
4. The increased availability and use of sexual enhancing drugs in this age group.
5. The idea that some providers are still targeting high-risk groups rather than assessing for high-risk behaviors as the criteria for sexual counseling and HIV testing (Illa et al., 2008; Stark, 2007).

The pool of studies about older persons living with HIV disease, though growing, remains small, and the number of studies on older African American women is even smaller. I searched EBSCO*host*'s multiple databases, inclusive of the education, health and nursing, philosophy, social work, and gerontology literature. I used the time frame of 2003 to 2013. The term *HIV in African American women* yielded 2,920 responses, 122 of which were qualitative in design. When the term *HIV in older African American women* was used, the yield was a total of 206 responses, seven of which were qualitative in design. Review of the qualitative studies showed that three studies investigated the risk factors for older African American women (Evans, 2011; Poindexter, 2005; Whyte, Whyte, & Cormier, 2008); two investigated their perception of risk (Akers, Berstein, Henderson, Doyle, & Corbie-Smith, 2007; Grant & Ragsdale, 2008); one study addressed stigma in this population (Payne-Foster & Gaskins, 2009); and the other focused on health education (Cornelius, Moneyham, & LeGrand, 2008).

When compared with the plethora of studies on HIV from the natural science perspective, the literature from a human science perspective has been minuscule. Qualitative research and, in particular, phenomenology, because the primary concern is uncovering the meaning of human experiences, “aims to bridge the gaps between stories of individual experiences and the phenomenon of human existence” (Madjar & Walton, 1999, p. 8). The aim of phenomenological research is to create descriptions and meanings of the structures or essences of a phenomenon. It does not provide theoretical or empirical explanations. Instead, this process seeks to gain an understanding of the meaning of the experience in one’s everyday life (van Manen, 1990). The aim of this phenomenological study is to understand the meaning of the experience of living with HIV disease for a group of African American women, age 50 and older.

This study adopted the CDC (2010) definition of the term *diagnosis of HIV infection* to mean a diagnosis of HIV sero-positivity, obtained by a screening test and followed up by a confirmatory test, such as the Western blot. The term *HIV disease* was used in this study regardless of the person’s acquired immunodeficiency syndrome (AIDS) status. Participants therefore were at various points along the continuum of the disease process.

Phenomenon of Interest

The phenomenon of interest for this study was the experience of living with HIV disease as described by older African American women. The question posed was: “What is the experience of living with HIV disease like for older Black/African American women?” Living with HIV disease can be a complex issue for persons of any age group, gender, or ethnicity (Fair & Ginsburg, 2010). Researchers have suggested that the experience of living with HIV disease for older adults is different than it is for younger adults in such areas as medication adherence, drug interactions, and supportive service utilization (Emlet & Berghuis, 2004; Gebo & Justice, 2009; Justice & Weissman, 1998). Likewise, the literature suggested that living with HIV disease for African Americans is in some ways different and in some ways similar to living with HIV disease for other racial/ ethnic groups of the population. Among the factors cited related to ethnicity were the association of stigma, socioeconomics, and the level of support system (Payne-Foster& Gaskins, 2009; Poindexter, 2007; Stoskopf, Richter, & Kim, 2001). Gender presents its unique differences. Studies have shown that men are better retained in HIV interventional programs that are brief and are based in hospitals or the workplace and ones that offer financial resources, whereas women respond better to interventions that are community based and provide social and emotional incentives. In addition, Durantini and Albarracin (2009) identified that men were more responsive to HIV intervention programs that included HIV testing and prevention. Other studies have highlighted that unlike men, women of reproductive age are stigmatized by their role as vectors, who transmit the infection to their unborn, and that older women, the most invisible population affected by this disease, are less likely to be referred for testing unless they disclose significant high-risk behaviors. HIV-related symptoms in this population have been known to be inaccurately diagnosed as transitory in nature and related to menopause (Lieberman, 2000; Tangenberg, 2004).

Justification for Studying the Phenomenon

The phenomenon of interest for this study is the experience of living with HIV disease within the context of older Black/African American women. When this phenomenon has been studied within the context of other groups, such as gay men, younger African American women, low-income White women, and the homeless, it has been associated with shame, stigmatization, isolation, sexual, and risk-taking behavior (Busch & Stevens, 2006; Lee, Kochman, & Sikkema, 2002; Payne-Foster & Gaskins, 2009; Wolitski, Pals, Kidder, Courtenay-Quirk, & Holtgrave, 2008). Findings from studies of other groups of people living with HIV, such as long-term survivors and a cohort of HIV-infected persons in China, have identified strategies that individuals have used to care for themselves and to normalize their post-diagnosis life. Some strategies include the following: reconstructing the meaning of time according to new priorities (Zhou, 2010); reinventing their identity, which may mean living more "moral" lives; embracing religion or finding other alternatives to leisure (Crossley, 1997; Gosselink & Myllykangas, 2007); and/or emerging self-advocacy and self-care activities (Hobbs Leenerts & Magilvy, 2000).

The literature regarding HIV/AIDS in the African American community has focused predominately on studies about risk-taking behaviors, including risk-taking adolescents, men having sex with men, intravenous drug users, sex workers, and women of childbearing age (Hlaing & Darrow, 2006; Jemmott, Jemmott, Fong, & Morales, 2010; Mor, Davidovich, McFarlane, Feldshtein, & Chemtob, 2008; Richter, Sowell, & Pluto, 2002; Siegel & Krauss, 1991; Sterk, Theall & Elifson, 2005). There has been a small body of information related to HIV disease in older adult African American women. These studies, the majority of which are quantitative in design, have focused on social cofactors that have contributed to HIV disease. These cofactors include drug use (Sharpe, Lee, Nakashima, Elam-Evans, & Fleming, 2004; Tortu et al., 2000), violence and economic motivation (Sormanti, Wu, & El-Bassel, 2004; Whyte, 2006), the secret behavior of the "down low" syndrome (men secretly having sex with men while maintaining sexual relationships with women), and the gender ratio imbalance in the African American community (Harris, Mallory, & Stampley, 2010; Whyte et al., 2008). For the most part, these studies have portrayed African American women as passive, dependent victims, thereby reinforcing negative stereotypes. Other studies have identified the strengths and contributions of the older Black/African American women in their traditional matriarchal and care-giving role as they sought to maintain their immediate and extended families during this

HIV epidemic (del Bene, 2010; Linsk & Mason, 2004; Linsk et al., 2009; D. S. Ruiz, 2008; Shambley-Ebron & Boyle, 2006). This group's previous spotlight in regard to HIV disease had been as primary caregivers and informal helpers for their children and grandchildren. They witnessed their life situation described in terms of stress, responsibility, burden, caregiver role strain, and role change and the effects of aging (Poindexter, 2007; Linsk & Mason, 2004). However, the burden of dealing with their disease has remained obscured, and their experience of living with HIV disease is poorly understood. What then is the experience of living with HIV disease for older Black/African American women who, traditionally, have been cast in the support role and who, like most older adult, are often perceived by society to be asexual? The voices of these women have not been clearly elicited and heard within the context of living with HIV disease.

This study offered an opportunity to provide in-depth understanding and capture the essence of the meaning of the participants' experiences of living with HIV disease. It also uncovered, from the participants' perspective, their interactions with nurses and health care providers. Nurses and health care providers are not insulated from the considerable lack of understanding and ongoing negative perceptions that exist in the mainstream culture regarding persons living with HIV/AIDS (PLWHA). Good patient–provider relationship had a positive influence on the individual's engagement in HIV-related health care and treatment adherence (George, Garth, Wohl, & Gavin, 2009), but distrust of health care providers was associated with some participants avoiding medical appointments. Vyavaharkar, Moneyham, and Corwin's (2008) study on the perception and experiences of HIV positive Black/African American women in the southern United States found that many of their participants reported a lack of caring and concern and poor attitudes and behavior from some caregivers.

It is hoped that the findings from this study will impact clinical practice by providing insights that may sensitize providers to the patients' experiences. The understanding and sensitization gained may lead to the emergence of population-specific interventions and to improvement in the quality of care delivered to older Black/African American women living with HIV disease.

Assumptions and Biases

I believe that many of the contributing factors to HIV disease in older African American women, as in other groups, are grounded in socioeconomic issues. In addition, I believe that Black/African American women are at an even higher risk of contracting HIV disease, secondary to the high prevalence rate of the infection within their community. However, in addition to socioeconomic factors and the high prevalence rate, I assume that there are other highly influential issues such as culturally determined role expectation, religion, and trust that play equally important roles in the decisional processes and life experiences of these women.

I also believe that the meaning of an experience changes over time and context. I assume that as the women lived over time with this disease, they would in their own unique way, make sense of their lives as they negotiated the intricate environments of their relationships, their culture, the health care system, the complex treatment regimes, lifestyle changes, and the stigma associated with this disease. This stigma, often the product of fear and ignorance, may cause unnecessary human suffering that interfered with the professional care of these women. However, because what makes one human is the ability and freedom to choose (Sartre, 1977), I believe that the participants over time would choose how they interpret and respond to their experiences. Finally, I believe that the understanding of the meaning of patients' experiences is an essential prerequisite for effective nursing practice.

Method of Inquiry

The method I chose to study the meaning of the experience of living with HIV disease from the perspective of the older Black/African American women was a phenomenological approach. Merleau-Ponty's (1945/1962) phenomenological philosophy provided the underpinnings of the study, because this perspective seeks to answer the question, "what is the nature or meaning of the phenomenon?" This perspective emphasizes the importance of relationships between and among persons and between humans and the world. Van Manen's (1990) methodical structure of human science research was the phenomenological research process used to guide this study. I chose van Manen's process because Merleau-Ponty's (1945/1962) work formed the basis of van Manen's methodical structures. For van Manen, research is a deliberate act of connecting oneself to the world, thereby enhancing one's relationship with the world.

Relevance of the Study for Nursing

Because the research literature within this proposed study's context was sparse, in this study I sought to uncover and understand the meaning of the experience of living with HIV disease for African American women age 50 and older and add to the body of knowledge on this phenomenon. The study illuminates the meaning of the "what is" that underlies this highly relational phenomenon (the experience of living with HIV disease).

Phenomenology, the research paradigm chosen for this study, is relevant for this study since this approach is patient centered and is congruent with nursing practice. The nature of the practice of professional nursing encapsulates the life experiences, interactions, and responses to actual or potential health problems of individuals and their families. Nurses are educated to be attuned to the whole person and not just to the unique presenting health problem. Van Manen

(1999) captured this perfectly when he observed that although nurses are knowledgeable about medical science and the associated health care equipment, technology, and procedures, patients expect more from nurses. Patients expect healing and caring hands and attitudes that touch not only the physical body but also the self and the whole embodied person (p. 33). According to van Manen (1999), phenomenology promotes the experience of agnostic and pathic care, making the participants more human in the eyes of the caregivers. Understanding the experience of persons living with HIV disease may provide nurses and other health care providers with alternative ways of thinking (Madjar & Walton, 1999) when caring for older adult African American women with HIV disease. This understanding may encourage nurses to listen differently, modify their own perspective, and ultimately improve the quality of their practice.

Munhall (2007 stated the following:

> The ultimate aim of nursing is to provide care for individuals and human systems experiencing the unfolding processes by using informed, timely and appropriate care based on human caring and understanding. Understanding essences in experience underpins fully caring for another. Further, knowing the person, group, population or institution is critical in nursing care. (p. 217)

The ultimate goal of phenomenological philosophy and research is to be fully human through an in-depth understanding of the meaning of the human experience. The purpose of this study was to understand the experiences of the everyday life of older Black/African American women as they live with HIV disease. The phenomenological understanding gained from this study may also help guide further research to improve the quality of care for persons living with HIV disease. This study further adds to the knowledge base of nursing science by illuminating the understanding of the meaning of living with HIV disease, as experienced by this group of older Black/African American women.

Summary of Chapter

Chapter I identifies the aim of the study and the research question. The phenomenon of interest (the experience of living with HIV disease) is presented and the literature cited to provide justification for the study within the specific context of older Black/African American women. My assumptions and biases related to the phenomenon are articulated. The relevance of the study to nursing is presented. In addition, the phenomenological perspective of Merleau-Ponty (1945/1962), the philosophical framework chosen to underpin the study, and van Manen’s (1990) research process, the chosen method of inquiry, are identified. Chapter II addresses the evolution of the study.

Chapter II

EVOLUTION OF THE STUDY

This chapter describes the evolution of the study. Beginning by framing the sociohistorical context of the experience of older Black/African American women and health care, the chapter then describes the context of human immunodeficiency virus (HIV) disease and its relationship to, and impact on, the population under study: older Black/African American women. Relevant literature is then used to comprehensively trace and illustrate the history of HIV disease from its initial emergence as an acute life-threatening infection through its transition into a chronic condition. The impact of HIV disease on various populations, including the population for this study, older Black/African American women, is addressed. A presentation of this scholar's experiences as a Community Health Nurse and a Clinical Nurse Specialist, caring for women and children with HIV disease, is also offered.

Sociohistorical Context of Older Black/Africans American Women and Health Care

In the United States, racial identity is a social construct that is measured by skin color. Having a different skin color often subjects Black/African Americans to considerable stigma, including clinicians' preconceptions related to nonadherence and unfavorable health outcomes. These preconceptions can result in actual or patient-perceived feelings of unequal treatment and disrespect from clinicians (Sims, 2010). According to Black feminist writer Hill-Collins (2000), all African American women share the common experience of being Black in a culture that disparages women of African descent. However, studies have shown the majority of Black women see race and gender as equally important in any political debate and identified sexual discrimination within the Black community as a problem. Those studies have also found that Black women, for the most part, do not make decisions about their health in isolation, but that these decisions are shared and influenced by Black men (Harnois, 2010; Hill Collins, 2000).

The advances in medical technology and preventative care have resulted in overall improvement in the health status of older women; however, despite these advances, there still exists a huge health disparity between Black/African American women and their White counterparts of the same age and socioeconomic status (National Center for Health Statistics, 2007). Older Black/African American women are stigmatized threefold through racism, ageism, and gender. Racism is a core contributing factor in the life experiences of older minority members, since they have had more extended experience with racism than any other age groups (McKinney, Harel, & Williams, 1990). Because of this, Becker and Newsom (2005) posited that the way ethnic minorities respond to illness and the health care system is influenced by their years of coping with racism.

Sims (2010) offered the sociocultural constructs of ethnic notions and healthy paranoia to describe older Black/African Americans' perception of their personal experience with the health care system. "Healthy paranoia" is the hyper-vigilance or protective behavior that results from years of earned suspicion and mistrust of the system. "Ethnic notion" refers to the "subtle shifts, interpretation of intention, ethno-cultural difference and context that may occur during health care encounters" (p. 500). In an ethnographic study of 50 Black women over the age of forty, Sims (2010) reported clinicians' interacting behaviors such as lack of eye contact, hesitancy to touch, and tone and speed of speech as cues that validated participants' perception of providers' bias. Some of those participants articulated their expectations that the health care system could actually be detrimental to African Americans. Martin et al. (2010), in a phenomenological study of care-seeking behavior of elderly African Americans, found that participants defined health as "the ability to be active." Other themes that emerged were the reluctance to use prescription drugs, the reliance on home remedies, and the avoidance of bad news. Distrust of physicians and the race of the provider were also important factors. The literature also shows that older Black/African American women often place the informal care of their immediate and extended family members over their own health care needs (Samuel-Hodge, Skelly, Headen, & Carter-Edwards, 2005).

Historical Context of HIV

HIV was first identified in 1981 (Gallo, 1991) as the retrovirus that caused decreased cell-mediated immunity by suppressing the T4 lymphocytes, which if left untreated, led to acquired immunodeficiency syndrome (AIDS). This syndrome manifested itself in the form of multiple opportunistic infections and unusual neoplasms that eventually lead to death. This new disease with its acute life-threatening outcome baffled the medical and public health care community.

The disease was initially believed to be a disease of young, gay, White men, because the first cases were observed in members of this group. This initial manifestation in an already marginalized group laid the foundations for stigmatization and discrimination. Later, as similar symptoms were identified among intravenous drug users and their partners, it became apparent that the disease was associated with the exchange of body fluids. As the disease became more discernible in the heterosexual population, especially among women, newborns, and persons who had histories of transfusions of blood products, it became evident that this disease affected every age, gender, and race. Biomedical and public health interest escalated, along with public stigma, discriminatory practices, and shame (Emlet, 2007). The proliferation of stigma and discrimination was heightened as the general public, including health care providers, became increasingly fearful of contracting the disease (Ruel & Campbell, 2006). The fear, stigma, and negative attitude about HIV disease were evoked because persons who contracted the disease were, and still are, viewed as contributing to their infection because of their own deviant behaviors, as well as because the disease is preventable, transmittable, and incurable (Sontag, 1990). The acquisition of a disease from sexual practice and illegal drug use was considered more willful and deserving of increased shame and blame (Sontag, 1990). High-risk populations, rather than high-risk behaviors, were quickly identified (Hawley, 1992; O'Brien, 1992). Unlike other diseases that arouse feelings of shame, infection with HIV was kept hidden, not from the patient, as cancer used to be, but from the patient's potential support system (Sontag, 1990).

As the disease spread in the heterosexual population, and the incidence among women began to rise, the issue of mother-to-child transmission became highly significant. Even though men having sex with men remained the highest subpopulation affected, African Americans quickly began to be disproportionately affected by this disease. The implementation of highly active antiretroviral therapies (HAART) in the mid-1990s signaled the evolution of HIV disease into a chronic disease (Halligan et al., 2009). The success of Protocol 076 (CDC, 1994) led to the drastic decline in mother-to-child transmission, vastly reducing the incidence of HIV infection in newborns in the United States and other areas of the world where medications were available. Recently, researchers (Cohen, Chen, McCauley, Gamble, & Hosseinipour, 2011) and Secretary of State of the United States Hillary Clinton (2012 International AIDS Conference) have promoted the concept of treatment as prevention and the vision of an AIDS-free generation.

HIV Disease in Women

In the early years of the epidemic, the majority of HIV infection in women was among injection drug users and sexual partners of injection drug users. In 1985, women accounted for 8% of the new HIV infections and AIDS diagnosis. Ten years later, the incidence rose to 20%, and by 2010 women accounted for 25% of new HIV/AIDS diagnosis (Figure 1). By 2008, of the 10,332 new cases of HIV disease identified among women in the United States, 67% were African American women, 18 % were Caucasian and 13% were Hispanics/Latinas. Heterosexual contact is now the primary identified transmission risk category for each ethnic group, at 87%, 75%, and 84%, respectively; whereas injection drug use accounted for 13%, 24%, and 15%, respectively (CDC, 2010). Factors that facilitated the transmission of HIV infection in women included sex during menstruation, bleeding during intercourse, and any inflammation or disruption of the genital mucosa (Anderson, 2005).

The success of HAART that resulted in the transitioning of HIV disease to a chronic manageable disease meant that people on treatment were living longer. However, women infected with HIV still faced complex issues that were unique to their gender, such as contraception, reproduction, a 2% possibility of transmitting the virus to their unborn children, and multiple gynecological conditions, including sexually transmitted diseases, cervical cancers, and menopause (McCall & Vicol, 2011). For women, the use of barriers during intercourse was not only a means of contraception but also critical for the prevention of sexually transmitted diseases. This barrier protection also minimized the transmission of and/or reinfection of other strains of HIV. Besides being able to initiate barrier protection with the use of condoms, the woman and her partner must then be able to proceed to long-term maintenance. This has resulted in negative outcomes for some women, ranging from abandonment to violence, when they sought to have their sexual partners adopt this change in sexual behaviors (Sormanti et al., 2004). Researchers Raiford, Wingood, and Clemente (2007) reported that among HIV-positive women, the degree of consistent condom use depended on the partner’s HIV sero-status, (51.6% with positive partners, 72.9% with negative partners). In addition, for the HIV-infected woman who wished to get pregnant, the use of this barrier method presented a dilemma.

HIV infection in women has been associated with an increased risk of vaginal candidiasis, human papilloma virus (HPV), and cervical cancer (Anderson, 2005). Researchers have identified that among women with HIV disease fear, denial, and low self-esteem have been some of the psychological barriers to accessing and utilizing mainstream health care facilities and cervical cancer screening clinics (Andrasik, Rose, Pereria, & Antoni, 2008). Sayles, Wong, and Cunningham (2006) found that women more often than men reported difficulty taking HIV medications openly in the home. This may have far-reaching implications for gender disparities related to HAART interventions.

HIV Disease in Older Adults

Early in the HIV epidemic, older adults were most likely to be infected through the receipt of infected blood products. In 1989, persons over age 50 accounted for 98% of the HIV infection cases attributed to infected blood products (CDC, 1998a). Although the introduction of routine blood screening drastically reduced this risk, the rates of infection from other transmission modes rose. HIV transmission in older adults now occurs primarily through male-to-male contact (MSM), injection drug use (IDU), and heterosexual contact (CDC, 2008). HIV disease in the older population comprises two distinct groups: persons age 50 and older who are newly diagnosed with HIV disease and persons age 50 and older who were diagnosed at a younger age and are growing older from this chronic illness.

HIV disease in the over-50 age group presents with a multitude of complexities not seen in the younger age groups, including issues related to society’s stereotypical values about sexuality and the natural biological aging processes. Society’s stereotypes that suggest that persons over 50 are asexual have resulted in little or no targeted HIV preventative education, assessment, or intervention compared with the massive efforts that have targeted younger persons. The aging of the baby boomers, the increased older female to older male ratio, and improvements in the treatment of erectile dysfunctions have been credited for the marked increase in sexually transmitted diseases and HIV infections (Levy-Dweck, 2005). Similar to the findings in other groups, HIV prevalence and risk perception do not present as sufficient motivation for persons over age 50 to adopt HIV preventative behavior or to seek HIV testing (Nichols, 2004). In addition, studies have shown that physicians are often reluctant to conduct sexual history on older patients, and these patients may be unwilling to acknowledge high-risk behaviors (Gebo & Justice, 2009; Nokes, 2011). Family and friends, too, are often reluctant to believe that persons of this age group are active sexual beings (Levy-Dweck, 2005)

Many of the symptoms of HIV disease, such as weight loss and changes in physical and mental cognition, resemble symptoms of other chronic diseases and some of the conditions associated with the normal aging processes. For instance, as the body ages the immune function declines. When this natural decrease is further complicated by the HIV diseased CD4 cells, these specific age-related factors—in addition to delayed HIV diagnosis, appropriateness of therapy, and other socioeconomic factors—have been identified as additional contributors that further challenge the person’s overall health status. The older adult with a declining immune system is incapable of responding to HIV in the same manner that a younger person would (Gebo & Justice, 2009; Levy-Dweck, 2005; Wolitski et al., 2009). In persons with long-term HIV disease, the impact of constant ongoing activation of the immune cells by the virus may increase the individual’s susceptibility to inflammatory induced diseases and bone disorders (Brown & Qaqish, 2006). Whereas HAART has been credited with reducing morbidity and mortality, current investigations indicate that older adults may have slower immune recovery and be more likely to develop more significant therapy-related toxicities than younger persons, despite this group's history of increase medication adherence (Conde et al., 2009; Gebo & Justice, 2009; Luther & Wilken, 2007). In addition, the prolonged exposure of individuals to the virus and HAART appears to increase morbidity and mortality from cardiac, renal, hepatic, and respiratory disease, as well as some cancers not directly connected to HIV disease (Gebo & Justice, 2009). It must also be noted that older adults have more comorbidities and preexisting disorders than younger patients, the impact of which is unknown. For the older person, these comorbid conditions may present a more serious threat to their health than HIV disease and, therefore, may be seen and treated as much more of a priority (Emlet & Berghuis, 2004).

HIV Disease in the Older Adult Woman

Several physical and psychosocial factors have been reported as contributors to the risk, diagnosis, and treatment of HIV disease in older women. The normal postmenopausal thinning of the vaginal wall and decrease in vaginal lubrication contribute to breaks in the mucosal integrity that increase transmission risk during unprotected sex (Anderson, 2005). Psychosocial factors include the decrease or lack of personal perception of HIV risk in this group and decreased condom negotiation skills (Akers et al., 2007; Corneille, Zyzniewski, & Belgrave, 2008; Stampley, Mallory, & Gabrielson, 2005; Threall, Elifson, Sterk, & Klein, 2003). Although there appears to be consensus in the literature that increased age is inversely correlated with HIV-risk perception, there is little regarding what shapes and contributes to the poor self-perception of risk (Smith, Lillie, & Larkin, 2007).

Providers also have been reported to have a low and sometimes distorted perception of older women's HIV risk. The findings from a study of 44 recently single women ages 45 to 68, and 31 primary care physicians indicated that although 64% of the women in that study considered themselves at high risk for HIV infection, the physicians rated advancing age and being female as lower risk factors for HIV infection (Grant & Ragsdale, 2008). Researchers have identified that physicians were less likely to initiate a discussion about sex with an older woman; however, if this discussion did occur, it was more likely to occur if the woman was African American (Grant & Ragsdale, 2008; Tessler Lindau, Leitsch, Lundberg, & Jerome, 2006). This reluctance on the part of physicians and other healthcare providers may translate to a false sense of security related to HIV risk. Other studies have found that despite the low perception of risk, women were more likely to agree to be tested if their provider recommended it (Akers et al., 2007).

The literature suggests that among older women, condom use and condom negotiation skills are deterred or enhanced by multiple cofactors, such as education, power, influence of partners, and the traditional meaning of trust and infidelity in the relationship (Jarama, Belgrave, Bradford, Young, & Honnold, 2007). Many older adult women's experiences with condoms and condom negotiation were related to birth control issues. Since pregnancy was no longer a concern (Jacobs & Kane, 2009), the perceived need for condom protection during intercourse was not a priority. However, findings by Corneille et al. (2008) indicated that some older Black/African American women reported a higher efficacy for negotiating condom use than their younger counterparts, although some participants reported suspicion about the effectiveness of condoms. Findings by Ward, Disch, Levy, and Schensul (2004) support an earlier study by Rodgers-Farmer (1999), which showed that 40% of older women expressed uncertainty about the effectiveness of condoms.

HIV Disease and Black/African American Women

The primary transmission risk for new HIV infection for women is heterosexual. Among Black/African American women, this route of transmission accounted for 85%, while for Latinas it accounted for 82% and for Caucasians 72% (CDC, 2010). Specific risk factors for African American women include involvement in a monogamous relationship with an infected husband/or partner or unprotected sex with a partner who has been incarcerated. Researchers have posited that the increase of HIV disease in Black/African American women is partially the byproduct of the mass incarceration of Black/African American men due to the drug wars, as well as subsequent prison activities such as crude tattooing procedures and unprotected MSM activities. This homosexual activity is often not acknowledged by the men nor revealed to the women. Researchers have noted that Black/African American women are less likely to date outside their race (Jones-DeWeaver & Avis, 2005). This culturally imposed boundary potentially increases their HIV exposure risks. Researchers have offered a sexual network model focusing on the concept of connectivity as a different perspective to identify at-risk groups and behaviors, to aid in the understanding of HIV transmissions, disparity, and prevention (Morris, Kurth, Hamilton, Moody, & Wakefield, 2009).

In the Black/African American community, churches have traditionally been the center of civic, social, and spiritual life. In the early years of the epidemic, churches were very silent about HIV disease. Recently, however Black church-based prevention programs have increased (Lindley, Coleman, Gaddist, & White, 2010; Smith Hatcher, Burley, & Lee-Ouga, 2008). Lindley et al. (2010) studied the health-related knowledge and attitude of African American pastors and parishioners and found that HIV stigma, shame, and homophobic beliefs were associated with parishioners age and gender. In addition, their findings showed that pastors who had lower levels of stigma were more likely to initiate HIV health promotion education programs in their churches. Older male parishioners were less knowledgeable about HIV than female and younger church members. In addition, one out of four parishioners had little sympathy for persons living with HIV/AIDS (PLWHA) whose transmission risk was “promiscuity,” and 25% of the parishioners believed that HIV/AIDS was a punishment from God.

HIV Disease and Older Black/African American Women

When HIV was studied in regard to older Black/African American women, it was initially looked at in relation to the women’s response to HIV disease in other family members, and then it was looked at in response to the women’s disease. The older African American women were depicted as examples of resourceful and courageous beings, who assumed the role strain and changes involved with taking on the new care-giving and custodial responsibilities for their adult children and grandchildren (del Bene, 2010; Lam, Weissman, & Zule , 2004; Linsk et al., 2009). Other studies have investigated this group in relation to grief and loss of their offspring to HIV/AIDS (Linsk & Mason, 2004; Poindexter, 2007; Schable et al., 1995). Few studies have investigated HIV disease in older adult heterosexual women, and even fewer have focused on older adult African American women (Mallory, Harris, & Stampley, 2009). In fact, the idea that older women are sexually active beings and, as such, are at risk for contracting HIV infection has been largely ignored by researchers and public health agencies. Of the studies that are available about HIV disease in older Black/African American women, some have suggested that women of this age group lacked the knowledge related to HIV prevention and treatment (Jackson, Early, Myers Schim, & Penprase, 2005). However, it is to be noted that when HIV first surfaced, many of the current older adult women were at or just past childbearing age. It is possible that there was at least a minimum exposure to some of the targeted preventative HIV-education strategies. The few studies that have focused on internal factors such as attitudes and perceptions indicate that women in this age group may have perceived themselves not to be at risk, and therefore, they were unresponsive to HIV messages and strategies.

A cross-sectional study of 514 women age 50 and older found that African American women, despite being at high to moderate risk for contracting HIV, had poorer HIV knowledge, lower perceived HIV risk, and little interest in HIV testing (Akers et al., 2007). Other recent studies, while acknowledging the increasing transmission rate in this population, have recommended interventions that were specifically developed and targeted for groups other than older adult African American women (Cornelius et al., 2008; Gentry, Elifson, & Sterk, 2005). Stigma and severe discrimination are among the many prevention challenges that older persons of minority races might face. These factors were identified as contributors to delayed testing and treatment and to the concealment of the HIV diagnosis from persons who normally provided supportive relationships. Being African American was positively correlated with higher stigma scores. Being African American and being exposed through heterosexual contact was negatively correlated with disclosure (CDC, 2008; Payne-Foster & Gaskins, 2009; Wolitski et al., 2009). Emlet (2006a) and Nokes and colleagues (2000) identified that persons over 50 years of age disclosed their HIV status to a smaller number of persons than did younger HIV-infected persons.

HIV Disease Within the Geographic Context of This Study

The geographic study site was the Bronx, a borough of New York City (NYC). The Bronx has the third highest HIV prevalence rate in NYC. With a population of 1.4 million people, the Bronx is one of the poorest congressional districts in the United States, with 37.4% of its population living below the poverty level. The ethnic makeup is 43% African American and 52% Hispanic. The PLWHA prevalence rate at the end of 2011 was 21% of the overall NYC population of PLWHA (New York City Department of Health and Mental Hygiene [DOHMH], 2013). The Bronx, like the other boroughs of NYC, has a plethora of public, not-for-profit, and community-based HIV health and social agencies.

HIV Disease in New York City

According to the 2013, New York City Department of Mental Health and Hygiene (NYC DOHMH), of the 113,319 persons living with HIV disease in NYC, 44.6% were African American, 44% were 50 and older, 28.6% were women, and 21% resided in the Bronx. Of the 32,398 female PLWHA in NYC, 58.3% were African American, 42.6% were age 50 and older, and 29.1% lived in the Bronx. The transmission risk categories identified for the overall female category were heterosexual, 48.6%; unknown/undetermined, 28.5%; and IDU 18.6%. Among the 18,670 African American women with HIV disease in NYC, 38.3% were age 50 and older, and 25.1% lived in the Bronx. In this group, 49.3% of the transmission risk was related to heterosexual activity, 18.3% was related to IDU, and 27.9% was related to the unknown.

HIV in the Bronx

The Bronx, the geographic area of NYC chosen for data collection, has the third highest rate of HIV infection in NYC. In 2011, there were 23,748 PLWHA in the Bronx. Of that number, 9,428 were women, 58.3% of the women were Black/African American, and 42.6% of the women were age 50 and older. This age group outranked all the others, followed closely by the 40–49 age group, with 33.6%. Within the immediate Bronx neighborhood where the data collection site is located, 59% of persons who reportedly had more than one partner in the past year reported that they did not use a condom at their last sexual encounter. Although residents in this area are more likely to be tested for HIV than residents of other neighborhoods in NYC

(42% vs. 23%), one third of the positive test results reveal a late diagnosis (NYC DOHMH, 2013). Of the approximately 71,000 residents of the Bronx, 34% are identified as living below the poverty level, and 33.3% were born outside of the United States. Here, the HIV diagnosis rate is 30% higher than the overall NYC's rate. Despite the fact that heterosexual contact was identified as the primary mode of transmission for women, fewer than 42% of this area's adults reported using condoms at their last sexual encounter. According to the statistics, in the immediate neighborhood surrounding the data collection site, there were 2,630 persons living with HIV disease. Of that number, 44.3% were women, 64.0% were African American, and 35.9% were age 50 and older. In this neighborhood, the identified transmission risk categories were heterosexual, 28.1%; unknown, 32.2%; and IDU, 20.6% (NYC HIV/AIDS Surveillance Statistics, 2009).

Experiential Context

My interest in HIV and women goes back to my graduate school experience in the early1990s. In addition to completing the course work in maternal–child nursing, I completed the subspecialty in HIV/AIDS Nursing under the direction of Kathleen Nokes and Peter Ungvaski, two nurse leaders in the field of HIV/AIDS. The framework for those courses was steeped in the biomedical model. Later, I developed and implemented several nursing community-based programs, focusing on family-centered HIV nursing care. As I was employed in the maternal–child health program of a large community health agency, most of the patients were women and their infants and children, who were living with and/or affected by HIV.

During the beginning of the epidemic, the populations most affected by HIV/AIDS were MSM, adolescents, and childbearing women and their infants. The HIV-related phenomenon facing older Black/African American women at that time was that they were abruptly being returned to the parenting, care giving, and guardianship role for their children and their grandchildren. My interface with the older Black/African American women during that period was to provide health education and support for them in their new role. I, as well as other providers, did not consider the older adults as a population at risk for HIV disease. The preventative education that my staff and I offered to these women was related to caring for their love ones, such as wearing of gloves, caring for cuts or breaks in skin integrity, proper handling of needles, and hand washing. I saw, first hand, issues and concerns about parenting, caring, enduring, and stigma that could never be captured or understood from a quantitative perspective. Soon, however, the overwhelming positive outcome of Protocol 076, (CDC, 1994, 1998b), the protocol that led to the marked decrease in maternal transmission of HIV and the identification and implementation of HAART, signaled the transition of the disease from an acute life-threatening one to a chronic, manageable one, and the urgency for ongoing concern for this group of older Black/African American women dissipated.

Within the context of HIV disease, this subpopulation of older Black/African American women has transitioned from that of support system and caregivers to that of individuals living with their own HIV disease. Having worked alongside women of this age group as they cared for their children and grandchildren during the early years of this epidemic, I believed that neither the biomedical nor the public health model was able to capture the meaning of the experience of these mothers and grandmothers. I felt an impassioned need to gain an understanding of the meaning of their personal experience of living with HIV/AIDS within this new context. I saw it as a means of giving voice to the silence of their lived experience. It was this knowledge, these experiences, and these concerns that have shaped my research interest in this area.

Summary of the Chapter

In Chapter II, the evolution of this study is presented. The literature describes the historical evolution of HIV disease, the impact of HIV disease on age, gender, race, and, finally, the population under study, older adult African American women. A description of HIV within the proposed study's geographic location is presented. The chapter concludes with the situated context of my life experiences that brought me to this interest. Chapter III describes the phenomenological approach.

CHAPTER III

REASEARCH APPROACH

The purpose of this phenomenological study is to understand what the experience of living with HIV disease is like for a group of older Black/African American women. This chapter begins with an introduction to the phenomenological approach. A brief discussion of the historical roots of phenomenology, the philosophical frameworks, and various schools of thoughts and research approaches follows. Merleau-Ponty's philosophical perspective, the philosophical frame work that underpins this study is discussed. In addition to van Manen's methodical structures of human research, the process that guided this study is identified. The rationale for the use of this approach is also presented. The chapter concludes with a brief summary of the aforementioned discussions.

Introduction to Qualitative Research

Munhall (2007) stated that qualitative research is concerned with discovery. Like all research, qualitative research explores the gaps in knowledge. This human science worldview provides an appropriate way for exploring research questions that allow for discerning the different ways knowledge is created (Van der Zalm & Bergum, 2000) and is the most meaningful way to describe, interpret, and understand human experience without reductionist measurements and instruments. In discussing the strengths of qualitative research methods, Lincoln and Guba (1985) posed the following:

1. Qualitative methods are multiple constructed and holistic.
2. There is an inseparable relationship between the person and his/her knowledge.
3. Only time and context can be generalized.
4. Entities are constantly evolving, therefore assigning cause and effect is impossible.

5. Research is intersubjective and value laden.

6. Phenomenology is but one approach within the qualitative paradigm.

Theoretical Perspective of Phenomenology

There are two main theoretical perspectives related to phenomenology. The first is the descriptive or eidetic approach. Developed by Husserl (1965), this approach focuses on description of the experiences. It requires that in order to ensure scientific rigor, researchers must shed or bracket all prior knowledge about the phenomenon under study to prevent biases or preconception related to the study. The second perspective is the interpretive or hermeneutic approach. Initially posited by Heidegger (2008/1962), this approach goes beyond the description of the experiences and seeks, through interpretations, to provide an understanding of the meaning or essences of participants' lived world experience of the phenomenon (Finlay, 2009; Flood, 2010; Van Der Zalm & Bergum, 2000). This approach acknowledges that the researchers' experiences and biases can never be fully bracketed; instead, researchers are expected to state their biases and assumptions up front. This researcher subscribes to the idea that one cannot entirely shed all prior knowledge about the phenomenon, but the researcher as research instrument, and by acknowledging one' biases, can bring a unique perspective to the study. It is this second approach that was chosen to underpin this study.

Historical Perspectives of Phenomenology

Phenomenology as it has been used in the social sciences and nursing is a philosophical perspective and research approach that emerged as a response to the positivist approach of the natural sciences. It is an attempt to restore "the reality of humans in their life world" (Munhall, 2007, p. 160). The primary philosophical stance of phenomenology is to get at "the thing itself" through direct personal experience and that the person is integral in the world. This paradigm acknowledges the inevitability of subjectivity in any exploration or description of reality. This subjectivity is essential, as it expands and enriches the authenticity of perceptions and understanding of the phenomenon. Because humans participate in the cultural, social, and historical context of the world, to be human means to be in the world (Munhall, 2007). Often referred to as the “classical phenomenologist approach,” research from this paradigm is undertaken either from a philosophical or phenomenological viewpoint and focuses on the meaning of experiences from the person’s own subjective perspective.

In phenomenological research, the methodology refers to the philosophical framework, the philosophical assumptions, and the characteristic of the human science perspective. It is the theory that underpins the method. This methodology includes: “the general orientation to life; the view of knowledge; and the sense of what it means to be human . . .” (van Manen, 1990, p. 27). Phenomenological research is used to study human experiences as described by the participants. To conduct research from a phenomenological perspective is to explore the way human beings experience the world (van Manen, 1990). This approach seeks to know the world in which we live by questioning the way individuals experience the world. In this study, participants were asked to talk about the experience of having HIV. They were asked for a description of the lived-through quality of their experience and a description of the meaning of the expressions of the lived experience. The objective was a description aimed at elucidating the full structure of the experience or what the experience meant to those who lived it. The outcome of phenomenological research describes how one orients to lived experiences. This process is concerned with understanding the phenomena instead of explaining it (van Manen, 1990).

Phenomenology was first described by Immanuel Kant (1724–1804). He proposed that phenomenology is the study of phenomena or things. Kant argued that there were human phenomena that could not be explained by cause and effect, that observation could not be the only reality, and that perception was more than just the act of observing. Later, the works of the German philosophers Edmund Husserl (1965) and Martin Heidegger (1962) and the French phenomenologist Merleau-Ponty (1945/1962) advanced the ideas of Kant and elucidated the philosophical and research underpinnings of this approach (Dowling, 2007). The following section identifies some of the phenomenological philosophers who have contributed to this approach. A discussion of their respective contributions is included.

Husserl's (1886–1938) Phenomenological Perspective

Edmund Husserl (1886–1938) was a German mathematician who is credited for being the father of modern phenomenology. Husserlian phenomenology sought to describe how the world appears to be and is experienced by persons through their conscious acts. He believed that all knowledge comes from experience. Experience, Husserl (1965) stated, is constituted or formed through consciousness, and consciousness is constituted or formed over time (past, present, and future). Time, he said, is integral to the meanings of the experience. Husserl's aim was to develop a research approach that described the world the way it appears in one's consciousness, and he challenged researchers to describe and explore the immediate experience before that experience is altered by preconceptions and theoretical preassumptions (Husserl, 1965).

Husserl asserted that an important characteristic of phenomenology is that it begins in the *life world*. This life world is the world of immediate experience, or the world as experienced in the natural, original, or pregiven state before contamination with assumptions and labeling occurs. Another concept that Husserl put forth was the phenomenological *epoche,* which he defined as the suspension of commonly held beliefs about the world. While the term *epoche* was used by the Greeks to mean a suspension of judgment, Husserl referred to this process as a questioning of presuppositions until they could be established on a more solid foundation. Husserl, being a mathematician, also described the process of phenomenological *reduction*, which he defined as placing the natural attitude toward the world in brackets. Bracketing is modeled on the mathematical tactic of placing brackets on that part of a mathematical equation that should be treated differently from the remainder of the equation (Husserl 1965; Macann, 1993).

Heidegger's (1889–1976) Phenomenological Perspective

Martin Heidegger, a fellow phenomenologist and student of Husserl, articulated that phenomenology is the study of the ways of human beings "being in the world." He articulated that the uniqueness about human beings was that they were "being - unto death" (Heidegger, 1962, 2008) In other words, humans were conscious about their own being and possibilities of their nonbeing. This is relevant for this study because human immunodeficiency virus (HIV) disease, unlike other medical diagnosis, is highly likely to remind one of the possibilities of one's own death. How older adult African American women experience these possibilities is unclear.

The phenomenology of Heidegger (1962) is based on an existential viewpoint that asserts that individuals have situated freedom; that is, they are free to interpret their world in their own way (Sartre, 1977). He disagreed with Husserl's concept of bracketing. He stated that a researcher's experience can never be fully bracketed, and at best, one can achieve a thorough and rigorous dialogue. It is therefore crucial that researchers are open and upfront with their view point (Heidegger 1962; P. A. Johnson, 2000; Macann, 1993). Heidegger's (1962) phenomenology is oriented toward interpretation and understanding, and he recognized that there is no such thing as an uninterrupted fact. To be human is to be in the world, and knowledge is acquired from understanding and interpretation. Comprehension, then, is always within the context of one's experience of the world, and therefore, it is not possible to be devoid of judgment, as we construct our own reality and interpretation. Involvement by participants in all phases of the research is considered to be an important component in the overall interpretation process. However, this involvement is in no way an attempt to seek absolute truth or valid analyses, as defined by the positivistic sciences. Instead, it is here that new meanings can surface and better interpretations be achieved.

Heidegger (1962) used the Husserlian term *life world* to capture the idea that people's realities are shaped by the world in which they live and that they are so embedded in their world that subjective experiences are intrinsically linked within the social, cultural, and political contexts of their lives. "Lived meaning," then, refers to the way a person experiences and understands his or her world as real or meaningful. The aim is to gain insightful descriptions, in-depth understanding, and interpretations of the way one experiences one's life world. Heidegger (1962) said that the researcher must seek an answer to the following questions: What is the nature of this being? What lets this being be what it is? Researchers are obligated to provide enough information about the research process to enable the readers to make their own interpretations (Heidegger 1962; Macann, 1993; Munhall, 2007; van Manen, 1990).

To interpret a text is to come to understand the possibilities of being as revealed by the text. Heideggerian phenomenology, referred to as *hermeneutic* or *interpretive phenomenology*, denotes the way one interprets the text of life and is based on the idea that "no interpretation is ever complete. No explication of meaning is final, no insight is beyond challenge" (van Manen, 1999, p. viii). The final interpretation is only to be accepted as tentative rather than as absolute or true.

Merleau-Ponty’s (1908–1961) Phenomenological Perspective

Merleau-Ponty (1908–1961), identified as one of the leaders of the French phase of the phenomenological movement, was concerned with the science experience of human beings. He studied and built on the works of Kant, Husserl, and Heidegger. Merleau-Ponty (1945/1962) proposed that phenomenology is the philosophy and study of essences and existences and that it always seeks an answer to the question “what is the nature or meaning of the phenomena?” He likened the work of the phenomenological researcher to the meticulous work of famous artists, in that it directs one to reach out and grasp the meaning on the world canvass in which the phenomenon or experience shows itself. Merleau-Ponty, like Heidegger (1962), contended that phenomenology is also a philosophical belief that the world is always there even before one begins reflection, and researchers’ challenges are to reconnect or achieve direct contact with the primordial world, free of the causal explanations and preassumptions (Heidegger, 1962; Mallin, 1979; Merleau-Ponty, 1945/1962).

Merleau-Ponty (1945/1962) identified four themes related to phenomenology: *description, reduction, essences* and *intentionality*. Phenomenology, he stated, is a *descriptive* science, distinct from other sciences. It does not take for granted the reality of the world, nor does it try to analyze participants’ comments for hidden meaning, but it sees the world as the beginning and return point of all scientific investigations. *Reduction* is the reflection on the description and is the process through which one first becomes aware of one’s relationship with the world and with the other subjects with which one shares the world. It requires a conscious effort on the part of the researcher to suspend previous knowledge and assumptions about the particular experience being studied. *Essences* are integral parts of one’s experiences. *Essences* are the expression of experiences in language that allows for the extraction of the real meaning from one's experiences. Transcendental reflection goes on to effect a second separation, taking the conceptual essences that have been detached by language and giving them just the right meanings. This process frees the essences from the firm grasp of a particular conceptual framework or theory and by doing so makes it possible to be resituated in the original experience. Because one is so enmeshed in being in the world, it is not possible to understand meaning and essences as they are occurring. The experience must be recalled and reflected upon (Macann, 1993). Merleau-Ponty subscribed to Husserl's explanation of *intentionality* to emphasize the concept of "to the things themselves," the "phenomenology of origins." He distinguished between an act and an operative intentionality as follows:

> Act intentionality is the intentionality involved in judgments and in any analysis of experiences, which takes an already constructed world of objects as the starting point. Operative intentionality on the other hand, is the intentionality in and through which such a world is brought into existence in the first place. (Macann, 1993, p. 163)

Key tenets of Merleau-Ponty's (1945/1962) philosophy include the concepts of embodiment, perception, intentionality, the knot of relationship, time, and morality. These concepts are pertinent to this study in that they form the basis of the four tenets of existentialism—lived time, lived space, lived body, and lived relations—described by Van Manen.

Merleau-Ponty (1945/1962) added the concept of embodiment to Heidegger's concept of *being in the world*. This is the belief that all action, or lack thereof, is performed on the basis of perceptions or original awareness of some phenomenon. The concept of *embodiment* refers to the idea of the interconnectedness between the consciousness, the body and the world. It is through consciousness that one is aware of being in the world, and the body is the primary vehicle through which individuals gain access, and therefore knowledge, of and to the world through their senses. For Merleau-Ponty, the body cannot be perceived as separate parts but must be understand as a whole, as it is lived. The body as it is lived is an experiential body, a body that opens onto a world and allows the world to be for us. Merleau-Ponty said that the human body is the vantage point of perception. It is the body, through its relationship with the lived situations, which initiates meaning to experiences. Embodiment is a philosophical approach or human state of being. It is the means through which people know the world by way of their bodies, especially through movements in time, space, language, emotions, and sexuality. Merleau-Ponty referred to this as the "phenomenal body" because the body and its appendages are not entities to be found in the objective space, but instead are mobilized by perception as seen in the individual speech and bodily gestures as the body gives meaning to the space it occupies (Merleau-Ponty, 1945/1962). He used the example of the human hand responding to a mosquito bite elsewhere on the body—not from an objective stance, but rather out of perception. According to Merleau-Ponty, we do not *have* bodies; instead, we *are* our bodies. "As the body grows, the meaning of space becomes modified" (Thomas, 2005, p. 71), and with aging, the body's abilities change. When illness is added to an aging person's lived situation, the relationship between the body and the world becomes even more disturbed. The person's existence is thoroughly disrupted. This disruption cannot be satisfactorily explained from a rationalist or empiricist perspective. The understanding of the existential skills of living with this new life world that are shaped by personal, physical, and cultural concerns foster a different dialogue between patients, nurses, and providers (Sunvisson, Habermann, Weiss, & Benner, 2009).

Perception, Merleau-Ponty (1945/1962) said, opens human beings to reality by providing a direct experience of the events and phenomena. This direct experience is to be contrasted with thinking and language, which deal with ideas and representations of the world. All knowledge takes place within the window that is opened up by perception, and all meaning occurs through perception. This perception is gained from one’s surroundings. As one grows, one learns and adapts to the norms and practices of one’s culture. Perceptions of a given entity, culture, or aspects of a perceptual experience emerge from a background or context and cannot be fully understood without knowing something of the specific context or background. The participant narrative reveals the form or figure of the experience. However, the background or context is the body, time, other people, and the world. The research method must therefore provide a careful and comprehensive description of both the form and the background of the phenomenon under study.

Intentionality is another of Merleau-Ponty’s (1945/1962) key tenets. He asserted that all human experience occurs in relation to stimuli in the life world (i.e., something other than oneself). In order to understand the meaning of an experience, one must describe the situated perspective or intentional stance of the event from the perspective of the person who experienced the event. This integral relatedness or interconnectedness between humans and the life world is referred to as *intentionality*.

Another key tenet for Merleau-Ponty is the *knot of relationship*. He defined this as “the interconnectedness with others” and “the intersections and engagement of a person’s path with the paths of others.” He espoused the importance of relationship and dialogue with others. This interconnectedness he termed the *knot of relationship*.

> In the experience of dialogue there is constituted between the other person and myself a common ground: my thoughts and his are interwoven into a single fabric. My words and those of my interlocutor are called forth by the state of the discussion, and

> they are inserted into a shared operation of which neither of us is the creator. We have here a dual being, where the other is for me no longer a bit of behavior in my transcendental field nor I his…. Our perspectives merge into each other, and we coexist through a common world. (Merleau-Ponty, 1945/1962, p. 413)

The most relevant aspect of *time*, another key tenet described by Merleau-Ponty (1945/1962), is the present. Time, he said, is a subjective experience that is ambiguous, as awareness of time is often within the context of meaningful experiences. For the participants in the proposed study, a significant time event may be the day they received their HIV diagnosis, or the time they disclosed their status to a significant other.

Having had the experience of war in his lifetime, Merleau-Ponty included the concept of *morality* as another key tenet. He emphasized the importance of language and communication. He spoke out against violence and envisioned a world where dialogue would take precedence over war. Merleau-Ponty's stance is the philosophical approach that underpins this study. This wholistic philosophical approach is relevant to nursing and to this study.

Van Manen's Method

This phenomenological study is guided by the methodical structures of human science research as elucidated by Max van Manen (1990). Influenced by the work of Merleau-Ponty (1945), Heidegger (1962), and Husserl (1965), van Manen, a Dutch-born Canadian educator, advocated the use of phenomenology in educational research. For van Manen (1990), "phenomenology is the application of logos (language and thoughtfulness to a phenomenon" (p. 33). Van Manen goes on to say that phenomenology asks the questions "what is this phenomenon in its "whatness" …what is the nature of this thing?" (p. 33) before any causal effect and theory is applied.

Phenomenology offers the opportunity to recall and account for the experience of space, time, body, and human relations as they are lived. It requires that one recapture the data (experience) of the world as they were met during the original experience, bearing in mind that the data of human science are the lived experience. Lived meaning refers to the way one experiences, understands, and describes the experiences of one's world. However, the description of the lived experience is dependent on understanding and language (van Manen, 1990). Thus van Manen supported Heidegger's stance that interpretive phenomenology cannot be separated from the text of writing. The text is the written descriptions of the participant's experience and is derived from the human research process. It is descriptive in that it names the experiences and, by doing so, allows the thing to show itself. However, as one describes the experience, the articulation is mediated by symbolic expressions such as tone, body language, and emotional responses. Thus, the recollections are no longer solely descriptive, but they now have added elements of interpretation or hermeneutics. Van Manen (1990) stated that in addition to description, the phenomenological text is also interpretive. He uses the term *descriptive* to include both terms *interpretive* or *hermeneutic phenomenology* and *descriptive phenomenology*. Van Manen encouraged researchers to use the term *person* or *participant* rather than *subject*, as *person* captures more the uniqueness that each human being brings to the study.

Van Manen (1990) identified four tenets of existentialism that are fundamental in the life world and suggested that phenomenological researchers use them as a guide for reflection in the research process. They are *lived time* (temporality), *lived space* (spatiality), *lived body* (corporality), and *lived relations* (relationality). These concepts are closely related to Merleau-Ponty's ideas on embodiment, intentionality, the interconnectedness with others, and the meaning of time. *Lived time*, according to van Manen, is one's subjective clock that interprets one's present, past, and future and identifies points along the life world experiences. *Lived space* refers to one's physical or emotional world or home and allows for inquiry into how one experiences one's daily life world. *Lived body* refers to the implication that persons are always bodily in the world. *Lived other* or *relationality* refers to the lived relationship one has with others. Van Manen stated that these four tenets are fundamental in unity with the life world, and while they can be differentiated, they cannot be separated. Throughout the research process, I watched for the emergence of these tenets, and when they appeared, I used them as a guide during reflection.

Identification of Van Manen's Methodical Structures of Human Science Research

Research is an intentional act of affixing oneself to the world, to be wholly a part of the world, or to be of the world. This inextricable connection van Manen referred to as *intentionality* (van Manen, 1990). For van Manen, hermeneutic phenomenological research may be viewed as "a dynamic interplay between six research activities" (p. 30). He identified these six methodical activities as follows:

1. Turning to the phenomena that seriously interest us;
2. Investigating the experience as we live it;
3. Reflecting on the essential themes that characterize the phenomenon;
4. Describing the phenomenon through the art of writing;
5. Maintaining a strong pedagogical relation to the phenomena; and
6. Balancing the research contexts by considering the parts and the whole.

Summary of the Chapter

Chapter III began with an introduction to phenomenology and the research design chosen for this study. The two main theoretical perspectives of the phenomenological approach are described. An explication of the historical background of phenomenology is given by presenting the philosophical perspectives and contributions of Emmanuel Kant, Edmund Husserl, Martin Heidegger, and Merleau-Ponty. A description of Merleau-Ponty's phenomenological perspectives and van Manen's method of research is also presented. The influence of Merleau-Ponty on van Manen's work leading to the identification of the four fundamental existentials: *lived time, lived space, lived body* and *lived relations*, which he offered to researchers as a guide for reflection, is identified. In addition, van Manen's six research activities are identified. Chapter IV includes the description and application of these six research activities to this study. A detailed discussion of the research procedure inclusive of the recruitment and sample selection approach, the protection of human subjects procedure, the data collection and analysis, the process for attaining rigor, and the risk and limitations of the study is presented.

Chapter IV

METHOD OF INQUIRY

The purpose of this phenomenological study is to understand what the experience of living with HIV disease was for a group of older Black/African American women. This chapter begins with the description and application of van Manen's six research activities to this study. The research question is delineated. The research procedure, inclusive of the sample selection, setting/access, data collection and method, is described. Procedures to ensure rigor and trustworthiness, determination of potential risk associated with the data collection procedure, and the protection of human subjects are presented. Incentives offered for participation are also addressed.

Application of Van Manen's Phenomenological Approach

Van Manen (1990) identified the following six research activities: turning to the phenomena that seriously interest us, investigating the experience as we live it, reflecting on the essential themes that characterize the phenomenon, describing the phenomenon through the art of writing, maintaining a strong pedagogical relation to the phenomena, and balancing the research contexts by considering the parts and the whole. This study was guided by the six activities.

Turning to the Phenomena

Phenomenological research begins and ends with the experience of the participants. To orient oneself to the phenomenon implies that one has to have a special interest in approaching the phenomenon. For example, this researcher approached the life world of this phenomenon (living with HIV disease) from the interest, orientation, and vantage point of a Black woman and a nurse. Once the researcher had identified an interest in the nature of the human experience, the next step was to formulate the phenomenological question. This question asked was what is the nature of the lived experience? For this study, the specific question was “what is it like (for you) to be living with HIV disease?” I heeded van Manen’s (1990) caution to be always mindful of the original question throughout the entire process. The essence of phenomenology is the opening up and keeping open of possibilities, but van Manen advised that researchers can only accomplish that if they keep themselves open. As the researcher, I did not simply raise the question, but I lived the question, and I became the question. Once the question was answered, the aim was to transform the description of the lived experience of the participants into a literary expression of its essences so that the text allowed for the reliving and/or rereflecting of the meaning of this powerful experience.

Investigating the Experience as Lived

The process of phenomenological research requires reestablishing contact with the original experience before any interpretations, biases, or preconceptions have been attached. This idea is captured by the term *turning to the things themselves* (Husserl, 1965). Merleau-Ponty (1945/1962) referred to this as the means of rediscovering the life world experience by arousing the original experience of the “thing.” As I interviewed the participant, I was conscious of van Manen’s (1990) caution that experiential “data,” or any descriptors of lived experiences, are never identical to the actual lived experience. All transformation of lived experiences is exactly that, transformations. In this phase as the researcher, I borrowed the experiences of the participants to facilitate the understanding of the phenomena. In so doing, I came to understand the nature of the phenomenon as an essential human experience. Although this phase began the data gathering process, the conversational inquiry was alternated with reflective and interpretive or hermeneutic interviews. Hermeneutic interviews allowed the participants to correct and/or clarify the data and to evolve into collaborative partners in this research process (Munhall, 2007; Van Manen, 1990).

The first two activities described above encompass the descriptive phase of the process. It was the narrative as told in the language of the participants. Here, the rich texts are generated and the reader is taken into the experiential world of the participants. The third activity signified the interpretative phase of the process.

Reflecting on the Essential Themes That Characterized the Phenomenon

The third stage of this process, phenomenological reflection, speaks to bringing to the forefront that which seems vague or incomprehensible. The activity is about uncovering or isolating the thematic aspects of the phenomenon. In attempting to understand and analyze the structure of the experience, van Manen identified the employment of phenomenological themes. A theme is described as the "experience of focus, of meaning, of point. … The form of capturing the phenomenon one tries to understand. … the needfulness or desire to make sense… the process of insightful invention, discovery disclosure…. Themes give shape to the shapeless" (van Manen, 1990, p. 87–88). As the data were reflected on, themes emerged, and I was able to identify these themes. As the lived experiences were studied and the emerging themes identified, the themes were reviewed for commonalities and reflected on for possible hermeneutic conversations with the researcher and participants. Incidental themes were then weeded out from the universal or essential themes. The essential themes were features that made the phenomenon what it was, and should these features be removed, the phenomenon would no longer be that "thing" (van Manen, 1990). The process of grasping the essentials was both easy and difficult. It was easy because it was often something that everyone knows about, yet it was difficult to reflect and explain clearly the experiential structure of what the "thing" really was (van Manen, 1990). I dwelled with the data by listening to the recorded interviews and by reading and rereading the transcripts and reflecting on the data. I looked and listened to the data to allow for the evolution of phenomenological description of the experiences. I attempted to grasp, through reflection, the essential meaning of the participants' experience of living with HIV disease.

The Art of Writing and Rewriting

Writing brings forth one's thoughts into a clear, readable medium. It freezes and exposes one's thinking and creates a reflective stance that distanced one from one's immediate lived involvements with the world (Sartre, 1977). Here, as outlined by van Manen (1990), I continued to reflect on the data—thinking, putting to language, writing, clarifying, and rewriting about the descriptions of the experiences—until the "thing," the essence, showed itself. Writing, said van Manen, "is not just externalizing internal knowledge, rather it is the very act of reflective inquiry and of discovery" (1999, p. viii).

Maintaining a Strongly Oriented Pedagogical Relation to the Phenomena

During this step, I remained strongly oriented to the research question: What is the experience of living with HIV disease for older adult African American women? Van Manen (1990) cautioned that, although there may be many temptations to settle for preconceived assumptions and to arrive at premature opinions, the phenomenologist researcher can never settle for false or superficial results. I learned about the phenomenon from the participants, and I unlearned previous preconceptions, biases, and stereotypes. In addition, I maintained a journal to document self-reflection, personal experiences, and the situated context and contingencies of the interviews. I took care to focus my attention on how the phenomenon was unfolding and the context within which it occurred.

Balancing the Research Context by Considering Parts and Whole

Periodically, throughout the study, I stepped back and reviewed how each part contributed to the whole study. In this way, I constantly paid attention to the design of the study and the research plan. I paid attention to emerging themes, initially using them as general guides. I reread the narrative as a whole, relistened to the audio-tapes, and returned to the participants for clarification as needed. I avoided interpreting the whole by its parts.

In the application of van Manen's (1990) research activities to this study, I questioned the life world of the participants' prereflective and uninterpreted experiences, as the participants and I mutually sought to discover the most essential being or essence of their experience of living with HIV. Through the concept of intentionality, the participants and I sought to understand and classify their conscious acts and experiences of the phenomenon. Through phenomenological intuiting, I came to know the phenomena as the participants described their perception of how the phenomenon showed itself to them. Attentive observation was used to describe the data as they emerged (van Manen 1990).

Research Procedure

The research procedure is the heart of the design, and the quality of the research design is often judged by the power of the proposed procedure (Lincoln & Guba, 1985). This process includes the procedure for protection of human participants, identification of the sample and sampling method, the data collection and data analysis, possible risk and limitation, and methods for assuring credibility of the findings.

Approach to the Protection of Human Participants

Institutional Review Board (IRB) approval was obtained from The Graduate Center, City University of New York and a local community health clinic that specializes in the provision of health care for persons with HIV disease. Once approval was obtained, I circulated a flyer at the site to the providers that described the study and its purpose and inclusion criteria, along with my name, contact information, and schedule of my on-site availability. Providers shared the information with patients, and interested persons spoke with me and shared their contact information. Meeting places were negotiated with each participant; 60% requested to meet at their home, whereas the remainder requested to meet at the clinic. I requested and obtained a private location within the facility to conduct the on-site interviews. Written informed consent was obtained from persons who met the inclusion criteria and expressed a desire to participate (see Appendixes A and B). The Nuremberg Code states that voluntary consent is an absolute essential for human research participants. In addition, it is the responsibility of the researcher to ensure the quality of the consent. This means that the participants are able to exercise free choice. The informed consent provided the participants with sufficient information about the research that enabled each to make an informed decision as to her willingness to participate in the study. The consent included a description of the study, its purpose, the participants' rights, identified risk and benefits of the study, the plans for maintaining confidentiality of the participants and the data, and the proposed dissemination of the findings.

Participants were reminded throughout the study that their participation was voluntary and that they could withdraw from the study, without any penalty, at any time, should they so wish. They were informed that the initial interview would last approximately 60–90 min and that it would be audio-recorded. They were also advised that additional meetings of approximately 30–40 min may be scheduled to seek clarity and/or concurrence of the data. In addition, participants were told that that the audio recordings of the interviews would be translated verbatim, and confidentiality was guaranteed. Participants were invited if they desired, to write in their own words any additional thoughts on the experience that they wished to share with me.

Participants were informed that, except for me, no one would know their identities, since they were linked to the data by nonspecific codes known only to me. Confidentiality was assured by assigning these codes and pseudonyms to each participant in the transcription document. Quotes that were cited from the transcripts were carefully screened to detect and erase any identifying information. Any names or means of identification mentioned during the interview were replaced by pseudonyms. All recording devices and transcripts were vetted to ensure removal of participants' identity. All electronic data storage devices containing the transcripts did not contain identifying information. Audio recordings were transcribed by a confidential transcription service, whose employees had participated in the Collaborative Institutional Training Initiative course on the Protection of Human Subject Research. In addition, each transcriptionist signed a subject information confidentiality agreement recognizing the role and obligations as a contractor in this project (Appendix C). Electronic data storage devices and transcripts were stored in a secured locked cabinet when not in use. This cabinet was only accessible by me. I used a private laptop with a protected password. For additional security, the data were backed up on a second thumb drive and locked in that secured cabinet. Audio recordings were heard by me, my advisor, and the transcriptionists. Participants were informed that when the study results were disseminated, their anonymity would be preserved, as all identifying information would be removed.

I conducted this research in a manner that was sensitive to and respectful of the participants and myself. A mutually agreed upon meeting time and place was scheduled, and privacy was guaranteed during the interviews. Recognizing that the recalling of certain experiences may evoke strong emotions for some of the participants, at the request of the site manager, I instructed participants to contact their individual case worker and/or provider should there be a need to access emotional health support. Although there were several instances of tearfulness during the interviews as participants recalled their experiences, no referrals were necessary. I was mindful that my role was that of a researcher and not a therapist, and I advised the participants clearly regarding my role. I was also aware that as the researcher, listening to some of these experiences might evoke emotional responses in me; therefore, I kept a journal of these incidents and my responses, and I consulted with members of my committee and appropriate resource persons throughout this process. As a small token of appreciation for the time spent during each interview, I provided each participant with a $15, $20, and $25 gift card for each respective interview. This card was redeemable in stores within the community.

Sample

A purposive sampling approach was used. This sampling strategy meant that participants and data collection sites were selected because they could purposely provide information about the phenomenon being studied. In phenomenological research, “It is essential that participants have experienced the phenomenon being studied” (Creswell, 2007, p. 128). Participants were recruited from a clinic that specialized in health care to persons with HIV disease. This clinic is located in a large, comprehensive outpatient facility, associated with a large public medical center in New York City. New York City is one of the epicenters for HIV disease in the United States. There was a good feasibility of obtaining appropriate participants due to the size and location of the selected site.

In qualitative research, the general guidelines regarding sample size are that the sample should not be so large that it is difficult and overwhelming to extract the richness of the data and that it should not be too small that saturation is unachievable (Onwueghbuzie & Leech, 2007). Saturation is achieved when, in the process of gathering and analyzing the data, the researcher encounters repetition and redundancy, and it becomes apparent that no new information is heard from the participants (Munhall, 2007). Creswell (2007) suggested that for phenomenological research, sample size can range from one to 10 participants. For this study, saturation was achieved by the eighth participant. However, two additional interviews were conducted, but no additional significant themes were elicited.

The inclusion criteria were self-identified Black/African American race, female, age 50 and older, with a diagnosis of HIV disease. The United States Census Bureau’s definition of Black or African American as a person who has origins in any of the Black racial groups of Africa was used (United States Census Bureau, 2010). The term *older adult* is defined differently within the context of HIV. Generally, this term refers to persons age 65 and older (Eshbaugh, 2008). However, within the context of HIV, older adult is used to denote persons within the upper age range of the epidemic. This originally stemmed from the earlier years of the epidemic when, based on the age distribution, the mean age of this group was so much older, compared with the mean age of the other groups (Gebo & Justice, 2009; Luther &Wilkin, 2007). Persons over age 50 were counted as a separate age group and labeled *older adults* (CDC, 1993). Currently, the CDC groupings are in 5-year increments through age 64, with age 65 and older being the final category. However, the previous designation of age 50 and older still remains a useful way of describing older persons living with this disease (Linsk, 2000). For the purpose of this study, older adult women were therefore defined as women age 50 and older.

The appropriate IRB approvals were obtained, and all ethical considerations as outlined in the appropriate areas were addressed. Ten women participated in the initial interviews. The interviews were audio-recorded and then transcribed verbatim. Once they were transcribed, a second interview was scheduled with the participants to make the transcripts available to the participants for any addition, modification, or deletions. Seven participated in the second interview. One participant was too ill to participate further. Another participant’s job and family responsibilities did not allow for additional face-to-face meetings; however, she initiated contact with the researcher. One participant was lost to further follow-up. During the data analysis phase, additional interviews were conducted with three of the participants, as this researcher sought to clarify and validate interpretations.

Access/Setting

A clinic that specializes in care to persons with HIV disease, located in a large, comprehensive outpatient facility that is part of an urban public medical center, was the data collection site selected. The aim and purpose of the study was discussed and approval to use the site for the data collection was requested. IRB and appropriate approval were obtained from CUNY Graduate Center and the data collection site. I initiated a relationship with the appropriate stake holder at the site in order to gain access to the providers and potential volunteers. Volunteers were recruited through flyers and/or referral by the health care providers. I met with volunteers to ensure that they met the inclusion criteria. I arranged the scheduling of interviews at the clinic or a mutually agreeable location. Privacy was guaranteed during the interview.

Data Collection

After informed consent was obtained, participants were asked to complete a short demographic form related to age, year of diagnosis, and current HIV status. The format of the interview was unstructured, lasted approximately 60–90 min, and was audio-recorded. The audio- recorded interviews were transcribed verbatim. A second interview of approximately 25–

40 min was scheduled to afford the participants the opportunity to review, validate, clarify, and/or make any correction to the transcribed data. The option of a third interview was offered to all participants. All participants verbalized a willingness to participate; however, only three participants' schedules permitted them to be available. This third hermeneutic interview was conducted to seek validation of essential themes and interpretation. In addition, participants were invited, if they desired, to write in their own words any additional thoughts on the experience that they may want to share with me. None of the participants took this offer. I kept a journal that documented my self-reflection, personal experiences, and the situated context and contingencies of the interviews.

Rigor

In phenomenological research, the researcher is the instrument of the perspective or methodology, and the participants are the repository of meaning through their narratives (Munhall, 2007). Rigor is achieved when the interpretation of the meaning of the experience is familiar, reasonable, and representative of the many dimensions of the experience. It should be an authentic and accurate interpretation of the participants' story. In addition, the reader ought to acquire some new and deeper insights into the experience and should recognize the revelation of essential essence of the experience that was previously hidden or not thought of before. The written text must be readable and interesting, and it ought to be clear that the researcher has addressed all ethical considerations (Munhall, 2007). This researcher has adhered to the phenomenological research perspective and will allow the reader to self-determine whether the interpretation of the meaning is reasonable based on the participants stories and the written text.

The criteria of reliability, internal and external validity, and objectivity used in the natural science approaches are not applicable to the human sciences; instead, the criteria for this paradigm is trustworthiness. Trustworthiness is composed of credibility, transferability, dependability, and confirmability (Lincoln & Guba, 1985). The strategies used in this study to achieve credibility were prolonged engagement, peer debriefing, and member checking. Prolonged engagement with the data collection site and the participants allowed for the development of trust between the providers and participants and the researcher. Debriefing with members of my committee and my fellow doctoral students allowed others to probe for my biases, helped me explore methodological and other relevant meanings, and provided opportunities for discussing the data and clearing any emotional barriers. Member checking allowed me to return to participants to clarify and verify analytic categories, themes, and interpretation.

Transferability, from a qualitative perspective, pertains not to generalization but to the idea of providing “thick descriptions” of the phenomena that will enable others “interested in making a transfer to reach a conclusion about whether a transfer can be contemplated as a possibility” (Lincoln & Guba, 1985, p. 316). Transferability for this study was obtained by the thick descriptions of the excerpts of the women’s stories and the researcher’s field notes.

Dependability and confirmability, the third and final components of trustworthiness, are closely related. These two areas were addressed by reconciliation of the raw interview data, data interpretations, field notes, and the researcher’s reflective journal notes. Confirmability was further achieved using an audit trail of the data.

In order to capture each interview as a whole, I read the text of each interview. I used a selective or highlighting analysis approach of the data to identify and document word groups, themes, and subthemes. This again was reviewed with selected participants to determine whether the analysis reflected their interpretation of their experiences. Transcripts of the data and the analysis were read by my advisor, a nurse researcher with many years of expertise in phenomenological research. It was expected that researchers, participants, and others would recognize the essential themes as relevant, understandable, and insightful and to have applicability to the phenomenon under study. Throughout this process, I utilized my journal and maintained ongoing dialogue with my faculty committee and my doctoral student peers to address any possibility of researcher bias or subjectivity on my part, thus enhancing the credibility of study.

Research Question

The research question was what is the experience of living with HIV disease for older Black/African American women? After a brief introduction, the study purpose and inclusion criteria were reviewed. The participants were asked an initial icebreaker open-ended question: "Tell me about yourself." For most of the participants, this was the only introduction that they needed to begin describing their life with HIV. For a few, an additional follow-up question was needed: "Would you please tell me what it is like for you to be living with HIV disease?" This question expressed my concern about the lived experiences of these women. This approach was chosen in order to get a deeper understanding of the meaning of being HIV infected at this stage of their lives. I hoped to capture "their lived experience in all its ambiguity, urgency and immediacy" (Finlay, 2009, p. 475). Participants were reassured that the stories I was looking for were their own and that I was interested in the personal experiences.

Risk Associated With the Study

There was no anticipated individual physical health or injury risk associated with this study. There was minimum anticipated risk to psychological health, in that I was aware that some participants might find the description of the meaning of the experiences of living with

HIV disease to be uncomfortable or stressful. After consulting with the principal stakeholder at the site, it was agreed that participants should be referred back to their case managers or providers in the event the participants experienced emotional stress and desired some intervention. Most of the participants at some point in their stories became teary eyed; however, all declined the referral back to their case managers or providers. They all verbalized some relief or catharsis after telling their stories to a willing listener.

Limitations

One limitation of this study is the possibility of subject bias. Because of the sensitivity of the phenomenon being studied, women volunteering for the study might not be representative of the facility's cohort of patients. Some women meeting the criteria might not have volunteered because of sensitivity and discomfort with the topic. Those volunteering may be the most outspoken and may have already identified ways of coping.

Summary of the Chapter

Chapter IV describes van Manen's six methodical activities and discusses its application to the study. Procedures for gaining access to the data collection site, the recruitment of the participants, sample selection, and sample size are addressed. In addition, the research procedure, inclusive of the data collection, data analysis, and study rigor, are identified. The approach for the protection of human subjects, including obtaining appropriate IRB and informed consent, are presented. Methods for assuring participant confidentiality, anonymity, and the protection and storage of data are included. The research question is further articulated. While there were no anticipated risks to this study, a procedure for addressing the possibility of adverse emotional responses is offered. The chapter concludes by articulating the limitations of this study. Chapter V addresses the analysis and findings of the study.

Chapter V

FINDINGS

The purpose of this phenomenological study is to understand what the experience of living with HIV disease was for 10 older Black/ African American women. This chapter presents the findings that evolved from the in-depth interviews with the 10 participants. The data collection process and data analysis are described in detail utilizing van Manen's methodological process. A sample appraisal and a description of the characteristics of the participants are provided. This is followed by descriptive summaries of the participants' experiences using as much of their own language as possible. The in-depth description of the data analysis process explicates the emergence of the essential themes and the textual interpretative statement.

Human experiences are the data of phenomenological research "the lifeworld, the world of lived experience, is both the source and the object of phenomenology" (van Manen, 1990, p. 53). Throughout the initial interviews (*N* = 10), I searched the "life world" of my study participants for their lived experience that upon reflective examination, would yield the essential characteristic of the phenomenon. As I approached each interview, I was mindful of van Manen's advice to elicit the description of the participants' experiences free of causal explanation or interpretation. However, before long I realized that the women's descriptions of their experiences were interspersed with their own rich explanation and interpretation. The challenge for me was to tease out the perceived experiences from the other areas of discourse. The participants' stories supplied the original text of the lived experiences.

Sample Appraisal

Ten self-identified Black/African American women, age 50 and older, who were diagnosed with human immunodeficiency virus **(**HIV) disease, and were affiliated with an identified HIV specialty clinic, located in the Bronx New York were interviewed for this study. The participants’ ages ranged from 50 to 76 years, with a mean age of 58.9 years. Years since diagnosis with HIV disease ranged from 10 to 27 years, with a mean range of 18.8–19 years. Their education levels ranged from ninth grade to 2 years of college. Two were currently employed, one full time and the other part time. The income streams for the remainder were disability insurance and/or social security. Their living arrangements were as follows: three lived with children and/or grandchildren, two lived with partners or spouse and children, two lived with spouse or partner, one lived with a mother, and two lived alone or with pets (Table 1).

Table 1

Participant Demographics

Participant	Age	Years since diagnosis	Personal relationship status	Highest grade completed	Employed	Employed full/part time	Living arrangement
1	54	12	Not in a relationship	11th	No	N/A	Lives with adult children
2	64	20	Widowed	11th	No	N/A	Lives with children & grandchildren
3	58	27	Widowed	12th	No	N/A	Lives with pets (cats)
4	56	22	In long term relationship	12th	No	N/A	Lives alone
5	58	17	Divorced	2 years college	Yes	Part time	Lives with extended family
6	51	17	Married	12th	Yes	Full time	Lives with spouse and children
7	51	23	In long term relationship	9th	No	N/A	Lives with spouse and children
8	76	22	Married	9th	No	N/A	Lives with spouse
9	64	17-19	In long term relationship	12th	No	N/A	Lives with partner
10	57	10	Widowed	9th	No	NA	Lives with children

Anonymity and confidentiality were of utmost importance. The women were informed of the steps that were taken to protect their anonymity when this study was disseminated. The anonymity of the participants was protected by the use of pseudonyms. Two of the women chose their own pseudonyms, and the remainder left it up to me. In addition, an individual numerical code was assigned to each participant. Any specific details that might inadvertently lead to the identification of a participant, such as a local streets or the name of neighborhood facilities, were modified. The women’s confidentiality was further protected through the use of an encrypted website for uploading the audio tapes for transcription.

Data Gathering

Ten women participated in the first set of interviews. The interviews were scheduled according to the availability of the participants at a location of their choice. Six participants chose to be interviewed at their homes, and four opted to have their interviews at the clinic. The interviews at the clinic were conducted in a private office to ensure confidentiality and privacy for the participants. While all participants agreed to a second interview to review and edit their individual transcripts, seven participated in the second interview. One participant declined due to personal and family health issues, another’s work schedule did not permit, and the third was lost to follow-up. Of the seven women who participated in the second interview, three agreed and were available for a third or hermeneutic interview. All interviews were unstructured and audio-recorded. Only one interview was conducted each day, except on one occasion, when a conflict in one participant’s personal schedule resulted in me having to conduct two interviews that day. Each of the initial interviews lasted approximately 1 hr and the follow-up sessions lasted 30 to 45 min. The stories are presented in chronological order beginning with the first participant interviewed and ending with the last participant interviewed.

Participants’ Stories

Before I began each interview, I reoriented myself to the research question. I did not use an interview guide, but instead used open-ended questions. I started each interview with an icebreaker question. I asked each woman to tell me about herself. For most of the participants, that was the only opening that was needed. For the others, I followed up by asking them to share the experiences of what it is like to be living with HIV disease. During the course of the interviews, I asked additional probing or clarifying questions as needed, to understand the meaning of the experiences described.

Participant 1: Thelma

Thelma is a 54-year-old mother of three adult daughters. She has a history of incarceration and drug use. She identified heterosexual transmission as her transmission risk. Thelma was interviewed at her home, an apartment she shared with one of her daughters. After ringing the front door bell, I was buzzed into the building and walked toward the apartment located on the ground floor of a multistory apartment dwelling. Upon entering the apartment, I noted that the room went from dark to dull when the lights were turned on. Thelma cleared the table and offered me a seat. I noticed that the tone of her voice was flat and monotonous. After we exchanged introductions, I reviewed the purpose of the study and obtained the consent and other paperwork. I then began the interview by asking Thelma to share with me what her experiences as a person living with HIV disease is and has been.

Thelma began by immediately describing the circumstances surrounding her diagnosis and how difficult it was for her to accept the fact that she had HIV disease.

> I was in the hospital. He [the provider] came and took blood, and about 15 min later I was positive. It was like somebody hit me with a hammer. It took me a while to accept the fact that I was HIV positive… I thought I wasn't going to live.

She described her mental state and voiced a sense of hopelessness for the future as the overarching thought of her perceived impending demise made any current or future plans seem useless.

> I would hear voices (in my head) saying, "What's the sense in buying clothes you only have a certain amount of time to live. … I was going for my GED and (the voices said)

> … “You are not going to pass. What’s the sense in you going to study for it?” When it was time for me to get my apartment, I would go looking for apartment …I said I don’t want no apartment. I don’t want no apartment. It was like I said earlier, this voice was like… “You are not going to do it.” It’s always every time I wanted to do something it would come into play. But I don’t know what happened. I fell back in that rut again. It always happen to me. Every time I get somewhere in my life … but I don’t know what happened. I just stopped.

Thelma described her struggle with depression “I used to cry. … I cry all the time. I see a therapist. I see a psychiatrist because I go through depression.” This state, she relates, has caused her to reluctantly accept the role reversal that has occurred in her relationship with her children as they attempt to protect her.

> My daughters, they know about my status. They stay on my case. When I stopped taking my meds one time they had a fit. They’re really supportive. They are so supportive. … If I tell them right now I’m sick, they will be at the hospital, one-two-three.

She described a complex web of friends and relationship:

> I got a few sets of friends, you know, I’ve got survivor friends that got the virus, another set that don’t know I am affected. Some of them is addicts, ex addicts, so that is how we relate. Some of them are still using, I don’t bother with them. Some are in treatment, I reach out to them.

Thelma described her relationship with her primary provider as caring. “My (provider) she’s sweet. She takes her time with me. I’ve been with her for over 10 years.” However, Thelma described a very troubling experience she had with a case worker,

> It wasn’t no helpful feedback; you know if I’m coming to you for help, I don’t expect you

> to down me because I got the virus. I'm surprised I'm not crying now because … but I used to cry each time I would talk about it.

Thelma spoke of coming to accept her HIV positive status, and how in so doing she now wants to help others by sharing her story. I noted that one of the few times Thelma emerged from her monotone was when she longingly described an experience she had while participating in an HIV educational session for inmates at a men's prison.

> I felt like I was on top of the world. I was going through the prison, knowing I was coming out of the prison and not being shackled (laughs). It's a different world when you're going in there with nothing on you, and you've got the captain escorting you to the men's wing. Yeah that's what made me, Yeah that felt good. I was the only woman. And I got so much applause when I finished and everything…. And I had cards and everything and I was giving them out because they wanted to know more about it [HIV]. Now that I have learnt to accept it, I would love to go back out and do presentations, but I would have to learn more. I have to study more. I love to talk about the virus and I want to teach people about it. Even my daughter, she asks me questions sometimes.

Thelma stated she is often forgetful, and so she devised strategies not only to help her remember but also to help her keep the secret of being HIV positive. "I've got to rememorize, I write on a piece of paper, then I write on another piece of paper—because I can't put everything only certain things—like my HIV, I don't put that on paper."

In addition to dealing with HIV disease and depression, Thelma is also living with diabetes and asthma. She described her struggle with medication interaction and adherence.

> I have to take 17 pills every day. Sometimes the house looks different. I do strange things like I want to go out at two or three in the morning. My daughter was like "Ma! It's 2 in

> the morning; you’re not going to find no store.” I’m like “what are you talking about? I am going to the store.” Well mind you I had my gown on and I had my slippers on. I was getting my coat to go to the store. I know it’s not the HIV meds, so (my provider) said it could be the Ambient and Lyrica. So they are trying to get me off that, but they can’t take me off it right now because I might go into seizures. … And I was on Atripla but I got resistant to that and they put me on Copelle that was working fine. When [the provider] came and tell me that, I’m resistant to Atripla, and I was like “Oh wow.” And I know why, because I haven’t been taking my medication like I’m supposed to. But I didn’t tell her, though. So now I know, [whispers to self] “Thelma, l—you have to take your medication.

Thelma said that her main concerns are dealing with the depression and struggling to live a drug-free life while living in an environment where illegal drug use was so prevalent. However, despite her struggles, she stated, she was most fulfilled when she was sharing her experiences and educating others about HIV disease.

Participant 2: Pearl

Pearl, a tall, well-groomed, healthy-looking 64-year-old woman, was interviewed at her home on a brisk February morning. As I entered the apartment, I thought she looked so healthy; her skin was as smooth as if it was polished. She told me she had been looking out her window in an effort to secure a parking space for me when I drove up. It reminded me of my days as a visiting nurse when my patients would sit at the window awaiting my visit. I could not help thinking that she was “looking out for me.” The immaculately kept apartment was spacious and inviting, and the sunlight streamed in through the window and through an overhead skylight. Initially Pearl had a nervous smile when she invited me into the apartment that she shared with her daughter and grandchildren. She had been briefed by the provider about the study and she wasted no time getting started. As she spoke I caught a hint of an accent. As the interview proceeded I noticed that Pearl became more relaxed. Her face glowed as she talked about her children and grandchildren. In response to me asking how she was, Pearl told me that compared to how she was when she first got sick, she was fine now. She spoke about having participated in several research studies, including one at the National Institutes for Health (NIH). She praised her doctors and health care providers for bringing her from the brink of death to where she is today. She said, "I met nice doctors and nurses. They call me their miracle baby."

Pearl related that more than 20 years ago while living in one of the United States territories, her husband died. She continued that upon retrieving his death certificate to make final arrangements, she found out that her husband died from a complication of acquired immunodeficiency syndrome (AIDS). Unable to believe her eyes, she chose not to acknowledge what the ramifications might be for her, and so she went about her life as though "nothing had happened." She avoided the health care system until she got so ill that she had to be taken from her home by ambulance:

> I said, no, this can't be happening to me. You know, this is not, that's not what I think my life is all about. …I was still in denial. I didn't …I didn't want to believe that. Oh he have it, but that does not mean I have it. You know, I was really in denial for a long time. Yeah, see at the time I was still in denial. Like I say, I got sick and didn't want nobody to know about it until it was too much, and my neighbor look at me and said, "Don't like how you are looking." So one night I couldn't get up and she called the ambulance and they came and they, I realized I did really have it also.

As Pearl related this part of her story she had a nervous sad smile. I saw this again when she described an experience she had while participating in a NIH research study in Baltimore.

> One nurse told me one time, I think she was in a bad mood. … She told me, “Why don’t you just lay down and die?” Yeah, she told me that [chuckles]. … You know, I noticed her walking around all the time, so I asked her “Why are you walking around all the time?” She say, cause it is what she have to do. I said, “All right.” So we get into a conversation, and I think she took up my record, ‘cause my record was close to my bed. And she said, “You know it would be best if you lay down and just die.” So when she left my doctor came in, and I told him what she said. So he said…. “We don’t do that. We try to build [the patient’s] spirit up not let them down.” And it was very painful that she said that to me, you know. And I think I took it hard for a while until my doctor sat down and let me know that that you could live with this stuff as long as God gives you strength and allows you.

This experience, Pearl said, left her fearful.

> That was a scary time, cause at that time I believed that I was just going to die because I got so small you know… [Whenever] I closed my eyes, and I open up my eyes fast and -... I said, ‘I wonder if this is my time?’ Every time I close my eyes, I would open it fast.

Pearl related that in addition to being scared, she worried about her children and the associative stigma that they might face.

> It was scary because I wasn’t worrying about myself at that time. I was worrying about my kids. My youngest was about 22 but I still worried about them. I made sure they were tested. I guess I got sick after they were born…I still got worrying about them….What’s gonna happen to them? And I was wondering [whether] other people might scorn them because of their mother.

Pearl described that people's responses to her, as a person living with HIV disease, have evolved over the years since her diagnosis.

> Now it is fine, but in the older days it was crazy. They figured that if they came close to you they gonna get it. They won't come too close… if they see me gonna take something to drink they won't come near. You know simple things like that. There's a few people who I have to sit down and really let them know "my touching you won't do you anything." Now it is much, much better. So you see in the past 10 years things has really changed.

Pearl, like most persons living with HIV and AIDS (PLWHAs), is also living with several comorbid conditions; however, she has prioritized the impact of these conditions on her life.

> I have diabetes. I have blood pressure and I have HIV… When she [doctor] told me I have diabetes, it was 2 years ago she told me I had it …I would take HIV more than I would take the diabetes because of how … the body react to diabetes.

Her face brightened as she talked about gratitude. Pearl spoke about staying positive, living every day, knowing she is OK and thanking God for each day.

> Just living every day, wake up every day and know that I'm OK that day. …Don't know what will happen in the end of the day but I know I could get up and open my eyes and thank God just for one more day. I know a lot of people who get sick, who have HIV and die, you know. So I am a lucky person to be still here. … Cause I have a lot of friends that gone leave me. They had HIV and they are dead, and I'm still here, so I'm happ—lucky, you know. .. I say to myself every day. I say "I'm a lucky person," cause God, I'm still here. I'm here.

She actually glowed and became animated as she spoke about her interactions with her family.

> My family is everything to me. I go to my doctor’s appointments and deal with my grandkids and laugh with my daughters. Whenever my daughter is going out she says, “You want to go Mom?” and we go. You know, so it’s cool, it’s alright. The family part, that’s what I am grateful for, that I have my family and friends. They come and lay down next to me. I know they are there for me.

Pearl verbalized her desire to help others who are dealing with HIV issues. Helping others she said is a way of giving back and it gives her joy to do so. Pearl related that often she is called upon by the clinic providers to speak to other patients about HIV because “that’s all I know. If I am at the clinic and somebody need to talk, they will say … you want to talk to this person? And they talk, and I talk to them.” In regard to a personal relationship, Pearl responds with a hearty laugh,

> I’m done with that. Had a friend, I just don’t see myself getting involved, you know, ‘cause I—now I’m scared maybe I might give it. So before I have to be worrying about doing that to somebody else, I’m fine! I’m just taking care of myself. I don’t want to bother. Don’t want to be bothered. We talk on the phone we laugh and talk but that’s as far as it goes.

Although Pearl stated she has accepted her life as it is, she added that she would not be human if at times she did not think about what might have been. She shared her hopes and dreams and mused about what other paths her life might have taken had it not been for HIV.

> Every time I think about something… about my life, about what it would be if I didn’t get HIV. .. There is a lot of things I wanted to do if, like, like I wanted to go back to school

> and have a good life. I wanted to make sure the kids are all right financially, you know? … There are a lot of ifs in just taking care of my family that I didn't get to do, haven't done, yeah. One time I wished I could have been a nurse, I really thought I could have been a nurse, and it was one of my beautiful dreams that I had, that to be a nurse and … yeah it was a beautiful dream.

After meeting Pearl, I thought that here was a woman who had made lemonade from the lemons that she was served. At no time during our meetings did she blame anyone or anything. I was struck by the "joy" she radiated as she expressed her gratitude for life and her family. I could not help thinking that being in her presence and sharing a piece of that radiance is a gift for anyone she comes in contact with.

Participant 3: Maria

Maria is 58-year-old woman who lives with her two cats in a one-bedroom apartment located in a large apartment complex. As I entered the apartment, I noted that her living room window overlooked the street. This window, Maria stated, allowed her to communicate with the world outside. The shades were opened when she needed to "holler" out to whoever was coming down the block, or verbally discipline a neighborhood child who might have indulged in or committed a block infraction. The shades were drawn when she chose not to be bothered by whatever was happening in the street at that time. Although she has no children of her own, Maria stated she felt an ongoing responsibility to use the experiences she gained as a sex worker and injection drug user to teach young people in her neighborhood how to protect themselves and not make the same mistakes that she did. I noticed that both her lower legs were bandaged. Maria explained that she has had a long history of leg ulcers as a result of using her leg veins as sites for illegal drug injection.

Diagnosed since 1995, Maria disclosed that although she continued to “work the streets” after her diagnosis, she always offered to have her patrons use condoms. She added that from time to time she would seize the opportunity to educate her patrons about condom use. She described one encounter she had.

> I asked him, “When you go out with these females out there in the street you don’t know what they got. They got gonorrhea, syphilis, and all that stuff and a bunch of STDs and all that. Don’t you think of what you are taking home to your wife, faithful, taking care of your house and the kids, and you out here… with everything you can find?” And he says “I never thought about that.”

Maria described how difficult it was to disclose her HIV status to her mother.

> I went to a friend first. …She [friend] told me, “Have you gone and told your mother yet?” I said, “Yeah, Yeah, I’m gonna tell her.” Finally I went… I sat there and looked at my mother for a minute and like. “Oh Lord, Jesus Christ, this is the hardest thing I got to do. Oh yeah, Mommy, I got the results… mommy, it came back positive.” It was hard. It was hard to see her sit there and cry.

Maria stated that she believed the burden of her HIV status was too difficult for her mother. It was a burden for her to carry. “You know, if my sister would have been alive, maybe it would have been less of a burden because she would have shared it with her… She asked me whether she could tell my brother.” The decision to tell her brother proved disastrous, for while he maintained a relationship with Maria while she was indulging in “other things,” the relationship changed when he found out she was HIV positive. She stated:

> My mother‘s been gone 19 years and my brother still don’t talk to me. … Things started getting different after my mother told him… And still to this day, like I write him

> Christmas cards and I put my phone number on it.

Maria recalled losing friends to HIV; “but then we seen people start dropping. Like we were a crowd of eight, I’m the only one that’s left.” Maria stated that she takes full responsibility for her life. She is grateful for still being alive. Her only regret was the damage she did to her legs, and she said: “If I knew then what I know now I would never inject myself in my leg. ... It was the fastest place for me to hit myself… due to the fact that that’s the best place that people would not look.” However, she laughingly added that although she planned to leave her legs to science when she dies, she needed them now, while she was alive, and therefore she wanted the ulcers to heal. Regarding stigma, Maria recalled a visit to her aunt’s home:

> She went and took the plates … and cleaned it with bleach. My uncle comes in. He says, ‘What is that bleach smell?” She goes “Oh ‘cause I sprayed roach spray”. ... and I told my uncle exactly what was going on… that she was washing the plates with bleach and that every time we come here she’ll give me Styrofoam plates and Styrofoam cups. Everybody else got glass and I got Styrofoam.

Maria stated that she fared well in prison because the problem she had with her legs was a distracter from her HIV status. However, other women with HIV disease did not fare so well. According to Maria, there was no confidentiality in prison. Everyday a list of the names of the women who had to attend the clinic was posted, and it was easy to determine who the inmates that had HIV disease were. Maria described her feelings of depression and paradoxically portrayed her current feelings of confinement as follows:

> My apartment is my jail cell, especially my room. I sit in that room and I cry. I get so depressed, so stressed out being in these four walls. I go to my appointments just to get some air and then I am rushing home for what? But I rush home and once I’m home like,

I’m home.

Maria tearfully explained her acceptance of her HIV status. “When I first found out … At first I didn’t think about it because I said that’s not me (sniffles) but it is me, that’s a part of me.” Maria told her story with a sense of brutal honesty. Scattered throughout her recollections of her relationship with her family were issues of multigenerational incest, domestic violence, and losses. However, when she described her relationship with her childhood boyfriend, who years later reentered her life, only to die a few years ago, there were many instances of love, intimacy, and hope.

Participant 4: Ginny

Ginny is a 56-year-old women who resided in a fourth floor walkup apartment. I was breathless by the time I arrived at her front door and could not imagine how she regularly climbed those stairs. Ginny met me at the door, and after we exchanged greetings, she asked that I take my shoes off. That was not a new experience for me, since as a visiting nurse I had encountered patients who had made the same request. However, the request was usually related to culture, and often the patients would provide slippers for their guests to put on before proceeding into the homes. Ginny told me this was her way of protecting her health by decreasing the amount of germs that came into her home.

Once we sat down, I reviewed the study purpose and sought Ginny’s permission to continue. Although I had not seen anyone else in the apartment, I had seen men’s shoes at the door and questioned whether we were alone. Ginny informed me that her long-term partner was asleep in the bedroom farthest from us. She assured me that even if he woke up, he was aware of her history and she had nothing to hide from him. However, I suggested that she close the doors before we proceeded and she did. Once we completed the paperwork, in response to my asking her to tell me about herself, Ginny began her story.

Originally from the Southern United States, Ginny's mother died when Ginny was in the eighth grade, and she was raised by an older cousin and an aunt. Despite a "lot of dysfunction in the household," she graduated from high school, moved to New York, and began to live on her own at the age of 17. On her own, without guidance since the 1970s, Ginny stated that she began drinking, first wine and then "out of boredom I got involved with drugs and … the unprotected sex." She denied ever using injection drugs, saying she is afraid of needles. Ginny has one child, age 21.

> I was pregnant and went to get myself tested. … And that's when I found out. In a way I knew, because 15 years before I had a dream, that I had AIDS. And it turned out to be true. … I was going to abort my son. That's when they used to give you money, like $25 or something if you were HIV positive … and I didn't go. I got high the night before [delivery] and I didn't know that my water broke…and 'cause I didn't go for prenatal care none of that. … So I went to bed when I woke up ...and a girl came, she was a prostitute, she came by and told me to sit down. She got somebody to call an ambulance and they came and got me. When I had my child, I let them know I was on drugs.

Regarding parenthood and her relationship with her child, Ginny said

> She [her cousin] asked me to sign over my rights. I never wanted to have a child. I was pregnant before and I've had abortions. It's really sad because I did not raise him. But even though I was on drugs I used to go around and help him out. She [cousin] used to make me clean up her house. And I felt so freaking guilty. And this went on for years. I miss him. And my son doesn't call. I get sad. But life goes on because I made a human error.

Ginny related how what she termed her life-changing experience occurred: “When I got arrested for being a user that saved my life. And I never looked back. When they put those clamps on me, I knew this was the beginning of the end, and I knew I would never look back. That’s when I surrendered and asked God to help me.” She described her experiences living with HIV at a halfway house:

> I did 14 months at Odin House. And it was pure hell. While at Odin House they would list everybody who was HIV on a paper. ‘Cause we were supposed to have 2 hours off the floor, where we could go to bed and take a nap … and I was very sick, but I would not tell them. Because are you kidding? These strangers, 4,000–5,000 different strangers, in my personal life, no way! I never revealed my status to anybody, any of the inmates, none of that. I just kept it to myself. And that’s why I was so sick. I caught PCP I almost died.

Ginny related an incident of perceived stigma:

> I remember his [her boyfriend’s] mother came to see me in the hospital. I know that she didn’t want to be there. She came because he [Ginny’s boyfriend] wanted her there. She was a retired beautician. I asked her to put my hair in one braid. She said “maybe later.” I said, “There is not going to be any later, you’re not coming back.”

Ginny has only used antiretroviral for 11 of the 22 years since she has been diagnosed. She spoke about her comorbid conditions and health care needs.

> I had a hysterectomy because they found I had precancerous cells on my uterus. I had pneumonia about four or five times, many episodes of PCP. When I got pneumonia I coughed blood. They put me in isolation because they think it was TB. I was in the ICU for five days. They told me I was the first one in the history [of the hospital] to come into

that hospital and walk out.

Listening to Ginny relate her story, this researcher was struck by the image of that 14 year old who lost her mother. At an age when a girl needs a mother figure, she had to fend for herself. I wondered if that little girl ever grew up. Ginny articulated the grief she had not only for the mothering she did not get but for the mothering she had not been able to give to her son.

Participant 5: Ella Mae

Ella Mae is a 58-year-old divorced woman. I interviewed her at the home she shared with her mother, located in a large apartment complex in another of the city's outer boroughs. Ella Mae stated that she chose to receive health care in another borough despite the inconvenience of time and distance. She has one child, who was raised by her ex-husband, when Ella's drug use interfered with her ability to care for the child. Ella Mae said "I should have known better, I had schooling, I worked for the city, I used to sing professionally, and things of that sort, but … drugs have no boundaries." Ella Mae did not need any probing to tell her story. "I like to share; I like to tell my story… It's about time someone asked us mature women how we are doing" she said. She began by expressing gratitude for the support her family had given her. "Everyone has been very supportive, because when I disappeared and I was using the substances, I left them, they didn't leave me. And I contracted the disease when I was using." Ella, like some of the other participants, spoke about having an inner sense of knowing that she was infected before she was diagnosed. She said, "I kind of knew exactly when it happened, too, because of the people I was hanging out with."

As Ella Mae described her experiences of her days "being out there with HIV and using," I could almost feel her transformation. The woman sitting across from me seemed worlds away from the person Ella Mae was describing.

> I was very dark, sick, and drained… I looked horrible; I looked like I was incinerated. … I have a picture that I carry and show it to all new residents. Before I “came in,” I used, I drank, I smoked cigarettes. I tried everything except heroin, only because I had a family member who was a heroin addict, and I saw what it did to him.

Ella Mae identified the people within her family with whom she shared her HIV diagnosis.

> I have a sister who has been near me since the beginning, my older sister, and there are still some family members that I haven’t disclosed to, but I know that they know. I told my son and my ex-husband that I have the virus.

Ella Mae spoke about her acceptance of her current place in life and of second chances. “I figure that this is my path now, this is where God has geared me for my second chance.” She described how she bargained with God, “I used to pray God a lot about if He’d only give me 5 minutes of clean time before I die, I would be grateful, and it’s been since 1999 that I have been clean.” Ella Mae’s face lit up as she spoke about her spirituality.

> I found God again. I was open to receive God again, which gave me a lot of strength. I believe in God. I believe in a higher power, and I know that it’s not me that’s bringing me to where I am today and taking me to wherever else I need to be.

Ella Mae described her life with HIV: “Every morning I wake up, I’m grateful. I try to make the best out of every day. I have medicals [appointments] to take care of because of medicines that I take that have side effects.” Like many persons her age, Ella Mae has many comorbid conditions, among which are chronic obstructive pulmonary disease, pulmonary hypertension, diabetes, sleep apnea and osteoporosis. She recently suffered a vertebral fracture, and as a result, she now ambulates with difficulty at times. Displaying a coy smile, Ella Mae acknowledged that on occasions she conveniently forgets her cane when going outside, knowing that she would suffer the painful back and leg consequences later.

Although Ella Mae acknowledged that she has concerns and does worry at times, she denied having depression. However, she acknowledged devising strategies, such as a song or thoughts of others who are less fortunate than her, to ward off any feelings of depression. Depression, she said, was the least of her worries.

Ella Mae's entire being lit up as she spoke with pride about her son. "All I need to do is think about him and I smile." Her son, she boasted, is brilliant and has been educated abroad in first-class boarding schools and colleges. He is currently pursuing his graduate studies at an elite university. His pictures, in various graduation gowns and in foreign locale, adorn her living room. Ella Mae admitted, however, that she often worried about whether her previous lifestyle and her current condition might harm her son's achievements.

Ella Mae denied having a current sexual partner. She said, "…it's very difficult for me… I haven't had sex in years, years, and it doesn't bother me. It's OK. It's OK. I've had sex before… I know what it is like." However, she has a close relationship with her ex-husband, her son, her mother, and her extended family members. On the day that we met for the interview, Ella Mae indicated that she and her sisters were meeting later that evening for dinner and to attend a show. Her mother died a week before our second interview. When I suggested that we reschedule the appointment, Ella Mae requested that we meet.

Ella Mae's story struck me as transformation in action. It was the transformation of a beautiful "well bred" woman, an artist, into what she termed, "the incinerated abysses of drugs and degradation," and her eventual "coming in" and transcendence. What lingered with me was her metaphoric use of time. Time, she stated, stopped when she succumbed to drugs, and the clock did not restart until she “came back in.” She has accepted having HIV disease as a consequence for dropping out. However, she does not see herself as victim. In fact, she emphatically stated she saw herself as being in a better place now.

Participant 6: Laura

I interviewed Laura at the clinic. She is a 51-year-old married woman with three children and three grandchildren. She works full time in a position that she proudly stated, she has held for over 25 years. Enthusiastically, she announced, “I am still able to get up every day and go to work.” Laura needed no probing and immediately began describing her experiences as a woman living with HIV disease. She was diagnosed with HIV in 1995 while pregnant with her last child. She shared that when she was first diagnosed she had 10 T cells. Now, 17 years later, thanks to the work done by her and her health providers, her viral load is undetected. Laura said, “I have never missed my appointments. I stay vigilant to my med-medication. …I am doing very well.” Laura asserted that she has never been sick or hospitalized for any HIV condition, and her only manifestation has been occasional tiredness. She refers to the day she got her diagnosis as “It was like yesterday… [Date] was like I was born all over again.” She recalled how she received her diagnosis.

> The doctor told me at the time I was diagnosed … I had AIDS. He didn’t tell me I had HIV … and he told me to terminate my pregnancy. I must have been in a daze for about 4 to 5 hours… I always expected for … homosexuals, people who using drugs to have AIDS … wow … That’s crazy you know. How did I contract AIDS? Everybody I was having sex with, they looked clean!” If I had listened to the doctor my child would not have been here now.

Laura described how she handled her neighbors’ curiosity regarding the visiting nurses’ home visits to her baby.

> The nurse was coming taking blood from her [the baby] and making sure I was giving her [the baby] the AZT medication, so she could be weaned off my antibodies. I just told them [the neighbors] she had extra digits and they wanted to be cautious.

Laura stated she employed the same tactics when self-administering her daily HIV medication at her place of employment. Her colleagues there assume that the medications are for diabetes and often reminded Laura when it was time to take the medications. She described her health care providers as being the best after she stopped seeing that first doctor. She added, “unless you have people in your corner telling you it is gonna be OK ... keeping you positive.”

Regarding disclosure, Laura stated she disclosed her status on a selective need-to-know basis. She recalled informing her ex-husband immediately after she received her diagnosis. He blamed her for the diagnosis, and it soon led to their break-up. As a result, Laura did not disclose to her two older children until about 7 or 8 years ago. Laura related that even though she has a very close relationship with her mother, she has only recently disclosed her status to her mother. Laura has since met someone and has been married for the past 8 years. She described her current husband as

> He is not just my friend, you know, he’s my lover, he’s everything. Because he took me at a stage where I always thought no man would have me again. And, see, when you are young you can start all over. When I was diagnosed, I was 35 years old. People don’t start over at 35. They are already living.

Regarding her life as a person living with HIV, Laura stated:

> I have been living every day with it, and it’s, it hasn’t hindered me. It hasn’t made me bitter. It just makes me appreciate life more. .. For the past 3 years I let nothing bother

> me. I used to let everything, you know, my husband, my kids, nothing, nothing. If I can't take care of it, it's just not meant to be taken care of, and I leave it in God's hand. I don't worry about it anymore. I get up about six o'clock. I test my blood sugar. I take my medications. I love life itself and at 51 every day is a miracle for me. I don't know about anybody else, but it's a good feeling… I can't tell you what it would have been like if I wasn't HIV positive cause I don't know. I know about now, and it's good. I'm happy. Some people are not happy with self. See, I'm happy with my inner self. I don't know any other life but the HIV life that I live, and it's good.

She put the HIV disease in perspective with her other health issues:

> Three years ago …I had a full hysterectomy; I bleed for like 10 months. … I had to have 10 transfusions. I don't know how I made it. I worked every day, bleeding every day... I almost died. You don't know what it is to want to live and almost have it taken away. Almost died, 7 years ago I got diabetes. I can't seem to get it under control. I love to eat. Six weeks ago, my sugar was 425.

> Laura described her gratitude at being alive and her incremental bargaining with God. When I was first diagnosed … 17 years ago, all I wanted to do was see my daughter graduate from high school... I can't believe it's 16 years later, and I have seen kindergarten, preschool, junior high school, and all I'm asking to do is—I just need 2 years. I am almost there. I'm staying positive. I asked him to also let me live long enough to see my grandchildren.

Laura describes herself as a loner who often takes alone time even from her husband. She describes those times as allowing her to think about how different her life could have been. Laura claimed that living with HIV disease is like fighting two battles: the battle of life and the battle with the virus. She described the battle of life as coping with the everyday twists and turns that life sends her way, whereas the battle with the virus is just trying to stay healthy. Although Laura said she lives in the here and now, she describes her alone time as soul searching thinking about tomorrow. She confirmed that she used to attend group therapy when she was first diagnosed; however, her job conflicted with the group schedule. She expressed a need to find a group that could accommodate her work schedule, because there are certain things only people living with the virus will understand.

Laura expressed thankfulness that she got the virus at a time when medications were available. Her advice to other women living with HIV disease virus is that they not stop living and to not live through the virus. Instead, she advocated that persons with HIV disease should live as though they do not have the virus. She stated that she recognizes that abstinence alone does not work, and so she counsels her daughter and her daughter's friends on the need to protect themselves. She verbalized a wish to be able to present at HIV education seminars, and especially to share her experiences with young people and help to educate them on safe sexual practices.

Listening to Laura, and then reading the transcripts of her interview, I envisioned Laura as an onion peeling and exposing her vulnerability layer by layer. Yet as she did so, she seemed to gain strength from the exposure. If I were to use one word to describe her, it would be *acceptance*. Listening to her, it was clear that there was no struggle with HIV disease. She was not trying to get away from HIV. It was not separate and apart from her. It was in her life, the life she has known for the past 17 years. Like any other life issue, she had developed strategies to cope with it. In doing so, she was much more than a woman with HIV disease.

Participant 7: Stacey

I interviewed Stacey at the clinic. Stacey was a 51-year-old woman, the mother of three adult children and six grandchildren. Stacey lives with her fiancée of 9 years and his son. Diagnosed with HIV disease 17 years ago while pregnant with her last child, Stacey reportedly contracted the disease from her husband, who was a drug user and allegedly had multiple partners. Stacey claimed she lost many of her belongings, including the family home, to his drug use.

In the past year, Stacey was diagnosed with diabetes and cervical cancer, and she is currently still receiving adjuvant therapy for the cervical cancer. In addition, she is receiving treatment for hepatitis C and liver failure. Having had frequent hospitalizations, Stacey voiced both admiration and frustration with her health care providers and the health care system. To protect her health, she avoids people who are coughing and sneezing. Stacey carries a little bottle of diluted bleach and Lysol with a bag of wipes in her handbag at all times.

Stacey explained that her relationship with her ex-husband was steeped in domestic violence, the frequency and extent of which only worsened after she was diagnosed with HIV. Her husband blamed her for contracting the disease. As a result, Stacey responded by distancing herself from others to hide the physical and emotional injuries. She was finally able to leave that abusive relationship, only to resume the cycle with subsequent partners.

Stacy described several experiences with stigma from health care professionals and from her friends.

> They [health care professionals] act like they don’t want to touch you, especially when they are taking blood. Some of them go through the whole mask thing. I can read them… Don’t treat me like I just came out the garbage can. I am a human. Back in the days when

> I delivered my child, they used to put signs on your door and your garbage can, it was red. One day I was near the nursery, and I heard this nurse say to another nurse, “Don’t touch the baby ‘cause she is HIV positive.” I bawled, I cried, I said, “give me my baby.” I was hurting so bad… Another time, “I went to my girlfriend’s house, she had a luncheon… and the other girls were there. They were sitting there with crystal glasses and stuff. …She gave me a plastic fork, plastic cup, paper plate… So the girls thought it was for one of the kids…. I went into the bathroom, and she went behind me… and started wiping down with beach. So when I sat at the table, the girls were like, “what’s with the cup? Why would she do that to you?”

Stacy stated that she left the luncheon without eating, and so did some of her other friends. Her advice to PLWHA is to eat before going to someone’s home and to not use the bathroom.

Stacey has disclosed her status to her children. Their reaction, she said, was disbelief, “because they figured it wouldn’t happen to older people.” She advocates for selective disclosure only to the people that are important in one’s life and only if the person disclosing feels comfortable with the person being disclosed to. “Even if you tell that person, you pray … every day that those people don’t tell somebody you know and haven’t told yet.” Stacey described how she set about educating herself about her illness.

> I learned about T cells, viral load, all of that. I asked her [doctor] what medications were on the market. I asked what the virus looks like. I actually looked at it, and it looks like a flower… so many colors …so many dynamics to it. It looks cute. It’s a cute thing, but it does a lot of damage. … I was collecting information. I was reading books. Soon as she [doctor] put a book down about AIDS, I was into it. I didn’t understand the words, but

> trust me, I wrote them down and went on the web. I learned... you have to maintain muscle mass, all that junk, immune system, how does it work? Now I am learning something about my cancer. … I want to get my body prepared. Chemo, radiology, and ‘cause the radiology tore me up.

In order of health care priorities, Stacey ranked HIV disease as number one, followed by the diabetes.

By the end of the interview Stacey got very teary eyed. I was struck by her genuine amazement that soon she would be 51 years, an age that she never thought she would live to be when she was first diagnosed 17 years ago. In addition, she appeared to be sincerely surprised that a man was willing to have her with all her health and social complications. She was grateful, however, that now she has someone in her life who, when she returned home, would say: “Hi honey, how was your day? What did you do? What did the doctor say?”

Participant 8: Sarah

Sarah chose to be interviewed at the clinic. Sarah is a 76-year-old mother of two adult daughters and a grandmother. She described a very close relationship with her children, especially her first daughter. Sarah has been married for the past 6 years to her husband, whom she met at a support group. Still the blushing bride, she laughingly referred to her married life as “wonderful.”

Once we completed the paperwork, Sarah began by saying, “I am a person who love life … likes to stay on the go … likes to help people if I can.” Incarcerated for 3 years and 2 months in a woman’s prison while she was still a juvenile, Sarah vividly recalled how, upon her release at age 18, she looked into the mirror in a relative’s home and realized that the child who went into that prison had emerged as a woman. She made a vow never to return to prison, and she never did. Sarah then described her experiences as a person living with HIV disease. She recalled her initial response to her HIV diagnosis in 1989 as difficult, She was already despondent over the recent death of her mother, and receiving the diagnosis made her sink further into despondency. One year passed before she was able to come to terms with the diagnosis and to seek treatment. “I thought I would never have no friends because I had this disease ... I was afraid to tell my daughters ‘cause I didn’t know how they would react.” She described how years before she had responded to a friend who had HIV disease.

> He told us … and I pushed him away because I didn’t want to catch none of this. … He was only a friend, not a... like a lover …me and certain people did not want him around us. And …he died without friends.

Sarah stated the recollections of how she behaved toward that friend still haunts her, and later, when she was diagnosed, she chose go on the offensive by telling “all my friends to keep them from laughing behind my back.”

Sarah said that once she accepted the HIV diagnosis, she began asking questions about and reading up on HIV disease. She questioned her doctors: “OK, what medicines can I take to subside this thing? I know it’ll never go away, but what can I do to live with this?” She said she stopped “using drugs and drinking liquor.” However, she noted that when she tried to “clean up” her act that was the time she got sick. “I couldn’t understand … all of a sudden I lost so much weight and my skin changed colors…I didn’t have no appetite.” Sarah stated that she believed the medication was causing her problems, and so she worked with her providers to change her medication. She also began to take complementary and alternative medication, such as cod-liver oils and Vitamin D. In addition, she said, “I stopped running the streets … stopped being out there in the world. … I started concentrating on how to take care of my body.” She credited her consistent and active participation in support groups for helping her cope with having HIV disease. “Talking about it and listening to people who have been sick longer than I … they helped me a lot.” She shares her phone number and makes herself available to help other group members who may be having a difficult time. Sarah stated she used the experiences, such as humor and attentive listening that she got from her past life as a bar maid, as strategies to help herself and others cope.

Sarah exuded self-confidence. “I feel good about myself … I have so many people that love me that I don’t feel alone… My goal is to build people’s self-esteem that they can feel the way I feel, great about themselves.” She credited her attitude to her faith in God.

> My whole life changed when I gave my life to God. …I was able to cope with it then …I feel like he [God] brought this disease on me to slow me down, like to do something significant in my life for somebody who got that disease.

A breast cancer survivor, Sarah was also living with diabetes and hepatitis C. However, while she participated fully in her own health care needs, she remained active in her outreach to others. Sarah described a story of a friend whom she introduced to the clinic.

> She was in [another] hospital for 2 weeks. … They didn’t tell her what was wrong. I brought her here… when they told her she had it I was there with her. I went into the room, and I saw tears in her eyes, and I told her “wipe your tears baby.” I said “Now all you do now is to talk to God and find a way how to live with this disease. Don’t let it bring you down... you don’t want to let it take hold of your mind, ‘cause once—if you let it take hold of your mind you are through.”

Like so many of the other participants, Sarah too stated that she wants to be able to help others, by writing a book about her experiences of living with HIV disease. Her positive self-esteem and her love for life and others permeated the interview. What keeps her going, she said, is knowing that she is making a difference in the lives of others.

Participant 9: Zoe

Zoe is a 64-year-old native New Yorker who lives with her partner in a beautiful well-kept two bedroom apartment. She is the mother of three grown sons and a grandmother of two. I interviewed Zoe, a tall and stately looking woman, at her apartment on a bright sunlit and windy spring day. Her grandchildren’s toys were visible throughout the apartment, and as she picked up the toys, Zoe reminisced about her recent fun-filled weekend with her grandchildren. Diagnosed in 1993 or 1995, Zoe made it clear that HIV did not define who she was as a person, and thus, she did not care to remember the exact date of her diagnosis. However, she had that information hidden among her important papers, where it could be retrieved if there was a precise reason for doing so. Zoe referred to herself as “a strong Black woman,” who was only made stronger by having HIV disease. Although she was confused and surprised and wanted to jump in front of a train when she first learned of her diagnosis in 1995, Zoe stated that she always had a feeling, way before her diagnosis, that something was wrong. However, in her providers’ eyes she did not fit the profile, and the test was never offered. She stated, “In the 80s, late 80s … I got a bad lung infection, but they never associated, because as I said, I did not fit… I was working, mother, didn’t … you know so. It was probably in there a long time.”

Zoe presented as a strong advocate for selective disclosure and to date, other than her providers, she has only disclosed to two people, one of whom is deceased. A breast cancer survivor, Zoe stated that whenever she got ill, her family naturally associated it with the breast cancer. She has chosen not to correct this perception. She debunked the idea that disclosure leads to increase social support. Zoe stated that for her, maintaining her independence and her matriarchal role in her family was more important than being placed in a “victim” role.

Zoe asserted that while she believed it was important to have good health care providers, as a PLWHA she had educated herself about the disease and was very sensitive and in tune with her body. She takes her medications at night, because she has always been a “night person.” Her body, she declared, has betrayed her. In the past 3 years, not only has she lost weight but she has also had a redistribution of body mass. This presented a problem when shopping for clothes, especially suits. In addition, she had a platelet problem and because of it bled easily. Occasionally she suffered from depression, but she had devised strategies to address this, which included shopping trips to her old neighborhood, and if all failed, she has a scream room in her home.

Zoe presented as a very strong Black woman. She indicated that she marched to her own drummer. For instance, she took her medication 5 days a week, despite her provider’s order of an uninterrupted regime. As her cell count had not suffered, she saw no reason to change. She stated that she depended very heavily on her life experiences to guide her decision making. Her description of her behavior was frequently paradoxical. For instance, she indicated that she experienced surprise and denial upon getting her HIV diagnosis, yet she later indicated that she had always had an unconscious knowing that she was positive. In addition, Zoe described having a very close relationship with her mother and other family members, yet she had not disclosed her status to them. She cited the family’s negative responses to other family members with HIV as the rationale for nondisclosure. Zoe credited her partner of many years with being her sole confidant and support related to her HIV disease.

Participant 10: Faye

Faye is a 57-year-old mother of four adult children and “many” grandchildren. I interviewed Faye in her two-bedroom apartment located on an upper floor of a large housing complex, where she lives with two of her granddaughters. Faye stated she is the sole caretaker for these two grandchildren because their mother was physically and emotionally unable to care for them. One grandchild was attending college and the other was in high school and “has bipolar and she is mild mentally retarded, mild.” I had previously made many unsuccessful attempts to arrange this meeting. When I finally met with Faye, it was perfectly understandable why she had not been available before then.

Looking much older than her 57 years, Faye ambulated slowly with an unsteady gait to a sofa next to a table with multiple medication containers. Before beginning the interview, Faye stopped to take some medications. Diagnosed with HIV in 2002, Faye indicated that she believed that the virus was transmitted through injection drug use. The virus, she said, must have been in her system for a long time, since she had stopped using drugs since 1986 or 1987. Like some of the other participants, Faye stated that she knew her status would be positive even before she took the test. She reported that her current HIV medications were working and that her viral load was now undetectable.

Living with HIV disease, Faye stated, was about keeping your business private, as most people tend to not want to be around someone who had HIV. For that reason, Faye stated she has not disclosed her status to her grandchildren. She stated she constantly is worried that the younger grandchild might inadvertently share information with her peers and/or teachers. Faye stated that she believed that her older granddaughter knew: “She is smart, she is in college and she has seen my medications, but I haven’t said anything to her.” Faye disclosed her status to her two older children. The two younger ones, Faye surmised, would not be able to handle it, because they are “too close” to her.

Faye described that living with HIV disease was only one of many multiple health conditions that she had. Diagnosed also with end-stage renal disease, she attended dialysis three days a week. On dialysis days she begins her days at 3 a.m. to be prepared for the 5 a.m. ambulette transport to the dialysis center and to ensure that her younger granddaughter was dressed properly for school. Faye related that upon returning from the dialysis center, she was often exhausted and would take a short rest before cooking and ironing her granddaughter's clothes for school the next day. On nondialysis days, the wake-up time was 5 a.m. Faye added that she had two serious health concerns: she needed a liver and a kidney transplant. She had been turned down by one hospital but was hoping that another area hospital would consider her. Faye said that her biggest concern was that she does not break down, that she does not get to the point where she cannot do for herself or her granddaughters, especially the younger one.

Faye stated she does not consider HIV a priority in her life. "I don't think it is the HIV that takes you out. It is all the other sickness that you can get by having that." She said it is hard to verbalize which symptoms or effects are related to the HIV disease and which are related to the liver or kidney disease. However, she has an inner sense that tells her. She credits her responsibility for her grandchildren as being the motivating factors which keeps her going, which prompts her to take her medication, to attend her appointments, and stay focused. "I truly believe if I didn't have them around me or, you know them here to do things for, I don't know what I, I probably just sit here and just mope my life away." She acknowledged that she does not do much for herself except go to dialysis and doctors' appointments and return home to cook and wait on her granddaughters.

Faye is a grandmother dealing with her numerous health issues, among which HIV is but one. The responsibility of being the sole caretaker of her two grandchildren, Faye said, highly motivates her to advocate for her own health care and maximize her health outcome. I envision Faye as an automobile running out of gas despite the long steep journey ahead. When I returned for my second meeting with Faye to review the transcripts, she informed me that she was turned down by the second hospital for the transplant procedures. The transplant board had assessed that she was not strong enough to withstand the procedures.

Summary of Participants' Stories

During the interviews with these women, I was amazed by their strength and resiliency. These women did not blame anyone or anything for their situation. Despite the stress they experienced and are still experiencing in their daily lives, they were willing to share their experiences with me. In addition, they were either involved in or were willing to share their experiences with others who were in similar positions and/or to prevent others from having the same experiences. They indicated that participating in this study was one means of giving back.

Data Analysis

In phenomenological research, the data gathering and data analysis are not linear processes; rather, they are part of the same process. Data gathering done in the interview process was augmented at times by reflection with the participants on the experience being described. During periods of reflection, the process of member checking allowed me to return to participants to validate or correct information. However, for purpose of clarity, the two processes are presented separately. This section describes in detail the steps taken in the data gathering and data analysis processes. Van Manen's (1990) methodological processes serve as the guide.

The first research activity is the *turning to the nature of the lived experience.* I turned to the nature of the experience by first identifying the phenomenon of concern: The experience of living with HIV disease for older African American women. That led to the identification of the research question: What is the experience of living with HIV disease for older Black/African American women like? I next moved to define the concepts within the research question. Adopting the CDC (2010) definition, living with HIV disease for this study referred to persons anywhere along the continuum of the disease process, from diagnosis to AIDS. I also used the CDC definition of older persons with HIV disease to mean persons age 50 years and older living with HIV disease. Black/African American was defined as persons of African ancestry living in the United States. Persons self-identified as being Black/African American. Once the concepts were defined and approval obtained from the data collection site and the Graduate Center, informed consent was obtained from the volunteers who met the criteria. Unstructured interviews were conducted, and each of the participants, Black/African American women over age 50, were invited to share their experiences of what it was like to be living with HIV disease.

The second activity, *investigating the experience as we live it,* was the gathering of the women's descriptions of their experiences with the phenomenon of interest, living with HIV disease. I obtained these accounts from the 10 participants through unstructured in-depth interviewing, under the guidance and support of my chairperson, a well-known doctorate-level qualitative researcher and academician of more than 30 years, and two doctorate-level academicians who are also qualitative researchers. In preparation for this process, I attended a 1-week intensive clinic, where I honed my qualitative skills by participating in workshops given by the world renowned qualitative philosopher and researcher, Max van Manen and his colleagues.

I used the service of a well reputed professional transcription service: The Qualitative Data Analysis Program University Center for Social and Urban Research, at the University of Pittsburg, to transcribe the interviews. The audio tape and the transcripts were uploaded through an encrypted website. All the transcribers who worked on this project were trained and certified by Collaborative Institutional Training Initiative and completed a confidentiality nondisclosure form (Appendix C). The service provided a timely turnaround time that facilitated review and modifications for the subsequent participants.

To ensure trustworthiness, upon receipt of the transcripts, I returned to the participants to seek validation of the accuracy of the transcribed audio-taped interviews. I met with seven of the 10 women to confirm their respective transcripts, share and receive input, and validate the descriptive summaries and emerging themes. (One participant was unable to meet with me due to personal and family illness; another's schedule did not permit a follow-up meeting, and one of the participants was lost to follow-up.) No corrections were made to the transcripts by any of the interviewees. When participants were asked whether they wanted to add any information, three of them offered additional information. However, upon review of the additional data, I realized that all comments were either repetitious or provided additional description of a previously related experience. All seven participants agreed that the transcripts were accurate records of their descriptions of their experience of living with HIV disease, as told to me.

Phenomenological reflection is the third research activity identified by van Manen (1990). He referred to this as *reflecting on essential themes*. Aimed to gain insight into the essence of the phenomenon, this activity involved "affectively appropriating, clarifying and making explicit the structure of the meaning of the lived experience" (p. 77), the outcome of which is to grasp the essential meaning of the phenomenon. I approached this process with the understanding that the meaning of a phenomenon is not singular; rather, that meaning is multidimensional and multilayered. This is a lengthy and repetitive process. A systematic approach to the analysis of the data was conducted for each interview and for the group, in an effort to understand each person's unique experience and the similarities and differences among the group. I created descriptive summaries, identified commonalities within the group, and grouped these commonalities into subcategories and categories. Next, I identified the emerging themes within these categories, to ensure that themes were representative of the group experiences. It was the analysis of the group's experiences that uncovered the essences of the experiences. To get to the essence, I sought to extract the essential themes from the emerging themes to identify the essence of the phenomenon and the answer to the research question. This analysis procedure is described in detail.

First Iteration of Data Analysis

I read each transcript in its entirety to get a complete picture of each interview. I returned to the audio version and my notes to correct and confirm tone or clarify language. I then began, by using the participants' words, to create an initial descriptive narrative summary of each participant's experience of living with HIV disease, and next reconciled them with the audio tapes and my field notes. This descriptive summary is presented above in the section **Participants' Stories.**

I listened to the audio tapes and read and reread the rich text of the transcripts, journal, and my field notes. I looked for the statements or phrases that seemed particularly essential or revealing about the experience of living with HIV disease for these older Black/African American women. Using the selective or highlighting approach, as described by van Manen (1990), I highlighted those statements and/or phrases. I then extracted those units of meanings or subcategories and listed them on a separate document. With these units of meanings in mind, I returned to the data and began to synthesize categories, using the participants' words to name the categories. This process yielded 30 units of meanings or subcategories and eight categories.

Table 2

Subcategories and Their Categories from the First Iteration

Units of meanings or sub-categories	Categories
Shock and surprise Denial Premonition or unconsciously knowing Anger Time marker/ A new beginning/change	Diagnosis experience
Feeling of depression & hopelessness Loneliness/ isolation Fear Shame	Emotions and feelings of loss (Emoting loss)
Self-perceived stigma/ internalized stigma Stigma from family and friends Stigma from health care providers	Experiencing stigma
Disclosing not disclosing	Keeping the secret
Dealing with losses Dealing with health care aspects of HIV disease Aging and other co-morbid conditions	Coping with adversities
Family Friends Healthcare providers A higher power/God/ spirituality	Relationships
Caring for self Seeking health promoting knowledge Caring for others Sharing and sustaining health promoting knowledge	Caring and sharing
Being grateful Hope Acceptance of this life Appreciation for this life Reaching out to a higher power/ spirituality Helping others/making a difference	Self-transcendence/moving beyond

The categories identified from this first iteration were the following: diagnosis experience, emotions and feelings of loss, experiencing stigma, keeping the secret, coping with adversities, relationships; caring and sharing; self-transcendence/moving beyond. These categories and their subcategories are presented Table 2. The narrative description, supportive of the 31 subcategories, and the eight identified categories of diagnosis experience; feelings and emotion of loss; experiencing stigma; keeping the secret; coping with adversities; reaching out to a higher power/spirituality; relationships; caring; self-transcendence/moving beyond follows. The participants' words are integrated into the narrative description.

Diagnosis Experience

For each of the participants, the experience of learning of their HIV diagnosis was a pivotal point in their experience of living with HIV disease. This experience was often described in detail. Many recalled the exact date, time, and circumstances surrounding this experience. Analysis of the data describing the participants' experiences around learning of their HIV positive status revealed five areas or subcategories. The five subcategories identified were shock and surprise, denial, premonitions, anger, and a time marker or new beginning. I initially labeled this category l*earning of the diagnosis*; however, as I continued to place the participants' statements into this category, I realized it was more than how and when they learned of the diagnosis. It included the women's immediate responses, subsequent reactions, and choices as they came to know their HIV diagnosis. I renamed this category *Diagnosis experience*.

Shock and Surprise

Though seven of the 10 women acknowledged participating in consistent HIV high-risk activity such as illegal drug use and unprotected sexual activity, eight reported some level of shock and surprise when they first learned of their diagnosis. Thelma, who had a history of illegal drug use said, “I was in the hospital. He [the medical provider] came and took blood, and about 15 minutes later I was positive. It was like somebody hit me with a hammer.” Pearl, the quintessential wife and mother, said “I didn’t know about it until he [her husband] died. When I went to get his medical, his death certificates and stuff, I found that he had HIV.” Three of the women learned of their HIV status as a consequence of prenatal care. Ginny said “I was pregnant and went to get myself tested, and that’s when I found out.” Laura said “If I didn’t get pregnant with my daughter, which will be 17 [years] on Christmas, I wouldn’t have known I had the virus. The doctor I had at the time I was diagnosed told me I had AIDS, and he told me to terminate my pregnancy. I must have been in a daze for about 4–5 hours.” Zoe, while describing an inner sixth sense of knowing years before she was tested, summed it up. “When I found out I had the virus, surprise! Confused! I wanted to jump in the train station! All of the above.”

Denial

Most of the participants articulated some level of denial upon first learning of their HIV diagnosis. Laura said “I could not believe it. All the people I had intercourse with were clean. Maybe they got the test wrong.” However only Pearl described a prolong state of denial. “I said no, this can’t be happening to me. You know, this is not—that’s not what I think my life is all about. …I was still in denial. I didn’t …I didn’t want to believe that. “Oh he have it but that does not mean I have it. You know, I was really in denial for a long time.” Pearl continued in denial for years later until she became so ill she had to be taken from her home by ambulance.

Premonition or Unconsciously Knowing

Some participants articulated having had a sixth sense or premonition related to the diagnosis. Zoe jokingly said, “I had that feeling … my luck is not that good… because I used to use drugs and I’ve been off them. I think … oh, damn, it had been 20 years before the virus caught me.” Faye stated that there was so much HIV disease in the community, that she knew it was only a matter of time before she would contract it. When I inquired further into this comment, she cited her own high risk behavior and the known and/or suspected behaviors of her partners. Ginny said, “in a way I knew because 15 years before [testing] I had a dream, that I had AIDS. And it turned out to be true.”

Anger

Several participants spoke of the anger they experienced in that early diagnosis period. Stacy described how her initial response culminated in anger. “I was numb; I walked from the hospital to my house… I was pregnant.” However, the numbness turned to anger when she confronted her husband, despite knowing of his past physical abusive behavior toward her. She ended up with a black eye that night. Ella Mae reported that for her the anger was directed toward herself, as she felt she “should have known better.” She believed that once she took responsibility, the anger dissipated.

A Time Marker/New Beginning/Change

The participants articulated that confirmation of their HIV-positive diagnosis was a time or transitional marker in their lives. The women indicated that something changed. For some, the diagnosis represented a pause, a new or different beginning, a new or different meaning, and/or a different direction for their lives. Pearl stated that she spent several years after the death of her husband refusing to consider the likelihood of being HIV positive. However, once she acknowledged it, the confirmation of her diagnosis was accompanied by hope and treatment options. For others, such as Maria that change or new beginning was not immediate. Ella Mae saw it as time to “come in” and return to her family. Maria stated that although she continued to be a sex worker after her diagnosis, she began to offer condoms to her patrons and at times counseled them about the risks of unprotected sex.

Participants articulated other time markers or turning points in their journey with HIV disease. They described points when they ceased to have the disease define who they were. HIV became part of their lives, however HIV was not who they were. Stacy in her way articulated the concept that the whole is more than the sum of its parts. “At first I didn’t think about it because I said that’s not me (sniffles), but it is me that’s a part of me, but it is not me.” Laura spoke of integration and coming to terms, “I can’t tell you what it would have been like if I wasn’t HIV positive, ‘cause I don’t know. I know about now, this is my life and its good.”

Emotions and Feelings About Loss

Participants described experiencing a range of feelings and emotions as they live each day with HIV disease. They spoke of the loss they felt for what might have been. Pearl spoke of her lost dream of becoming a nurse. Zoe described the loss of her once perfect figure and her inability to purchase clothing the way she used to because of the redistribution of her body fat, which is a side effect from HAART. Faye mourned the loss of her health. Laura spoke of the loneliness and self-isolation she felt, even while in the company of others. Depression was almost universal. Five subcategories were illuminated here feeling depressed, hopelessness, loneliness/ isolation, fear, and shame. These were placed in the category labeled: *feelings and emotion about loss***.**

Feelings of Depression and Hopelessness

All of the participants identified some level of depression associated with their lives as persons living with HIV disease. For the few who did not initiate this topic on their own, I inquired about it. Participants indicated that the depression was a fluid, reoccurring emotion that they experienced at different times and stages. That emotion, they indicated, could be triggered by anything, such as a familiar voice, a certain locale or an illness issue. Thelma related, “I used to cry. … I cry all the time. I see a therapist. I see a psychiatrist because I go through depression.” Maria implicated her living space as a contributing factor to her depression: “My apartment is my jail cell, especially my room. I sit in that room and I cry. I get so depressed, so stressed out being in these four walls.” Some of the women also identified their strategies for coping and responding to the depression. Ginny reached out to her providers for support. She said, “When I feel myself getting depressed, I … come here and talk to my doctor.” Zoe described days when she felt like “Ahhhh!” She has a scream room that she uses when that feeling comes on and she is alone. If it gets “really bad,” she literally takes a walk down memory lane, by visiting her childhood neighborhood where she just walks the street and window shops. Because of her weight loss, Zoe stated that shopping for clothes brings her depression to the surface. Laura, acknowledged feelings of depression, but stated she quickly dismisses it and does not let it get the better of her. Ella Mae, the artist, while she denied having depression, pointed out how she relies on her previous artistic skills to help her cope with feelings. She said, “ If I feel any kind of worrisome that may go into depression, I always have a trigger, a song, a thought, a person to think about; and there’s people worse off than I am you know.”

Thelma was the only participant who conveyed a feeling of hopelessness. She was very graphic in describing this feeling. “I would hear voices [in my head] saying, ‘what’s the sense in buying clothes you only have a certain amount of time to live’ … I was going for my GED and [the voices said] …. You are not going to pass. What’s the sense in you going to study for it?”

Loneliness and Isolation

Participants voiced the perceived feelings of isolation they experienced even while immersed in daily relationship with others. Ginny articulated the magnitude of the situation: “I try to live well, but I am very, very lonely. It [HIV] alienates me [voice cracks] … it's so—you get so lonely. It's sad. I'm a beautiful person. And I am a very lonely person." Laura made the distinction between loneliness and being alone; she denies loneliness but stated she enjoys spending time by herself. "I spend a lot of time with myself. I spend a lot of time alone." Laura described herself imposed isolation.

> When I first got diagnosed, I shunned away from a lot of people, with the fact that if I got sick no one would notice. So I distant—you know I made my visits very short. I didn't have a lot of people visit me because what if I got sick? And people would notice and you'd be changes, and I didn't want people to see that.

Fear

Many of the participants articulated some type of fear and being afraid. Pearl painted a visual picture of her fear of dying:

> [T]hat was some scary time. 'Cause at that time I believed…that I was gonna die because I got so small, you know. … Thought I was going to die. …Every time I closed my eyes I—open them fast, and I said, "wonder if this is my time," every time I close my eyes I would open it fast.

Sarah stated that while she did not fear death, she feared losing relationships: "I thought I would never have no friends because I had this disease." She was also afraid of disclosing to her children, fearing that their reaction might not be supportive. Zoe continued to fear that disclosure of her status would cause her to lose her matriarchal role in the family.

Shame

Some participants expressed feeling a sense of shame regarding their HIV status. Laura recalled the self-imposed shame she felt upon learning her diagnosis. "When I was first diagnosed, I kept it to myself, you know, not out of so much embarrassment, but just shame of knowing, you know, I was very loose, very reckless with my life." Sarah believed that her friends would all leave her. Faye lived each day fearing the shame that might befall her granddaughters should the teachers and other children find out. Ella Mae verbalized shame and embarrassment about her previous lifestyle.

Experiencing Stigma

As persons living with HIV disease, all the participants reportedly experienced some level of stigma from friends, relatives, and/or the health care system. These subcategories of stigma were initially immersed with other subcategories related to coping, but the issues of stigma, as related by the women, were so pervasive that after conferring with my advisors, I decided for the time being, to have it as a separate category labeled *experiencing stigma.*

Self-Perceived or Internalized Stigma

All participants articulated that they had preconceived beliefs that most of society had hostile attitudes toward people with HIV disease. The women verbalized concern not only about their own situation, but also about the stigma that might be perpetuated on their children and the people in their lives. Thelma voiced this concern: "When I think about what's gonna happen to my kids … I worried that people might scorn them because of their mother." Ella Mae too worried that her past life and HIV status might impact her son's future success.

Stigma by Family and Friends

Participants all described various levels of stigma they sensed from relatives and friends. Maria described how she was treated at a relative's home:

> My aunt, we went to her house to eat. She went and took the plates down and cleaned them with bleach. … Everybody else got glasses, and I got Styrofoam cups. Whenever I went to

get food, I would tell her, “I would have cash and carry stuff, put it in aluminum.” I did not hang around.

Stacey too related an incident of stigma while at a friend’s home. “I went to my girlfriend’s house, she had a luncheon. … And the other girls were there. They were sitting there with crystal glasses and stuff. …She gave me a plastic fork, plastic cup, paper plate.” Pearl discussed how she dealt with her friends: “I had to sit down and really let them know, my touching you won’t do you anything.” Zoe, while claiming to have a close relationship with her mother, refused to disclose to her mother because of her mother’s reaction to other family members with HIV disease. Sarah acknowledged her own negative behavior toward a friend who was diagnosed before she was.

Stigma by Health Care Providers

For the most part, participants indicated that they had positive relationships with their health care providers. However, they also related incidents that occurred with clinicians that were less than desirable. Stacey described her ongoing experiences with health care providers. “They act like they don’t want to touch you. Especially when they are taking blood, some of them go through the whole mask thing. … Don’t treat me like I just came out of the garbage. I am a human being.” Pearl recollected an earlier time when a nurse advised, “Why don’t you just lay down and die?”

Keeping the Secret

All participants acknowledged an ongoing dilemma of if, how, when, and to whom to disclose or not disclose their HIV status. All participants described various ways of keeping their HIV status a secret. Ginny captured this theme: “I don’t talk my business, not about HIV positive. It’s still hush-hush in 2012. Still the same people judge you.” Although only one participant openly expressed a fear of exposure, all participants described strategies they had developed to keep the secret. Thelma stated, “I’ve got to rememorize, then I write on another piece of paper, because I can’t put everything only certain things, like my HIV, I don’t put that on paper.” This category of maintaining the secret captured the various statements related to disclosure and nondisclosure as articulated by the participants.

Disclosing/Not Disclosing

Participants indicated that their lives as PLWHA entailed an ongoing process of maintaining the secret along a continuum of nondisclosure to disclosure. Nondisclosure/disclosure entailed the decision either not to or to divulge private information, feelings, and ideas to a close member of one’s network, receiving a response from the recipient, and using the perceived quality of the response to determine future disclosure. Imbedded in this continuum are issues of control and support. Ginny shared how she gradually disclosed to her family. “My …children are older, 35 and 31 year old. They didn’t even know I had the virus until about 7, 8 years ago… and my mom she couldn’t believe that I held that for so many years, ‘cause I am close with my mom.” Thelma articulated the difficulty of disclosure:

> It’s hard to disclose to another person that is not affected. [If the person] is the same status as I am, then I don’t have to go through the problems of explaining to them that I’m… Well, all I got is my brother, he knows. My sister knows. My sister down South, don’t know. I feel not to disclose to her because I don’t know how she would accept it, so I leave it just like that there. Mom she worries about my health, so as long as I’m—she knows I am diabetic and the swelling in my feet, but she does not know that I’m HIV positive. I don’t think I want to tell her. So I’ll just keep it just the way it is. And that’s about that.

Maria, in preparation for disclosing to her mother, practiced on a friend. “I went to a very good friend of mine first and asked her how she felt about it…before I went to my mother.” Zoe, a staunch supporter of disclosing only on a need-to-know basis, has disclosed to only two persons, her significant other and a friend who is since deceased. Zoe meanwhile hangs on to the control that her matriarchal role in the family affords her by adamantly rejecting the idea of disclosing her status to her family. A self-described “strong Black woman,” Zoe indicated that she views disclosure as a gateway to diminishing strength and decreased situational control. For Thelma and Pearl, disclosure to their children afforded them the support and protection of their children. Faye chose to disclose to the stronger members of her family, while withholding the information from those who were “too close” or dependent on her. Ella Mae stated that she discloses to other PLWHAs to help them understand that there is life with HIV.

Coping With Adversities

The participants spoke of hardships and difficulties they experienced as older women living with HIV disease. These included dealing with the symptoms of HIV disease, managing the challenges of adhering to the medication regime, navigating a complex health care system, coping with the losses of relationship, coping with the demise of loved ones, and dealing with HIV stigma, all compounded by the comorbid conditions of aging. Three subcategories illuminated here were (a) coping with losses, (b) dealing with the health care aspects of HIV disease, and (c) confronting aging issues and other comorbid conditions. This category was initially labeled *losse*s. However, upon further reflection, I realized that losses were but one of the issues that participants were responding to as they lived each day with HIV disease. I renamed this category *coping* and later *coping with adversities*.

Coping With Losses

Participants described the many losses that they suffered as a result of HIV. These losses included their friends, relationships, roles, and independence. Maria solemnly recalled, “ then we seen people start dropping. Like we were a crowd of eight, I’m the only one that’s left.” Pearl also lamented the demise of friends: “I have a lot of friends that wasn’t that lucky, you know. And although they were on the same medicine that I was on, they still, there was something lacking.” However, she acknowledged a different type of loss of friendship by saying that by having HIV disease, “I realize who were my friends and who wasn’t my friends. Ella Mae described how HIV and drug use resulted in her loss of parenthood, “She asked me to sign over my rights. … It’s really sad because I did not raise him. I miss him. And my son doesn’t call. I get sad.” HIV stigma presented its unique loss of the previous self. Whereas some of the women described actual losses, others described perceived losses. Pearl spoke of lost dreams: “I really thought I could have been a nurse, and it was one of my beautiful dreams that I had, that to be a nurse.”

Dealing With Health Care Aspects of HIV Disease

As persons living with HIV disease, participants voiced concerns related to health care adherence, medication interactions, and HIV-associated illnesses. Thelma stated:

> I was on Atriplia but I got resistant to that, and they put me on Copelle, that was working fine….When [provider] came and tell me that, I’m resistant to Atripla, and I was like “Oh wow.” And I know why, because I haven’t been taking my medication like I’m supposed to. But I didn’t tell her, though.

Ella Mae too, spoke of her struggles with medication interactions: “I have a lot of ailments from the side-effects of my medication… I have a lot of ailments. I take a lot of medications.” Laura listed her many ailments. “I had a hysterectomy … I had precancerous cells on my uterus. I had pneumonia about four or five times …many episodes of PCP. When I got pneumonia, I coughed blood. They put me in isolation because they think it was TB. I was in the ICU for 5 days.”

Sarah stated, “I’ve had pneumonia twice, I’ve had a breast removed, I’ve had a hysterectomy, during, all since I’ve had the HIV. I’ve had all this. And I can learn to live with it all.” Pearl summed it up this way, “I realize that as long as I took my medicine I could live a lot longer, so I’ve been doing that.”

Confronting Aging and Other Comorbid Conditions

The lives of these women are further complicated by the effects of the normal aging process and the comorbid conditions that accompany aging. In addition, many were dealing with the residual effects of their previous illegal drug use. Thelma stated, “I have asthma, swelling in legs, depression, diabetes; memory loss.” Ella Mae, in addition to acknowledging her musculoskeletal problems, stated, “my lungs are bad because of the smoking…that I did when I was using.” Pearl and Laura are living with diabetes, while Faye is struggling with renal and liver disease.

Relationships

Participants all commented on the connectivity they had, or sought with friends, family, health care providers, and a higher power. Relationship with family included the support received by and from the participants, as well as the lack of support. Participants also addressed issues of intimacy. The subcategories identified were (a) relationship with family, (b) relationship with friends, (c) relationship with health care providers, and (d) relationship with a higher power. Subsumed within the subcategory of relationship with friends was the issue of intimacy. These subcategories were labeled *relationships*.

Relationship With Family

Ginny lamented the loss of a parental relationship with her son. “I miss him… my son doesn’t call. I get sad. But life goes on because I made a human error.” Maria too lamented the loss of relationship with her brother once he learned of her HIV diagnosis. Ella Mae, on the other hand became animated when she spoke of her relationship with her son. Pearl and Thelma articulated the support and comfort they get from their daughters. Faye, as the sole caregiver of her granddaughters, discussed how important it was to become healthy in order to provide for the girls. Thelma said “The family part, that’s what I am grateful for, that I have my family.”

Relationship With Friends

All participants spoke about the importance of having friends and friendly relationship with others. Thelma described a complex web of friends: “I got a few sets of friends, you know, I’ve got survivor friends that got the virus, another set that don’t know I am affected.” Pearl acknowledged that living with HIV disease has caused her to “realize who my friends are and who wasn’t my friends.” Sarah stated she feared losing her friends should they learn of her HIV status. She has since built up a network of friends from among her support group peers.

Intimacy

The women spoke freely about their sexual intimacy status. Some (*n* = 6) indicated that, as they live their lives as older women with HIV, sexual intimacy is not something that they are seeking. Thelma reported being fearful and anticipated rejection: “I’m not looking for a relationship because I don’t want to get hurt, and I don’t want to hurt the next person, especially if you are not positive. …I don’t know how the person accepts me for being HIV positive.” Pearl stated, “I’m done with that. …I just don’t see myself getting involved, you know, cause I, now

I’m scared maybe I might give it. So before I have to be worrying about doing that to somebody else, I’m fine! I’m just taking care of myself. I don’t want to bother.” Ella Mae summed up the issues of intimacy this way, “it’s very difficult for me… I haven’t had sex in years, years and it doesn’t bother me. It’s OK. It’s OK. I’ve had sex before… I know what it is like.”

The other participants (*n* = 4) reported that they were sexually active. All four participants were in long-term relations, and their partners were aware of the women’s status. Three of the four participants acknowledged that they and their partners were not using any barrier protection. Laura, after years of wondering what man would want her, was in awe at having found a partner to share her life. “We’ll be married 8 years. And the conversation of me having the virus or infecting him never came up again. He is not just my friend, he is my lover, he is everything.”

Relationship With Health Care Providers

Participants placed much emphasis on the relationship that they had with their primary care provider. The data collection site, one of the oldest HIV comprehensive care clinics in the area, has experienced very little staff turnover throughout the years. Consequently, the women have had a long and positive history with the clinic providers. Thelma stated “I met nice doctors and nurses. They call me their miracle baby.” Laura expressed thankfulness that she got the virus at a time when medications are available. Although the women have nothing but praise for the clinic providers, it is clear that for the most part, they see themselves as partners in their care. Sarah said “I asked them to show me what way I can build myself up… I listen to what they told me. I took certain medicines… certain I would not take.”

Participants articulated that when they ventured out from the safety of their medical home to attend to other health care needs, such as dental or other specialist services, the relationships with other providers were often less than satisfactory. Ella Mae described feeling like herded cattle when she attended a new podiatry clinic. She spoke of the stares and hushed tones of the front office staff as they put her new chart together, and she wondered whether the podiatrist used double gloves for all his patients

Relationship With God/a Higher Power/Spirituality

All the participants spoke of hope and of their relationship to God. They related feelings of being thankful to God or a higher being for the gift of life this many years after being diagnosed with a disease that many thought was terminal. The women spoke at length about gaining inner strength through their relationship with God. Ella Mae spoke of her relationship with God:

> I found God again. I was open to receive God again, which gave me a lot of strength. I believe in God. I believe in a higher power, and I know that it’s not me that’s bringing me to where I am today and taking me to wherever else I need to be.

Laura, too, described her relationship with God: “If I can’t take care of it, it’s just not meant to be taken care of, and I leave it in God’s hand.” Pearl spoke of her thankfulness to God for life and living one day at a time:

> Just living every day …wake up every day and know that I’m OK that day. …Don’t know what will happen in the end of the day, but…thank God just for one more day. I know a lot of people who get sick, who have HIV and die, you know. So I am a lucky person to be still here.

Sarah described her relationship with God: “going to church more often. Giving my life to God, things started changing. …I was able to cope with it (HIV disease) then. It was no longer in my mind …and no longer in my heart.”

Care

As I listened to the participants' stories, it was clear caring was threaded throughout their experiences. However, caring was multifaceted. It included the self-caring that was apparent as the women spoke of comanaging their health and medical conditions: adhering to medical appointments and their medication regime and adopting lifestyle changes related to nutrition, exercise, stress reduction, and illegal drug use reduction or cessation. However, these women were not satisfied with passively receiving and implementing the self-care information. A significant part of caring for self was the self-initiative the women took in actively seeking the knowledge to care for self. Participants spoke of fervently reading the HIV literature, questioning their providers to gain information, and tuning in to their bodies rhythm and responses. Caring also included a subcategory of caring for others. Despite their own needs, these women described instances of ongoing caring for others. I initially named this category *coping with HIV disease and its comorbid conditions*. However, as I read and reread the transcripts, I heard the voices of the women as they further extended this care process by sharing the knowledge they gained with others. The identified subcategories were (a) caring for self, (b) seeking health-promoting knowledge, (c) caring for others, and (d) sharing and sustaining health-promoting knowledge with others. This category was labeled c*aring and sharing.*

Caring for Self

Self-care included caring for HIV conditions and the comorbid conditions associated with being an older Black/African American woman. Issues of adherence to HIV regime and drug resistance are echoed by several participants. Many of the women have diabetes and hypertension, two chronic diseases that are pervasive within the overall Black/African American communities. Thelma stated

> I was on Atriplia, but I got resistant to that, and they put me on Copelle that was working fine. When [provider] came and tell me that, I'm resistant to Atripla, and I was like "Oh wow." And I know why, because I haven't been taking my medication like I'm supposed to. But I didn't tell her, though. So now I know [addressing herself], "Thelma, you have to take your medication!"

Ginny stated "I used to watch how they [nurses] did my IV and hooked up the machines, and it got to the point where they wouldn't come back in time; I learnt how to unhook myself." Laura said "I used to think that the virus used to weigh a lot. It weighs a lot on your mind, a lot… I just trying to stay healthy… I never miss my appointments. I stay vigilant to my med, my medications."

Seeking Health-Promoting Knowledge

Imbedded within the participants self-described experiences of caring for self were the passionate desire and strategies they employed to obtain knowledge about HIV disease, **i**ncluding the treatment and management of the physical and psychosocial aspects; knowledge about navigating the health care system, including insurance issues; and how to share the information with others, including their providers. The knowledge gained from this initiative seemed to elevate the status of the women from simply patients to that of care partners. Stacey described how she educated herself on her condition:

> I learnt about T cells, viral load, all of that. I asked her [doctor] what medications were on the market. I asked what the virus looks like. I actually looked at it, and it looks like a flower… so many colors …so many dynamics to it. It looks cute. It's a cute thing, but it does a lot of damage. … I was collecting information. I was reading books. Soon as she [doctor] put a book down about AIDS, I was into it. I didn't understand the words, but,

> trust me, I wrote them down and went on the web. I learned... you have to maintain muscle mass, all that junk, immune system, how does it work? Now I am learning something about my cancer. … I want to get my body prepared.

Zoe had not only educated herself about HIV disease, but in addition, saw herself as an equal partner in her health care decisions. She realized that because she was a “night” person, her rhythm was such that for her taking her medication at nights was best. She has chosen to take her medications 5 days per week despite her physician’s recommendations for a 7-day regime. So far, the evidence has supported her decision, as her viral load remained undetectable. That concept of equal partnering was reflected in Ella Mae’s words as she spoke about navigating the health care system:

> I have a lot of medicals … X [her provider] has taught me how to branch out there and get the help that I need for myself… Instead of her always referring me to places, I come back with information and give it to her to help other people… I found a doctor who accepts my insurance, because I had to change my insurance to get my thyroidectomy, because the hospital did not accept my insurance. … I am looking for something a little more personal… I don’t like feeling like I am herded like cattle.

Caring for Others

Caring for others was a common concern for the participants. Faye, the grandmother caregiver, while dealing with her complex care issues, including liver and kidney failure, was driven by the need to provide the care her grandchildren needed. Faye said, “I be tired some time, but I keep on moving… She don’t have no one else, but me.” Maria, who is mostly homebound due to her leg problems, used her window as a conduit to influence the behavior of the neighborhood children. Ginny, who did not get the opportunity to raise her own child, helped struggling working mothers in her neighborhood by caring for some school age children, sending them off to school and helping with their homework.

Sharing Health-Promoting Knowledge With Others

This subcategory captured concern and caring for the larger community. Each and every participant articulated a need to "give back" by sharing their knowledge and experiences with others who are in a similar position and/or to prevent others, especially young people, from making the same mistakes. Thelma longingly wished for an encore of her presentation in a men's prison. Ella Mae said "I started to work at the facility that I was a resident. I became a peer volunteer and now I am staff." She counsels others on dealing with the dual issues of HIV disease and drug use and stated that she willingly shares her story when the need arises. Maria spoke of leaving her legs to science. All the women spoke about capturing their experiences by writing a book. Thelma said "I would love to go back out and do presentations, but I would have to learn more. I have to study more. I love to talk about the virus, and I want to teach people about it." Ella Mae stated "I like to share; I like to tell my story. I don't do it as much as I should, but I get with people individually, maybe because I know they will open up more if it is an individual thing." Sarah participates in a network of support groups in which she shares her experiences and expertise with others.

Self-Transcendence

These participants, living each day with HIV disease, described increased awareness of their vulnerability and mortality. Despite their daily struggle with the physical and emotional toll of HIV disease, (the complex effects of the HAART, dealing with age and comorbid conditions, navigating the complex health care system, subsisting on income that is at or below the poverty level, living in neighborhoods where illegal drugs are readily available, and coping with HIV stigma), these women manifested not a sense of disappointment but a heightened awareness and readiness to expand or transcend the self-boundary, to make a difference in their lives and the lives of others. Every participant, no matter how stressful her current life was, identified a need to provide HIV preventative education or a willingness to share her experiences with persons in similar circumstances. They emphasized their connectivity with others and relationship with God or a higher being as being therapeutic. As they struggled with their complex issues, these women identified hope, acceptance, and appreciation for their life situation as being part of the transformative process. These three subcategories, (a) hope, (b) acceptance of this life, and (c) appreciation for life, were captured in the category labeled *self-transcendence.*

Hope

The subcategory of hope was threaded throughout the women's stories. For many of the participants, they learned of their diagnosis when HIV disease was transitioning from an acute to a chronic disease. The public sentiment was that HIV disease was terminal, yet these women continued to have their individual hopes and dream. Laura stated that her hope throughout her 17 years of living with HIV disease was to see her daughter graduate from high school. Laura said she never lost that hope. Now, with her daughter at age 16, Laura is hoping for 2 more years. "I just want those 2 years. Let me see her graduate." Pearl articulated her hopes and dreams of what might have been. "I wanted to go back to school and have a good life. I wanted to make sure the kids were alright." Faye, as the sole guardian and caregiver for her two grandchildren, and despite her many comorbidities, including end stage renal disease and a failing liver, continued to hope to be accepted to the transplant list so she can continue to provide for her grandchildren. At times that hope is coached in spirituality.

Acceptance of This Life

The participants’ stories demonstrate that for them, acceptance is a nonlinear process. Although all the women appeared to have accepted that they have HIV disease, that acceptance for each appears to be at various points on a continuum. Laura said

> I can’t tell you what it would have been like if I wasn’t HIV positive because I don’t know. I know about now, and it’s good. I’m happy… See, I’m happy with my inner self. I don’t know any other life but the HIV life that I live, and it’s good.

Ella Mae, the artist, spoke of her acceptance of her current place in life and of second chances: “I figure that this is my path now, this is where God has geared me for my second chance.” Sarah too echoed this: “I feel like God brought this in my life for one reason: to help others… That’s my purpose in life, to try to keep others healthy as I feel in my heart.”

Appreciation for Life

A reoccurring theme expressed by participants was their sense of appreciation. Laura said

> I am living everyday with it, and it’s—hasn’t hindered me. It hasn’t made me bitter. It just makes me appreciate life more… I tell you, I love—I love life itself, and at 51, every day is a miracle—for me.

Pearl said

> Just living every day, wake up every day and know that I’m OK that day. …Don’t know what will happen in the end of the day but I know I could get up and open my eyes and thank God just for one more day.

Sarah said “I am a person who loves life.

All the participants reported that despite having HIV disease, they are in a better place. Pearl stated “I just changed, you know, just being happier, I guess.” Ella Mae spoke of gaining strength from sharing. She said “ I believe in God. I believe in a higher power and I know that it’s not me that’s bringing me to where I am today and taking me to wherever else I need to be.” Maria compared the stability of her apartment and her monthly disability checks to the instability of the years while she was on illegal drugs.

Second Iteration

I conducted additional readings of the transcripts to reconcile them with the categories, subcategories, and descriptive narrative of the women’s stories and to assure that the categories and subcategories captured meaningful responses directly connected to the research questions. I synthesized the concepts within the categories, using the subcategories as additional guide points. From this analysis, specific themes emerged. The themes were reviewed, reduced, and/or collapsed, regrouped, and renamed.

Emergence of Themes

The themes that emerged were (a) knowing, (b) emotional ebb and flow, (c) nondisclosure/disclosure, (d) experiencing HIV stigma, (e) relationship, (f) spirituality, (g) caring, and (h) self-transcendence. These themes were common to this group of older (over age of 50 years) Black/African American women who were living with HIV disease.

Knowing

The theme of *knowing* was articulated by all the participants. This theme captured the process of knowing that began with the participants learning of their HIV diagnosis and encompassed the initiative that the participants took in seeking to educate themselves about HIV disease process, management, treatment, and self-care. This process of knowing came full circle with the women sharing the knowledge gained with others. All participants, without any probing, recalled and identified their diagnosis as a critical time marker or life changer for their lives with

HIV disease. As the women recounted this particular experience, they recalled specific details related to locale or space, points in time, relationships, their bodily presence, and their responses as they came to know diagnosis. Thelma said “I am fighting through this process of HIV. I am learning more about it.” Sarah said “I asked the doctors. OK what medicine can I take to subside this thing? I know it’ll never go away, but what can I do to live with it?” Thelma recalled her most fulfilled moment was when she did an HIV presentation at a men’s prisons.

Emotional Ebb and Flow

Most of the participants described experiencing a range of feelings and emotions associated with their situation as they lived each day with HIV disease. These emotions could be triggered anywhere along a continuum from a thought or memory, a song, or knowledge of deterioration in their health status. Everyone spoke about depression on some level. Ella Mae, while denying depression, spoke about being aware of possible triggers and identified her strategies for fending off depression. Zoe acknowledged “those feelings” and took trips to her childhood neighborhood and/or used her scream room, whereas Thelma consistently kept her appointments with her psychiatrist.

Nondisclosure/Disclosure

The category of keeping the secret was recategorized as *nondisclosure/disclosure*. Participants described their everyday struggle, on some level, with maintaining the secret of their status and determining when, where, and to whom to disclose. Maintaining the secret for some was a protective mechanism for self and family. The decision to disclose or not disclose was sometimes used as a means of control, such as for Zoe, who believed that disclosing would diminish her status in the family. Sarah and Thelma were more comfortable disclosing to other PLWHAs, and Laura preferred her colleagues at work to believe she was an uncontrolled diabetic who had to take numerous medications. Faye was very fearful that her granddaughter might inadvertently divulge the secret at school.

Experiencing HIV Stigma

The theme of *HIV stigma* was pervasive as the women each recounted details of self-perceived associative and/or discriminatory behavior they felt because of their HIV status. These incidents of stigma came from family, friends, and members of the health care profession. Associative stigma, which is stigma experienced by relatives, caregivers, health care providers, and/or other persons associated with persons with HIV disease (Poindexter, 2005), also presents a problem .In some cases the stigma was anticipated, as in the case of Thelma, who worried about how others might treat her children and grandchildren. Ella Mae, too, voiced concern about whether her son’s future may be tarnished if her condition was to become known.

Relationship

The theme of *relationship* captured the connectivity the women had with their family, friends, and healthcare providers. Relations could be familial, friendships, and/or sexual intimacy. Relationship with family played an important part in the life of theses participants. Ella Mae saw moving in to assist in the care of her aged mother as giving back for leaving the family. Maria mourned the loss of her relationship with her brother, who deserted her once he found out about her HIV status. Thelma and Pearl, although concerned about the role reversal in their relationship with their daughters, still cherished the new close relationship that they have with their children. The women all spoke of the impact that HIV has on sexual intimacy. Some indicated that it was better and safer to be asexual, whereas others like Laura and Sarah were able to establish and maintain intimate relationships.

Spirituality

The theme of *spirituality* emerged as the women recounted their relationship with God or a higher power as they reached out and negotiated their needs and wants. The women often spoke about talking to God and surrendering to God. Ella Mae said

> I found God again. I was open to receive God again, which gave me a lot of strength. I believe in God. I believe in a higher power and I know that it's not me that's bringing me to where I am today and taking me to wherever else I need to be.

Laura described her relationship with God: "I just asked God to let me live long enough to see my granddaughter born. I don't ask for anything else. And in those 7 years I have had two more grandchildren, so I am blessed."

Caring

The theme of *care* emerged as the women described the various strategies they used to adopt and integrated self-care activities into their lives. They acknowledged the difficulties of the health care system and adaptation of their health care regime; however, they all had an understanding of their role in keeping themselves healthy. They further described caring activities toward their own and other children, their families, and their communities. They developed different strategies for obtaining knowledge about HIV disease and the willingness to share that knowledge for the betterment of their families and their communities.

Self-Transcendence

Each of these women, having lived with HIV disease for no less than 10 years, described herself as now being in a better place because of, or in spite of, HIV disease. For some, being in a better place, meant that they now had an apartment, a consistent income, and some sort of a supportive system. Others were in new and different relationships with their children and/or partners. Most were actively involved in supportive networks where they shared their experience and expertise with others less fortunate. The women all spoke of acceptance and appreciation for life and alluded to a sense of well-being despite their physical conditions. This theme I refer to as *self-transcendence*.

I shared these eight themes (knowing, emotional ebb and flow, experiencing HIV stigma, nondisclosure/ disclosure, relationship, spirituality, caring, and self-transcendence) with three of my participants to get validation as whether these themes captured their descriptions of their experiences living with HIV disease. The participants agreed that indeed, the themes were reflective of their experiences. I consulted with my advisor, a doctorate-level qualitative nurse researcher, on the emerging themes and on the feedback I received from the participants.

Third Iteration

I began the next step of the process: to identify the essential meaning of the phenomenon, the meaning of living with HIV disease within the context of these older Black/African American women. To do this, I attempted to identify the essential themes that—without which—the phenomenon would lose its meaning.

Determining Essential Themes

Focusing on the research question, I again immersed myself in the participants' description of their experiences. I listened to the audio recordings. I read and reread the transcripts and the eight themes that emerged from the previous reflections. I collapsed and reassigned themes and labels. To illustrate, I saw that the theme *knowing* alone did not capture the essence. As the women spoke about becoming consciously aware of their diagnosis, they differentiated between being told of their diagnosis, as a result of testing, and of actually coming to terms or making peace with the condition. Once they arrived at the latter, they were no longer passive. This was most indicated when the journey of seeking additional knowledge about HIV disease, first for self and then for sharing that knowledge with others, began to emerge. After several attempts, I relabeled that essential theme *knowing as power*. As I reflected on the term *knowing as power*, I saw that although it captured the “driving force” the women articulated that fostered their ongoing desire to seek information, the force that appeared to liberate them from their previous life situation and propelled them beyond, it was not yet on point. After several discussions with my advisor, I arrived at the term *knowledge as empowerment*. I used the same process for determining all the essential themes. The essential themes that evolved were (a) knowledge as empowerment, (b) responding to one’s emotional life, (c) concealing while revealing, (d) caring while being cared for, (e) dealing with HIV stigma, (f) maintaining relationality, and (g) self-transcending adversity and becoming.

Essential Theme 1: Knowledge as Empowerment

The theme of knowing and the subcategories of seeking knowledge and sharing knowledge were combined to form subthemes of a newly labeled essential theme, *knowledge as empowerment.* This essential theme and subtheme captured all aspects of knowing as articulated by the participants.

Essential Theme 2: Concealing While Revealing

The category keeping the secret and its emergent theme of nondisclosure/disclosure were condensed into the essential theme *concealing while revealing*. This essential theme captured the paradoxical processes that participants articulated related to sharing and hiding details of their HIV status. The women’s stories revealed that this was a very dynamic emotional yet thoughtful process, as the decision to divulge this information could either foster or damage relationships.

Essential Theme 3: Dealing With HIV Stigma

The theme of *dealing with HIV stigma* was consistent and ongoing. The women described how stigma, whether perceived or actual, impacted their quality of life by contributing to feelings of fear, shame, guilt, and depression. Having lived with HIV disease for more than a decade, these participants reported that they were still ever-vigilant for stigmatizing behaviors from friends, family, and health care providers and that they had developed strategies for preventing and/or responding to stigma.

Essential Theme 4: Maintaining Relationality

This essential theme of *maintaining relationality* traversed through all the themes and captured the human-to-human connectivity that the women had and/or desired. This essential theme encompassed the relationship the participants had and sought with their families, friends, and health care providers. It included the seeking and sharing of knowledge, caring for others, and the processes that underpinned the decisions to conceal and/or disclose their HIV information. Incorporated in this essential theme is the intimacy and sexual choices of these women.

Essential Theme 5: Caring While Being Cared for

The category of caring and its subcategories of self-care and caring for others were condensed into the essential theme *caring while being cared for*. This label captured the various types and levels of caring received and given by the participants and also the knowledge participants sought for self-care and to share with others. All the women were actively under the care of health care providers, and some were being cared for by relatives and friends. Participants were all knowledgeable about self-care and had initiated various lifestyle changes, such as the cessation of smoking and illegal drug use, nutritional support, adherence with antiretrovirals, and making and keeping clinic appointments. Despite caring for their own health care needs, the participants were all caring for others. Faye, as the sole caregiver for her two grandchildren; Maria, as she supervised and disciplined the neighborhood’s children from her window; Laura, as she cared for the children of single mothers in her building; and Ella Mae, who gave up her apartment to be close to her elderly, ailing mother. They all were involved in caring relationships.

Essential Theme 6: Responding to One’s Emotional Life

The thread of emotional ebb and flows persisted throughout the women’s stories. Upon receiving the HIV diagnosis, the women described a multitude of emotional responses that included denial, anger, and fear. Over time, other emotions and feelings emerged. The overwhelming emotion articulated was depression, followed by loneliness and isolation. However, after living for over a decade with HIV disease, the women also articulated a sense of joy, happiness, and gratitude to be alive. This did not negate the occasional feelings of loneliness, isolation, and shame that reoccurred from time to time, such that the women were constantly on guard to tend to these emotional feelings. This emergent theme and subcategories emerged as the essential theme: *responding to one’s emotional life*.

Essential Theme 7: Self-Transcending Adversity and Becoming

The category of coping with adversity and its subcategories of dealing with losses, dealing with the health care aspects of HIV disease, dealing with the psychosocial aspects of HIV disease, and aging and its comorbidities were combined with self-transcendence and becoming, the subthemes of spirituality/reaching out to a higher power, hope, acceptance, and appreciation for life to form the essential theme labeled *self-transcending adversities and becoming.* This theme was the driver and the outcome of all the other themes.

Interpretative Statement and Model

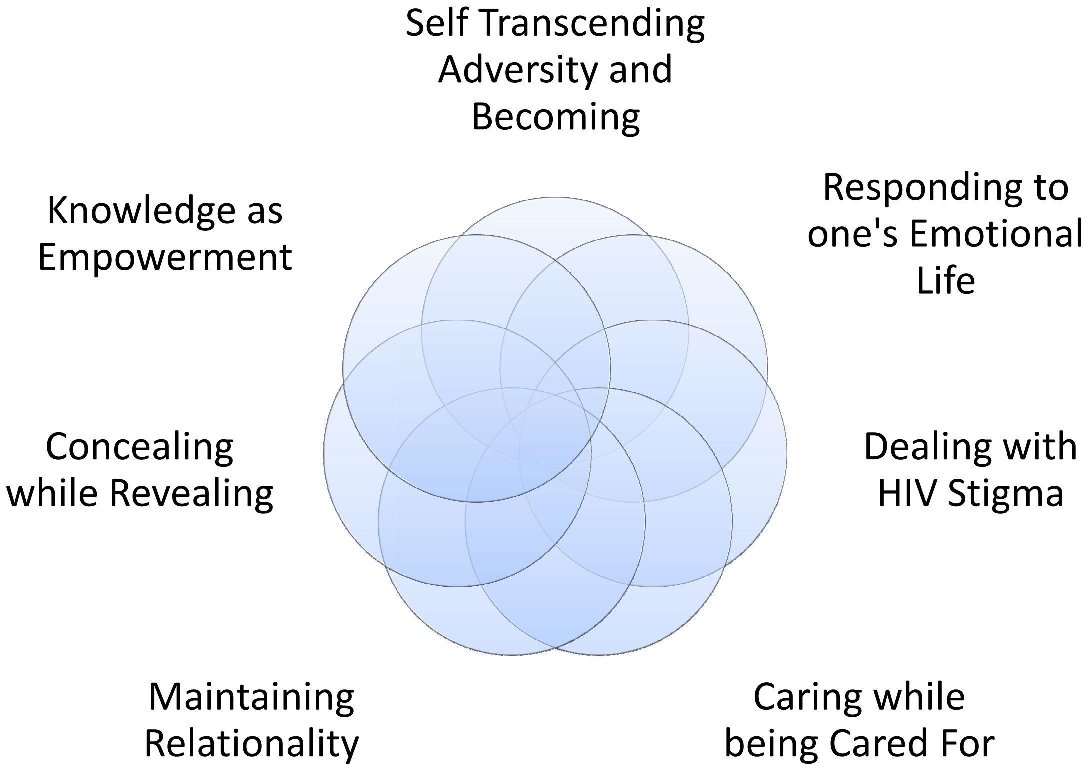
The findings of the data analysis are presented in two forms. First, a textual interpretative statement of the essences is presented. A model is used to illustrate a pictorial representation of the statement.

Textual Interpretative Statement

Phenomenological writing is the fourth process described by van Manen (1990); however, in phenomenological research, writing is not linear. It occurs throughout the research process. Once I determined the essential themes, I began to formulate the textual interpretive statement. This textual interpretive statement expressed the essential themes of the women's descriptions of their experience of living with HIV disease and facilitated the final reflection process. It identified the essence of the phenomenon and answered the following research question: What is the experience of living with HIV disease like for this group of older Black/African American women? I approached this by reflecting further on each of the essential themes, the emergent themes, and the categories and subcategories. I consulted the transcripts to extract the textual support imbedded in the participants' stories to validate the interpretative textual statement. I then combined the essential themes to describe the essence of the experience as elicited by the research question.

The answer for this group of older Black/American women to the question "what is the experience of living with HIV disease like for older Black/African American women?" is reflective in the textual description. The meaning of living with HIV disease for this group of older Black/African American women is a dynamic process of self-transcending diversity and becoming as they tend to their emotional life, while coping with HIV stigma, using knowledge as empowerment, concealing while revealing, striving to maintain relationality, and caring for others while they themselves are being cared for. Self-transcendence was the overarching theme. Although the interpretative statement appears linear, the model (Figure 1) more accurately depicts the essences as interrelated. The model further illustrates the essential themes as circular patterns interconnecting and contributing to each other as they increase in complexity to transcend and become the whole.

Figure 1. Model: The Meaning of Living With HIV Disease for Older Black/African American Women



Chapter Summary

This chapter presents an in-depth description of the sample, the data collection, data analysis, and the research findings of the study. The transcripts were analyzed using van Manen’s (1990) methodological guide as the framework. Descriptive summaries of the participants’ stories were developed using as many of the participant’s words as possible. Categories, emerging themes, and seven essential themes were identified from which evolved a textual interpretative statement and a model of the essences that answered the research question. In Chapter VI the conclusions of the study and reflection on the findings are presented. The findings are synthesized with the current literature and an application of the findings to a nursing theory is presented.

Chapter VI

REFLECTIONS AND CONCLUSIONS ON THE FINDINGS

This phenomenological study was conducted to understand what the experience of living with HIV disease is for a group of older Black/African American women. In order to gain insight into the experience, I interviewed 10 Black/African American women age 50 and older with a diagnosis of HIV disease about their experience. Through unstructured interviews, the women's description of their experiences generated the data for this study. Under the guidance of three doctorate-level qualitative researchers, I analyzed the data, using van Manen's methodological processes. Utilizing the selective or highlighting approach, as described by van Manen (1990), I categorized, revised, and relabeled statements or phrases that responded to the research questions multiple times searching for the emergent themes. By continuous reflection on the data, I developed subcategories, categories, and emergent themes that evolved into the essential themes, which were validated with Creswell's (2007) guidelines.

Conclusion

The findings revealed seven essential themes: knowledge as empowerment, concealing while revealing, dealing with HIV stigma, responding to one's emotional life, maintaining relationality, caring while being cared for, and self-transcending adversity and becoming. Self-transcendence was the overarching theme. From these essential themes evolved the interpretative statement that illuminated the meaning of the experience of living with HIV disease for this group of women. The meaning of living with HIV disease for this group of older Black/African American women is dynamic interrelated patterning processes of self-transcending adversity and becoming, responding to their emotional life, using knowledge as empowerment, concealing while revealing, striving to maintain relationality, and caring for others while they were being cared for.

The findings suggest that the meaning of living with HIV disease for this group of older Black/African American women was a dynamic process of being and becoming or emerging. Being embodied the women’s daily life patterns. The experiences they described demonstrated their ability to confront and rise above multiple physical, psychosocial, and relational losses. The women described their struggle with social adversities such as drugs, poverty, and HIV stigma, while managing the affects and comorbidities of HIV disease (medication interaction; breast and cervical cancer; bone, liver, and renal disorders; depression, and fatigue). These conditions were compounded by other conditions such as diabetes, hypertension, and other age-related health problems. Ever present and lingering in the background were the psychological responses of their inner emotional life. Sometimes joyful and happy, other times anxious, moments were triggered, often without notice, bringing forth varying degrees of emotions and feelings and forcing a conscious acknowledgment, a reminder of the secret they harbored. Engaged in the never-ending process of determining when, where, to whom, and how much of their condition to disclose, the women constantly weighed the pros and cons of their communication and decision to share. They emphasized the importance of relationships, as they strived to establish, reestablish, and/or maintain connectivity to their personal, transpersonal, and interpersonal relationships. They have learned to gain power through the process of seeking and sharing knowledge as they cared for others while they themselves were being cared for. By stepping outside of themselves and focusing on others, and by attaining and sharing knowledge, the women demonstrated patterns of self-transcendence and becoming. Self-transcending by its very definition promoted a new way of becoming. The findings of this study have implications for nursing education, research, and clinical practice. There are also implications for persons faced with adversities. Like most research, this study has some limitations and some recommendations for future research.

Relationship of the Findings to the Extant Literature

This section illustrates the relationship of the findings of this study to the extant literature. Consideration of the essential themes that emerged from the descriptions of the participants' experiences provided the direction and framework for the review of the literature. In a grounded study approach of rural women living with HIV AIDS (Leasure, Young Seideman, & Pascucci, 2009), the researchers identified five categories that were common to the participants: dealing with HIV, being supported, self-care and managing symptoms, negotiating the health system, and altering life plans. Unlike the present study, those women defined their experiences as an ongoing emotional burden of having a fatal transmissible and stigmatizing disease. The category of *being supported* was unidirectional, as the women in that study spoke only of the support they received and, unlike the current study, did not identify any support they gave to others. The categories of self-care and managing symptoms were similar to the present study's findings. Lindsey's (1996) study with non-HIV, chronically ill people found that chronically ill people described their experience as honoring self, seeking and connecting with others, creating opportunities, celebrating life, transcending the self, and acquiring a state of grace. These findings are similar and supportive of the current study.

Relationship of the Essential Themes to the Literature

The seven essential themes identified in this study are interrelated and overlapping. The interrelatedness of these themes constitutes the pattern. Each of the themes has been described and interpreted from the narratives of the participants' experiences of living with HIV disease.

The following section describes the relationship of the essential themes to the extant literature.

Knowledge as Empowerment

The theoretical literature has addressed the notion of patient acquisition of health knowledge and empowerment. *Health knowledge*, a term often used interchangeably with *health literacy*, refers to the knowledge, attitudes, and behaviors associated with a particular health concern. Rubenilli, Shulz, and Nakamato (2009) have argued that health knowledge and health literacy should be an integrative concept in order to capture how a person judges different situations within the broader context of the person's experiences and values. Other researchers have posed that health knowledge and empowerment together are predictors of health and behavioral outcomes (Schulz & Nakamato, 2005). Camerini, Schulz, and Nakomoto (2012), in a study to test a model to identify the role of health knowledge and empowerment on behavior and health outcomes found, found that while self-management did not mediate the relationship between knowledge and empowerment on health outcomes, it did have a significant positive effect of the impact dimension of the empowerment scale on health outcomes.

According to Charmaz (1991), persons with chronic illness viewed learning of their diagnosis as one aspect of health knowledge. Illness trajectory and post diagnosis decisions were subsequently weighted against the prognostic expectations of that diagnosis. This study's participants demonstrated that the acts of seeking, attaining and sharing knowledge were the transitional or transformative vehicles that empowered them and took them to another level of being. These findings were similar to those by Walulu and Gill (2011), who found that women with HIV disease sought information from a variety of sources as a means of coping and learning about the disease processes, thus empowering themselves in their self-care activities. Coward and Kahn (2004), in a study of women with breast cancer, found that their participants found meaning and purpose by seeking health-promoting information.

In a proposed model of health care empowerment M. O. Johnson (2011), defined empowered patients as those who were engaged, informed, collaborated and tolerant of uncertainty. Johnson stated that patients who were empowered tended to take better care of themselves. Theorists Crawford Shearer and Reed (2004) reformulated the definition of the concept of empowerment as defined by Barrett‘s (1990, 1998) theory of power enhancement, Newman’s (1990, 1994) theory of expanding consciousness and Reed’s (1997) theory of participatory process of well-being. The reformulated definition the theorists offered was a proposal of what they believed Rogers’s view of empowerment would be. Rogers posed that humans want to participate knowingly in the change and patterning with their environment (Rogers, 1980). Empowerment, is a “complex and participatory process of changing oneself and one’s environment, recognizing patterns, and engaging inner resources for well-being” (Crawford Shearer & Reed, 2004, p. 257). This reformulated definition of empowerment differs from the traditional paternalistic nurse–patient relationships and is more congruent with Rogerian science. Crawford Shearer (2004) echoed this definition in her theory of health empowerment. She added that “health empowerment is a relational process that emerges from the person’s recognition of his or her own personal and social-contextual resources” (p 6). From this perspective, the nurse neither empowers nor disempowers, but instead facilitates the empowerment process.

The findings of the current study identified the concept of knowledge as empowerment. Knowing began with learning the diagnosis; however, the knowing the participants emphasized was not the passive stance of being told the results of the HIV test. Many did not do much with that information. The knowing they emphasized was more related to the point in time when they wanted to know about the condition. Included in this process were varying degrees of acknowledging and owning of the condition. This knowing was no longer passive. Igniting slowly for some, this need to know fostered the quest for actively seeking self-care information. Self-care required the acquisition of disease- and intervention-related knowledge. The acquisition of this knowledge took the women to another level. They became “expert patients.” The literature describes expert patients as patients who are able to effectively self-manage their long-term condition (Kielmann & Cataldo, 2010). Bandura (1995) referred to this as “self efficacy.” As the women in this study became more knowledgeable about their condition, they became empowered. In so doing, they were not satisfied with just knowledge for self, but also for knowledge that they could then share with others. This is different from Barrett’s (2010) power as knowing participating in change theory. For Barrett, the theoretical journey began as she attempted to gain an understanding of powerlessness. Barrett stated that people are always participating in change, but their participation is not always in a knowing manner. Power, she stated, is the capacity to knowingly participate in change. For the participants in this study seeking, attaining, and sharing the knowledge were enmeshed with or facilitated the empowering process. The women described the conscious or unconscious decision to change that fostered their quest for knowledge. Attaining and sharing the knowledge empowered them and took them to another level.

Concealing While Revealing

The process of hiding a stigmatizing condition is called *concealing* (Oswald, 2007). Harrison Shannon & College (1998) used James Baldwin’s fictional writings to posit that within the Black community, secrecy was a sociocultural defense that historically dealt with survival issues. The authors offered that secrets can be both functional and dysfunctional and are “actively manifested as metaphorical escape through religion, music, aggression and substance abuse” (p. 174). For the some of the participants in this study, HIV was relegated to another family secret, along with childhood/familial incest, domestic violence, and mental health issues (Wyatt, Carmona, Loeb & Williams, 2005). Responsiveness to HIV disclosure included previous coping strategies, such as disclosing on a need-to-know basis and viewing disclosure as a means of falling from grace within the family and the community. Nondisclosure was viewed as a means of self-protection. For some, close relationships, such as with a mother or sibling, did not necessarily mean that disclosure was easier or more forthcoming. This is consistent with the findings of other researchers who found that older adults were unwilling to reveal their HIV status, (Emlet, 2007; Nokes et al., 2000; Shehan et al., 2005). In a meta-synthesis of qualitative findings on stigma in HIV-positive women, Sandelowski, Lambe, and Barroso (2004) found that women with HIV disease were engaged in a never-ending work of making, reversing, and remaking decisions about HIV disclosure. These women were constantly determining when, to whom, and how much to disclose, as they worried about the effects of disclosure, especially on their children.

The participants in this study reported that the experience of living with HIV for them involved the paradoxical behavior of disclosing and/or not disclosing important information about their world to others. This behavior is supported by one of the principles of Parse’s (2011) humanbecoming theory that posits that humanbecoming involves configuring rhythmical patterns by revealing–concealing, enabling–limiting, and connecting–separating. The avoidance of disclosure behavior was also reported in persons with other illness who see both the concealing and avoiding disclosure of their illness as a means of distancing the illness from the self and avoidance of stigma (Charmaz, 1991).

Coping With HIV Stigma

Stigma was originally defined by Goffman (1963) as “spoilt identity,” an undesired “differentness” the dishonoring and/or the censuring by others. According to Goffman, both the stigmatized person and the person(s) doing the stigmatization respond to the discomfort of stigmatization by isolating themselves. A more recent definition is the devaluation of persons because of their affiliation in an “unacceptable” group (Croker, Major, and Steele, 1998). Since the beginning of the epidemic, persons with HIV disease have been stigmatized as being promiscuous and/or for having alternative lifestyles. The relationship of HIV-associated stigmatization has been addressed in the literature (Foster, 2007; Jacobs & Kane, 2010; Poindexter, 2005). For midlife and older women, HIV-related stigma has been identified as a barrier to HIV testing and prevention. Older women face the double stigma of HIV and ageism and a societal expectation that because of their age they should no longer be having sex (Emlet, 2006b). Researchers Jacobs and Kane (2010) found that internalized stigma and fear of stigma from potential partners may increase the likelihood of older women continuing high-risk sexual practices. For the women in this study, being Black/African American added to the list of stigmas. Each participant had a laundry list of stigmatizing incidents.

Caring While Being Cared for

Caring means that persons, events, and things matter to people (Benner & Wrubel, 1989). From a philosophical perspective, Mayeroff (1971) related caring to personal growth, and Heidegger (1962) in his description of authentic versus inauthentic caring, suggested that the meaning of being in the world is to be caring. The theorist Jean Watson (Watson & Woodward, 2010) described the philosophy of caring as involving a human caring and relationship-centered process. It includes the will, intent to care, and the caring actions that accompany them.

Caring in this study entailed self-care, which encompassed the adherence to healthcare appointments and medication regime, the adaptation of lifestyle changes related to nutrition and stress reduction, the active seeking of the necessary knowledge for self-care, caring for others, and sharing the knowledge gained from the experiences of living with HIV disease with others. Similar findings were reported by Plach, Stevens, and Keigher (2005) in their study of self-care of women growing older with HIV and/or AIDS. Those findings showed that self-care had “two major aspects: the nurturing of their physical health and sustaining heart body and soul” (p 540). In terms of physical health, participants discussed focusing on health-promoting activities, devoting themselves to wellness and confronting their HIV symptoms. For those participants, sustaining heart, body, and soul referred to the inner strength that they got from being optimistic, having changed their ways of thinking about HIV, life and death, and their faith in God (Plach et al., 2005). The theme of spirituality among women recovering from breast cancer was supported by Coward and Kahn (2004). Similar findings related to physical health were elicited by Emlet, Tozay, and Raveis (2011), who, while examining resilience and the HIV experience in 25, older adults, identified the theme of self-management. This theme included the concept of self-care (i.e., medication and clinic adherence and maintenance of a healthy balance of diet and exercise). Hobbs Leenerts and Magilvy (2000), in a grounded study of Caucasian women with HIV disease, identified that although failure to attend to self-care was a reoccurring theme prediagnosis, postdiagnosis, and over time, the women began to invest in health and self-care.

In the United States, women caring for family members and others living with HIV disease is fairly commonplace, (Boyle, Ferrell, Hodnicki, & Muller, 1997; Linsk et al., 2009; Poindexter, 2007; Robinson, 1997). However, unlike data on regions like sub-Saharan Africa, the data on studies of U.S. women with HIV disease caring for others is sparse (except for mothers with HIV caring for their infants and children). The findings of a study done by Coward (1995) on persons living with the end stage of HIV disease found that those participants exhibited a sense of urgency in receiving and giving assistance to others in meaningful situations. The findings of this current study support Coward's study in this sense and therefore add to the knowledge base.

This study's participants articulated that their care-giving activities were highly significant aspects of their lives. For some of the women, caring for others was the primary motivating focus of their lives, whereas for the others, it was an important component integrated into other aspects of their lives. This partially supports Bunting's (2001) findings on a group of women caregivers of persons with HIV diseases (*N* = 9). Three of these caregivers were themselves HIV positive. That study's findings showed that care giving and sustaining the care giving relationship were primary foci in the caregivers' life. Bunting's study identified "role transition, managing behavior, reciprocal caring, balancing independence, and managing distance as categories of care-giving within the context of caring for persons with HIV disease. The HIV-infected participants (*n* = 3), unlike the non-HIV infected participants in that study and the participants in this current study, found managing the distance between themselves and the person they cared for very painful (Bunting, 2001). It must also be stated that the care giving identified by participants in the current study was not reciprocal in nature, as the participants for the most part cared for persons (children and the elderly) who were not likely to return care giving.

Maintaining Relationality

Participants in this study emphasized the importance of relationship in their lives. They described the process of evolving from the initial response to isolate themselves from others upon learning of their diagnosis to acceptance and a zealous need to connect with others. This need to connect with others spanned the continuum of past, present, and hope for future relationships. The literature supports this phenomenon. Researchers have identified three main ways that persons maintain meaning in their life: belonging, doing, and understanding oneself and the world. *Belonging* refers to how one fits with one's social environment and includes the acceptance from others. *Doing* refers to one's need to engage in fulfilling activities in the quest to achieve self-efficacy. *Understanding oneself* and the larger world is a way of acquiring a sense of meaning in one's life. Van Manen (1990) identified relationality as one of the four fundamental existentials (lived time, lived space, lived body, and lived relationship with others) by which all humans experience the world. It is the lived relationship that is maintained with others in the interpersonal space we share with them.

Responding to One's Emotional Life

Participants in the current study described a range of emotions and feelings that they experienced as they lived their lives as older women with HIV disease. These emotions and feelings were constant reminders of their HIV condition. Attention to these emotions and feelings paved the way for the development of the self-care agency processes whereby the women began to seek and attain HIV information and knowledge. Hobbs Leenerts and Magilvy (2000) in a grounded study with Caucasian women living with HIV supported these findings. Their participants described a range of experiences including fear and isolation. Over time, and through acknowledgement of their despair, the women began a process of investing in self. A subset of that self-investment was feelings and emotions. This category, metaphorically described as "touching both sides," captured the process "in which the women learned to live in the complexity of positive and negative emotions" (p. 66).

Self-Transcending Adversity and Becoming

Adversity, according to the *Merriam-Webster Dictionary* (2011), is “an extremely unfavorable experience or event; a difficulty, danger or state of affliction.” Researchers have noted that since the days of slavery within the African American culture, religion is closely linked to healing, overcoming adversity, and survival, whereas death is often juxtaposed with survival and community (Becker & Newsom, 2005; Fett, 2002; Kalish & Reynoldsi, 1976). Becker and Newsom (2005), in a study of chronically ill older African Americans, identified a resilient philosophy that emerged in the face of life-threatening disease. Their participants, after overcoming the initial setback on learning of their condition, demonstrated high levels of determination, perseverance, and tenacity, regardless of the severity of their illness.

In the current study, the participants articulated adversities such as the demise of friends and family members and changes in relationships, coping with HIV stigma, dealing with physical and psychological effects of HIV disease, and the added issues of the aging process and dealing with the socioeconomic and geopolitical climate of their neighborhoods. The women found meaning as they gave of themselves to others and their communities. The women’s descriptions of the joy and satisfaction they got from reaching out and helping others were poignant. Thelma’s most memorable moment was walking through the prison with the warden and delivering a presentation on HIV, “because it is the only thing I know well… but I need to know more.” Joy radiated from Pearl; joy she said, she felt just because she was alive—so much so that others contacted her, just to experience some of that joy over the phone. Ginny was orphaned at 13 and had missed the opportunity to raise her own child; however, despite her many problems, she was helping to raise the children of single mothers in her building.

Persons faced with adversities, in order to survive, have an inherent capacity to step outside of themselves to reach out, relate to, and find new purpose and meaning in their lives (Frankl, 1963). This, Frankl termed *self-transcendence*. Maslow (1962) identified transcendence as the eighth level in his hierarchy of needs. It occurred after the individual, having undergone the process of self-actualization, reached out to help others self-actualize. In describing her theory of self-transcendence, nurse theorist Reed (2010) defined self-transcendence as moving beyond one's current situation to a broader awareness of others and the environment. In this way self-transcendence is interrelated with relationality.

The literature on self-transcendence and HIV disease is sparse. Mellors, Coontz, and Lucke (2001) described how persons living with HIV disease transcended the emotional and physical effects of their condition. They identified three themes, creating a meaningful life pattern, connectedness, and self-care. Included in the theme of creating meaningful patterns were the concepts of life transforming, personal development, and life satisfaction or well-being. The participants in that study related how living with AIDS was life transforming and caused them to reprioritize their priorities values and goals. Participants identified connectedness as a shared meaningful relationship. Self-care included the process of maintaining health and wellness. Wayman and Gaydos, (2005) conducted a qualitative study of self-transcendence through suffering (breast and ovarian cancer, HIV disease, death of child, and unexpected unemployment). Their study's findings identified themes of self-transcendence that were similar to the current study's findings. Their themes, turning point, change, gratitude, humility, and elemental experience, were reportedly consistently present in their participants' lived experience. "Turning point" referred to the point in time when participants turned, surrendered, and learned how to ride the wave and live in the flow. Ellermann and Reed (2001), in a study of self-transcendence and depression in middle-age adults, found that self-transcendence was a significant inverse correlate of depression, thus supporting Reed's theory and this current study's findings.

"Becoming," according to Parse (2011), is structuring meaning multidimensionality in cocreating rhythmical patters of relating, while cotranscending with possibilities (p. 12). In the current study, the participants described a trajectory of their struggles and experiences over time. They articulated behaviors that captured a sense of transcending the self by reaching outside of the self to seek and attain knowledge (meaning), to share that knowledge with others, and so in their own way care for others. Participants described the now, or their current position in life, as a different and better place. This is consistent with the findings of Reed (2004).

Application to Nursing Theory

Pamela Reed's Theory of self-transcendence is based on Martha Roger's (1980) theory of unitary human being. Reed (2010) described Rogers' concept of pandemensionality in relation to the nature of one's awareness of personal wholeness, where one faced with adversity looks inward and reaches outward, integrating the past, present, and the future to find meaning and purpose.

The theory of self-transcendence proposes that when one faces a life-threatening illness or critical health related change, one's awareness of one's vulnerability increases. The perception of that heightened vulnerability fosters an openness/readiness to transcend the self-boundaries, to achieve a sense of well-being. "The self boundary is reflected in perspectives regarding the inner self and the relatedness to others, the environment, nature, machines and technology, and the perceptions about relationships between body–mind–spirit and death" (Reed, 2010, p. 420).Two assumptions that underpin Reed's theory are that humans are dynamic open living systems, and humans possess a unique inner capacity to integrate life's complexities related to health-related problems in a way to facilitate well-being, thus creating the potential for healing. Reed proposed that individuals are often able to achieve this well-being themselves, by expanding or altering the self-boundaries and by presenting new perspectives, modifying old beliefs, connecting with others, and reaching out to something greater than themselves. However, when individuals encounter difficulty with the process, a need for nursing is created. Knowledge, Reed posed, is developed in the midst of adversity and nursing because of its focus on human beings and health is in a unique position to foster knowledge development for patients who are dealing with complex health situations (Reed, 2008).

A diagnosis of HIV disease has been described by the participants in this study as a significant time marker or life-defining event. This significant health-related change exposed participants to varying degrees of physical, psychological, and social vulnerability. The findings of this study support Reed’s (2010) theory of self-transcendence by capturing several significant forms of expanding one’s self-boundaries. This expansion of the self-boundaries occurs through interpersonal, intrapersonal, and transpersonal ways of coping or growing within adversity. The interpersonal- and intrapersonal-boundaries expansions were revealed in the themes of relationality, reaching out to others, caring for self and others, using knowledge as empowerment, and tending to the intrapersonal boundaries of their inner life emotions and the revealing–concealing process. The women in this study demonstrated the transpersonal or spiritual ways they expanded their self-boundaries by reaching out and by their connection to a higher power or God to give meaning and purpose to their lives. This, Reed (2010) stated, is the process of self-transcendence, which promotes the ongoing health process or a new way of becoming.

For this group of older African American women, the meaning of living with HIV disease is a dynamic process of self-transcending diversity and becoming as they tend to their life emotions, using knowledge as empowerment, confronting HIV stigma, concealing while revealing, striving to maintain relationality, and caring for others while they themselves are being cared for. The study has implications for theory building, education, research, and practice as it relates to nurses and their understanding of the experiences of patients with HIV disease. It also illuminates questions for future research related to understanding the meaning and impact of adversity, self-transcendence and becoming, tending to one's emotional life, concealing while revealing, dealing with HIV stigma, maintaining relationality, caring while being cared for, and knowledge as empowerment on the lived experience of persons with HIV disease.

Implications for Nursing

This phenomenological study of older women living with HIV disease is crucial for informing nursing education, practice, and research, as this study provides an emic perspective and enhances the understanding of the world of the study participants. Nurses' central concern is about people, their experiences, and their responses to health concerns. The nurse considers the whole person inclusive of his/her relationships. This study was conducted for the purpose of understanding the experience of older Black/African American women living with HIV disease. The findings of this study add to the knowledge base of nursing education, practice, and research.

Education

The knowledge generated from this study is offered to scholars as new understandings of the experience of older women living with HIV disease. Scholars armed with this understanding will appreciate the multidirectional care-giving abilities of this group of older Black/African American women, and the literature will show that having HIV disease did not dull the innate care-giving capacity that older black African American women are often credited for having.

Divisions of nursing education must continue to transition from the positivist perspective of the medical model toward a humanistic perspective that embraces the patients’ experience. This paradigm shift must be integrated into the curriculum throughout the continuum of nursing education. The findings of this study point to the need for nurses to be educated to operate from the perspective of assisting and facilitating patients in their self-management and self-transcendence processes. Nurses educated in this perspective will be open to the idea that patients have the inherent capacity to self-transcend and achieve well-being in the face of adversities. These nurses will know that nursing care is needed as the patients encounter barriers to the self-transcendence process. Nurses can assist in this process by enhancing patients’ knowledge and by assisting the patients to attain the knowledge needed for their empowerment.

Practice

The implications of this study in the area of practice are partially subsumed in the implications for education. The transition of HIV disease to the chronic care model and the impact of the Affordable Care Act imply that nursing has a larger role to play in helping patients with HIV disease to manage their health concerns. Nurses, in addition to the agnostic and technological expectations, must be willing to translate the theories of the discipline into practice at the bedside. The willingness to be genuinely present with these patients will provide them with safe and caring environments along with the time and space to allow for self-reflection on their experiences, their strengths, and connectedness. By listening attentively to the women’s experiences nurses will better understand how to see and care for these older women with HIV disease as individuals. The findings indicate that nurses caring for older women with HIV disease must be willing to accept these women as partners in their own care and be cognizant that at any time while receiving care, these women may be tending not only to their own physical, socioeconomic, and emotional life, but to the life of others. Nurses must recognize that the women's need for connectedness is an integral part of their well-being, and as such must be respected and/or facilitated. By having insight into the patients' experiences, nurses will be cued in to the how and when to provide the necessary knowledge needed to foster trust and respect, thus assisting and enhancing the women in their own self-empowerment process. This new knowledge will also facilitate an openness and understanding of the possibility of patients' inherent ability to transcend their adversities. In the process of caring for Black/African American women living with HIV disease, this study's findings offer nurses a way of putting new meaning into their everyday world of practice and interaction with patients.

The study also has some practical implications for nursing practice. The findings indicate that for this population, there is an implicit need for consistent sexual assessment and education on safe sexual practices, as well as on assessment of and education related to medication adherence. In addition, the participants clearly identified that there is an ongoing need for supporting and assisting older women with HIV in their disclosure process. The issue of HIV stigma remains a reality in the lives of persons with HIV disease. Nurses, as patient advocates, are in pivotal positions to reduce HIV stigma by educating themselves, members of the health care profession, and society about the impact of HIV stigma.

Research

The purpose of all research is to advance the knowledge base of the profession. This research by studying the experience of living with HIV for this group of older Black/African American women contributes to the body of knowledge in this area. New knowledge has been generated in relation to women with HIV disease caring for others while they cared for themselves. Although the literature has vast numbers of studies on women as caretakers of persons with HIV disease, the data on persons with HIV disease caring for others is sparse. A number of potential questions related to the relationship and/or impact of age, culture, and ethnicity emerged from the findings of this study. This emphasizes the need for further research through the replication of this study and studying the phenomena in relation to the variables of age, other cultures and ethnicities, and the concepts that evolved from the findings. Potential questions include the following: What is the experience of living with HIV disease for older persons of other races and ethnic groups? Are the experiences of Latinas and Caucasian women different or similar to this group of Black/African American women? What roles do age, gender, and ethnicity play in the experience of living with HIV disease? Other questions related to the essential themes may be asked: Does self-transcendence occur in other age groups or is it an inherent quality of older persons who are moving through their natural developmental milestones of self-actualization?

Studies from a quantitative perspective are posed: Is there a relationship between age, the chronicity of HIV disease over time, and self-transcendence? What is the relationship between the phenomenon (living with HIV disease) and the essential themes identified in the findings (self-transcending adversity, caring and being cared for, knowledge as empowerment, HIV stigma, maintaining relationality, concealing while revealing, and tending to one's emotional life). What is the relationship between self-transcendence and the essences revealed in this study in the experience of older women living with HIV disease?

This study also demonstrated that Merleau Ponty's phenomenological approach and Van Manen's methodological processes are viable philosophical approaches and research processes for framing nursing studies that seek to investigate the experience of the living with HIV disease for older Black/African American women. Alternative approaches such as grounded theory may provide additional theoretical support for some of the findings identified in this study. Finally, these findings suggest that a paradigm shift is needed away from focusing on the pathology of aging and HIV disease and toward better understanding how persons despite aging and HIV disease persevere, overcome, and self-transcend obstacles.

Implication of Health Disparities

The implications for health disparities are addressed from a Black feminist perspective. Black feminist Hill Collins (2000) argued that all African American women share a common legacy of struggle. For Black women, that struggle raised the expectation that they be always simultaneously cognizant of being feminist, long before feminism was popular, and being African American. Black/African American women traditionally since the days of slavery have been able to seamlessly integrate the so-called male roles of autonomy and independence with the traditional feminine roles of caretaking and nurturing. However Hill Collins argued that Black/African American women self-defined and possessed the spirit of self-reliance and independence. This echoed the findings of Becker and Newsome (2005) that, in a 10-year qualitative study of 60 African Americans between the ages of 49 and 91, identified that “without exception respondents testified to their high degree of autonomy and repeatedly pointed to their independence” p. S217. This spirit of self-reliance and independence was evident among all the participants in this current study.

Another factor cited for the profound disparities of HIV disease among Black African American women is under education. In this study, all participants had a ninth grade or higher education. Half of the participants had completed the 12th grade, and one had 2 years of college.

Black feminists and other researchers have offered the triple burden of racism, sexual oppression, and economic constraints as factors that place low-income Black/African American women at greatest risk for contracting HIV disease (Gentry, Elifson & Sterk, 2005; Hill Collins, 2000). None of the participants in this study identified racism or sexism as contributing factors to their condition as persons living with HIV disease. However, they all described discriminatory incidences related to their HIV status. Several participants described incidents of childhood incest and partner violence. The incomes of all the participants in this study were at or below the federal poverty level. The majority of participants depended on and interfaced with the social system for their economic well-being. However, despite their financial challenges, the participants made no direct mention of their socioeconomic conditions. Yet as I listened differently and more intently, I heard participants’ concern about the untimely receipt of their food stamps and of not wanting to be a burden to their significant others and family members. I heard of the disrespect one participant experienced when a new case worker visited her home without first calling. I heard, as a matter of fact, of their daily interface with illegal drugs and violence, which was the norm in their neighborhoods. As I listened to the voices of the participants, I heard their passion about self-advocacy, self-reliance, and independence. The women did not blame anyone for their lives’ situation.

In discussing disparities in the prevalence of HIV in the African American community, the case has been made that Black women are disproportionately affected by HIV disease. Some of the women in this study referred to their sense of the inevitability of contracting HIV disease due to the overwhelming predominance of the HIV in their neighborhoods. Morris et al. (2009) argued that network connectivity was the predominant driver of HIV transmission in Black/African American women. Other researchers cited low male-to-female ratio, cultural norms, and the increased rate of Black male incarceration as other major contributing determinants to this disparity (Adimora & Schoenbach, 2005; Morris et al., 2009; Potterat, Brewer, & Brody, 2008; Sohler, Xuan Li, & Cunningham, 2009). Those studies acknowledged that although women, on the whole, experience poorer health outcomes than men, women's disparity in health outcome related to HIV disease in communities of color are even more pronounced. However, for the participants in this study, access to care was perhaps one of the most positive factors in their lives. They all had health insurance and access to a comprehensive, state-of-the-art health care facility with a group of highly knowledgeable providers.

Limitations of the Study

As in the case of any research, this study has some limitations. One limitation of this study was the homogeneity of the sample. The sample was drawn from participants who receive care from a single HIV comprehensive care clinic. The clinic is located in a lower socioeconomic area, and the participants' income was reflective of the area. The geographic surrounding of the clinic has been referred to as an epicenter of HIV disease. However, the area has vast HIV resources such as the clinic that provides state-of-the-art HIV care, open access to care, and renowned clinicians who promote and encourage shared decision making between patients and providers. This type and quality of health care facility, service, and service providers cannot be assumed to be representative of the health care rendered to, or utilized by a majority of older Black/African American women with HIV disease. It is also possible that the providers' involvement in the recruitment process might have biased the participants' decision to be involved in the study. Some volunteer bias might have also been present, as most of the participants had previous experience with various types of HIV research processes.

Recommendations

Recommendations are offered based on the findings, analysis, and conclusion of this study. Replication of this study is recommended in order to develop a larger sample of information in order to gain a more comprehensive understanding of the experience of older Black/African American women. The findings suggest that there is a need for additional research that looks at the phenomena of living with HIV disease from each of the identified essential themes or essences that would further enhance the data on this phenomenon. It is also recommended that future studies include more diverse samples of women in terms of age and ethnicity to determine whether other participants would describe similar or different experiences. The outcomes of this study illuminate the need for continued research into the diversity of human experiences of persons living with HIV disease. A change in recruitment strategies to address possible provider recruitment bias is also recommended.

Researcher's Reflections

The culmination of this study encompassed my reflection on the theoretical findings, the participants, and the overarching theme of self-transcendence. This study, by its methodological approach, did not set out to test or support any theory. However, as the findings of this study are correlated to the current literature, it is evident that perhaps no one theory is adequate to explain the complexity that is a human experience, and perhaps a meta-theoretical approach would be more appropriate to the understanding of the diversity that is human experience. Reed (2008) and Reed, Gehrling, and Memmott (2008) stated that the incorporation of the concepts and theories from other theories and disciplines into nursing theory development can strengthen nursing knowledge by extending and enhancing the explanation the human process and by guiding nurses in theory-based interventions that promote understanding and reconstitution. The phenomenological approach afforded me the luxury of allowing the findings to settle and be viewed where they fell and not to be forced into any one theoretical perspective. In this sense, the phenomenological approach helped me to develop a variety of approaches to building and understanding knowledge.

Reflections on the Participants

I reflected on the paucity of direct description from the women on their racial/ethnic and socioeconomical condition. Throughout the women's narratives, there were only two brief referrals to ethnicity. On one occasion, a participant referred to herself as "a strong Black woman" and the other was when the researcher asked a participant to describe what if anything being an older Black/African American woman meant to her experience. That second participant expanded on the issue of age and being a woman with HIV. No additional mention was made about ethnicity. This raised questions that could be used to generate future research, such as the following: Is ethnicity or race a significant factor in the experience of living with HIV disease? Does the experience of older Black/African American women differ from older Caucasian women or women of other ethnic groups? What role did the researcher's racial and ethnic make-up play? Did the participants assume that a researcher who was of similar racial/ethnic background already knew the community narrative (Van Wormer, Sudduth, & Jackson, 2011) and so it was more expeditious to skip over the experiential impact of age and ethnicity?

Review of the participants' demographic data highlighted some similarities and some differences between this group of participants and the literature. Unlike other studies that found loneliness brought about by solitary living was a factor in the lives of older persons living with HIV disease, for this group of participants, 80% of the them lived with a spouse/ partner and/or children, and 50% were married and/or in a long-term relationship. The time since the participants' diagnosis ranged from 10 to 27 years, providing insightful information into what the long-term experience of living with HIV disease is.

Despite the strength and autonomy the participants demonstrated, the issue of sexual intimacy and sexual decision-making practices remained problematic. Six of the women chose to remain celibate, identifying fear of rejection and/or fear of infecting another person as the main reasons. For the remaining participants, safe sexual practices were not always adhered to. Researchers have identified that high self-efficacy skills, having an HIV-negative partner, and perceived partner's acceptance of condom use are instrumental in consistent condom usage (Raiford et al., 2007). Although it was beyond the scope of this research to follow-up on these issues, these are topics for future research.

The stories described by these women illustrate the 10 or more years that they have lived with HIV disease have been difficult times. The pathway to where they are now has been rocky and nonlinear. Those with histories of illegal drug use recognize that every day that they are drug free is a victory for them. However, despite the difficulties, the women were constantly attempting to attain higher levels of well-being.

Reflections on the Overarching Theme

Self-transcendence according to Frankl (1963) is an inherent capacity that persons have when faced with adversity that allows them to step outside of themselves to reach out, relate to, and find new purpose and create new meaning in their lives (Frankl, 1963). Self-transcendence according to Reed (2004) is moving beyond one's current situation to a broader awareness of others and the environment. Erikson (1974) stated that middle adulthood, ages 40–60, is the stage of generativity versus stagnation. In this stage, adults, in order to set aside thoughts of their own mortality, attempt to seek happiness by caring for and guiding the next generation and creating things that benefit the world, thus achieving a sense of accomplishment and leaving a lasting mark. Reflecting on the overarching theme of the findings of this study makes me wonder how many of the findings are about self-transcendence and how much are about generativity? Is generativity a subset of self-transcendence or is it self-transcendence?

Further reflections of the findings caused me to also wonder whether the participants' age and the amount of time living with HIV disease were major contributing factors in the achievement of the self-transcendence that was articulated by these participants. Further studies looking at persons of different ages and at different points along the disease continuum may give insights into the process of self-transcendence and identify factors that hinder and enhance this process.

The conclusions from this study incorporate the research question and the findings. This phenomenological study was conducted to answer the research question what is the experience of living with HIV disease for Black/African American women age 50 and older? Merleau Ponte's (1945/1962) philosophical perspective served as the underpinning framework for the study. The findings were uncovered by conducting unstructured interviews and in-depth analysis using the seven steps of van Manen's methodological structures of human science research: turning to the phenomena, investigating the experience as we live it, reflecting on the essential themes, describing the phenomena through the art of writing and rewriting, maintaining a strong and oriented relation to the phenomena, and balancing the parts and the whole (van Manen, 1990).

The findings of this study indicate that the experience of this group of older Black/African American women living with HIV disease is a dynamic process of evolving patterns of being and becoming cocreated by the seven essential themes resulting in the textual interpretative statement: The meaning of living with HIV disease for this group of older Black/African American women is dynamic interrelated patterning processes of self-transcending adversity and becoming, tending to one’s emotional life, coping with HIV stigma, using knowledge as empowerment, concealing while revealing, striving to maintain relationality, and caring for others while being cared for.

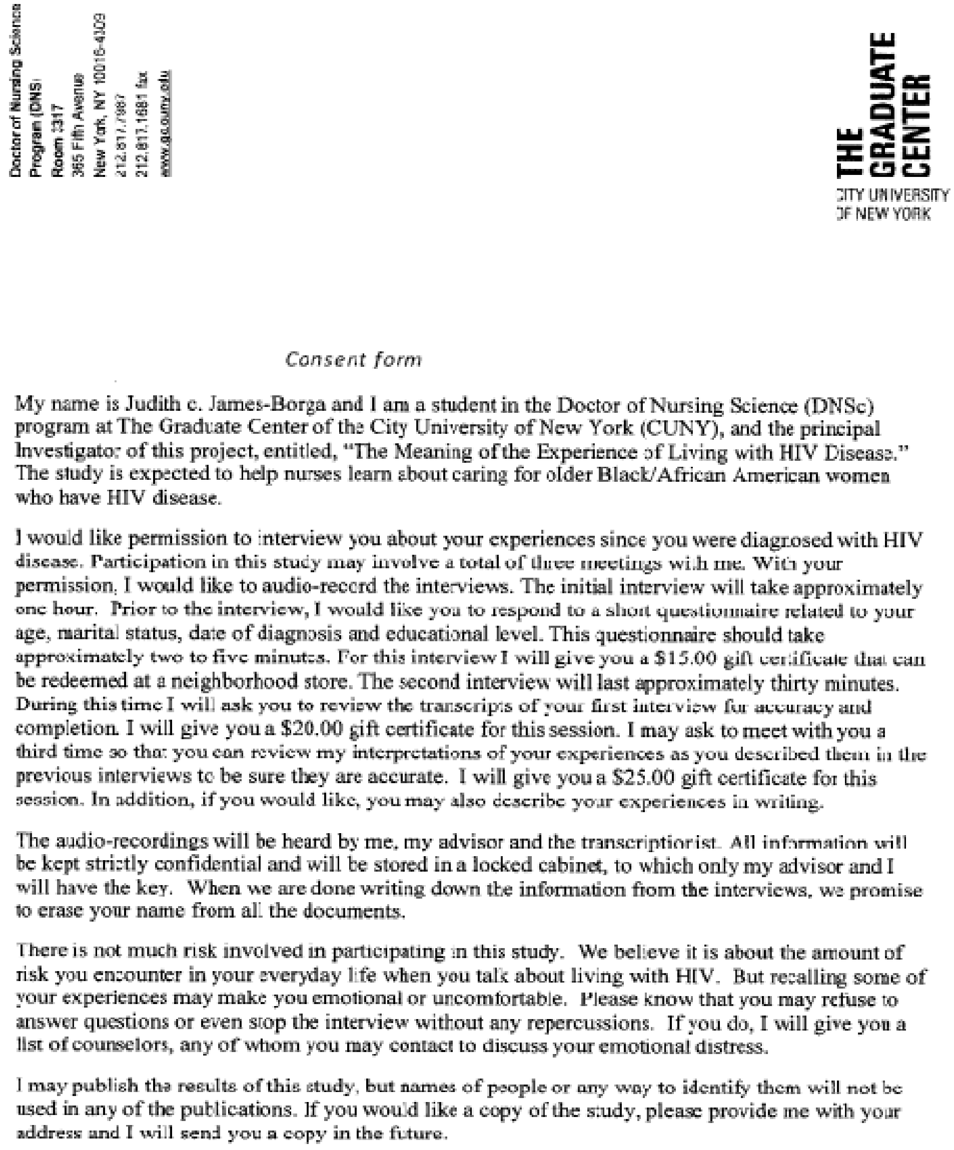
The overarching theme of the findings was self-transcendence. The elements present in the structure of the textual definition correspond to the principles of Reeds theory of self-transcendence, thus providing support for that theory. This study’s findings add to the literature on the lived experiences of older Black/African American women who are living with HIV disease.

Summary of the Chapter

Chapter VI addresses the reflection and conclusions on the findings of this study. The relationship of the findings to the current literature is described. The findings highlight the complexity of the human experience and that multiple theoretical approaches may be needed to gain insight into the human experiences. However, as the overarching theme pointed to self-transcendence, the findings were applied to Pamela Reed’s theory of self-transcendence. Limitations and recommendations for future researcher are offered and the implications for nursing education, practice, and research are identified.

Appendix A

Informed Consent Procedures



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THE GRADUATE CENTER
CITY UNIVERSITY OF NEW YORK

Consent form

My name is Judith c. James-Borga and I am a student in the Doctor of Nursing Science (DNSc) program at The Graduate Center of the City University of New York (CUNY), and the principal Investigator of this project, entitled, "The Meaning of the Experience of Living with HIV Disease." The study is expected to help nurses learn about caring for older Black/African American women who have HIV disease.

I would like permission to interview you about your experiences since you were diagnosed with HIV disease. Participation in this study may involve a total of three meetings with me. With your permission, I would like to audio-record the interviews. The initial interview will take approximately one hour. Prior to the interview, I would like you to respond to a short questionnaire related to your age, marital status, date of diagnosis and educational level. This questionnaire should take approximately two to five minutes. For this interview I will give you a $15.00 gift certificate that can be redeemed at a neighborhood store. The second interview will last approximately thirty minutes. During this time I will ask you to review the transcripts of your first interview for accuracy and completion. I will give you a $20.00 gift certificate for this session. I may ask to meet with you a third time so that you can review my interpretations of your experiences as you described them in the previous interviews to be sure they are accurate. I will give you a $25.00 gift certificate for this session. In addition, if you would like, you may also describe your experiences in writing.

The audio-recordings will be heard by me, my advisor and the transcriptionist. All information will be kept strictly confidential and will be stored in a locked cabinet, to which only my advisor and I will have the key. When we are done writing down the information from the interviews, we promise to erase your name from all the documents.

There is not much risk involved in participating in this study. We believe it is about the amount of risk you encounter in your everyday life when you talk about living with HIV. But recalling some of your experiences may make you emotional or uncomfortable. Please know that you may refuse to answer questions or even stop the interview without any repercussions. If you do, I will give you a list of counselors, any of whom you may contact to discuss your emotional distress.

I may publish the results of this study, but names of people or any way to identify them will not be used in any of the publications. If you would like a copy of the study, please provide me with your address and I will send you a copy in the future.

Appendix B

Site Consent procedures 1

BIOMEDICAL RESEARCH ALLIANCE OF NEW YORK LLC

JACOBI MEDICAL CENTER
SUBJECT INFORMATION AND INFORMED CONSENT FORM

Study Title: The meaning of the experience of living with HIV disease: a study of older Black/African American women
Protocol Number: HIV Disease
Principal Investigator: Judith James-Borga, RN
Institution/Addresses:
Jacobi Medical Center - 1400 Pelham Parkway South, Bronx, New York 10461

North Central Bronx - 3424 Kossuth Avenue Room 10A, Bronx, New York 10467
Telephone: 516-526-9495 (24hour)
HHC#____________________

You are being asked to be a subject in this study because you are a woman with human immunodeficiency virus (HIV). This consent form explains the research study. Before you decide if you want to be part of this study, you need to know why the research is being done, what it will involve and the risks and benefits. Ask the research staff to explain anything that is unclear. Please take time to read this information carefully and feel free to discuss it with your relatives, friends and your primary care physician. To take part in the research study, you must sign this consent form.

DISCLOSURE OF FINANCIAL INTEREST

Neither Jacobi Medical Center nor Ms. James-Borga is receiving payment to conduct this research study. Ms. James-Borga is doing this study as part of her requirements as a student in the Doctor of Nursing Science program at the City University of New York.

STUDY PURPOSE

Subjects in this study will be interviewed about their experiences as someone living with HIV disease. The purpose of this study is to contribute knowledge to help nurses' better care for older Black/African American women who have HIV disease.

NUMBER OF SUBJECTS AND LENGTH OF PARTICIPATION

This is the only study site for this project and about 12 subjects are expected to enroll in the study.

Participation in this study may involve a total of three meetings with me. Study participation may last up to about a month if you are asked to come for all three visits.

STUDY PROCEDURES

The first interview will last approximately one hour. Prior to the interview, I will ask you to respond to a short questionnaire related to your age, marital status, date of diagnosis and educational level. This questionnaire should take approximately two to five minutes.

☐

The second interview will last approximately thirty minutes and will be scheduled one to two weeks after the first interview. During this time I will ask you to review the transcripts of your first interview for accuracy and completion.

☐

I may ask to meet with you a third time, so that you can review, verify, and edit my interpretations of your experiences as you described them in the previous interviews. This meeting will take about 30 minutes.

☐

In addition, should you desire, you may also give me a written description of your experiences of living with HIV disease. This written description of is optional.

Your interview will be audio-recorded. If you do not want your interview audio recorded, you cannot be in this study. The audio-recording will be heard by me, my graduate school advisor and the transcriptionist (person who types up the information from the recording). All information gathered will be kept strictly confidential and will be stored in a locked cabinet. Only my advisor and I will have access to the cabinet. At any time during the interviews you may refuse to answer questions or stop the interview without any penalty.

RISKS OF STUDY PARTICIPATION

The risk involved in participating in this study is minimal, that is, it is no more than that encountered in everyday life. However, recalling some of your experiences may cause some emotional responses and discomfort. You will be given a list of counselors who you may contact if you experience any emotional distress.

NEW INFORMATION

If any new information is learned about this study that might affect your willingness to stay in this study, you will be told about it promptly.

BENEFITS

There is no benefit to you for being in this study. However, it is hoped that your participation will add to the knowledge for health care providers that will help older Black/African American women with HIV disease in the future.

COST

There is no cost to you to be in this study. You and/or your medical insurance will still be responsible, in the usual way, for the costs of your medical care.

REIMBURSEMENT FOR PARTICIPATION

You will receive compensation toward your study visit related expenses. For the first interview you will receive a $15.00 gift certificate. You will receive a $20.00 gift certificate for the second session and a $25.00 gift certificate for the third session. The gift certificates can be used at a neighborhood store. You will receive the gift certificate at the end of each visit or as discussed with the study staff.

COMPENSATION FOR INJURY

Because this study involves only the gathering of information and requires no specific procedures, tests, or treatments, no research-related injuries are expected. No financial compensation will be offered by the sponsor, Jacobi Medical Center, the researcher or the Biomedical Research Alliance of New York. The Health and Hospitals Corporation (HHC) will treat subjects regardless of their inability to pay.

You are not waiving any legal right to seek additional compensation through the courts by signing this form.

ALTERNATIVES

This is not a treatment study. Your alternative to giving the interviews is not to participate.

WITHDRAWAL AND VOLUNTARY PARTICIPATION

Your participation in this study is voluntary. You may refuse to take part in this study, or once in the study, you may stop at any time. You should inform the researcher if you want to leave the study. Your decisions will not affect your current or future medical care or any benefits to which you may otherwise be entitled.

You may be withdrawn from the study at any time without your consent by the researcher or regulatory authorities for any reason. This may happen, for example, if it is believed to be in your best interest, if you do not follow the study instructions, regulatory authorities end your participation in the study or for other administrative reasons. The Health and Hospitals Corporation (HHC) may terminate this study or your participation in this study at any time.

CONFIDENTIALITY

If you would like a copy of the study results, please provide me with your address and I will send you a copy in the future.

To the extent allowed by law, every effort will be made to keep your personal information confidential. However, information from this study will be submitted to the researcher, the researchers graduate school advisor, doctoral committee and others at the institution authorized to review study materials. Study materials which identify you and the consent form signed by you, will be looked at by these people and regulatory agencies, the Institutional Review Board, and the Biomedical Research Alliance of New York. While these parties are aware of the need to keep your information confidential, total confidentiality cannot be guaranteed. The results of this research project may be presented at meetings or in publications; however, you will not be identified in these presentations and/ or publications.

Authorization To Use And Disclose Personal Health Information

Federal regulations give you certain rights related to your health information. These include the right to know who will be able to get the information and why they may be able to get it. The investigator must get your authorization (permission) to use or give out any health information that might identify you.

If you choose to be in this study, the investigator will get personal information about you. This may include information that might identify you. The investigator may also get information about your health, including: Research records

Records about phone calls made as part of this research

Records about your study visits

Information about your health may be used and given to others by the investigator and staff. They might see the research information during and after the study.

Your information may be given to the sponsor of this research. “Sponsor” includes any persons or companies that are working for or with the sponsor, or are owned by the sponsor. Information about you and your health which might identify you may be given to:

Biomedical Research Alliance of New York (BRANY)

The Institutional Review Board

HHC Corporate Research Staff Members

Your personal health information may be further shared by the groups above. If shared by them, the information will no longer be covered by the U.S. federal privacy laws. However, these groups are committed to keeping your personal health information confidential.

If you give permission to give your identifiable health information to a person or business, the information may no longer be protected. There is a risk that your information will be released to others without your permission.

Information about you and your health that might identify you may be given to others to carry out the research study. The sponsor will analyze and evaluate the results of the study. In addition, people from the sponsor and its consultants will be visiting the research site. They will follow how the study is done, and they will be reviewing your information for this purpose.

This Authorization does not have an expiration date. If you do not withdraw this Authorization in writing, it will remain in effect indefinitely.

By signing this consent form, you are giving permission to use and give out the health information listed above for the purposes described above. You do not have to sign this consent form. If you choose not to sign this consent form, you will not be able to be in this research study. Your decision not to sign this consent form will not have any effect on your medical care and you will not lose any benefits or legal rights to which you are entitled.

You have the right to review and copy your health information. However, if you decide to be in this study and sign this permission form, you may not be allowed to look at or copy your information until after the research is completed.

You may withdraw or take away your permission to use and disclose your health information at any time. You do this by sending written notice to the investigator at the address on the front of this informed consent form. If you withdraw your permission, you will not be able to continue being in this study, but you will not have any penalty or loss of access to treatment or other benefits to which you are entitled. When you withdraw your permission, no new health information which might identify you will be gathered after that date. Information that has already been gathered may still be used and given to others. This would be done if it were necessary for the research to be reliable. Notice Concerning HIV-Related Information: The recipients of HIV-related information are prohibited from redisclosing it without your authorization unless permitted to do so under federal or state law. You also have a right to request a list of people who may receive or use your HIV-related information without authorization. If you experience discrimination because of the release or disclosure of HIV-related information, you may contact the New York State Division of Human Rights at 212-480-2493 or the New York City Commission on Human Rights at 212-306-7450.

These agencies are responsible for protecting your rights.

CONTACTS - QUESTIONS, CONCERNS

If you have any questions, concerns or complaints about this research or you feel you have a study related injury, you can Judith James-Borga at 516-526-9495 or Judi8095a@aol.com, or contact her advisor, Dr. Keville Frederickson, at 212-817-7985 or Keville.Frederickson@lehman.cuny.edu.

If you have any questions about your rights as a subject in this study, or complaints regarding this research study, or you are unable to reach the research staff, you can contact a person independent of the research team at the Biomedical Research Alliance of New York Institutional Review Board at 516-318-6877. Questions, concerns or complaints about research can also be registered with the Biomedical Research Alliance of New York Institutional Review Board at www.branyirb.com/concerns-about-research.

CONSENT - SIGNATURES

I have read this form and know what is involved with the study.

By signing this form I am agreeing to have my interviews audio-recorded.

You will receive a signed copy of this form to take with you.

I voluntarily agree to be in this study.

________________________ ________________________________ ______

Subject's Name (Print) Subject’s signature Date

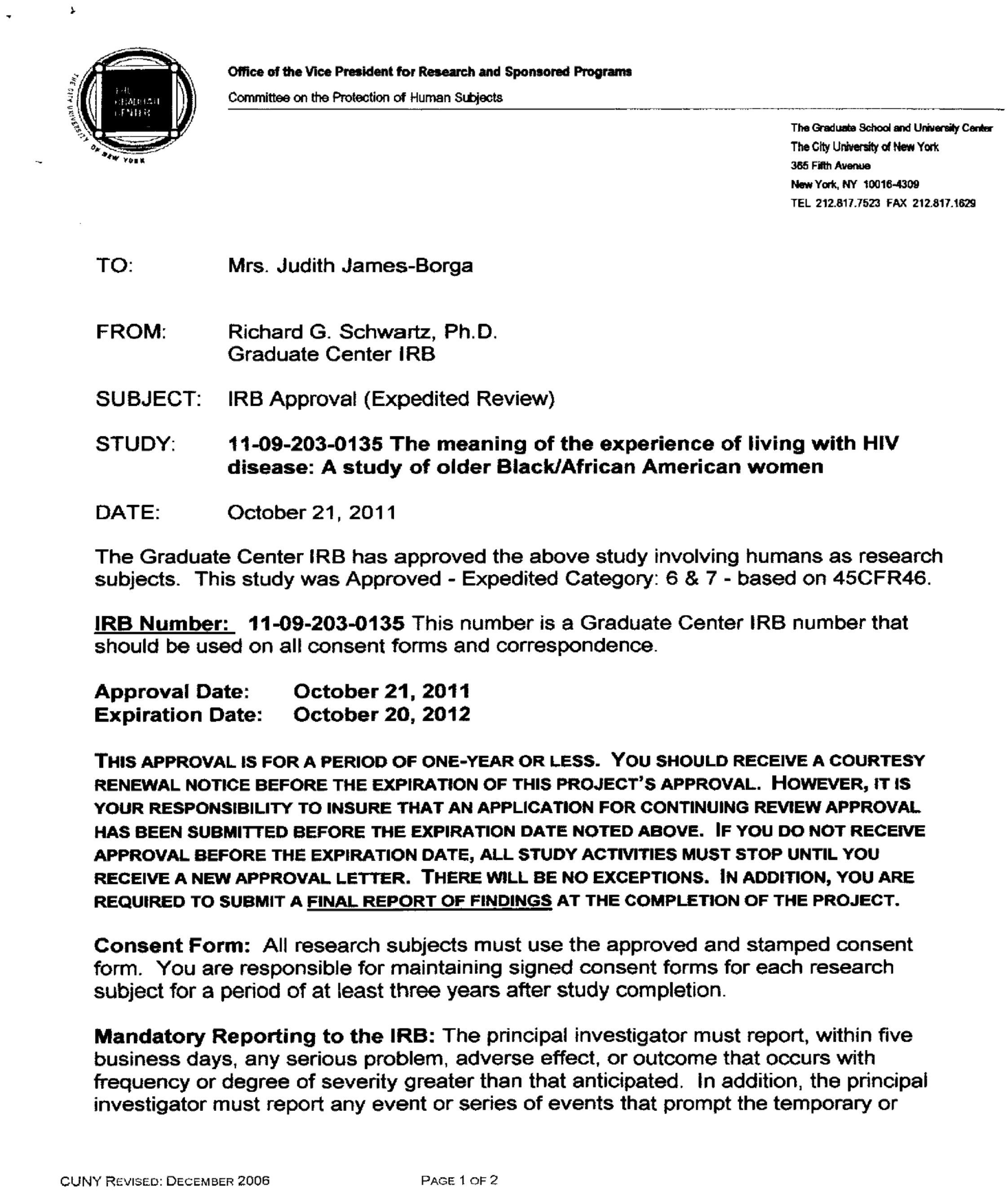
________________________ ________________________________ ______

Investigator's Name (Print) Investigator’s Signature Date

Version A Protocol#: HIV Disease Page 5 of 5 IRB approved from 12Jan2012 through 01Jan2013.

APPENDIX C

CUNY IRB Approval



Office of the Vice President for Research and Sponsored Programs
Committee on the Protection of Human Subjects

The Graduate School and University Center
The City University of New York
365 Fifth Avenue
New York, NY 10016-4309
TEL 212.817.7523 FAX 212.817.1629

TO: Mrs. Judith James-Borga

FROM: Richard G. Schwartz, Ph.D.
Graduate Center IRB

SUBJECT: IRB Approval (Expedited Review)

STUDY: **11-09-203-0135 The meaning of the experience of living with HIV disease: A study of older Black/African American women**

DATE: October 21, 2011

The Graduate Center IRB has approved the above study involving humans as research subjects. This study was Approved - Expedited Category: 6 & 7 - based on 45CFR46.

IRB Number: 11-09-203-0135 This number is a Graduate Center IRB number that should be used on all consent forms and correspondence.

Approval Date: October 21, 2011
Expiration Date: October 20, 2012

THIS APPROVAL IS FOR A PERIOD OF ONE-YEAR OR LESS. YOU SHOULD RECEIVE A COURTESY RENEWAL NOTICE BEFORE THE EXPIRATION OF THIS PROJECT'S APPROVAL. HOWEVER, IT IS YOUR RESPONSIBILITY TO INSURE THAT AN APPLICATION FOR CONTINUING REVIEW APPROVAL HAS BEEN SUBMITTED BEFORE THE EXPIRATION DATE NOTED ABOVE. IF YOU DO NOT RECEIVE APPROVAL BEFORE THE EXPIRATION DATE, ALL STUDY ACTIVITIES MUST STOP UNTIL YOU RECEIVE A NEW APPROVAL LETTER. THERE WILL BE NO EXCEPTIONS. IN ADDITION, YOU ARE REQUIRED TO SUBMIT A FINAL REPORT OF FINDINGS AT THE COMPLETION OF THE PROJECT.

Consent Form: All research subjects must use the approved and stamped consent form. You are responsible for maintaining signed consent forms for each research subject for a period of at least three years after study completion.

Mandatory Reporting to the IRB: The principal investigator must report, within five business days, any serious problem, adverse effect, or outcome that occurs with frequency or degree of severity greater than that anticipated. In addition, the principal investigator must report any event or series of events that prompt the temporary or permanent suspension of a research project involving human subjects or any deviations from the approved protocol.

Amendments/Modifications: All amendments/modifications of protocols involving human subjects must have prior IRB approval, except those involving the prevention of immediate harm to a subject. Amendments/modifications for the prevention of immediate harm to a subject must be reported within 24 hours to the IRB.

Stipulations:

I-9. Other Description: *No answer entered.*

If you have any questions, please do not hesitate to contact Kay Powell in the IRB Office at 212-817-7525.

Good luck on your project.

cc: Keville Frederickson
DNS Program

Sign the Verification Statement below. Return the original signed copy of this memo to the IRB Office and retain a copy for your records. The IRB Office must receive a copy of the signed verification statement before research may begin.

VERIFICATION:

BY SIGNING BELOW, I ACKNOWLEDGE THAT I HAVE RECEIVED THIS APPROVAL AND AM AWARE OF, AND AGREE TO ABIDE BY, ALL OF ITS STIPULATIONS IN ORDER TO MAINTAIN ACTIVE APPROVAL STATUS, INCLUDING TIMELY SUBMISSION OF CONTINUING REVIEW APPLICATIONS AND PROPOSED PROTOCOL MODIFICATIONS, AS WELL AS PROMPT REPORTING OF ADVERSE EVENTS, SERIOUS UNANTICIPATED PROBLEMS, AND PROTOCOL DEVIATIONS. I AM AWARE THAT IT IS MY RESPONSIBILITY TO BE KNOWLEDGEABLE OF ALL FEDERAL, STATE AND UNIVERSITY REGULATIONS REGARDING HUMAN SUBJECTS RESEARCH INCLUDING CUNY'S FEDERALWIDE ASSURANCE (FWA) WITH THE DEPARTMENT OF HEALTH AND HUMAN SERVICES OFFICE OF HUMAN RESEARCH PROTECTIONS.

11-3-11

Signature of Principal Investigator — Date

Keville Frederickson 11-5-11

Signature of Faculty Advisor for Student Research — Date

The City University of New York

Human Research Protections Program
Herbert H. Lehman College (CUNY) HRPP Office

DATE:	March 25, 2013
TO:	Judith C James-borga, MS
FROM:	Herbert H. Lehman College (CUNY) HRPP Office
PROJECT TITLE:	[393143-1] The meaning of the experience of living with HIV disease: A study of older Black/African American women
SUBMISSION TYPE:	Continuing Review/Progress Report
ACTION:	APPROVED
APPROVAL DATE:	December 7, 2012
EXPIRATION DATE:	December 6, 2013
RISK LEVEL:	Minimal Risk
REVIEW TYPE:	Expedited Review
REVIEW CATEGORY:	Expedited review categories # *6 & 7*

Thank you for your submission of Continuing Review/Progress Report materials for this project. The University Integrated IRB has APPROVED your research. This approval is based on an appropriate risk/ benefit ratio and a project design wherein the risks have been minimized. All research must be conducted in accordance with this approved submission.

Please remember that informed consent is a process beginning with a description of the project and assurance of the participant's understanding, followed by a signed consent form(s). Informed consent must continue throughout the project via a dialogue between the researcher and research participant. Federal regulations require that each participant receives a copy of the consent document.

Please note that any modifications/changes to the approved materials must be **approved by this IRB prior to implementation.** Please use the appropriate modification submission form for this request.

All **UNANTICIPATED PROBLEMS (UPS)** involving risks to subjects or others, NON-COMPLIANCE issues, and SUBJECT COMPLAINTS must be reported promptly to this office. All sponsor reporting requirements must also be followed. Please use the appropriate submission form for this report.

This research **must receive continuing review and final IRB approval** before the expiration date of December 6, 2013. Your documentation for continuing review must be received with sufficient time for the IRB to conduct its review and obtain final IRB approval by that expiration date. Please use the appropriate continuation submission forms for this procedure. PLEASE NOTE: The regulations do **not** allow for any grace period or extension of approvals.

If you have any questions, please contact Tara Prairie at (718) 960-8960 or tara.prairie@lehman.cuny.edu. Please include your project title and reference number in all correspondence with this committee.

NEW YORK CITY HEALTH AND HOSPITALS CORPORATION

160 Water Street, 11th Floor

New York, New York 10038

HHC CENTRAL OFFICE APPROVAL LETTER

To: James-Borga, Judith MD

From: Central Office Research Reviewer

Date: 01/30/2012

Title: The meaning of the experience of living with HIV Disease: A study of older Black/African American Women.

HHC Protocol Number: 12-004 IRB Number: BR 12-01

Dear Dr. James-Borga**,**

This research project has been approved by the HHC Central Office Research Reviewer and is authorized for implementation at Jacobi Hospital for no longer than 365 days beginning on 01/30/2012 unless specified for a lesser approval period by the IRB. This authorization is contingent upon current documentation of IRB and HHC approval for all types of IRB reviews for the duration of this research project. No investigator may recruit any patients or continue research project implementation unless all types IRB **and** HHC approvals are both documented as current. As a principal investigator, it is your responsibility to notify your Facility Research Coordinator within 72 hours if your protocol has been withdrawn, suspended, terminated, and/or closed by the IRB.

NYC HHC requires that investigators:

- Ensure research-related tests and procedures rendered during the course of the research project are not billed as ‘standard of care’ but billed to the research project agreement, grant, or contract;
- Provide the facility with a list of all subjects initials, where recruited and/or enrolled, medical record number and protocol number upon request;
- Obtain IRB **and** HHC approval for all amendments and modifications;
- Report all adverse events to the IRB;
- Report all local serious adverse events to HHC;
- Report changes that require further conflict of interest disclosure;
- Ensure that signed informed consent documents are kept in the subjects medical record; and
- Notify the HHC about changes in sponsored program funding agreements, grants, or contracts.

If you have any questions about this letter or other research matters, please call your Facility Research Coordinator.

CC: Facility Research Review Committee

THE CITY UNIVERSITY OF NEW YORK

SUBJECT INFORMATION CONFIDENTIALITY AGREEMENT

Name:______________________________________

Position:______________________________________

I recognize that, in the course of my participation as an investigator, co-investigator, or an agent or contractor of an investigator conducting *CUNY* human subjects research, I may gain access to subject information, including information about health, mental health, medical care, or payment for health care, that must under law must be treated as confidential and disclosed only under limited conditions. I agree that:

1. I will keep confidential all information to which I gain access that is or can be identified to a particular subject (described in this agreement as "information").

2. I will access and use information only in connection with a research protocol that has received CUNY Institutional Review Board approval, or for reviews preparatory to research for which I have received authority to conduct from the entity or individual maintaining the information.

3. I will not redisclose information except to the extent required by applicable laws, including but not limited to federal laws governing drug and alcohol treatment programs-and-state laws governing HIV information, or as permitted under the terms of a research subject's written authorization or an IRB's waiver of the authorization requirement.

4. 1 will not discuss information in public places or outside of work.

5. I will access information only concerning subjects for whom IRB approval has been given, and will not access information for other individuals, except during a review preparatory to research with the approval of the entity or individual

maintaining the information.

6. 1 will take all reasonable and necessary precautions to ensure that the access and handling of information are conducted in ways that protect subject confidentiality to the greatest degree possible. This includes maintaining such information in secured and locked locations.

I understand that it is my obligation and responsibility to maintain the confidentiality of all subjects' information. Improper disclosure or misuse of such information, whether intentional or due to neglect on my part, may be a breach of privacy and/or confidentiality and a violation of federal regulations, which could result in the loss of my continued access to subjects' information or other penalties for myself or my institution.

Signature:______________________________
Date:___________________________________

A study of the meaning of the experiences of living with HIV disease.

DEMOGRAPHIC QUESTIONNAIRE

Thank you for agreeing to participate in this study. Please complete the following demographic questions.

Code__________________

Q1. In what year were you born? ____

Q2. Race: Please Circle the correct response Are you Black//African American Yes No

Q.3 When did you first learn of your HIV status Date: ___________

Q4. Personal Relationship Status:

What is your current status? o Married o Widowed

o Divorced or separated o Never married

o In a long term relationship o Not in a relationship

Q5. Education: o Attended school Yes No

What is the **highest** degree or level of school you have completed?

Nursery school to 8th grade

9th, 10th or 11th grade

High school graduate - high school diploma or the equivalent (for example: GED)

1 -2 years of college, no degree or Associate degree (for example: AA, AS)

Bachelor's degree (for example: BA, AB, BS)

Graduate degree or professional degree (for example: MA, MS, MEd, MSW, MBA, JD, MD)

Q5. **Are you currently employed:** Circle one Yes

No

If employed, are you:

Employed full time.

Employed part time

Q6. Do you live:

Alone

With a spouse or partner

With a spouse and children

With extended family

With friends

Protocol: 11-09-203-0135

JJB A study of the meaning of the experiences of living with HIV disease.

The meaning of the experience of living with HIV disease: a study of older Black /African American women
Protocol: 11-09-203-0135

Sample Questions

To conduct research from a phenomenological perspective is to explore the way human beings experience the world (van Manen, 1990). This approach seeks to know the world in which we live, by questioning the way individuals experience the world. In this study, participants are asked to talk about the experience of having HIV. They are asked for a description of the lived, through quality of their experience, and a description of the meaning of the expressions of the lived experience. The objective is a description aimed at elucidating the full structure of the experience or what the experience meant to those who lived it.

While the formal research question is:

What is the meaning of the experience of living with HIV disease for African American women?

At the first interview, the participants will be asked an initial open ended question:

“Tell me about yourself.” This question will act as an icebreaker to the research question,

The follow-up questions will be:

“Would you please tell me what it is like is for you, to be living with HIV disease?”

“Since you have been diagnosed with HIV, describe for me your experiences with friends, family and health care providers.”

As the participants describe their experiences, I may ask specific questions to clarify their descriptions.

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