2010

African American Women Living with HIV/AIDS : A Phenomenological Inquiry

Lonar Anthony Umadhay

AFRICAN AMERICAN WOMEN LIVING WITH HIV/AIDS:
A PHENOMENOLOGICAL INQUIRY

DISSERTATION

Presented in Partial Fulfillment of the
Requirements for the Degree of
Doctor of Philosophy in Nursing

Barry University

Lonar Anthony Umadhay, MSN, CRNA

2010

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by

Lonar Anthony Umadhay

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APPROVED BY:

Jessie Colin, PhD, RN
Chairperson, Dissertation Committee

John McFadden, PhD, CRNA
Member, Dissertation Committee

Shane Neely-Smith, PhD, RN
Member, Dissertation Committee

Claudette Spalding, PhD, ARNP, CNAA
Chair, Division of Nursing

Pegge Bell, PhD, RN
Dean, College of Health Sciences

Abstract

Background: African American women (AAW) account for the majority of new HIV/AIDS cases in the US (CDC, 2006). Although researchers have begun to examine important issues associated with AAW and HIV/AIDS, research delving into the in-depth understanding of the complexities of their lived experience has been limited.

Purpose: The purpose of this study was to explore the lived experience of AAW living with HIV/AIDS.

Methods: A qualitative method in the tradition of phenomenology provided the most meaningful platform for understanding the human experiences of AAW living with this disease. The research question "What is the lived experience of AAW living with HIV/AIDS?" was answered through semi-structured, face-to-face, audiotaped interviews that lasted no more than one hour. A purposive sample of 14 AAW over 18 years old who self-identified as HIV- positive and residing in South Florida were interviewed. Participants were contacted for a second one-hour, face-to-face meeting after data transcription for verification and member checking. The researcher used the hermeneutic phenomenological approach by van Manen (1990) that encourages use of a concurrent, continuous, and dynamic cycle. This cycle involves the process of describing, interpreting, and textual writing for data analysis.

Results: Three related themes of *shattering self*, *constructing meaning,* and *empowering* emerged through this phenomenological investigation. These themes vividly illuminated the totality of this experience filtered through these AAW's existential lifeworlds of space, body, time, and human relation. Starck's (2003) middle range theory of meaning provided a framework for gaining a deeper and more authentic understanding of this phenomenon.

Conclusion: The essence of this lived experience is a dynamic process that includes the initial shattering of one’s view of self and the world, an attempt in reconstructing prior assumptions and finding meaning in a negative situation, and an empowering experience of being in control and achieving one’s life purpose. Study findings illustrated the vital need for meaning construction through the suffering experienced by AAW with HIV/AIDS. Thus, for healthcare providers, understanding the deep level at which this experience affects AAW appears to be a fundamental precursor for the provision of effective and culturally sensitive support.

DEDICATION

This work is dedicated to my study participants.

Fourteen courageous and selfless women who reflected on their past,
relived their painful experiences, and shared their most intimate stories.

These women have inspired me to become more fully human.

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CHAPTER I

Problem and Domain of the Inquiry

Introduction

> My name is Pam, I'm an addict, and I'm HIV positive. Now, you've got a choice right then and there if you want to take this any further. Either way, it's still not leaving me. When I walk away from you, I'm still an addict, I'm still HIV positive, and I'm still Pam …I think that healthcare workers need to listen to the patient. Two years ago, I finally got a doctor who *touched* me. How are you gonna diagnose me or give me any kind of proper care when you won't even touch me? (P. N., 47, Brooklyn, NY)

This poignant anecdote of an African American woman living with the HIV infection was one of many such transcripts from *Inspiring Stories: Women with HIV (Profiles of Courage)*, posted on The Body: The Complete HIV/AIDS Resource website (The Body: Health Resources Corp., 2006). No qualitative or quantitative data analysis exists in these heart wrenching stories, and each illustrates a different concern that accompanies life for a person with HIV. Clearly, the passage of time has not lessened the impact of this disease in every aspect of the infected person's life.

After three decades, HIV remains one of the most deadly infectious diseases that ever challenged the global health system. Since the discovery of the disease, 25 million deaths have resulted from HIV/AIDS worldwide. Every day, 6,800 people get infected with HIV and 5,700 die from AIDS related illnesses (Joint United Nations Programme on HIV/AIDS [UNAIDS], 2007). In the United States, the Centers for Disease Control (CDC) reported that 56,300 new cases of HIV occurred in 2006 (CDC, 2006). These statistics reveal that HIV remains a major health crisis and an alarming reality confronting nurses and other healthcare providers throughout the world.

HIV has decreased the quality of life and widened healthcare disparities among millions of people. In spite of the advances in interventions and the decrease in HIV infection rates in other risk groups, African American women (AAW) remain disproportionately affected. The rate of AIDS diagnosis in AAW was 20 times more than the rate for white women in 2005 (CDC, 2005), and African Americans represent 66% of women with new HIV infections. In 2004, HIV infection was the leading cause of death in AAW aged 25-34 years and the third leading cause of death for AAW aged 35-44 years (CDC, 2006).

The phenomenon of increased HIV incidence and morbidity in AAW is complex. The literature suggests there are disproportionately high infection rates and large numbers of this population at risk for HIV infection. Concurrently, as a group AAW experience greater difficulties in accessing care and adherence to treatment regimens. These disparities in healthcare translate into poor health outcomes related to preventable illness and deaths (National Minority AIDS Council [NMAC], 2006). Although the literature has begun to examine the important issues associated with AAW and HIV, the holistic perspective of AAW with HIV warrants further exploration. Understanding the life-world of these women as they live with HIV infection is crucial for healthcare professionals as they strive to provide unbiased, culturally competent and compassionate care to this marginalized population and construct interventions to effect improved outcomes.

Statement of the Problem

The HIV epidemic has caused immense human suffering, economic damage and loss of lives. Worldwide, a staggering 285 persons will be infected with HIV every hour (UNAIDS, 2007). Nearly half of this population will be women of ethnic minority groups. The disproportionate impact of the HIV/AIDS epidemic on racial and ethnic minorities, specifically the AAW population, is increasing. In-depth understanding of what constitutes this complex phenomenon, and the resulting unique experiences (e.g., idiosyncratic meaning of daily reality) of this group is sorely lacking. Understanding the experience of AAW living with HIV is imperative for nurses and other healthcare providers, so they may provide appropriate interventions to this marginalized population. Appreciating the experiences of these women living with HIV is fundamental in rendering holistic, compassionate, and culturally appropriate care that is integral to the practice of nursing and necessary to decrease this ethnic epidemic of catastrophic proportion.

Purpose of the Study

The purpose of this study was to describe the life experiences of AAW living with the HIV infection in an effort to shed new light on how this group constructs meaning structures and provide intricate effects of this phenomenon on the lives of those affected. The researcher described, interpreted, and communicated the meaning of living with the epidemic through the stories of individuals who experienced this phenomenon. This qualitative phenomenological study highlighted AAW’s experience and expressions of their lifeworld as they perceived them.

Research Question

The overarching research question that guided this study was as follows: "What is the lived experience of the African American woman living with HIV?"

Significance to Nursing

This study's significance is that it provides insight into the unique experiences of a specific ethnic group of women living with HIV—a group not commonly heard—through their authentic stories. Through deeper understanding of these women's experiences, biases might be decreased as nurses come to appreciate and recognize the unique factors involved in this phenomenon. In addition, understanding their experiences may facilitate higher levels of context-dependent nursing care that is informed by compassion and insight gained from the patients, themselves.

The significance of this study will be to communicate the phenomenon of living with the HIV infection through the stories of AAW experiencing this illness. This study highlighted these women's healthcare-related concerns, uncovered the idiosyncratic meanings of their illness, and will allow healthcare providers to understand this complex experience and the resources these women need to support a positive outcome.

Professional nurses are charged with the responsibility to provide culturally competent care. This is a challenge for nurse educators, practitioners, and researchers because of the diverse population of the United States. This study provides an in-depth description and interpretation of the experience of living with and making meaning of HIV for victims, particularly AAW. Understanding their lived experiences through their own personal and authentic stories may help both nurses and patients mutually participate in identifying healthcare needs and may enhance facilitation of compassionate, culturally tailored interventions.

Nursing Education

Cultural competency is considered essential to professional nursing practice. Both the National League for Nursing Accrediting Commission, Inc. (NLNAC) and Commission on Collegiate Nursing Education (CCNE) address the need for preparing professional registered nurses to meet the needs of a highly diverse population. The NLNAC (2005) mandates that academic nursing programs ensure their graduates are able to render culturally competent nursing care at basic and advance practice levels. CCNE (2008) supports the rationale for integrating cultural competence as a required core competency in nursing education that will address and attempt to eliminate healthcare disparities in preparing professional nurses. The nursing literature is prolific on the topic of cultural competence, and the profession has taken a leadership role in this initiative; cultural competence terminology and definitions were provided by nurses over two decades ago (Campinha-Bacote, 1995; Leininger, 1991; Meleis, 1996). Rosenjack-Burcham (2002) provides an encompassing definition by describing five different components of culture competence: awareness, understanding, sensitivity, interaction, and skill. *Cultural awareness* refers to developing a consciousness of culture and the ways in which culture shapes values and beliefs. *Cultural knowledge* refers to the acquisition of information about different cultures. *Cultural understanding* refers to the ongoing development of insights related to the influence of culture on the beliefs, values, and behavior of diverse groups of people. *Cultural sensitivity* develops as one comes to appreciate, respect, and value cultural diversity. *Cultural interaction* refers to the personal contact, communication, and exchanges that occur between individuals of different cultures. And finally, *cultural skill* is the ability to communicate effectively and to incorporate the client's beliefs, values, and practices into the provision and planning of care (Rosenjack-Burcham, 2002).

Despite challenges related to cultural diversity in the U.S. population, integrating cultural competence in nursing curriculums, including diverse types of relevant knowledge (e.g., AAW’s experience with the HIV infection), is required if we are to rigorously adhere to mandates of NLNAC (2005) and CCNE (2008). These academic efforts promote application of the major components of cultural competency defined by Rosenjack-Burcham (2002) in rendering care to this specific population. Findings from this study may increase awareness and may provide a deeper understanding of the idiosyncratic lifeworld experienced by this marginalized and vulnerable population. Findings of this proposed study may help in developing a context-specific curriculum focused on the unique needs of AAW dealing with the HIV infection. Failure to do so may result in a group of biased and uninformed healthcare workers entering the nursing profession.

Nursing Practice

Leninger (1978) supports the thesis that “the most unifying, dominant, and central intellectual and practice focus in nursing is caring” (p. 13). No discipline is viewed as having this direct an involvement in meeting the needs of patients. It is clear that most nurses in clinical practice perceive caring as the essence and core of nursing. Appreciating ways of understanding the experience of people going through an illness is fundamental for compassionate and competent nursing care. Roach (1992) emphasized that competence without compassion is brutal and compassion without competence is irresponsible.

The increasing incidence of AAW being infected with HIV poses a challenge to clinical nurses and their efforts to provide competent and compassionate care to this marginalized population. Advancing the understanding of AAW as they live with the HIV infection through this investigation is integral to the provision of nursing care. In appreciating these women's experiences, the nurse and the patient may mutually acknowledge priorities of care and enhance ways of caring to support health and well-being.

This study contributes knowledge toward development of cultural competence in clinical nursing practice. Watts (2003) indicated that the presence of healthcare disparities provides compelling evidence that issues of race or skin color still persist. Nurses providing care for African Americans, particularly those with HIV, may be challenged to bridge the racial divide and incorporate culturally relevant content in practice. To do this, they must incorporate the idea of race consciousness for this vulnerable population (Watts, 2003). Like other health professions, nursing has subscribed to building an evidence-based practice. Findings of this study may add to nursing's body of knowledge by investigating a phenomenon with which nurses will increasingly be faced. Detail-rich descriptions of the lived experience of AAW living with the HIV infection may highlight these women's healthcare concerns and the challenges they face. Thus, findings provided a deeper understanding of this complex experience, a description of the AAW's vulnerable state, and the resources these women need to support a healthy and positive outcome. Information gathered from this study can be used to design effective health interventions specific to this ethnic group and to promote informed, culturally appropriate healthcare, also considered a significant safety issue (Joint Commission on Accreditation of Healthcare Organizations, 2007).

Lastly, intervening to end social bias and prejudice remains a challenge for the nursing profession. In the American Nurses Association (ANA) Code of Ethics for Nurses with Interpretive Statements (2001), nurses were called to advocate for members of marginalized groups. In Provision 1, the Code of Ethics requires that "the nurse, in all professional relationships, practices with compassion and respect for the inherent dignity, worth, and uniqueness of every individual, unrestricted by considerations of social or economic status, personal attributes, or the nature of health problems." Again, in interpretive statement 1.2, ("Relationship with Patients"), the Code of Ethics affirms that the nurse "establishes relationships and delivers nursing services with respect for human needs and values, and without prejudice." This study adds support to this important calling of the nursing profession.

Nursing Research

Nurse researchers are committed to building a knowledge base supported by data from scientific inquiry. Nurturing a culture of evidence-based practice in nursing is essential to the advancement of clinically effective interventions. Sigma Theta Tau International (2005) defines *evidence-based practice in nursing* as the "integration of the best evidence available, nursing expertise, and the values and preferences of the individuals, families, and communities who are served." The advancement of nursing research results in the acquisition of knowledge necessary for the nurse to practice competently and design effective interventions based on scientific data. Evidence-based practice has the potential to promote improved patient outcomes (Profetto–McGrath, 2005). The phenomenon of living with the HIV infection in AAW is poorly understood. This increasingly common diagnosis places these women in a state of vulnerability that was further investigated in this study, and this inquiry supports the initiatives of the nursing profession to build a scientific body of evidence in which to base clinical practice. Understanding the idiosyncratic meaning of living with the HIV infection for these AAW highlighted their healthcare concerns, risk behaviors, gaps in support, and knowledge deficits. Results of this study also contribute to nursing research through theory building and knowledge generation, which provide greater insight into nursing science as it relates to life with HIV experienced by a marginalized population. Findings also provide both nurses and patients with new science to mutually plan and design effective interventions that promote health and wellness specific to the needs of this group.

Public Policy

Policymakers, administrators, and stakeholders may use findings of this study to fully understand the ramifications of living with this epidemic and to make decisions about funding based directly on the experiences of the people they are trying to help. Understanding this phenomenon may increase awareness of the needs of this specific population and encourage further research related to the care of this group. Finally, findings may be used to establish practice standards for female African American HIV patients and improve their access to quality care.

Philosophical Underpinnings

A philosophical framework provides the basic set of beliefs that guides a study (Speziale & Carpenter, 2007). The framework helps the researcher conceptualize and contextualize through the philosophical frame and thus serves to provide a direction and focus. The framework also assists the researcher in explication of data and allows for establishment of standards of acceptability for study methods and findings.

This study described and interpreted the experiences of a specific group of individuals as they live with an illness. Since knowledge of human behavior was being sought, a component of subjectivity was inherent in the assumptions guiding this investigation. Describing and interpreting lends itself to a philosophical framework that embraces multiple realities and contexts. This is consistent with a post-modern perspective, which supports the belief that reality is contextual and unique (Speziale & Carpenter, 2007).

Qualitative Approach

In order to better grasp the rich details and meanings of the experiences of AAW living with HIV, the lived experience of this phenomenon needed to be explored. The overarching question proposed was: “What is it like to be an African American woman infected with HIV/AIDS?” Exploring the experience of a life phenomenon and crediting meaning to its structures favored the use of qualitative research methods. Creswell (1998) supports this rationale, adding that qualitative research methods are more suitable for topics that require detailed exploration. Thus, fully capturing what it was like to live as an African American woman with the HIV infection warranted in-depth investigation.

The aim of this study is to gain a deeper understanding and see the world through the eyes of AAW living with HIV. Exploring this phenomenon and detailing the meaning of this experience supports the use of a qualitative research method over a quantitative design. A qualitative methodology in the tradition of phenomenology provided the most meaningful platform for describing, exploring, and understanding the human experiences of these women as told in their own voices.

Phenomenology

*"*Phenomenology aims at gaining a deeper understanding of nature or meaning of our everyday experience" (van Manen, 1990, p. 9). It is the study of a concept or phenomenon with the goal of understanding the meaning of individuals' experiences with the concept or phenomenon (Creswell, 1998). This descriptive approach seeks to elucidate the structure and essences that give form and meaning into the lifeworld of the people or persons being studied. Phenomenology attempts to make the invisible visible (Osborne, 1994).

Five philosophical assumptions are embedded in the phenomenological paradigm: ontological, epistemological, axiological, rhetorical, and methodological (Creswell, 1998). *Ontology* is the study of the nature of reality and is concerned with what constitutes the world. In phenomenology, the ontological assumption is that there are multiple realities and different perspectives. *Epistemology* addresses the relationship between the researcher and what is being studied. It is the study of the nature of knowledge and justification. The epistemological assumption in phenomenology is described as transactional subjectivism, in which the researcher is closely engaged in the study. *Axiology* refers to the role of values in the study. In this respect, the researcher acknowledges that the study is value-laden and accepts and embraces the presence of biases. *Rhetoric* involves the language of research, assumed to be literary and informal. Finally, *methodological assumption* refers to the process of research and how the inquiry would proceed. In phenomenology, the methodological assumption is inductive, contextual and develops within an emerging design (Creswell, 1998).

A qualitative research design in the tradition of phenomenology was the choice for determining the essence of this phenomenon and uncovering the meaning structures in the experience of AAW living with HIV. Speziale and Carpenter (2007) describe phenomenology as a "science whose purpose is to describe a particular phenomenon or the appearance of things, as lived experience" (p. 76). They also emphasize that it "is as much a way of thinking or perceiving as it is a method" (p. 77). This methodology was warranted in order to understand the life experiences of these women after an HIV diagnosis. Through a reflective evaluation of their experiences, meaning was applied to the phenomenon of being African American and living daily with the HIV disease.

The phenomenological approach allowed for sensitivity as the lifeworlds of AAW with HIV were explored, supported an interpretative component, and promoted reflection as a means of understanding. The *lifeworld,* understood as what is experienced pre-reflection without conceptualization, often includes what is taken for granted or perceptions considered as common sense (Husserl, 1970). The question "What is the experience like?" attempted to discover meanings as they were lived in everyday existence. The focus was to understand or comprehend meanings as they were experienced. Phenomenology is a philosophical position from which reflective insight communicates a relationship between the human experiences represented as themes, compassion, and self-understanding (van Manen, 1990).

There are many approaches to conducting phenomenological inquiries. Since this researcher sought rich contextual descriptions and interpretations of life experiences specific to a particular group of people, a hermeneutic phenomenological approach was appropriate. Hermeneutic phenomenology “edifies the personal insight, therefore contributing to one’s thoughtfulness and one’s ability to act on others” (van Manen, 1990, p. 7). van Manen’s human science approach is founded on the combination of phenomenology and hermeneutics. Nursing is concerned about understanding the experience of being more human. Human science research questions the intimacies and secrets of what constitutes the world within. According to van Manen (1990) “Research is a caring act, to know which is most essential to being (p. 5).” In seeking to understand the idiosyncratic meaning of living with the HIV infection for AAW, the researcher chose to use the approach by van Manen to uncover the meanings of everyday human experiences through human science. van Manen (1990) encourages the use of a concurrent, continuous, and dynamic cycle that involves the process of describing, interpreting, and textual writing with the ultimate aim of fulfilling our nature to become more fully human (see Figure 1).

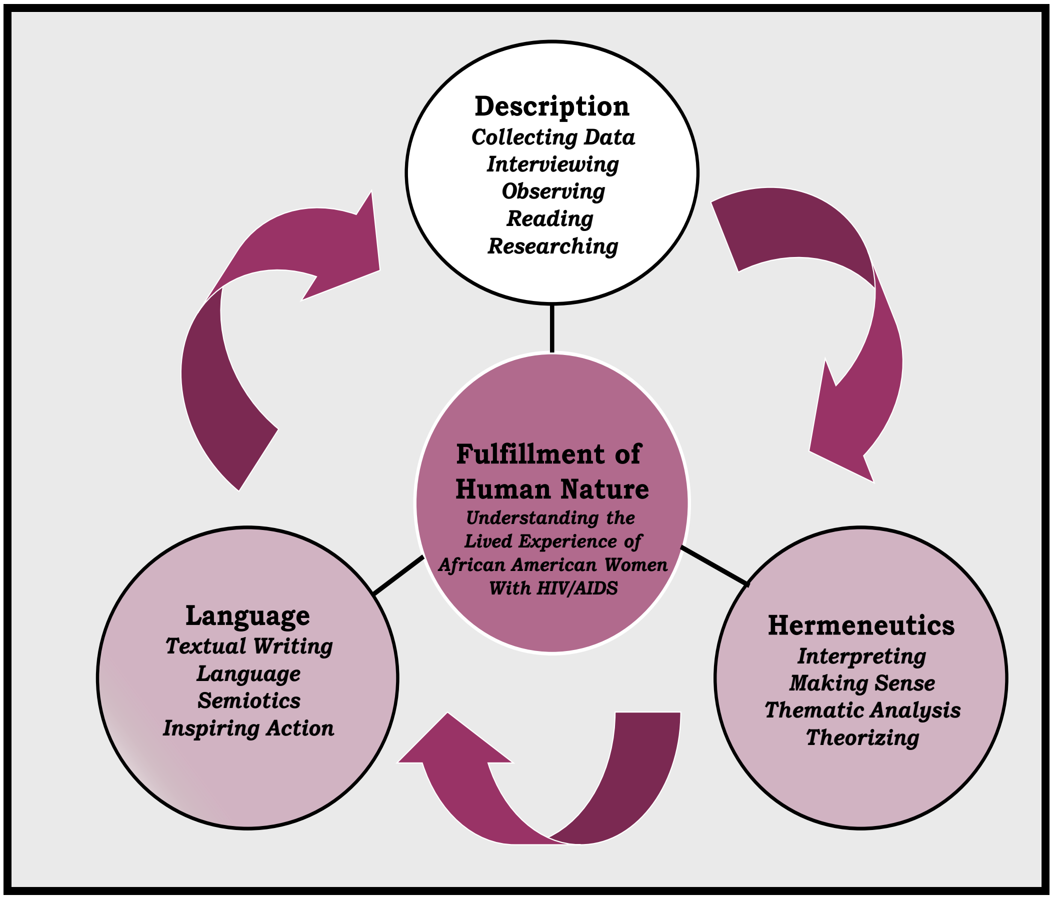


Figure 1. Umadhay's (2009) Phenomenological Exploration Process (adapted from van Manen, 1990, p. 2-8).

With this hermeneutic phenomenological method as a framework, participants focused, described, and reflected on the world in which they live as AAW with HIV. Open-ended questions were used to provide participants with an opportunity to articulate their lived experiences and become collaborators in the study. Participants' descriptions and interpretations of their lived experiences and the researcher's self reflection were used during data analysis. Analysis and interpretation of data were interwoven with data collection. This process then involved enriching these perspectives through literature, poetry, and other art forms. The researcher's interpretations were then reviewed by participants to determine if the essence of their lived experiences had been accurately captured.

Scope and Limitations of the Study

The sample population of this study included English-speaking AAW residing in South Florida, 18 years or older, who self-identified as HIV-positive. This purposeful sampling procedure decreased generalizability of findings to the larger population, so findings are applicable only to the group of participants interviewed and this geographic location. Moreover, this study included only stories from those individuals who voluntarily shared their lived experiences.

Summary

This phenomenological study highlighted the lived experience of AAW living with HIV/AIDS as they perceived it. This inquiry described these individuals' physical and psychological responses to this experience as their reality and lifeworld. Understanding the meaning of this experience will add to the knowledge base of healthcare providers as they integrate the information into their practices, education, and research activities.

CHAPTER II

Review of Literature

Introduction

The AIDS epidemic has caused immense human suffering, loss of lives, and economic damage. Nearly half of the population directly affected will be women of ethnic minority groups. The disproportionate impact of HIV/AIDS on racial and ethnic minorities, specifically African American women (AAW), has continued to escalate (Gilbert & Wright, 2003), but the experiences of these women—their unique circumstances and perceptions (i.e., idiosyncratic meaning they bring to the experience) as they struggle to live with the HIV infection—have not been well described and are thus poorly understood. The impact of this gap in knowledge may have sobering consequences for this population, particularly as it relates to nurses and other healthcare providers on the front lines of care who must provide appropriate interventions. Appreciating the experiences of these women may be fundamental to rendering holistic, compassionate, and culturally appropriate care that is both integral to the practice of nursing and necessary to decrease this epidemic ethnic catastrophe.

A search of relevant literature across disciplines was conducted to discover major concepts surrounding the phenomenon of AAW living with HIV. Using a search engine provided by a university on-line library, the following computer databases were employed: Cumulative Index to Nursing and Allied Health Literature (CINAHL Plus), MEDLINE in PubMed, ProQuest, OVID, and Science Direct. Key words used in the search were HIV, AIDS, HIV/AIDS, African American women, African American, Black, Black women, lived experience, and nursing. Citations were limited to those in the

English language and to articles published since 1981, since HIV or AIDS was unknown prior to 1982. This review will begin with a historical perspective of the HIV/AIDS phenomenon, followed by an examination of literature relevant to identified concepts. Synthesis of the literature reveals what is known and not known about the experiences of AAW living with HIV.

Historical Context

The first known article about AIDS was published on June 5, 1981, when the Centers for Disease Control and Prevention (CDC) reported that five young homosexual men were treated for biopsy-confirmed pneumocystis carinii pneumonia (PCP) at three different hospitals in Los Angeles, California. All five patients had laboratory confirmed cytomegalovirus and candidal mucosal infection. Two of the five died. A month after, the CDC reported that during the preceding 30 months, 26 cases of Kaposi's sarcoma had been reported among gay males and that eight had died, all within 24 months of diagnosis (CDC, 1981).

The term AIDS (Acquired Immune Deficiency Syndrome) was first used in July 1982 and was properly defined by CDC as a disease linked to blood. At that time there were 853 known deaths in the US related to AIDS (Kher, 1982). A report from US Health and Human Services announced that a virus causing AIDS had been isolated and was named HTLV-III (Altman, 1984). In 1985, The US Food and Drug Administration (FDA) licensed commercial use of the first blood test for AIDS. There were a number of medical, social, and ethical matters that had to be considered before the test could be widely used. Concerns particularly centered on the issues of confidentiality and the meaning of a positive test (Pear, 1985).

The first International Conference on AIDS was held in Atlanta, Georgia in 1985. This prompted the World Health Organization (WHO) to consider AIDS as a pandemic and initiated the call for concerted worldwide action. During that time there were 5,636 known deaths related to AIDS in the US (Kort & Aragon, 2008). On October 3, 1985, Rock Hudson died of AIDS. He was the first major public figure to openly acknowledge he was suffering from AIDS. Hudson's death made *AIDS* a household name and helped bring it to the forefront of public concern (Berger, 1985). In 1986, the virus responsible for AIDS was renamed human immunodeficiency virus (HIV) by the International Committee on Taxonomy of Viruses. At that time a report from WHO announced that as many as 10 million people worldwide could be infected with HIV (Marx, 1986).

Dramatic progress in treatment of AIDS was noted in 1987. The first anti-HIV drug, azidthymidine (AZT), was approved by the FDA. Initially used as a chemotherapeutic drug for cancer, AZT was known to slow the progression of AIDS (FDA, 1987). Between 1995 and 1996, two classes of anti-HIV drugs, protease inhibitors and non-nucleoside reverse transcriptase inhibitors, were approved by the FDA (Kolata, 1995). That same year, the International Conference on AIDS revealed that highly active antiretroviral therapy (HAART) was extremely effective in reducing the amount of viral activity in the bloodstream. HAART, a combination therapy of anti-HIV drugs, was found to cause significant improvement in the immune system of AIDS patients (Canadian HIV Trials Network, 2006). The introduction and widespread use of HAART has since resulted in falling morbidity and mortality rates among HIV-positive persons (Green, 2004). This treatment represented the end of an era in which a diagnosis of

HIV/AIDS was perceived as a death sentence and marked the beginning of an era in which HIV/AIDS is perceived as a chronic but manageable disease.

HIV as a Chronic Illness

While the introduction of HAART to treat HIV/AIDS in 1996 helped make symptoms manageable for those with access and significant reductions in US death rates were reported, it also signified the reality of HIV as a chronic disease that was here to stay(Green, 2004). Some authors argued that HIV should be defined as a manageable and chronic illness rather than a terminal disease. Catalan, Green and Thorley (2001) raised valid concerns regarding the perception that HIV/AIDS was not as serious or could be cured, now that it was treatable as a chronic illness:

> HIV is, and has always been a chronic illness to the extent that it lasts years, and to date cannot be cured. Describing HIV as a chronic illness implies that it is a less severe condition, manageable, if not altogether curable condition. It is essential to highlight that chronic is not the same as mild or unimportant (p. 2).

Catalan et al. also argued that the impact of this combination therapy (HAART) was overwhelmingly but not uniformly positive.

In the context of HIV/AIDS as a chronic illness, Shernoff (2002) described changes in psychological and emotional complexities for people living longer with the disease and psychosocial impacts of new treatments. The author stated that with the advent of HAART, patients who thought they would die experienced a newly found hope and health outlook that could also be disorienting and elicit a wide range of emotional reactions. Shernoff recommended that healthcare workers acknowledge the pervasiveness of both hope *and* doubt as patients made the transition to understanding they may live much longer with the disease. Shernoff also urged practitioners to assist patients in recognizing and confronting uncertainty and ambiguity related to HIV/AIDS as a chronic illness.

Accordingly, adjustment to living with the virus became a focus. Bova (2001) investigated factors that influenced adjustment to chronic illness of women infected with HIV/AIDS using a cognitive appraisal model of stress and coping (Lazarus & Folkman, 1984). A cross-sectional descriptive survey was conducted with 101 HIV-infected women; 18 of them (17%) were of African American descent. The following instruments were used to measure variables in the study: Meaning of Illness Questionnaire (appraisal of illness), Functional Social Support Questionnaire (social support), HIV Symptom Experience Inventory (symptom severity), and Medical Outcomes Study Short Form Survey (adjustment to chronic illness). Results indicated that appraisal of illness events had a significant and direct impact on immediate and long-term outcomes. These findings are consistent with the stress and coping model developed by Lazarus and Folkman. Social support did not appear to be a significant mediator of illness adjustment; likewise, illness stage or severity had minimal effects on adjustment and disease outcomes (Bova).

A program designed to help HIV-infected women adjust to the disease was developed as a result of Bova's (2001) study. The Positive Life Skills (PLS) 10-week workshop was designed to help women reframe negative meanings associated with their illness and assist them in managing physical symptoms. The cognitive appraisal or meaning attributed to HIV/AIDS was found to be a key variable influencing adjustment and adherence behaviors (Bova). The PLS workshop sought to improve participants' HIV cognitive appraisal through art, science, and alternative therapies. Small focus-group sessions were used to conduct open-ended group interviews and closed-ended surveys to evaluate women's responses to the PLS workshop (Bova, Burwick, & Quinones, 2007). Responses indicated participation in the workshop effectively increased adherence to anti-retroviral therapy. The women also scored high on the Medical Outcomes Study HIV Health Survey (MHI-5), which was used to screen and evaluate mental well-being. The researchers concluded that the women experienced a better sense of well-being and less depression after the PLS workshops. This study supported the effectiveness of a theoretically derived intervention aimed at improving adjustment to chronic illness and adherence to a treatment regimen among HIV-infected women (Bova et al.).

Development of anti-HIV treatments and medications meant that more people were living longer with HIV/AIDS. But the challenge of promoting medication adherence remains a struggle for healthcare workers to this day. Although Bova et al. (2007) concluded that improved appraisal of the disease increased adherence to a medication regimen, some authors focused on the impact of personal health beliefs and attitudes as variables impacting treatment adherence. Recently, in a sample of 34 adults, of which 29 (85%) were African American, Kemppainen, Kim-Goodwin, Reynolds, and Spencer (2008) investigated how personal beliefs about causes and meaning of HIV related to personal beliefs about medication adherence. The authors used the Illness Perception Questionnaire (IPQ) and the AIDS Clinical Trials Group Reasons for Non-Adherence to Medications questionnaire to measure these variables. The majority of participants (91%) believed that HIV/AIDS therapies would help control the disease. Persons who believed the cause of HIV/AIDS was because of chance or bad luck ($p=.03$) or because of God's will ($p < .001$) were most likely to believe the progression of their illness depended on chance and fate. Respondents currently adhering to medical treatment were also most likely to believe that HIV was caused by chance or bad luck (*p* =. 038) or God’s will (*p* = .016). The authors concluded that adherence interventions may be more effective if they are tailored to match the patient’s individual perceptions, opinions, and beliefs. Kemppainen et al. also recommended that spirituality should be further explored as an important coping resource embraced by the HIV- infected patient.

Development of more effective combination HAART ushered in a new perception of HIV/AIDS, one that would elicit a wide range of emotional reactions. From death threat to chronic condition, some authors argued it should be defined as a manageable, rather than terminal illness. Hence, this brief review of the literature revealed a new set of psychosocial impacts for people living longer with HIV/AIDS and challenges for healthcare workers related to addressing these complexities as result of HAART. Factors that improved adjustment and coping strategies that supported treatment adherence in the context of HIV as a chronic illness were also investigated. One glaring deficit in the literature, however, was the idiosyncratic meaning HIV/AIDS victims assigned to the fact that this therapy made it possible for them to live longer with the disease.

Psychological and Psychosocial Effects of HIV

Since the beginning of the AIDS epidemic, current treatments have made it possible for persons with HIV to live longer and enjoy more productive lives. However, stigma and discrimination exist and have detrimentally affected the lives of these people. Rose et al. (2008) reported that prejudice is related to the two most common modes of HIV transmission: sexual intercourse and intravenous drug use. Conservative values and societal norms support stigmatization of HIV-positive individuals and result in their reluctance to use healthcare services for fear of additional discrimination. The continued prejudices against this group have seriously impacted this population's ability to access services and potentially life-saving treatments (Rose et al.). As front-line healthcare providers, nurses are called upon to alter the social structures that detract from the health and well-being of any disenfranchised group.

The experiences of rural HIV-positive AAW in utilizing healthcare were explored by Vyavaharkar, Moneyham and Corwin in 2008. The authors conducted focus groups to investigate perceptions of 22 HIV-positive AAW regarding availability, accessibility, and quality of healthcare and social services. To guide the study and serve as a framework for coding data, the health services utilization conceptual model was used. Results of the study revealed that basic services were lacking and the quality of services available to meet participants' most important needs was inferior. Participants also reported that the experience of stigma and discrimination is one of the barriers to utilization of services. Study findings were consistent with reports of Kennedy, Mathis, and Woods (2007) that African Americans continue to distrust medical institutions and the healthcare system. Both Vyavaharkar et al. and Kennedy et al. emphasized that lack of cultural competence among providers is one of the most dynamic factors relating to this mistrust and inferior quality of healthcare services.

A study by Simbayi et al. (2007) investigated internalized stigma, depression and discrimination among 420 HIV-positive men and 643 HIV-positive women in South Africa. The AIDS-Related Stigma Scale (internalized stigma), Center for Epidemiological Studies Depression Scale (depression), and Social Support Questionnaires (social support) were used to measure the variables. Participants were also asked to complete a questionnaire that addressed demographic data, current health status, experiences of discrimination-related events, and the use of alcohol or prohibited substances. The study revealed that 40% of participants experienced discrimination and the majority reported feeling dirty, ashamed or guilty about their infection. The authors concluded that urgent social reform was needed to decrease the stigma of HIV in South Africa. Simbayi et al. also suggested that effective HIV/AIDS interventions should be adapted to the specific social conditions of a subpopulation.

Schaefer (2007) studied women's responses to being diagnosed with the HIV/AIDS infection. A longitudinal qualitative study design was used to investigate 55 participants over a period of two years. The study revealed that most women did not suspect they had HIV when being tested and were shocked and devastated when they received the results. Long-term effects of the diagnosis revealed depression, increased drug use, and attempted suicide. Schaefer also noted that the women needed support extending beyond the immediate period of diagnosis. Findings of this study support results of an older investigation by Catalan (1996) regarding the psychological and social consequences of HIV/AIDS infection in women. Catalan concluded that HIV-positive women have substantial levels of psychological and social morbidity that require adequate mental health intervention from healthcare providers.

The psychological and psychosocial effects of HIV have been reported in the literature. Stigma and discrimination have been identified as key barriers to improved health outcomes in ethnic and underrepresented populations. Cultural incompetence has been recognized as a major factor for minority distrust of the current healthcare system. Further investigation is needed to explore how healthcare providers may assist patients to break social structures that detract the marginalized population from health and well-being. A thorough understanding of their illness experiences, gaps in support, and knowledge deficits may minimize these healthcare disparities.

Motherhood, Spirituality, and HIV

Studies focusing on HIV-infected women and their children have emerged over the past two decades. Anxiety about children and their future care appears to be common to all HIV- positive mothers, regardless of race (Andrews et al., 1993). Anxiety, responsibility, and emotional pain have been associated with being a mother infected with HIV/AIDS. But Andrews et al. found that the presence of dependent children also contributed to a positive outlook on life and better coping strategies for HIV-positive mothers. Participants also reported that their children reduced feelings of isolation, were catalysts for positive behavioral change, and were the main reason for them to persist.

Regan-Kubisnki and Sharts-Hopko (1995) explored the needs, choices and decisions faced by HIV-infected mothers (N=38; n=24 AAW). from an infectious disease clinic site. Semi-structured interviews were conducted to elicit information about how they conceptualized their illness and how this conceptualization influenced decisions and choices about HIV/AIDS. The interviews were audiorecorded and transcribed verbatim, and a descriptive qualitative content analysis method was used for transcript analysis. Major themes that emerged from these verbal reports included: *uncertainty, effects of children*, and *spirituality*.

The issue of uncertainty pervaded many of the other themes. Participants reported uncertainty about their children and their children’s futures, rather than their own futures. The topic of children was not directly addressed in the interviews but emerged as the most important factor influencing participants’ decisions about their HIV status. Consistent with the findings of Andrews et al. (1993), having children was a great motivation in the lives of these mothers. They reported making significant lifestyle changes in order to live longer for their children.

Spirituality was also an unanticipated finding by Regan-Kubinski and Sharts-Hopko. The mothers reported a newfound spirituality in their lives and a renewed relationship with God as a response to the HIV infection. Dealing with HIV/AIDS seemed to trigger an examination of spiritual matters as a new source of comfort in these women’s lives. The authors emphasized that mothers’ appraisals of factors related to the HIV infection may have facilitated or hindered her response to the illness and that how mothers viewed their illness was a complex and multi-factorial process. Therefore, the authors reinforced the need for a holistic understanding of the idiosyncratic meanings assigned to the HIV illness as a basis in designing effective nursing interventions (Regan-Kubinski & Sharts-Hopko).

A recent study conducted by Polzer-Casarez and Miles (2008) supported the aforementioned findings of Regan-Kubinski and Sharts-Hopko (1995). Both studies reported that spirituality is a cultural strength for African American mothers infected with HIV. Polzer-Casarez and Miles explored how spirituality affected the lives of these women. Participants identified that their intimate and personal relationship with God was a way to deal with the stresses and challenge of a life with HIV and that their relationship with God resulted in hope and less worry and distress over the possibility of death. These women perceived God as a benevolent figure with the power to heal, a power in control of their lives. At the same time, the women expressed that they needed to participate in spiritual practices for God to take action. The spiritual practices involved prayer, reading the Bible, and church attendance (Polzer-Casarez & Miles).

Spirituality and prayer were also explored in relation to adjusting to HIV/AIDS, not only for mothers but for the general population infected. Coleman et al. (2006) studied prayer as a self-care strategy, reporting that prayer was used by both HIV-positive African American men and women as a self-care strategy. Chi-square analyses were used to examine potential relationships between gender and the use of prayer in managing four HIV-related symptoms: fatigue, nausea, depression, and anxiety. Prayer proved to be an effective self-care strategy for managing three of the four HIV-related symptoms in more than 50% of 448 respondents. A higher proportion of women used prayer to manage HIV-related fatigue. More men reported using prayer to manage nausea and depression. The authors conclude that the cultural strength of spirituality for many African Americans needs to be emphasized in developing culturally sensitive approaches in nursing practice (Coleman et al.). Nurses were urged to support and foster spirituality and prayer to assist African American patients in coping with and managing symptoms and to facilitate their trajectory towards optimum health and wellness.

The experience of HIV-positive African American mothers parenting an HIV-positive child was investigated by Shambley-Ebron and Boyle (2006). In planning appropriate nursing interventions, culture plays an essential role in illness management and child-rearing decisions for this specific population. Recognizing this, a critical ethnography design was used by the authors to explore the values, experiences, traditions, and beliefs of 10 AAW living with HIV/AIDS and caring for a child who was also HIV-positive. Creating a “life meaning” emerged as an overarching cultural theme. After accepting their condition and acknowledging past mistakes, the mothers initiated a way of creating meaning and purpose in their lives as a result of the HIV infection. Focusing their energy on strong mothering that included providing, protecting, and preparing the children, brought meaning to these women's lives. Shambley-Embron and Boyle noted that these African American mothers used cultural strengths and traditions to mother their children and create a life meaning and purpose.

Studies involving HIV-infected women and their roles as mothers have begun to appear in the literature. Based on this review, the experience of motherhood with HIV is complex and multifaceted. Children were identified as an essential and central theme in these women's perception of the HIV illness. African American mothers also used spirituality as a cultural strength to deal with the emotional stress and physical fatigue of HIV/AIDS. A gap in the literature persists, however, regarding the social realities of African American mothers living with HIV/AIDS as a chronic illness and how they deal with this ethnic epidemic. Although the cited studies provided greater insight into the cultural experiences and health practices of this specific ethnic group, further exploration is warranted.

African American Women and HIV/AIDS

HIV/AIDS has long been seen as a problem that affects men, and more specifically, gay men. In the US, 73% of all diagnosed cases are men (CDC, 2006). However, on a global level, nearly half of the adults living with HIV/AIDS in the world are women (UNAIDS, 2006). The CDC (2006) reports that globally, 60% of 15 to 24-year-olds infected with HIV are females. Most HIV infections in women are contracted through high-risk heterosexual contact; thus, women are more susceptible than men through heterosexual sex transmission. This is a major risk factor that contributes to the rapid increase in new HIV infection rates in women (Rose et al., 2008). Hence, it is possible, if not probable, that women may overtake men as the predominant gender affected by the virus. Yet for the past three decades, the emphasis on this disease has been focused more on men while consequences for women have been overlooked. Hegyvary (2006) challenges nurses and other healthcare providers to address differences in healthcare through open discussion in order to correct conflicts and inequalities that result in healthcare disparities, including gender differences.

In 2001, Hader, Smith, Moore and Holmberg conducted a qualitative study and identified the following reasons why AAW, in particular, have increased HIV/AIDS incidence and deaths: high infection rates, difficulty accessing anti-retroviral therapy, and poor adherence to treatment as compared to other groups of women. In 2006, the National Minority AIDS Council (NMAC) reported that race and ethnicity, alone, are not risk factors for HIV infection. Poverty and other social structural influences have been identified as factors associated with higher incidence of HIV/AIDS among African Americans. AAW are already at high risk for discrimination, sexual abuse and racism. These social machineries have been reported to decrease their ability to protect themselves against this disease (NMAC).

Factors related to HIV infection and prevention in the AAW was explored by Mallory (2008). A grounded theory approach was used to study how rural AAW became infected with HIV. A total of 10 AAW were recruited for semi-structured interviews that occurred in their homes. All interviews were audiorecorded and transcribed verbatim. Qualitative data analysis software was used to organize transcribed data. A constant comparison analysis method was used to construct descriptions from the participants' transcripts. All participants reported that their infection was related to sex with a man or men. Some of them also reported engaging in high-risk activities associated with HIV infection, such as sex trading. The desire for intimacy, coupled with inaccurate risk appraisal of sexual partners, was identified by participants as the major contributing factor to exposure. Mallory (2008) suggested that in order to improve HIV/AIDS prevention initiatives, AAW should be given information about how to protect themselves in the context of intimate relationships. Treatment decisions were not discussed in this study.

A pilot study conducted by Russel and Smith (1999) investigated the holistic lifeworld of five HIV-infected AAW. The authors focused solely on the essence of being an African American woman dealing with the infection. A phenomenological approach was used to describe how the women conceptualized their lives and illness. Themes that emerged included: experiences of violence and addiction believing that it couldn't happen to them, shock and denial with the diagnosis, uncertainty as a present state of their illness, the secretive nature of their lives stemming from fear and stigma, and their need to protect their families, especially their children. The authors concluded these women undergo complex experiences and need to be better understood before effective healthcare interventions can be designed and implemented. Alhough the findings are significant, the authors suggested further exploration and replication since this pilot study was limited to a small sample size. In addition, this data is now ten years old.

Experiential Context

My profound interest in HIV grew out of my personal and professional experiences as a registered nurse over the past 18 years. I have provided care to HIV-positive patients in a variety of settings. Personally, I have cared for friends who suffered this disease and assisted them with their healthcare needs. I also have suffered the loss of a close friend who passed away due to AIDS-related complications. As I enhanced my readings about HIV and AIDS, I discovered a vast amount of literature and studies conducted with the homosexual population. Although evidence shows that incidence of HIV and morbidity in AAW is escalating at an alarming rate, scant research has been conducted to shed light on this experience from the holistic perspective of this population. As a minority myself, I began to realize that I needed to investigate this phenomenon to better understand the lifeworld of these women—to help them, ultimately, by informing nursing practice with culturally competent responses to their needs. My life experiences triggered my desire to explore the lives of AAW with HIV/AIDS. Through the voices of these women, I wanted to tell their personal stories and their daily experiences living with this disease. Through their uniquely remarkable lenses to the world, I wanted to see their lives as they journeyed on.

In qualitative research, the investigator is closely involved with the participants. In order for me to discover the true essence and meaning of living with HIV for AAW, I took measures to be cognizant of my individual biases and attempted to set aside and bracket preconceived perspectives, learned feelings, and personal experiences to improve my ability to accurately hear the voices of participants. van Manen (1990) described *phenomenological reduction* as a process of addressing the potential influence of the investigator’s beliefs and preconceived biases but acknowledged that complete suspension of judgment is not possible. I used a reflective journal to engage in phenomenological reduction and bracketing, and I maintained openness and neutrality while thoughtfully listening to participants as they answered open-ended interview questions. I managed to avoid leading statements or nonverbal reactions that may have influenced participants’ responses to my inquiry. van Manen (1990) described reality as being co-created by the investigator and participants; therefore, I engaged participants to examine the themes that emerged in the study, to clarify descriptions of their lived experiences, and to validate my accuracy in viewing their experiences through their lenses and hearing their stories through their voices.

Summary

The increased incidence of AAW infected with HIV and the barriers they face in accessing healthcare are clearly identified in the literature. Life with the HIV/AIDS infection does not only have important physiological consequences but major psychological and social impacts. While efforts to contain this epidemic are ongoing, and despite advances of HIV treatments and the decline of new HIV infections in other risk groups, AAW remain disproportionately affected. Thus, a critically needed imperative for healthcare providers is to develop a much more accurate understanding and culturally sensitive response to the realities facing AAW women living with the disease.

The literature also reports that people infected with HIV experience stigma and discrimination. African Americans in general continue to distrust the healthcare system, and their distrust is significantly related to the lack of cultural competence by healthcare providers. As healthcare workers, nurses are challenged to provide holistic, humane, and culturally appropriate care (Sigma Theta Tau, 2005), and the increasing number of AAW living with HIV/AIDS presents a challenge. In-depth understanding of the complexities facing this population and an integrated, holistic view of their situations is necessary to provide nursing care that encompasses the specific needs of this population. The literature lacks this type of current, in-depth knowledge of the holistic experience of living with HIV/AIDS and of HIV treatments specifically designed for AAW. Only one study by Russel and Smith (1999) was found that approached this level of understanding. Since then, the landscape of healthcare has changed through the influences of economic woes, globalization, post 9/11 concerns, and a different political complexion.

Investigating the lived experience of AAW with HIV/AIDS may facilitate nursing practice that is holistic, context-dependent, and informed by compassion and competence. The healthcare provider needs to deeply understand and appreciate this experience before effective and appropriate interventions can be designed and implemented. Through understanding, biases might be decreased as nurses come to appreciate and recognize the unique factors involved in the lives of these women. Greater insight through further studies of AAW's holistic experiences with the HIV infection will help highlight cultural idiosyncrasies and health practices that may potentially reduce the healthcare disparities that currently exist.

CHAPTER III

Methods

Introduction

This chapter describes the method used to investigate the lived experience of AAW living with the HIV infection. The philosophical framework that guided and supported use of a qualitative research method is presented. The overarching research question directing this study is discussed. Research methods, including sampling, data collection and data analysis procedures are outlined. Specific procedural protocols for each component are identified. Finally, the standards of quality and verification, and ethical considerations related to this study are discussed.

Research Design

Philosophical Framework

The philosophical framework that guided this study is based on the human science approach of hermeneutic phenomenology. *Phenomenology* is both a philosophical and a theoretical position from which reflective insight communicates a relationship between the human experiences represented as themes and self-understanding (van Manen, 1990). *Hermeneutics* is a means of gaining understanding of a phenomenon through interpretation. *Hermeneutic phenomenology* "…edifies the personal insight, therefore contributing to one's thoughtfulness and one's ability to act on others" (van Manen, 1990, p.7). Through a hermeneutic interview process, participants focused, described, and reflected on the world in which they live. This promoted articulation of their lived experience and involved the participant as a collaborator. Participants' descriptions and interpretations of their lived experiences are addressed, including the researcher's self reflection. Accounts of the phenomena obtained from literature, poetry and the arts are used to further understand this phenomenon.

Rationale for a Qualitative Study

Quantitative research design directly attempts to influence a specific variable with the purpose of testing hypotheses about cause and effect relationships. The assumption of a quantitative study is that the world is made up of facts that can be discovered. The main purpose is to establish relationships and explain causes. Quantitative study utilizes pre-established methods that rely upon a deductive reasoning approach. The researcher acts as a detached observer; very little personal interaction occurs between researcher and participants (Polit & Beck, 2003).

The purpose of a qualitative study design is to construct multiple realities and understand situations from the viewpoint of participants directly involved in the process. The major assumption in a qualitative approach is that the truth is socially constructed by different individual views of the same situation. This form of research employs inductive reasoning that is emerging and flexible (Munhall, 2007). The researcher is immersed in the process and takes an insider’s role during the investigation to better understand the participant’s experience (Creswell, 1998).

The aim of this study was to gain a deeper understanding of the world through the voices and eyes of AAW living with the HIV infection. Exploring the phenomenon to understand the idiosyncratic meaning individuals attached to this experience favors the use of qualitative research methods over a quantitative design. Living as an African American woman with HIV/AIDS is a complex life phenomenon requiring in depth exploration. Qualitative methods are appropriate for topics that require detailed discovery (Creswell, 1998).

Rationale for a Phenomenological Study

In order to gain insight into the lives of AAW diagnosed with HIV/AIDS, phenomenology allowed the researcher to gain in-depth understanding of each participants' lived experience. Guided by van Manen's human science approach, which combines both phenomenology and hermeneutics, enabled the researcher to view the phenomenon as the participant's lived experience and gain an in-depth understanding of their lifeworlds.

Phenomenology is "a science whose purpose is to describe a particular phenomenon or the appearance of things, as lived experience" (Speziale & Carpenter, 2007, p.76). A qualitative phenomenological design is warranted in order to understand the life experiences of these women after an HIV diagnosis. Utilizing this approach will describe the essence and uncover meaning structures in the experiences of the study participants. Through a retrospective evaluation of the moment, meaning is applied to the phenomenon of the lived life.

The use of phenomenology is an appropriate method for this study by enabling the phenomenon of living with HIV/AIDS to be structurally and systematically analyzed, thereby allowing in-depth interpretations of these lived experiences. The purpose of this form of research "…is to act as an advocate in progressing human life by increasing its thoughtfulness and sensitivity to situations" (van Manen, 1990, p.21). Thus, this study will attempt to present the reality of an HIV/AIDS diagnosis through the senses and interpretation of those AAW who experience it.

The fundamental model for van Manen's (1990) approach to phenomenology is reflection on the textual descriptions of experience as actually *lived* rather than conceptualized or theorized. This serves to heighten one's sensitivity and awareness. van Manen's approach involves an interplay of four procedural activities. These are as follows:

1. *Turning to the nature of lived experience*. This begins the process of orientation to the phenomenon, formulating the questions and presenting assumptions and biases.
2. *The existential investigation*. The phenomenon is investigated as lived experience where experiential descriptions are obtained from participants and other sources such as the written and performed arts, and phenomenological literature.
3. *Phenomenological reflection*. Through reflection, essential themes that comprise the phenomenon can be uncovered.
4. *Phenomenological writing*. This refers to describing the phenomenon through the art of writing and rewriting. Through this process the researcher gains a linguistic understanding of the experience.

An interpretation of how van Manen's phenomenological approach was applied to investigate the lived experience of AAW with HIV/AIDS is depicted in Figure 2.

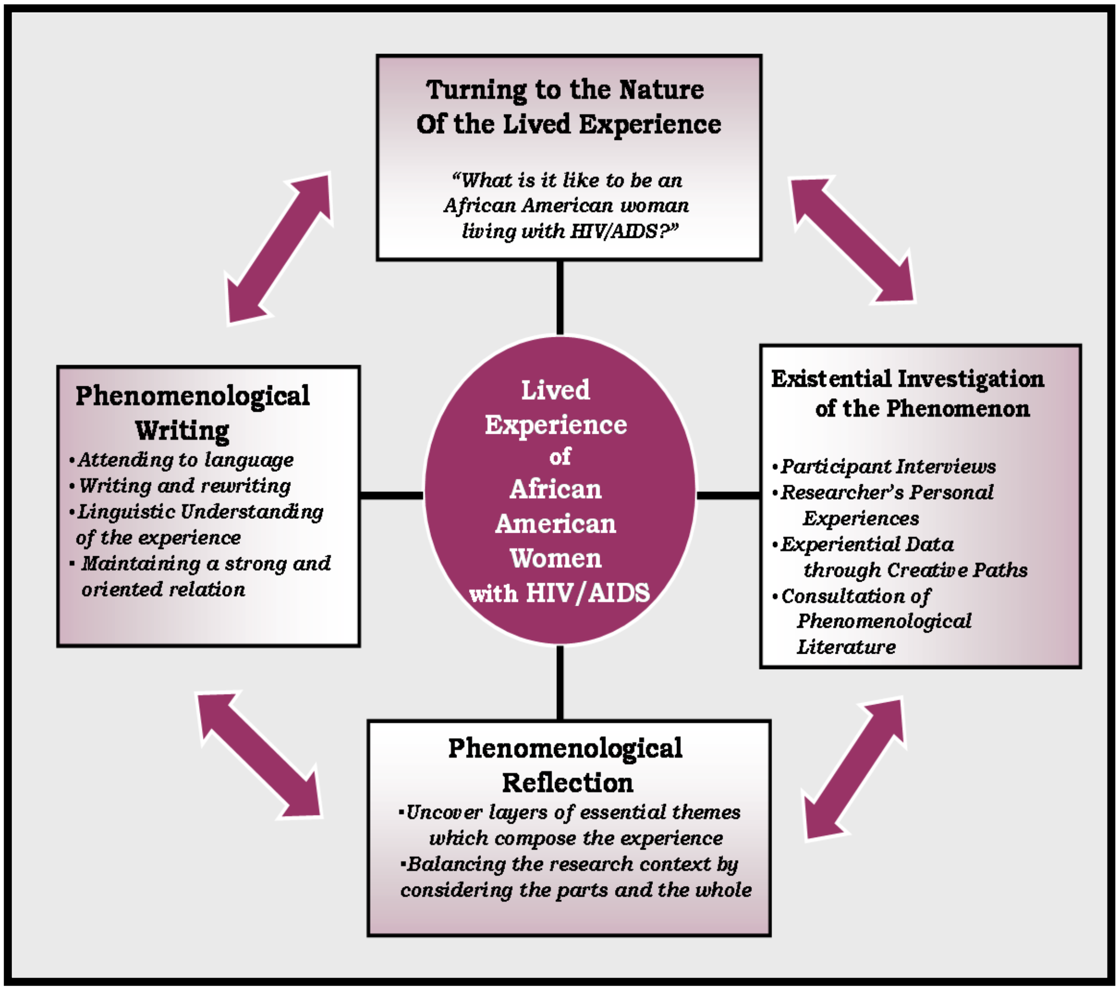


Figure 2. Umadhay's (2009) Phenomenological Approach to Investigating the Lived Experience of African American Women with HIV (adapted from van Manen, 1990).

Ethical Considerations

Qualitative research must be guided by stringent ethical guidelines. The rights and welfare of participants in this research study was rigorously protected. Approval from Barry University Institutional Review Board was obtained prior to commencement of the study (see Appendix G). All participants signed an Informed Consent Form (see Appendix A), giving the researcher the consent to interview them and use their individual and aggregate responses in the study. Participation was strictly voluntary and participants were informed that they could elect to decline to participate at any time with no adverse effects to them or their health. The potential for emotional distress when a participant discussed her situation was certainly a possibility in this study, so any participant who voiced excessive or irresolvable emotional distress as a result of the interview was told she would be referred to a community social services program that is free of charge for support (see Appendix B). As stated in the Informed Consent Form, participants were also informed of the following:

1) They may choose to stop the interview and withdraw their participation from the study at any time. If they choose to withdraw, their information will not be used in the study.

2) They may refuse to answer any specific question or questions.

3) They may ask that the audiotape recorder be turned off at any time. The researcher will continue to use the information they share unless the participant decides to completely withdraw from the study. If they choose to withdraw, their information will not be used.

Confidentiality and the participants' right to privacy was thus assured. Although this research was not anonymous in nature, data obtained was held in confidence to the extent permitted by law. However, if a participant expressed an imminent intention to harm herself or someone else, the investigator was obligated to share this information with appropriate mental health and/or law enforcement authorities. The following procedures were followed to ensure confidentiality:

1) Participants were asked to choose a pseudonym to be used in place of their actual name throughout the investigation.

2) Any published results of the research refer to quotes or group themes only and no actual names were used in the study.
3) All paper transcripts, documents, and field notes obtained from this research were stored in a locked cabinet in the researcher’s home office. Pseudonym and audiotape codes were stored separately from the code keys in a locked file cabinet in the investigator’s home office. Signed Informed Consent Forms were kept in a locked file cabinet in the researcher’s home office separate from the rest of the data.
4) All study audiotapes were destroyed after the accuracy of data transcription had been verified and member checking had occurred during the second meeting. If for any reason the second interview did not take place, the audiotape was stored in a locked file cabinet in the researcher’s home office and was destroyed 90 days after the initial interview.
5) Security of electronic documents was maintained with the use of an exclusive, password-protected personal computer at the researcher’s office. Electronic transcripts will then be deleted from the researcher’s personal computer five years after the completion of the study. All paper transcripts, documents, field notes, and consents will be destroyed by shredding five years after the completion of the study.

Sample and Setting

Purposive sampling was used to conduct this study. The use of purposeful sampling is appropriate to gather information-rich data strategically and purposefully (Patton, 2002). This technique, used frequently in qualitative research, involves selecting participants based on the aim and purpose of the study (Creswell, 1998). This ensured that the researcher selected participants who have undergone the phenomenon being investigated. It also facilitated a search for participants who would voice a richness of information suitable for detailed research.

Obtaining access to this population was challenging. Several recruitment mechanisms were therefore considered. Recruitment included placing an advertisement (see Appendix C) in local newspapers and South Florida HIV/AIDS support group websites. The advertisement contained study and researcher's contact information for interested participants, allowing for voluntary initial contact with the researcher. In addition, the researcher used snowball sampling procedures. Colleagues aware of the study and participants who had consented to an interview were also given a flyer (see Appendix D) with the researcher's contact information for them to distribute to those they thought might be interested in participating. Interested participants contacted the researcher through a secure, confidential, and password-protected email account and phone number used exclusively for the study.

The researcher gathered data until saturation was achieved. Saturation involved continued interviews and data collection until no further new information was discovered; this usually occurs with no more than 20 participants (Creswell, 1998).

Inclusion Criteria

Criteria for inclusion included: consenting women who self-identified as being of African American descent; residing in South Florida; over the age of 18 years old; English speaking; self-identified as HIV-positive; and willing to speak about their experiences of being HIV- positive. No limitation was imposed on the time frame since diagnosis, in order to fully understand their experiences across age ranges and to identify commonalities across experiences.

Exclusion Criteria

Exclusion criteria included men, individuals under the age of 18 years old; women who did not self-identify as African American and HIV-positive; those who did not reside in South Florida; and those who were unable to speak English.

Interview Questions

What is the lived experience of AAW living with HIV? This phenomenological question explored the meaning of this specific situation to these individuals. To better understand, the researcher interacted with participants by taking an insider's role during the study (Creswell, 1998) and functioning as the main instrument of data collection, interpretation, and written explanation (Berg, 2001). In order to elicit data, the participant was asked several prompting and clarifying questions (see Appendix E).

Demographic Data

Demographic information was obtained for the following categories: current age, age and year participant tested positive for HIV, educational background, current living arrangements and marital status, number of children (if any), profession or occupation, current residence, and geographic location during childhood and adulthood (see Appendix F). These data assisted the researcher in understanding the situational context of the phenomenon for each participant, identifying commonalities, and describing study participants.

Data Collection Procedures

Data collection procedures commenced upon the approval of the Barry University Institutional Review Board (see Appendix G). Eligible applicants were fully informed of their rights as participants and instructed about the purpose of the study, then asked to sign an Informed Consent Form (see Appendix A). Participants were asked to choose a pseudonym to be used throughout the investigation in place of their actual names.

Data collection involved an initial face-to-face, semi-structured interview utilizing open-ended questions. The first interview was scheduled for one hour (see Appendix H: Interview Protocol). This was conducted in a private and mutually agreed upon neutral location. The researcher obtained clarification to understand concepts being expressed by the participant. The researcher also focused on being a listener and avoiding personal opinions interjected during the process (Creswell, 1998). To ensure verbatim transcription, the interviews were audiotaped. The researcher used two audiotape recorders during each interview process in case of equipment failure. Participants received a $25 grocery store gift card as a token of appreciation after conclusion of the initial interview.

From there, the researcher immediately took notes focusing on nonverbal behaviors, verbal emphasis, and overall affect of participants during the interview. These notes were taken to enhance the transcription process. Post-interview thoughts and reflections were recorded in the researcher’s journal. Upon completion of the interview, the audiotape was immediately transcribed.

All audiotaped interviews were transcribed verbatim using a transcription service. The transcription service signed a Third Party Confidentiality Form (see Appendix I).

Prior to transcription, quality of the tapes were reviewed to ensure as much accuracy as possible in understanding the participant's conversation.

After completion of the first interview, transcription, and initial data analysis, the participant was contacted to schedule a second meeting to last no more than one hour. The purpose of the second meeting was to review the transcripts, engage the participant in examining the themes identified by the researcher, and clarify the participant's descriptions of lived experiences (Creswell, 1998). The second meeting was not audiotaped. All participants reviewed a copy of their transcription to ensure accuracy and that the transcription was what the participant intended to say. The audiotapes were destroyed immediately after the accuracy of data transcription had been confirmed.

Data Analysis Procedures

Each interview was conducted, transcribed, and analyzed prior to subsequent interviews. This process helped the researcher identify themes, possible redundancies, and assess for data saturation. The researcher read each interview transcript multiple times. Notes and memos in the researcher's reflective journal were also reviewed as they related to transcribed interviews. After reading and reviewing the data in detail, the researcher described, classified, and interpreted emerging commonalities to formulate themes; in short, the researcher attempted to construct a universal description of the experience. Findings were situated within the context of the literature to identify implications for nursing science, knowledge development, and practice.

Data analysis in this study adhered to the tradition of rigor and trustworthiness of qualitative analysis. First, the researcher used bracketing and attempted to suspend judgments through identification of preconceived and personal biases. Reflective journaling was used to help the researcher maintain an open view by bracketing preconceived ideas and feelings. Second, documentation of the study will be described in accurate detail. Activities of the researcher will be recorded transparently for audit and to ensure confirmability. Finally, procedural and analytical rigor will be achieved by adhering to strict participant screening eligibility criteria and utilizing the same interview questions with same standardized format and recording tool.

Research Rigor

Consensus on the use of specific techniques for evaluating rigor and trustworthiness in phenomenological research has not been achieved. This is because phenomenological inquiry adheres to a philosophical perspective rather than a hard set of methods (Creswell, 1998), and this does pose operational challenges. In this study, the following criteria were used in ensuring research rigor and trustworthiness as presented by Lincoln and Guba (1985): credibility, transferability, dependability and confirmability. Additional techniques that will be used to help the researcher establish trustworthiness of the study remain open to unexpected findings.

Credibility

The researcher aimed to achieve accuracy of data and data analysis by taking the analyzed data back to the participants to ensure congruence. In addition, the analyzed data was reviewed by members of the dissertation committee who are experts in both HIV/AIDS-related research and phenomenology. Together with the researcher, the experts evaluated the investigative process in order to ensure credibility.

Transferability

Transferability to others in similar situations will be promoted through presentation of results and collaboration with experts in this field of study. A thorough description of the sampling procedures, setting and data enable readers to determine transferability of results. This also allows others to evaluate the study and determine applicability of the research findings (Speziale & Carpenter, 2007).

Dependability

Lincoln and Guba (1985) described dependability as *auditability,* meaning that researchers should be able to follow the investigator's decisions throughout the study and come to similar conclusions. This was achieved by maintaining an audit trail documenting the development of the study and by providing an adequate amount of evidence to stakeholders interested in reconstructing the process. Information regarding the phenomenon of living with HIV/AIDS in the AAW population, sampling procedures, and data collection procedures were described in detail. Describing the steps as transparently as possible leaves an audit trail for interested parties to follow, enabling them to read and evaluate the methods, and determine if the study is useable.

Confirmability

Confirmability represents freedom from bias or neutrality and was established by bracketing and *epoche* (Lincoln & Guba, 1985). Identification of preconceived ideas, experiential context and continuous journaling were used to ensure authenticity. The researcher set aside personal experiences with HIV/AIDS. Maintaining a journal helped bracket preconceived ideas and feelings to maintain an open point of view during the research process. These steps occurred throughout the process, particularly prior to interviewing and data analysis.

The primary goal of continuous reflective journaling will be to foster an understanding of the unique experience of living with HIV/AIDS by those who participate in this study. Identifying and writing the researcher's preconceived thoughts assist in putting aside personal experiences. This also served as a process of sorting out the researcher's feelings and experiences to separate them from those of the participants. Reviewing the analyzed data with the participants and the dissertation committee members who are experts in the field of study also mitigated the effects of researcher bias.

Summary

This chapter described the methods to be used to investigate the lived experience of AAW living with the HIV infection. The researcher plans to use the phenomenological philosophical framework to guide this study. In order to deeply understand this lived experience, a qualitative approach in the tradition of phenomenology was followed as a methodology. Data collection procedures in the form of structured interviews were discussed. Criteria for research rigor and trustworthiness as presented by Lincoln and Guba (1985) will be strictly adhered to. Additionally, ethical considerations in conducting this study to ensure the rights and welfare of the participants were described.

CHAPTER IV

FINDINGS OF THE INQUIRY

Introduction

This chapter details the significant findings of this phenomenological inquiry into the lives of African American women (AAW) with HIV/AIDS. An aggregate demographic representation and individual descriptions of the 14 participants are discussed. The process of data analysis and the related themes that represent the totality of these women's lived experience with the epidemic is chronicled. Finally, a summary of the major findings discovered through exploratory conversations with the participants is presented.

The goal of this phenomenological inquiry was to describe the life experiences of AAW living with HIV/AIDS. van Manen's (1990) approach to qualitative inquiry guided the researcher to uncover the meaning structures and to provide intricate effects of this phenomenon on the lives of those women affected by the disease. Through the personal stories of those individuals experiencing this phenomenon, the researcher was able to describe, interpret, and communicate the meaning of living with the HIV/AIDS.

van Manen's (1990) six activities served as the main guide for data collection and analysis. This hermeneutic phenomenological approach engaged the researcher's senses to the appearance of the phenomenon in whatever form it took. The essence of the researcher's interest in the phenomenon was founded with a sense of thoughtfulness. By keeping open to all emerging possibilities as they appeared or as they were concealed, the researcher maintained engagement with participants in the process of discovery.

The researcher used personal experiences as a starting point, obtained personal narratives from the women, reflected on the data, and through this process uncovered essential themes. A final synthesis of the material into a whole narrative text followed. Data collection involved face-to-face conversational interviews in an intimate, uninterrupted, and private environment, which afforded the researcher an opportunity to build a collaborative relationship with participants about the meaning of the phenomenon. Participants used their stories to describe their lives with HIV/AIDS. The narratives, authentic and true to the women's experiences, allowed the researcher to fully understand the multidimensional perspectives of their everyday existence, and to see through their lenses and hear through their voices what it was like for them to live with HIV/AIDS.

The interviews were audiotaped and transcribed verbatim to allow the researcher to listen and re-listen, read and re-read each participant's story and contemplate the essence of the experience. Post-interview thoughts and reflections were recorded in the researcher's journal. These reflections focused on the nonverbal behaviors, verbal emphasis, and the overall affect of participants during the interview.

The researcher started phenomenological reflection with silence, letting the question of how AAW see their lives with HIV/AIDS take residence within. It was essential to maintain a sense of openness to different variations and appearances of the phenomenon, whenever and wherever they emerged. The researcher began to gradually understand the experience and uncover the essences of the phenomenon universally interwoven with life in general.

Listening to each interview and simultaneously reading the transcribed narrative allowed the researcher to remain true to the participant's story. Reflecting on the participants’ facial expressions, emotions, voice inflections, and non-verbal expressions during the interview provided the researcher an opportunity to capture meanings that may have been concealed by the inadequacy of spoken words to describe an experience. The researcher contemplated the participants’ unique experiences through self-reflection and suspension of presuppositions and biases by writing and rewriting comments in the margins of the transcribed narrative texts.

Each successive interview provided new data and was compared to the existing data, in an attempt to find commonalities and differences. Comparisons were accomplished mentally and visually through phenomenological grids constructed by the researcher. The phenomenological grids allowed the researcher to visually view a participant’s expressed descriptions and interpreted meanings alongside others. This provided a snapshot of both the universal and singular essences ascribed to the experience. The researcher had no pretense to generalize as this was not the purpose of the study. Throughout the study, differences and intricacies emerged and were embraced. What mattered was thematic resonance, where the descriptions and essences were familiar and possible for someone else.

This process was not linear or method-driven. It involved a circular movement in an attempt to deeply explicate the central meaning of the phenomenon (see Figure 2, Chapter 3). The process required time, creativity, and necessitated the researcher to be a thoughtful listener to what was said and not said. Over a three-month period, the researcher resided within all the data collected and reflected on emerging themes to engage in phenomenological writing. Numerous initial abstractions and themes emerged. Resemblances and differences regarding the lived experience of the phenomenon became apparent. Multiple readings, reflection, and re-writing were performed to derive the true essence of living with HIV/AIDS for these AAW. This led to a natural and logical reduction of the data, culminating into related themes that represented their experiences within each woman's cultural context.

The construction of a phenomenological text was informed by the researcher dwelling within the question, "What is it like for the African American woman to live with HIV/AIDS?" The researcher engaged in uninterrupted time blocks of deep phenomenological reflection and writing. This included activities of contemplation and dialogue with dissertation committee members who are either experts in phenomenology or the study of HIV/AIDS in vulnerable populations. This led to further correlations made to different literary art forms and films. The transcribed narrative text and essential descriptions ascribed to the experience were shared with the interview participant during a second meeting for member checking and to ensure accuracy. After the twelfth interview and meeting sequence, saturation was achieved through data redundancy. Two additional participants were interviewed to confirm that saturation occurred. By the completion of the study, a total of 14 women participated. The related themes of *shattering self*, *constructing meaning*, and *empowering* emerged as a total representation of the African American woman's life with HIV/AIDS.

Demographic Representation

The 14 AAW varied in age, ranging from 35 to 53, with a mean age of 47.2 years. The age during diagnosis of HIV/AIDS ranged from 22 to 49, with a mean age of diagnosis of 33.5 years. The participants had been living with HIV/AIDS ranging from 4 to 26 years, with a mean of 13.6 years. Four women reported contracting HIV/AIDS from exclusive heterosexual partners who failed to disclose their HIV status, one through gang rape, and the rest from a vigorous history of prostitution, unprotected heterosexual activities with multiple partners, alcoholism, and substance abuse.

All women were US citizens and lived in Miami-Dade County. Twelve of the women described living in low-income housing, and two women were in a transitional shelter during the time of interview. Two women were born in Georgia, one in St. Thomas, one in Nassau, and ten in Florida. Their levels of education varied from 9th grade to some years of college.

Nine of the 14 women were on Medicare disability benefits. The remaining participants were employed in various positions such as grocery store cashier, hotel housekeeper, legal assistant, HIV peer counselor and HIV case manager. All participants volunteered on a regular basis for HIV/AIDS-related activities. Some women reported pathophysiologic comorbidities. Two women reported a history of renal failure, with one on chronic hemodialysis and one with a cadaver kidney transplant one year prior to the interview. Another participant reported remission from breast cancer after chemotherapy and a bilateral mastectomy. Two women reported chronic asthma, and one suffered from residual neurologic deficits from thromboembolic stroke. One woman was partially blind.

Characteristics of the Participants

The following description of the participants taken from the narrative interviews provides a context of their thoughts, values and lived experiences. The participants are introduced using their self-identified pseudonyms to respect confidentiality. The interactions between the researcher and the participants were rich, powerful and moving.

Most of the women were thoughtful and reflective when queried about their lives with HIV/AIDS as an African American woman.

Woman of God

Woman of God is a 42-year-old single mother, diagnosed with HIV/AIDS in 1989. During the interview, she frequently mentioned how she valued education and how proud she is of her son, who is a college scholar for business administration. Woman of God grew up and graduated high school in Miami. She was taking some computer classes before her kidney transplant in 2009. She is looking forward to completing her computer degree once she gets clearance from her physician to go back to school.

Currently, she is living with her boyfriend, who is also HIV positive. They met at a support group meeting two years ago. Woman of God is currently on disability but volunteers at a local HIV clinic. She likes to speak in public about her life experiences as an African American woman with HIV/AIDS. She believes that her life with HIV/AIDS is a blessing from God that has given her a second chance at life.

Yvette

Yvette, 42, works as a legal assistant in a law firm in Miami. She was diagnosed when she was 32 years old while dating a guy who failed to disclose his positive HIV status to her. She was born and grew up in Atlanta, where most of her family currently resides. Yvette initially isolated herself from her family for six months after her HIV/AIDS diagnosis. She felt devastated and was afraid to die. Currently, when asked about her relationships with friends and family, she states that it is "perfect" and that she "wouldn't change a thing." She looks forward to living life and seeing her grandchildren grow up. She wants to be a part of the "cure." When I asked Yvette about her intimate relationships, she responded by saying "I am not looking for a relationship right now. I need to work on myself."

Christina

Cristina was diagnosed with HIV/AIDS in 2005. She described her life previously as promiscuous; she engaged in unprotected sex. She was "shocked" and "devastated" from the diagnosis. Cristina identified the nursing staff as her greatest advocates and emotional supporters during the initial stages of her disease. She is currently dating a guy who is also HIV-positive. She loves to dance and cook. When asked what her plans are for the future, she said she wants to get married to her boyfriend. At 53, Cristina believes that living with HIV is not a "death sentence," but is another opportunity to live a much better and fuller life.

Sharon

When Sharon was diagnosed with HIV in 1989, she was in complete denial. She asked to have the test repeated again. She believed that there was no reason for her to have the "virus" because she only had one exclusive sexual partner all of her life. Her partner failed to be honest about his HIV status.

Currently, at 50 years old, she volunteers at a local HIV clinic and helps prepare meals at a homeless shelter. She attends support groups twice a week and goes to Church every Sunday. She is on disability benefits due to residual neurological deficits from a stroke she suffered in 1999. Sharon has five grown children. At the time of the interview, she was not involved in an intimate relationship.

Alicia

Alicia, 52, likes to be around people that are like her – HIV positive AAW. She attends support groups and finds strength through her friends at the local HIV clinic. She contracted the virus in 1998 through unprotected sex with multiple partners. She engaged in prostitution and used crack cocaine. During the period of her initial diagnosis, she felt afraid and shameful. She waited four years before disclosing her status and getting treatment. For Alicia, living with HIV is a new beginning. Currently, she is “clean” and denies “working the streets.” She feels loved and accepted by her family. She has one grown son who has refused to speak to her since her disclosure in 2002. “It’s his loss,” she said about him. Alicia is on disability benefits.

Shortcake

Shortcake used to live a life of “drugging and drinking.” “But I don’t do those things no more ... .” she said. In 1997, at 28 years old, she was shot and raped in the streets. She decided to get tested for HIV and tested positive the same year. Now at 40 years old, she lives alone on disability benefits for multiple co-morbidities related to HIV/AIDS. She keeps her scheduled appointments in the clinic and takes her medications religiously to “beat HIV.” Shortcake hopes to live long enough to see a cure for HIV.

Sky

I met with 48-year-old Sky in her office, where she currently works as an HIV/AIDS case manager. She was diagnosed 4 years ago during a visit to the hospital for pneumonia. Admitting that she came from a “vigorous” background of substance abuse and prostitution, Sky attributed her diagnosis to her past lifestyle. Her husband, who is HIV-negative, divorced her after her diagnosis. They have 3 young children together. She has not disclosed her condition to her children or any family members. “My children are not ready . . . I am not ready.” She sees her life with HIV as a “blessing.” She believes there is a “reason” for her still being alive and she considers her work for HIV as “part of God’s plan.”

Elaine

Elaine contracted HIV from her ex-husband of 16 years who failed to divulge his positive status. She was angry, ashamed, and felt isolated. After a year, she decided to disclose her HIV/AIDS diagnosis to her children and family. She organized a “festive” family picnic to tell everybody she had the “virus.” This disclosure was a “big weight off her shoulder.” Elaine still maintains a friendly relationship with her ex-husband and refers to him as a “partner.” She has not dated anyone since her divorce. She devotes her time working as a peer counselor for an HIV clinic. She stated that “helping other women like me is helping me live with HIV.”

Peach

Peach, 47, wants to live longer. She takes her HIV medications and keeps her clinic appointments without fail. She wants to complete her GED. She also wants to speak to black teenage girls about her life with HIV/AIDS. Peach contracted the virus in 1995 after a life of multiple, unprotected, heterosexual sexual encounters. She believes that talking about her previous life experiences will help save other young women from being infected. She has a long-term partner who is also HIV positive.

Tiffany

“I used to be a needle user . . .,” Tiffany answered, when asked how she got infected with HIV. She is a 50-year-old, single mother of six. Presently, she maintains a clean and healthy lifestyle to live longer. Tiffany feels optimistic about her life with HIV. She regularly speaks at Church about HIV testing and prevention. She believes her "speech will help someone else." When asked what she sees herself doing in the future, she smiles and responds "dancing with my children and grandchildren."

Debra

"I wanted to die." Debra wanted to commit suicide when she was told she had HIV/AIDS in 2001. She contracted the "virus" from the man she thought was an exclusive partner of nine years, who never disclosed he was HIV-positive. He left her and their children while she was hospitalized. She felt lost. She did not know what HIV was and did not understand what was going on with her body. HIV classes and support groups helped her comprehend her life with the disease. Her family and three children served as her support during the diagnosis. She said "they were not just a shoulder but a wall to lean on; they took care of me." At 55, Debra is now living with and caring for her children and twelve grandchildren.

Lala

Lala, 35, was laid off from her job as a cashier in a grocery store a few months before the interview. She currently lives in a transitional shelter until she can find a job to pay for an apartment. She was born in the Virgin Islands and has no family here in the US. At 22, she contracted HIV while she "worked the streets" of Miami. She refused to get treatment and went back to the streets to prostitute for crack cocaine. Lala continued her high risk behaviors for ten more years. "I was mad," she said.

In 2008, she "accepted and started loving" herself. She is presently in a comprehensive HIV program that provides support groups and counseling. She said, "I take my medications because I know it will help me." Lala believes that telling her story will eventually save someone.

Lady

Lady works as a housekeeper at a local hotel. She lives in a Salvation Army transitional shelter. Her income as a housekeeper is not enough to pay for rent. She got infected in 1997 by her boyfriend. After her diagnosis, she turned to drugs and alcohol to relieve her anxiety associated with her disease. She found inspiration in Magic Johnson to turn her life around after ten years of "drinking and drugging."

Pamela

Pamela, 53, tested positive for HIV in 1983. After 22 years of living with HIV, she has not disclosed her condition to any family members. Only a few close friends know of her status. She considers her "sisters" in the support group she regularly attends as her family. She has been on disability for four years and is on chronic hemodialysis three times a week. She currently lives alone in low-income housing.

Themes

The 14 participants passionately expressed their experiences living with HIV/AIDS. Rich descriptions of their feelings, emotions, and thoughts were shared during the narrative interviews. Thematic structures of this experience surfaced from multiple readings of the narratives, repeatedly listening to their voices, reflecting on the nuances of their expressions, and recalling their moods and affect. Writing and re-writing led to an emergence of three major related themes: shattering self, constructing meaning, and empowering. These themes vividly illuminated the lived experience of AAW with HIV/AIDS and represent the totality of this experience and filters through these women's existential lifeworlds of space, body, time, and human relation as they live with the "virus."

Figure 3 depicts the researcher's conceptual representation of the lived experience of AAW with HIV/AIDS as described by participants in this study. The related themes of shattering self, constructing meaning and empowering emerged through this phenomenological investigation. The researcher visualized these themes as encapsulated in the lived experience of AAW with HIV/AIDS. No clear boundaries between these themes were found, which means the experiences of one participant could belong to more than one of the themes. It was also possible to identify an overlap between themes within the dimension of the lived experience. One theme does not diminish the importance of the other; in fact, each circle adds to the totality of the phenomenon.

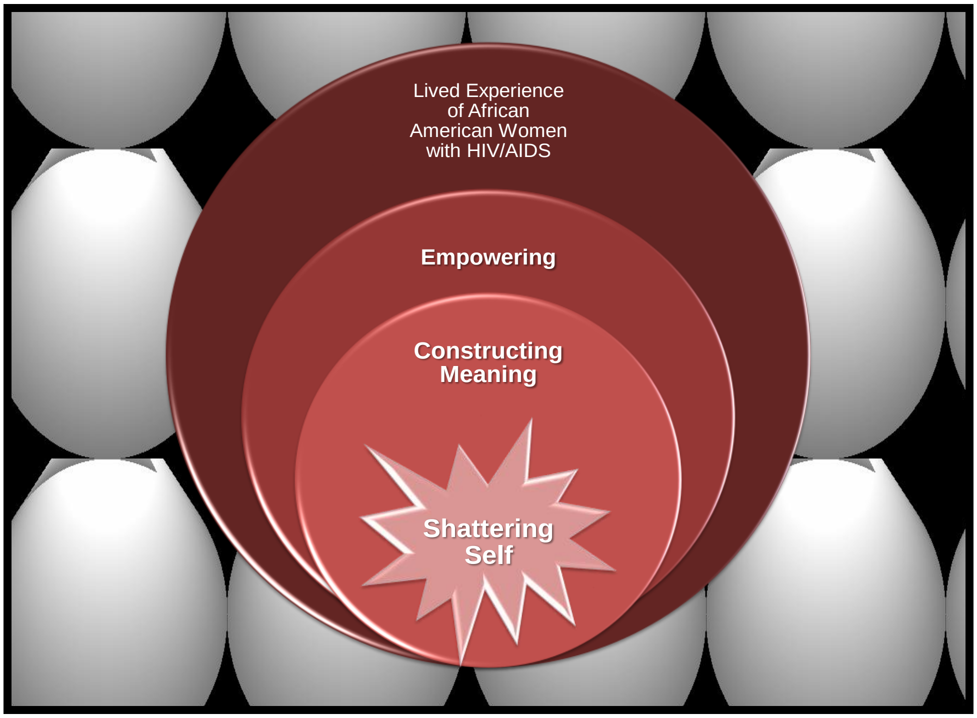


Figure 3. Umadhay's conceptual representation of the lived experience of AAW with HIV/AIDS

Shattering Self

Shattering is an adjective that describes severe damage or destruction. It is also defined as breaking suddenly into pieces (McKean, 2005). The participants described a wide range of emotional responses that involved feelings of shock and severe devastation of self following the initial diagnosis of HIV/AIDS. For them, hearing the words “You have the virus” was a stressful, life-changing phenomenon. Debra’s following comments mirrored those of other participants.

> I was really stressed, you know, because I didn’t know how to deal with it. I didn’t understood. I didn’t know what that virus was because it ain’t . . . something I ain’t never had. I was crying and everything. It’s something that I ain’t ever had in my whole entire life. But I was in suicides. I didn’t want to live because this something that I ain’t ever had in my whole entire life.

The HIV/AIDS diagnosis did not only contain important physical and physiological consequences for these women but resulted in major psychological and sociocultural impacts. Each participant responded to the news about her HIV/AIDS diagnosis with negative feelings or emotions. For Shortcake, it was anger: “I wanted to kill the son of a bitch!” For Elaine, it was flight: “Suicide was my way out.” Alicia’s overpowering emotion was shame: “God, what will my children think?” And for Sharon, it was shock: “The roof caved on me; it was dark.” But all women consistently expressed a sense of feeling broken when told they were HIV positive. As Peach recalled,

> When I found out that, you know, that I have the virus, I thought I’m gonna die and I was just scared. I was devastated. I cried . . . I felt like I broke into a million pieces, you know. At the time I am just not me anymore.

The other women similarly used words as “smashed,” “crushed,” “torn part,” “destroyed” and “devastated.” *Shattering self* emerged as a theme that signified the complete havoc experienced by participants upon receiving the diagnosis of HIV. Shortcake compared her feelings to the sudden pain she felt when she got shot in the head and raped, “You know, I got hit in the head with a gun and got raped. Just like that – it hurt so much and boom! I blacked out.” These women felt broken or destroyed, alone and estranged, a shattering sense of self and everything that had been familiar about their world and surroundings before the diagnosis. They were catapulted into an immediate awareness of the precariousness of their own mortality. The poignant words of Yvette upon hearing her diagnosis illustrated the major theme of shattered self:

> I was shocked and devastated. I was destroyed. The only thing I knew was that people died from it, and I said I was gonna die. My life is over. You know, that’s all I was thinking . . . that I was dying. I cried and cried and cried. It felt like somebody just thrust a sharp knife in here (pointing to her chest), and I just broke into small pieces . . . I was afraid to go to sleep at night ‘cause I thought I might not wake up. I thought, “Maybe I am better off dead.”

AAW viewed themselves as the primary caretakers of their families, but the initial reaction to the HIV/AIDS diagnosis incapacitated some participants’ from fulfilling familial roles and responsibilities. Elaine described how her image as a mother and grandmother was impacted by the diagnosis, how she lost her position as a caretaker and her sense of identity as a strong African American woman. “I was very, very devastated . . . afraid. I had grown kids and I had grandchildren to take care of. And I didn’t know what to do, I just cried for days.” The women described how their self-images as mothers, grandmothers and caregivers shattered after the HIV/AIDS diagnosis. Most women in the study echoed Elaine's thesis that their inability to define themselves resulted in feelings of inadequacy or incompetence. Woman of God recalled:

> Still crying, I said to the nurse "I need to go home. Let me go home first and make sure everything is ok at home for my baby." I kept crying, thinking that my baby comes first, cause he can't do stuff like – take care of himself. My husband don't do crap . . . . Can I tell you something? We Black women do things – we somebody's sister, mama, wife. Them people need me to do stuff for them. I'm ok with that. But when she (the nurse) said I am positive, I thought "If I'm sick, how can I do things for them?" I just kept crying.

Some women described how their relationship with family and caring friends got destroyed initially during diagnosis. They expressed the difficulty of being alone and having no peers for support or with whom to discuss the implications of HIV/AIDS in their lives. They felt an overwhelming sense of isolation and aloneness due to fear of rejection. They described how their connections with the external world – defined by their relationships – shattered because of HIV/AIDS. Sky tearfully recounted,

> I didn't know what to do. I didn't know who to talk to. I didn't know who to turn to (pause). And I didn't know how they (referring to her children) were gonna accept me and other people was gonna talk. I went through about six months without anybody to talk to. I felt I lost the people around me. Gone.

Likewise, Christina described her feelings of isolation when told she had HIV/AIDS,

> I was in shock, speechless. After the nurse left, I cried and cried. It felt like I was in a small dark room by myself. I was afraid, away from everybody: my kids, my

> friends, and my family. All of them disappeared – that's how it felt . . . for three years.

Self-destructive behaviors were also manifested and communicated by some of the participants after the initial diagnosis of HIV/AIDS. Their shattered sense of control was manifested by their sense of hopelessness and impending death. Shortcake was very angry and desperate. She contracted the virus after getting shot and gang raped – something that was out of her control. She disclosed this feeling within the first few minutes of the interview:

> I went back to the streets. I can't do no nothing no more. I was gonna die anyway. So what the fuck, I'll screw anyone for 20 bucks to buy my crack and get high. I didn't care. I thought "Shit, that virus is gonna kill me soon." I was done. I was broken, you know what I mean?

Some women felt that their lives were lost and destroyed by the disease. They felt that they completely lost control over their lives and that death was imminent. Lala thought her diagnosis of HIV/AIDS was a "death sentence," something she could never get a handle on. She painfully described her feelings:

> That's a day I could never forget 'cause that's when my life changed . . . I was only 22 back then and I thought 'That's it, I am gonna die at 22. Who knows, I may be dead tomorrow.' I just got real rebellious, so angry, and I went back to the streets and I tried to, you know, fuck everybody that wants to . . . you know what I mean? I was using drugs, I was getting high, you know. I was back in the streets drinking and drugging. That went on for ten years.

Shattering self was illustrative of the initial psychological and emotional chaos these women experienced when told they had HIV/AIDS. They described a feeling of brokenness: their sense of self shattered, external relations broken, and control lost. “A broken glass, yes, that’s how it felt. Like somebody hit me with a sharp tool and I shattered into thousands of small pieces, scattered everywhere . . . across the room,” Yvette poignantly recalled.

Constructing Meaning

Meaning in health-related literature has been defined as the significant perceptions an individual ascribes to one’s life, place in the world or specific situation in a specified time (Skaggs & Barron, 2006). Sifting through data during multiple readings allowed another related theme of constructing meaning to emerge from the narrative stories presented by the women who participated in this study. Constructing meaning emerged as a transformative process that occurred as the women attempted to re-order their perceptions within the context of HIV/AIDS. A common thread running through the narratives is how the participants made sense of their lives with HIV/AIDS. Inherent in every participant was the need to try and construct meaning about their everyday experiences with the disease. The circumstances of these AAW’s diagnosis compelled them to sort through their lives and reconstruct them in the context of living with the disease. Woman of God viewed pain and suffering as part of her life with HIV/AIDS. She reconstructed the meaning of pain and suffering as neither positive nor negative – but something that needs to be accepted. She stated,

> Nothing in my life comes easy. I just try to take every day one day at a time. I just try to live, eat right, live right and do to keep everything going. I have my bad

> days and I have my good days – but so do you (referring to the researcher). I believe things happen for a reason and God cares. God cannot take all the bad things in the world. If I have pain, it is ok. It is part of everybody's life, not just with HIV.

Likewise, Sky described her challenges of living with the epidemic as part of everyday life. Initially she saw HIV/AIDS as a threat that would shatter her relationships with her children. She was able to redefine the meaning of her situation as a way of reaching out to re-establish valuable relationships despite the difficulties of being HIV positive. Sky smiled as she talked about her life:

> I'm living a life, you know, a normal life. Of course there are challenges but I don't have to face it alone. My children are great. They say, 'Mama did you take your pills? Or mama you need to eat more . . . you need to get to bed. It's getting late.' I'm ok now. It is no different from anybody else.

Initially, the women struggled to reorganize their shattered reality to accommodate something that did not fit their understanding of the world. Most of them left their previous lives to make significant and meaningful life changes and to engage in fulfilling activities. Two of the participants directly work for an HIV/AIDS agency. The others volunteered on a regular basis for HIV/AIDS-related programs. Elaine, who works for an HIV/AIDS agency, recounted how she positively coped with the disease:

> I found myself leaving the pity party, and I wanted to help other women that were being infected, because I started talking to people and I started finding out that you have a lot of women out there—preacher's wives, teachers, nurses, all kind of people—that are HIV positive. And a lot of the women are getting it from

> heterosexual intercourse. So I came into an agency to work, the agency that I'm in now. And I came in on a voluntary basis. And this agency I help people, but this agency helped me to grow and accept what it is that I have and to put a positive impact on it.

Faced with this undeniable reality of her HIV/AIDS infection, Lala was able to transform this experience of despair to a sense of hope and reconstruct the meaning of "death sentence" to a reinvigorated appreciation of life. She viewed this as a second chance at living. Like most of the participants, she had to change her perception of dying to that of living with HIV /AIDS, of having another chance at a purposeful life by helping other women construct positive meaning structures out of their initial perceptions of the HIV/AIDS diagnosis. She explained,

> I'm learning how to live with it -- you know what I'm saying? It's a part of me, you know, and long as I take care of myself and I do what I need to do, you know, I'm okay. I got a lot of positive friends, and that's something 'cause you know you're not alone. To know you're not in this thing alone is a good thing. Now, I want to live longer . . . and I want to help other girls like me live longer. I think telling those girls on the streets my story will help them see that you can live with the "virus." Even if I help just one girl it's worth telling my story, you know what I mean?

The HIV/AIDS diagnosis also threatened the meaning structures these women attached to themselves as African American women. For some participants, their self image of being strong caregivers of the family was initially destroyed when they got diagnosed. They had to undergo subsequent changes and transformative processes that would support their view of self. Woman of God described her strength and how she looked at HIV/AIDS as something she had to "defeat" for the sake of her children.

> You can either grow and accept it and live with it and make the best out of your life, or you can either brow-beat yourself and it defeats you. Okay. With me, I have grown and I have accepted it, and I've learned to work, even fight, with it. I've learned to make HIV work with me to help other people, if that's what's needed of me. I don't let it bother me anymore. Child, I have children and grandchildren to take care of. And church, my sisters need me at church. I won't let that damn "virus" slow me down.

The experience of living with the HIV/AIDS epidemic irreversibly altered the lives of the study participants. These women began to confront their losses and restore their shattered being. Over variable time frames, they began to contain their suffering and started to live enriched lives. For most of the participants, HIV/AIDS distilled, clarified, and highlighted some of the more important aspects of living. Elaine described her life as "gift." She continued to say,

> For everything that AIDS took away from me, I got back a new vision of what really matters. It took my focus away from myself and redirected it more towards others. This is what it means for me to live with HIV: before, it was focusing on what I've lost, but now it is more like what I can do to be constructive and help others find a purposeful life with this disease. It is truly a blessing.

By transforming their pain and suffering, they became hopeful and were able to visualize previously unforeseen gains of their disease state. They began to feel a redefined sense of control and a new sense of purpose by becoming more connected with other HIV-positive AAW.

The participants felt an intense need to give back to their “sisters” and help other women adapt to their new life with HIV/AIDS. These new feelings positively affected the meaning these women ascribed to HIV/AIDS. All of the participants realized that HIV/AIDS afforded them with new opportunities and possibilities in life. The epidemic provided them with a renewed way of being to construct new meaning from their loss. Constructing meaning emerged as another related theme and was vividly described by the participants as they continue to live and cope with HIV/AIDS.

Empowering

Empowering was the theme expressed by the participants as they described their current lives with HIV/AIDS. *Empowering* is having the freedom to act, think, respond, initiate and decide on things that would significantly affect the lives of the participants. Their sense of empowerment or gaining control over their diagnosis began to evolve over varying time frames. For some of the women it occurred sooner than others. They narrated in detail how they mobilized their resources and focused on their strengths to gain control of a situation in which they initially perceived themselves as helpless.

In this study, most of the participants expressed that strength from a higher power and the social interaction with AAW with HIV/AIDS provided them with the support they needed to feel in control to improve their view of life. Woman of God expressed physical and emotional comfort by participating in meditation and prayer. She found inner strength and power through God despite the everyday struggles related to her diagnosis. She described this inner sense of power as follows:

> I’m stronger now because of God. I go to church and pray. He’s the only one that can help me, and I believe that I am alive now because of Him (pause). I don’t worry anymore like I used to. I enjoy my life, eat healthy, go to my doctor’s appointment, and take my medications. As long as I do these things, I will be ok. I am in control of my life because I have God.

Likewise, Lala revealed being empowered and liberated from HIV/AIDS because of her relationship with God:

> God played a major role in everything that I am today. With His grace and mercy I am well. I can’t go backwards. I gotta go forward. You know, you learn from your mistakes and not to continue doing ‘em again. God has forgiven all my mistakes and I am stronger now. I’m not worried anymore. I do what I have to do to stay alive, but I won’t dwell on it too much. You know, it’s done, it’s done. I can’t change it. But I do what I have to do to stay healthy, you know. I can’t change it. It’s what it is – it is God’s will and I’m cool with that.

These women were also able to identify the positive resources they have available through support groups and women like them who are HIV-positive. The participants utilized these resources to take control of a devastating situation instead of letting this situation dominate their everyday lives. Lady, who worked as a housekeeper and lived in a shelter with other HIV-positive women, derived strength from other women in the shelter. She narrated her situation as follows:

> In my little circle where I live at, there’s a program called Here’s Hope. And it’s about 90 of us that are positive there in the shelter. So we all relate. We help

> each other out. I think we are stronger because of each other. When I have not so good days, I know I'm not alone – anymore.

The participants also mentioned being empowered by having role models. Debra described being motivated by the everyday struggles of others who lived with HIV/AIDS. She admired others who were unafraid to talk openly about the disease. Magic Johnson was mentioned as an example of how to live and fight with a terminal illness.

Debra stated,

> After I seen that Magic Johnson, he was diagnosed with it, he was my inspiration, He's strong and healthy now. There's a lot of other people too, friends that I have. I'm in a program and we're learning to live with it, you know, it's not life-threatening. We are each other's inspiration to be strong. Living with this disease gave me control over my life.

Another way in which these women felt empowered is through the collaborative relationship they developed with their healthcare providers. They felt the need to be involved in their health care as much as they needed to take charge of their lives. All of them viewed living with their disease as an opportunity to regain control. Most of them took an assertive and active role in their health care. Yvette described,

> I want to live to see my children and grandchildren grow up. I do everything he (referring to her primary care physician) tells me to do. But if I feel that there are things that need to be done, or need to be done right, I let him know. Even though he is trained to handle it, I cannot give up that much control over my life.

When asked about her relationship with her primary care physician, Shortcake said,

> My doctor is good. He's Spanish. It don't matter to me what color he is. 'Cause inside we all got the same color blood. What matters to me is he cares. He's compassionate. He cares about how I feel, you know, And I hear it in his voice. I tell him this is not working, he listens. We sit down and he asks me what I think will work. It helps me, cause sometimes the medication make me sick. Or the appointment is hard, you know, I have to take the bus so we need to work out the schedule so I can be at the clinic or get my labs done. We decide together.

The participants experienced a transformational process that helped them gain control over their own lives. The women in the study felt empowered. They identified their strengths and resources to assert a positive outcome and improve their lives. Spirituality, support from women who are also HIV-positive, role models, and the collaborative relationship they have with their health care providers were the events that empowered participants to take charge and live with HIV/AIDS.

When placed within the context of the entire phenomenon, the themes that emerged from the participants' narratives represent an experience of finding meaning and purpose in life, regardless of life circumstances. The related themes of shattering self, constructing meaning and empowering led the researcher to reflect on the theory of meaning as it relates to the lived experience of AAW with HIV/AIDS.

The theory of meaning by Patricia Starck (1985) was developed to assist individuals to find purpose in life, regardless of circumstances. This theory was based on the work of Victor Frankl (1961), who found meaning to be the primary motivational force in life. Frankl also noted that life has meaning even in great suffering and that individuals have the freedom to find meaning or choose what stand to take in an unchangeable situation. Starck’s theory of meaning is supported by three concepts: life purpose; freedom to choose; and human suffering. These concepts provided a framework to better understand the findings of this study and will be further discussed in the next chapter.

Summary

The narrative stories in this study were an evocation of an emotionally-laden, complex, and multidimensional life phenomenon experienced by AAW living with HIV/AIDS. Through phenomenological descriptions, the researcher attempted to elucidate the meaning ascribed by these women to their everyday lives. Guided by Max van Manen’s (1990) phenomenological method of inquiry and analysis, this investigation provided the researcher with rich and thoughtful descriptions and increased understanding of what it is like for an African American woman to live with the pandemic. The descriptions were developed from the women’s experiences and provided a clear and vivid view into these women’s lives. A deeper understanding of this experience was obtained. This understanding and its correlation with the theory of meaning will be further explicated in the Chapter five. The outcome of this process enabled the researcher to capture the embodiment of the phenomena by uncovering the major themes of shattering self, constructing meaning, and empowering.

CHAPTER V

DISCUSSION AND CONCLUSION OF THE INQUIRY

Introduction

This chapter presents the discussion of the findings to a phenomenological investigation into the lived experience of AAW with HIV/AIDS. The meaning and significance of this study will be explored. An interpretative analysis of the themes that emerged from the study will be detailed and correlated with published literature, film, and music. A discussion of the interconnection between the findings of the study and the theory of meaning will be analyzed. The limitations of the study and its implications to nursing education, practice, research, and public policy will be identified.

Exploration of the Meaning of the Study

"What is the lived experience of AAW with HIV/AIDS?" This phenomenological question allowed the researcher to discern the meaning and essence of a unique and complex phenomenon experienced by the participants of this study. Hearing the HIV/AIDS stories through the voices of AAW and seeing their world of living with a life-threatening disease enabled the researcher to illuminate a clearer understanding of this phenomenon. The participants shared compelling stories and intense descriptions of their everyday life experiences with the epidemic. As the personal narratives were collected, experiential descriptions from existing published literary art forms were sought. In addition, the researcher engaged in multiple, concurrent activities that involved journaling, highlighting expressions of meaning through music and film, tending through the meaning of words in conversations, and searching the essence of this phenomenon in everyday life activities.

Interpretative Analysis of the Findings

Shattering Self

Receiving the diagnosis of a life-threatening illness, such as HIV/AIDS, has a profound emotional effect on everyday life. “Shattering self” represented the emotional havoc these women initially felt during their diagnosis of HIV/AIDS. It represented the various emotional reactions to this illness, adjustment problems for a variety of symptoms, and social stigma associated with HIV/AIDS. The diagnosis evoked strong emotional reactions that caused some of the participants to look at their lives as being broken. The theme “shattering self” or the breaking of one’s sense of self emerged as the participants described their experiences. Intense personal & emotional reactions of devastation were reported by the AAW who participated in this study.

The theme of shattering self mirrors the findings of Simbayi et. al. (2007) that men & women living with HIV/AIDS feel dirty, ashamed, and guilty of their status. The study conducted in Cape Town, South Africa consisted of 420 HIV-positive men and 643 HIV-positive women. The authors reported that 40% of the participants experienced discrimination and one in five lost a place to stay or a job because of their disease. Internalized stigma was prevalent and depression was substantial in their study population. Lee, Kochman, and Sikkema (2002) also reported similar findings in their study conducted in the United States. Lee et al. asserted that high levels of internalized stigma significantly contributed to levels of depression, anxiety, and hopelessness. This is consistent with the feelings of Sky, a study participant as she poignantly shared, “I was so scared, I knew I was gonna die. I immediately felt death. That’s how it was then.” The haiku poem “Results” by Tara Betts also succinctly illustrates the HIV diagnosis as a death sentence:

Results

Open envelopes
unleash death warrants
HIV positive.

The researcher also found a similar pattern of development in a qualitative study by Flowers et al. (2006). In-depth semi-structured interviews with 30 HIV-positive Black Africans living in London, UK were conducted to investigate the psychological impacts of an HIV diagnosis. The study population consisted of 17 women and 13 men. Utilizing an interpretative phenomenological approach, three major themes emerged: *contextualizing HIV status within the broader experience*; *HIV stigma and disclosure*: *negotiating a spoiled identity*; and *the impact of diagnosis: confronting a new identity*. Flowers et al. reported that the HIV diagnosis negatively impacted the psychological well-being of all the participants in their study. Most reported an initial period of shock at being told of their positive HIV status. This state of shock was followed by confusion, social withdrawal, and depression. Akin to the findings of this current research, the participants in the UK study felt that their identity and complexity as human beings were obliterated during the HIV diagnosis, which produced immediate and dramatic negative impacts to their sense of self. This was also exemplified by study participant Debra, a mother of three at the time of diagnosis, as she struggled to separate the impact of the illness with the burden of the diagnosis. She recalls:

> I was thinking who would want to take my children. I wanted to give them up (she starts crying). And me, I wanted to commit suicide and end it all . . . since that time, you become a different person. I just become another black woman with the virus, you know. Your previous life, your job, everything you believed in . . . Boom! Broken.

A study conducted in Iran by Mohammadpour, Yekta, Nikbakht-Nasrabadi, and Mohraz (2009) parallels the findings of this current research. The authors conducted a phenomenological study to better understand and describe the lived experience of HIV-infected Iranians during the period immediately following an HIV diagnosis. Four HIV-positive women and nine HIV- positive men participated in semi-structured interviews to describe their feelings when they were initially informed of test results. Two main themes emerged: (1) *doubt and delay in coming to terms with the diagnosis and testing* and (2) *associated impacts*. The authors concluded that the participants experienced a critically stressful event marked by extreme feelings, reactions, and psychological crises after receiving the diagnosis. Mirroring descriptions of the AAW in this study, the fear of HIV as a fatal illness and associated stigma, discrimination, and rejection were pervasive experiences of HIV-positive Iranian participants.

Similar experiences were also poignantly captured in a novel by Sapphire titled *Push* (1996). In 2009, this novel, already adapted for the stage, aired as a major motion picture, *Precious.* This is a powerful story of Claireece Precious Jones, an illiterate, overweight, 16-year-old, HIV-positive African American girl living in the New York City neighborhood of Harlem. As a young girl, Precious endured unimaginable pain from her dysfunctional family. Repeatedly raped and impregnated twice by her father, the young girl contracted the AIDS virus from him and was suspended from school because of her second pregnancy. Although her father died from AIDS-related complications, Precious continued to suffer constant physical, emotional, and mental abuse from her unemployed mother, but after enrolling in an alternative school, she was inspired by her new teacher, Ms. Rain, to change the direction of her life. An excerpt from this novel captures the emotional havoc and shattering of self experienced by Precious as she revealed to her classmates her diagnosis of HIV:

> Nurse at clinic say to me, “You are HIV-positive.” I look at my friends in the circle and I tell them, test say I’m HIV-positive. And all tongues dead, can’t talk no more. Rita Romero hug me like I’m her chile (child), and I cry and Ms. Rain rub my back and say let it out, Precious, let it out. I cry for every day of my life. I cry for Mama. And I cry for my son, the song of my life. . . . Hammer in my heart, beating me— I feel like my blood a giant river swell up inside me, and I’m drowning. My head all dark inside. I say I drownin’ in river . . . .

The theme of *shattering self* represented the initial emotional chaos experienced by the AAW interviewed in the current study. The AAW described a feeling of devastation, being broken, and of imminent demise when told they had the HIV virus. This theme reflects the findings of Stevens and Doerr (1997) in a qualitative study that described women’s subjective experiences of being informed of a positive HIV status. The authors interviewed 38 low-income, HIV-infected women of diverse racial backgrounds. Sixteen AAW consisted of 43% of participants in this study. Stevens and Doerr noted that the discovery of HIV seropositivity was viewed as a traumatic life event. The metaphor of *calamity* was described by 53% of the participants. This parallels the description of study participant, Peach, as she recalls the day she got diagnosed with HIV, “I felt like the roof was caving in on me. I felt a sharp blow . . . and in instant I was broken. Everything around me went dark.” Like the women in this study, the women in Steven and Doerr’s study also expressed an initial feeling of shock, fear, anguish, and suicidability. The HIV diagnosis was also portrayed as a rupturing event perceived with deep distress and great loss. The metaphor of calamity and the emerging theme of shattering self are captured in the following poem about the HIV virus, “Viruses,” by Lamont Steptoe in the book, *Fingernails Across the Chalkboard: Poetry and Prose on HIV/AIDS from the Black Diaspora :*

> invisible things
> are killing us
> viruses
> are armies and bombs
> we are murdered
> genocided by a hidden hand
> slowly we discover destruction
> our tears and screams
> beseeching heaven
> for mercy

Constructing Meaning

Constructing meaning is another related theme that emerged as the AAW described their lives with HIV/AIDS. According to Frankl (1969) human beings cannot exist in a world where there is no meaning. Meaning is central to a life of purpose. Life without meaning creates an “existential vacuum” (Frankl, 1985). The experiential world must be structured to provide meaning or the only alternative is suicide. During the initial diagnosis of HIV/AIDS, these women experienced a shattering of assumptions with regard to their basic conception of themselves and their world. This set the scene for the participants to adopt different ways in which they could ascribe meaning and make sense of their experiences of being HIV-positive. In order for these women to regain a sense of control and reaffirm their direction in life, they had to accommodate something that did not previously fit with their understanding of the world. Their meaning structures were threatened and shattered by the illness. These structures needed to be re-organized and the women had to construct meaning in order to incorporate their present life with the “virus.”

Skaggs and Barron (2005) conducted a comprehensive concept analysis of searching for meaning in negative events. The authors described the cognitive processes that occur when people experience an event that disrupts their perceived normal environment. Components of searching for meaning included global meaning and situational meaning. *Global meaning* refers to an individual’s perception of one’s life or position in life. *Situational meaning* refers to the individual’s perception of a specific event. Meaning is shattered when the individual’s situational meaning is incongruent with their global meaning (Skaggs & Barron). This work substantiates the findings of this study regarding the fact that the process of constructing meaning began after the women’s environment was disrupted by the “virus.” For the women in this study, the diagnosis of HIV/AIDS assaulted their plans for the future and their view of life and death. Sky realized she could not escape AIDS. During the interview she eloquently explained how she dealt with it.

> AIDS is not a death sentence. I saw it as a warning. God gave me this warning. A warning for me to start living life . . . to wake up and smell the roses. You know what I mean, to live a life of purpose and really work on things that matter most. For me, it's my children. I take care of myself and do the right things because I will live for my children . . . despite the virus.

Sorajjakool and Seyle (2005) noted that it is inherent in humans to seek understanding and make sense out of life. The human need to ascribe meaning becomes intensified when an individual is faced with a life-threatening illness. In their study of breast cancer survivors, the authors suggested that the need to construct meaning is basic to a person's state of well-being in order to survive. The authors concluded that the women in their study struggled to make sense of something that is totally senseless. They needed to construct meaning in the presence of their breast cancer in order for them to move forward and effectively cope with their diagnosis (Sorajjakool & Seyle). These findings are similar to those of the participants in this current study. For example, Cristina poignantly described how she effectively coped with her diagnosis, "I know I have a terminal illness, but I am not terminally ill. I have to see AIDS as something I have to live with, not something that will kill me."

The researcher found a similar pattern of development in a grounded theory study by Hall (2001) that generated a substantive theory of meaning construction from loss in individuals who had been affected by the suffering associated with AIDS. Participants included 11 HIV-positive and six HIV-negative individuals. All participants had lost family members, friends or significant others to AIDS. The sample consisted of 10 White males, 4 White females, 1 African American male, and 2 African American females. The participants were asked to discuss the role of AIDS volunteerism as it relates to their loss or suffering. Akin to the findings in this current study, constructing meaning was described by Hall's sample as a transformative process, whereby those individuals infected with the virus, and their friends and families, were able to transform suffering and construct meaning from loss to develop new ways of thinking and being. Hall noted that through AIDS volunteerism, the participants were able to contain their suffering experiences and embrace transformations that allowed them to construct a new and more positive meaning to their loss (Hall). These findings parallel the theme elucidated by Peach as she offers an explanation of how she ascribed meaning to her diagnosis.

> I see living with HIV as a gift and a chance to give back. I share my experiences to other women to help them get through. For me, it makes me feel good to help and feel that I am not alone. That there are other sisters like me. And that we all could make it through.

The theme of constructing meaning in the lives of AAWwith HIV/AIDS has also been illustrated in film. The HBO movie *Life Support* (George, 2007) captured this experience in the character of Andrea. This motion picture was inspired by the true and compelling story of Andrea Williams, played by Queen Latifah. Andrea was an HIV-positive, former drug addict living in Brooklyn, NY. The movie presented a touching and poignant tale of her journey to the brink of self destruction and despair, and her inspirational fight to regain her identity and family. She struggled to maintain a happy life despite being HIV-positive. The story chronicled Andrea's passionate fight to make things right and create meaning in her life through her involvement in an AIDS outreach group.

The soundtrack of the film, titled *Life Brings Change (*performed and co-written by Jamie Foxx), further illuminated the ways an individual may construct meaning out of a desperate situation. The music complemented Queen Latifah's performance as she breathed life into the character of Andrea, a victim who was able to make sense of her illness as a blessing despite unchangeable circumstances. An excerpt from the song brings to light a story of loving, losing, letting go, and finding light at the end of a long, dark tunnel.

Now, maybe the world doesn't see you
And maybe they don't understand
Just ‘cause you don't see the footprints
Don't mean that they're not in the sand
But Love brings change, oh yes it does
Oh, Love brings change when you need it.

I know you're surrounded by strangers
It feels so alone in your heart
But when everyone stands in the darkness
No one can ever tell them apart

But Love brings change, oh yes it does
Oh, Love brings change when you need it.

When you look eye to eye with an angel
Don't mean that it's always the end
Sometimes it the start of a new blessing
That comes in the form of a friend (Bereal, Burwell, & Foxx, 2007)

As the women in this study were faced with a life-threatening illness, they struggled to answer the question "Why?" They constructed meanings out of their shattered assumptions in order to positively cope with their diagnoses. The women took an active role in taking care of themselves and maintained a positive attitude to help them live longer. This experience is eloquently captured in an excerpt of the poem *Death is for the Dead* by River Huston, an HIV-positive award-winning female poet, author, and journalist:

AIDS, AIDS, AIDS
Oliver Wendell Holmes once said
"To find true happiness, get a terminal illness
And take good care of yourself"
Real good care pajama parties, cookies & milk, afternoon naps kinda care
Lots of LOVE, LOVE, LOVE

I see angels flying above everyone's head
I see miracles all day long
in oranges, brown fat crawly bugs,
on the big time journey across the towpath

ducks in winter, Gingko trees raining yellow
GINGKO, GINGKO, GINGKO
my dog smiling and wagging its tail
to the rhythm of three sweet altos
*"knock, knock, knocking on heaven's door"(*Huston, 1993)

Empowering

The participants of this study expressed notable accounts of their experience with HIV/AIDS as "empowering." The women's descriptions specifically included "feelings of in control," "strength," "pulling myself up," "sharing to others and healing myself," "take charge of my life," "head up high" and "moving on." Empowering is another related theme that emerged from the AAW's narratives of their lives with HIV/AIDS. Gibson (1991), in an analysis of the concept of empowering in women, described *empowering* as a multidimensional process through which an individual focuses on strengths and abilities to help one gain control over his or her own life. As Gibson described, *empowering* "is a social process of recognizing, promoting and enhancing people's abilities to meet their needs, solve their problems and mobilize the necessary resources in order to feel in control of their own lives" (p.359). For the women in this study, existential beliefs, such as faith in God are general beliefs that gave them strength and control over their lives, even out of damaging experiences. Woman of God reflects on her perspective on living with HIV/AIDS:

> I pray every day. My Lord has given me strength to live with the virus. I am stronger now . . . I am whole. I have the power to change my life and to control where I’m headed.

The findings of this current research that illuminated empowerment through spirituality in AAW mirrors the conclusions of Polzer-Casarez and Miles (2008). These authors described how HIV-positive African American mothers effectively coped with their diagnosis through their spiritual relationship with God. Longitudinal semi-structured interviews were conducted with 38 HIV-positive African American mothers who all reported a Christian religious affiliation. The purpose of the investigation was to describe how spirituality impacted the lives of the participants in the context of coping. Through content analysis, Polzer-Casarez and Miles found that a personal relationship with God is central to how African American mothers successfully adapted to their HIV-positive status. The women in their study viewed God as in sovereign control and believed that their relationship with God required active participation on their part. Participation for these women meant activities that involved prayer, church attendance, and reading the Bible. The women expressed that active participation was essential to their improved health status. Consistent with the findings of this current research, Polzer-Casarez and Miles concluded that spirituality may be a potential cultural strength that empowers AAW with chronic illness, particularly those with HIV. Artistic expression of this spiritual strength and empowerment was captured by Jacqueline of Durham, NC, the grand prize winner of the *2009 Fight HIV Your Way* photo essay:

> Someone once said . . . ‘Life isn’t about how to survive the storm,
> But learning how to dance in the rain.’

> Having lost my husband and child to AIDS
> I lift my head to the heavens
> in a sea of calm
> And give GOD praise

The photograph can be accessed through (http://www.fighthivyourway.com/winners.aspx).

Further support for the psychological benefits of spirituality was gained from the findings of Coleman (2003). Through a descriptive cross-sectional study of 117 African American men and women living with HIV/AIDS, Coleman concluded that spirituality significantly contributed to the mental well-being and functional health status of African American men and women living with HIV. In a literature review of the concept of spirituality in health sciences, Chiu, Emblen, Van Hofwegen, Sawatzky, & Meyerhoff, (2004) revealed the common themes that relate to spirituality: existential reality, transcendence, connectedness, and power/force/energy. These themes parallel the experiences of participants in this current study. Most of these AAW focused on and utilized the strength of their spirituality to gain control and feel empowered over their disease. Shortcake expressed this sense of empowerment through spirituality as she recalled this process.

> I was angry and sad . . . you do that, and then with the help of God, you move on. You go through the steps and pull yourself up. I pray a lot. It is not easy, but I let God take charge of my life. With God, I feel secure. He is the one driving, and I know I will get where I need to be.

An excerpt from the song lyrics of *Jesus Take the Wheel* by Carrie Underwood expressively captured the voice of Shortcake's narrative:

> Jesus take the wheel
> Take it from my hands
> Cause I can't do this on my own
> I'm letting go
> So give me one more chance
> Save me from this road I'm on
> Jesus take the wheel (James, Lindsey, & Sampson, 2005)

Most of the women sought social interaction with other HIV-positive AAW. They expressed that support groups provided beneficial sources of information, encouragement, and strength. Elaine actively sought help from an AIDS service organization. She reached out and shared her experiences in a support group and individually with other women who had AIDS. At the time of the interview, Elaine worked as a volunteer in an HIV/AIDS clinic. She intensely described her HIV/AIDS advocacy as uplifting and hopeful. Speaking about her life experiences with HIV/AIDS provided her opportunities to self reflect and feel empowered. Elaine poignantly narrated how her involvement in the support group influenced her view of life with HIV/AIDS:

> When I first started speaking about how I live every day with this epidemic, I would always leave feeling strong and empowered. I think a lot of my sisters that have the virus feel as if they are walking alone inside a dark tunnel, and they can't see the end. I felt like that before. I have been there. Attending these support groups help you see the light at the end of that tunnel. You know, I see myself as

> a small link of a chain. I’m part of a long collective chain of experience, strength, and power of Black women that have HIV. I will make that chain strong by my voice and words speaking about AIDS.

Clearly, Elaine felt empowered and liberated to speak about the suffering she experienced with HIV/AIDS. Several participants in this current study spoke of finding a “voice” to express who they are and what they cared about. For most participants, finding their “voice” offered them a renewed sense of self-control over their lives. This empowering experience has been captured as an artistic representation in the lyrics of *Sing* by Annie Lennox. Lennox described the song as an “anthem that could be used as a symbol of unity and empowerment, and help spread the message to the world.” The official music video of *Sing* begins with Nelson Mandela advocating for HIV/AIDS, “You can help break the silence, talk about HIV and AIDS. Let us use the universal language of music to sing out our message around the world.” The music video can be accessed at: http://www.youtube.com/officialSINGcampaign

Sing

Sing, my sister . . . sing!
Let your voice be heard
What won’t kill you will make you strong
Sing, my sister . . . sing!

You don’t need
To disrespect yourself again
Don’t hide your light behind your fears

My women can be strong
You've known it all along
What you need
Is what you haven't found

Women are the mothers of the world, my friend
I tell you womankind is strong
Take your beautiful self up to the heights again
Back to the place where you belong

C'mon my sisters now
Sing loud and sing proud
Sing my sister . . . sing!
Use your voice to call out
Let your voice be heard
Use your voice
For freedom (Lennox, 2007)

Theory of Meaning

Inherent in every individual is the need to try to make sense out of life, out of things seen, heard, and experienced. The need to find meaning is an integral part of being human. Frankl (1969) noted that people find meaning in life through their creations, experiences and encounters with the world, no matter what their life circumstances. But the need to create meaning becomes more evident when a person is confronted with crisis or a catastrophic event (Schwartzberg & Janoff-Bulman, 1991). The effect of trauma questions the meaning of an individual's existence and shatters their basic assumptions of self and the world. The theory of meaning (Starck, 1985) was developed to psychologically assist individuals, groups, and communities handle stressful, traumatic, and life-changing events. The essential underpinnings of this theory were based on the work of Frankl (1984).

The following fundamental assumptions represent the foundation of the theory of meaning:

1. Search for meaning is the primary motivation of life (Frankl, 1984). This asserts that the whole world has meaning and purpose, and therefore every life experience potentially hides meaning in itself, which cannot vanish under any circumstance. Thus, life holds meaning even in the most miserable of situations.
2. Another postulate is that people have freedom to choose their responses to their environments (Frankl, 1984). Individuals have the freedom to find meaning in what they do, what they experience, or take a position when faced with a situation of inescapable suffering. *Suffering* is defined as a challenge wherein the individual has an existential choice regarding how to approach any given set of circumstances.
3. Finally, every human being is inspired by a striving or yearning for meaning (Frankl, 1984). When individuals find meaning in life, they will endure any suffering. The person's pursuit of a meaningful existence or purposeful life brings satisfaction and healing.

The findings of this current research have led the researcher to an interconnection between the lived experience of AAW with HIV and the theory of meaning. The related themes of shattering self, constructing meaning and empowerment correlate to the major concepts of Starck's theory of meaning.

Concepts of the Theory of Meaning

The building blocks of Starck's Theory of Meaning (1985) are human suffering, freedom to choose, and life purpose. The theory was developed to help people who are experiencing inescapable suffering to better cope, by looking at ways in which they can find meaning in their lives. Starck suggests that meaning is a journey towards achieving life purpose and that the individual has the freedom to choose a position in spite of unchangeable suffering. Figure 5 depicts relationships among the concepts in the theory (Starck, 2003, p. 135).

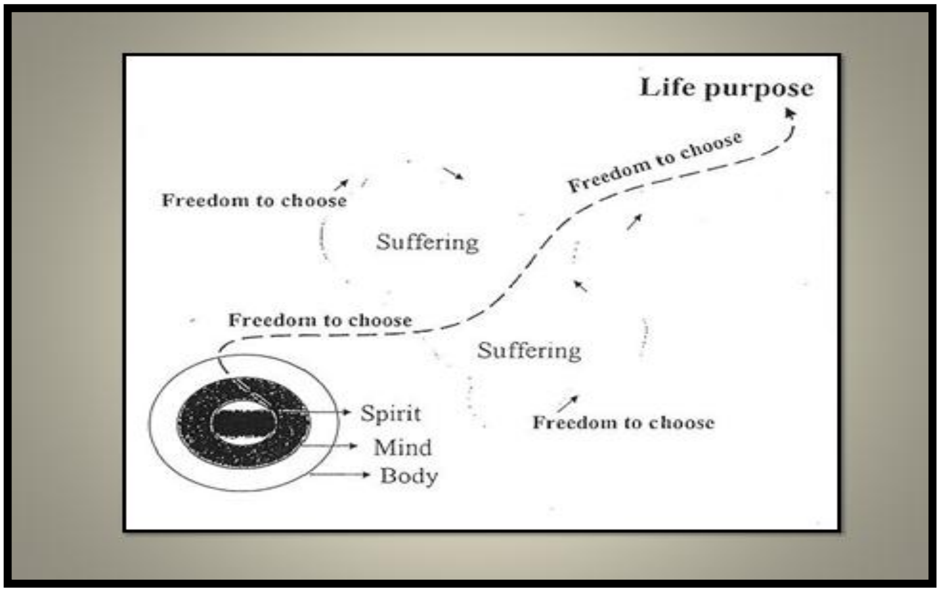


Figure 4. Theory of Meaning (Starck, 2003)

Human Suffering

Human suffering is one of the three concepts of the theory of meaning. Suffering is a pervasive and unavoidable phenomenon in human experience. It is a subjective, unique and an all-encompassing experience that may vary from “simple, transitory discomfort to an extreme anguish, despair or apathetic difference (Starck & McGovern, 1992, p. 27). Cassell (1982) described suffering as a state of severe distress experienced by the whole person’s body, mind, and spirit. The experience of suffering is associated with events that threaten the wholeness of the person or present an impending destruction of an individual’s sense of self.

The concept of human suffering offers another explanation of “shattering self” elucidated from singular and shared daily life experiences of the women that participated in this current research. Receiving the HIV/AIDS diagnosis presented a threat to crucial aspects of every participant’s sense of self, being or existence. For most women, the initial reaction was traumatic, resulting from the shattering of their basic assumptions of themselves and the world prior to the diagnosis. Study participant, Lala, shared her feelings of profound devastation the day she got diagnosed with HIV/AIDS. Her narrative was riveting and compelling as she correlated the date of her diagnosis, June 6, 1996, to the integer 6-6-6 she associated with the “beast” (in modern popular culture as the *anti-Christ* or the *devil*)::

> June 6, 1996. Wow. Ooh. I could never forget that day ‘cause it’s 6-6-96 and I thought, it’s the mark of the “beast” on me. On myself. And I was like, wow. When I sat back and I thought about it, June the 6th, the sixth month; the sixth day, 1996. I’ll never forget that day. That’s a day I could never forget ‘cause

> that's when my life changed. I felt like it was the end of the world, my total destruction. They call that apocalypse in church, you know.

Freedom to Choose

Another concept of the theory of meaning is freedom to choose. Starck described this as a "process of selecting among options over which one has control" (2003, p. 132). Frankl (1984) pointed out that human beings are essentially free to distance or to rise above and beyond the environment, events of fate, and even their own selves. Humans have the option to choose their own attitude by allowing themselves to discern the meaning of possibilities attached to a specific situation. The concept of freedom to choose one's position involves meaning-making and meaning-discovery processes that modify the individual's reality. The patterns of meaning adapted by an individual play a role in his or her adaptation to a terminal illness (Shuster, Steeves, and Richardson, 1996). Frankl also stressed that individuals have the freedom to transcend suffering and find meaning in their lives, regardless of circumstances.

The concept of *freedom to choose* supports the theme of constructing meaning that emerged in this study. The women in this research experienced transformative processes of creating meaning from their illness and suffering. They struggled to understand and make sense of their experiences with the disease. In their attempt to regain a sense of control and re-adjust the direction of their lives after the diagnosis, they had to ascribe meaning to a traumatic and devastating situation. The participants felt they had the freedom to choose their attitude and coping strategies towards HIV/AIDS. All of the participants demonstrated positive coping strategies that resulted in successful adaptation to and feelings of empowerment over the "virus."

Elaine described how she had a choice to attach a positive meaning to HIV as an opportunity.

> I found myself leaving the pity party. Okay. You can either grow and accept it, live with it and make the best out of your life or you can either brow-beat yourself and it defeats you. Okay. With me, I have grown and I have accepted it, and I've learned to work with it. I've learned to make HIV work with me to help other people. Everybody has a choice and I chose to define HIV as an opportunity for me to get better and give back. That is what life with HIV means for me.

Life Purpose

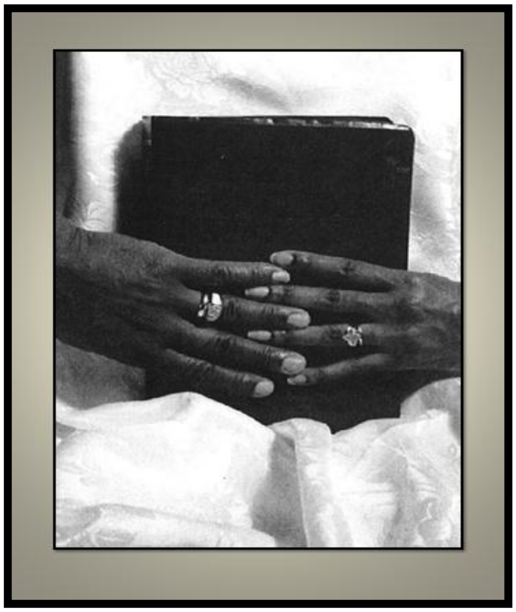
The final and central of the theory is *life purpose*. Starck (2003) described this concept as the summation of an individual's existence to find meaning and establish one's purpose in living. Uncovering life purpose is a means of transcending one's self, an inherent characteristic of being human. Frankl (1984) specified that people transcend in three ways: by giving back to the world creatively; by experiencing the world through receptiveness to others or the environment; and by adopting an attitude of acceptance when faced with an unchangeable situation or suffering.

Experiencing an unchangeable event of being diagnosed with HIV/AIDS is the one thing that inspired a discovery of meaning in a previously superficial existence for some of the participants of this current research. Accepting that all life involves some suffering empowered these women to use their illness to better understand and control their life situations. Pamela felt her diagnosis was not only something that needed to be accepted but that was inherently a thing of value. HIV/AIDS unlocked her previously dormant inner strength and potential to empower her to speak and actively volunteer in an HIV/AIDS program. Pamela smilingly shared her experience:

> I used to be drugging and drinking until I got sick. My new life with AIDS changed my outlook. I used to focus on myself and on what I thought will make me feel good, you know, like crack and all those kinds of things. But now, my focus is keeping myself healthy so I can do things for others. Working in the clinic makes me really feel good. I know I'm doing something positive and making a big difference.

The concept of life purpose supports the theme of empowering that represents life with HIV/AIDS for the remarkable AAW that shared so openly in this study. The concept of life purpose is analogous to the empowering experience participants in this current research expressed during the narrative interviews. Figure 5 reflects the interconnectedness of the concept of life purpose and empowering as captured in an anonymous photo essay entry at the *2009 Fight HIV Your Way* web site: (http://www.fighthivyourway.com/winners.aspx). This entry was given an award of distinction.

Figure 5. Award of distinction winner to the *2009 Fight HIV Your Way* photo essay contest.



> There are times we feel life's unfair, but GOD shows us differently. Amazingly He shows us, in our journey of life that there are second chances. WE must learn to look above our circumstances and dream big. Then life proves we "all" are predestined with a purpose, beyond HIV. (Anonymous, 2009)

"Making a contribution" or "leaving a legacy to make the world a better place" are common descriptions that support one's life purpose. This may come as an urgent calling to complete something an individual considers meaningful or purposeful. The participants in this current study engaged in various activities of volunteerism in multiple HIV support organizations. Most of them transcended their own circumstances, discovering the strength to advocate for other victims of the disease and coming to understand this role as a central purpose in their lives. Research participant Sky, a peer counselor at a local HIV clinic, presented me with a copy of a poem during the interview. "This is my life purpose," she explained. For Sky, the poem *Let's Confront AIDS* (Brutus,

1993) brings the reality of living with HIV into stark focus. A framed copy of the poem hangs in her office:

Let’s Confront AIDS

Let’s talk openly about AIDS
about the pain and grief
about the anger and fear
about the deep sense of loss

Let’s confront the dread scourge:
sing songs about the pain it brought
write poems of how it made life more dear
how it exposed the ugliness of hate

Let’s have festivals to challenge AIDS
write books that record our response
have parades the defy the bigots
Come, lets talk openly about AIDS (Brutus, 1993)

Summary of the Interpretative Analysis of Findings

The scope of the theory of meaning provided a framework to generate a deeper and more authentic understanding of the lived experience of AAW with HIV/AIDS. Underpinning this phenomenon are the themes of shattering self, constructing meaning, and empowering. Receiving a diagnosis of HIV was a life shattering experience that left many of the participants with a profound sense of despair and emptiness. The women in this study were forced to recreate the meaning structures and assumptions they held prior to their illness. This provided a setting for the participants to explore different ways to ascribe and make sense of their lives with the "virus." The positive awareness of a newly constructed self gave them the ability to transform suffering and construct meaning that would assist them in developing new ways of being. Figure 6 is a phenomenological conceptual model derived from this current study. The related themes of shattering self, constructing meaning and empowering were supported by the concepts of the Theory of Meaning (Starck, 2003) in the following adapted framework.

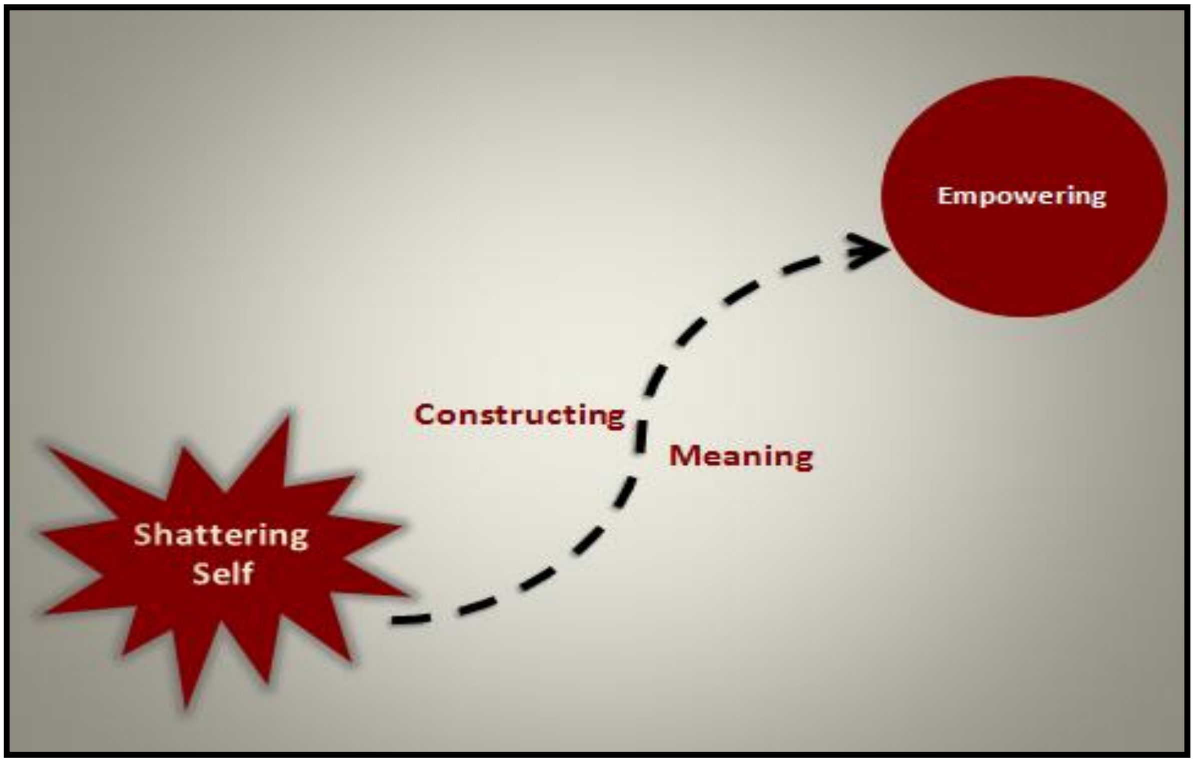


Figure 6. Umadhay's Phenomenological Conceptual Model of the Lived Experience of AAW with HIV/AIDS (adapted from Starck, 2003)

Implications of the Study for Nursing Practice

Understanding the complexity of living with HIV/AIDS for AAW has implications for health care professionals who work with this specific population. Deeply appreciating and understanding the core level at which the experience affects these women may be fundamental to providing effective, sensitive support. HIV-positive individuals need time to redefine themselves and to develop a sense of purpose and restored equilibrium. The participants in this study demonstrated that learning to live with a chronic and possibly fatal disease is a process that occurs over varying time periods.

The theme "shattering self" should remind practitioners that the initial period during diagnosis may not be an appropriate time to provide therapeutic information about HIV/AIDS. At this stage, the women may need information for psychological and social support. The present findings emphasize the important role of support groups play towards effective coping and adaptation. Structured support groups provide an environment in which the participants are free to share their experiences with other people who listen, who understand their experience, who experience the same daily challenges, and who do not attempt to provide explanations or advice.

Participants consistently labeled their helping behaviors or giving to others as self-enhancing or self-affirming activities. Practitioners may be instrumental in developing structured programs that facilitate roles and acts of volunteerism to encourage helping behaviors in individuals with HIV/AIDS. Structured support groups, volunteer opportunities to help other women with HIV, and opportunities to participate in research studies may help this population overcome the negative impact of HIV/AIDS and begin constructing meaning from their illness. The practitioner may help create these opportunities that provide a new setting for finding new purpose, creating new meanings, and increasing self worth for the HIV-positive population.

This increased understanding also brings an element of empowerment. The experience of a life-threatening diagnosis caused a collapse of prior meaning structures the participants attached to themselves. All the women in this study were able to restore meaning and purpose through an adjusted orientation to life. Spirituality was repeatedly mentioned as positive resource of hope amidst a serious diagnosis. Relationship with God was viewed as source of support in managing the illness and reducing distress related to illness. This study elucidated that spirituality is interwoven in the meaning-making and empowering experiences of living with HIV/AIDS. This offers the potential for practitioners to design interventions and care delivery approaches that support spiritual adaptation to the disease. It is imperative for health care professionals to recognize that spirituality may be a potential cultural strength in AAW with HIV/AIDS.

Implications of the Study for Nursing Education

The findings of this study illustrate the fundamental need of meaning construction in the suffering experience of AAW with HIV/AIDS. The process of constructing meaning occurs when both practitioners and clients engage one another to create understanding and coherence in which possible meanings or choices emerge to serve as a catalyst for healing (Willis, Grace, & Roy, 2008). Basic nursing education should include introductory knowledge of meaning construction to assist clients to make sense of their health and healing concerns. Cognitive skill development in assessing client’s experiences and outcomes of meaning construction should also be integrated in the educational structure. Affective coaching in purposeful awareness and self-reflection in support of constructing meaning may help develop a context-specific nursing curriculum.

Increased awareness and deeper understanding of the idiosyncratic lifeworlds experienced by AAW living with HIV/AIDS resulted from this phenomenological investigation. Through the thoughtful and descriptive narratives of these women, a deeper appreciation of an Afro-centric perception of health and illness emerged. These findings may be used in designing a culturally sensitive curriculum focused on the unique needs of this specific population. Integrating this information promotes educational frameworks that generate informed, unbiased, and culturally competent practitioners.

Implications of the Study for Public Policy

Despite the degree to which AAW are affected by the HIV AIDS epidemic, policies aimed at reducing the incidence and attending to the special needs of this marginalized population are lacking. The ways in which society has responded to the HIV crisis among AAW and other stigmatized groups reflect a complex interaction of cultural, social, and moral factors. Clearly, the national prevention response to the epidemic pervasive to this population is ineffective.

This phenomenological investigation allowed for meaningful insight into the health-related values and attitudes of AAW. The findings provided a snapshot of the cultural realities experienced by these women. This is an important step toward understanding the perceptions and interpretations of a socially constructed disease by the women primarily affected by it.

An effective approach from which to generate policy solutions to address the problem of HIV/AIDS in AAW should reflect perspectives and understanding of the epidemic consistent with the cultural values and assumptions of these women. An Afro-centric paradigm (Gilbert & Wright, 2003) should frame the strategies, priorities, and action agenda in policy development. Application of the findings of this study fosters a culturally congruent approach toward development of initiatives that may lessen the impact of the HIV/AIDS crisis among this disenfranchised population.

Implications for Future Research

More in-depth investigations need to be conducted that focus on HIV/AIDS and AAW. Research strategies that allow meaningful insight into the health-related beliefs and behaviors of this population are urgently needed. Investigative approaches should include both positivistic and post-modernistic traditions to identify and conceptualize the effects of the epidemic on these women. A systematic collection and analysis of empirical and experiential data is needed to build a strong foundation for designing relevant and meaningful interventions that improve outcomes for these women.

Further development of the concepts of constructing meaning in life-threatening illness is also needed. The state of the science revealed that there is no universal set of attributes that currently exists regarding this concept. Concept development is an integral component in strengthening a profession’s body of knowledge. Likewise, research examining the failure to find meaning or unsuccessful attempt to find meaning in the negative event of HIV diagnosis is suggested. Finally, development and testing of psychosocial interventions to foster therapeutic environments that encourage meaning discovery and meaning making in persons with life-threatening illnesses requires further study to build stronger support for evidenced-based practice.

Limitations of the Study

The sample population of this study included English-speaking AAW over the age of 18, residing in Dade County, who self-identified as HIV-positive or who had been diagnosed with AIDS. This study included only the stories of those individuals who voluntarily shared their lived experiences. The women described their experiences selectively, based on their perceptions of the researcher and how and to whom their stories would be told. The researcher recognized that the same questions may have been answered differently with a different researcher, in a different venue, and at a different place in time. This limits ability to generalize the findings of this investigation. However, as with all studies within a qualitative tradition, results are not intended to be generalized but are regarded as exploratory in nature.

Many of the women already knew each other as support group members or in other venues, and this familiarity may have influenced their responses. Although interviews were conducted on an individual basis, the participants may have spoken to one another about the data gathering procedures, given the relationships and close proximity these women have with each other. This may have influenced how they responded to the questions about their life experiences with HIV/AIDS. Social desirability may have prompted them to speak about their experiences to support or endorse what other women stated.

Conclusion

The presence of HIV/AIDS is of growing concern in the African American communities. Specifically, AAW carry a disproportionate burden of this epidemic. Living with HIV/AIDS as an African American woman is a complex, multifactorial, and unique phenomenon. The focus of this phenomenological investigation was to obtain a deeper understanding of these women’s life experiences. The narrative descriptions of the study participants provided greater insight into their cultural realities and health experiences. Authentic understanding of the women’s universal experience of constructing meaning within a life-threatening illness and the singular psychosocial expressions that arose from this phenomenon was achieved. The essence of this lived experience is a dynamic process that includes the initial shattering of one’s view of self and the world, an attempt to reconstruct prior assumptions and find meaning in a negative situation, and an empowering experience of being in control and achieving a purpose in life that had not been imaginable before being diagnosed with HIV/AIDS.

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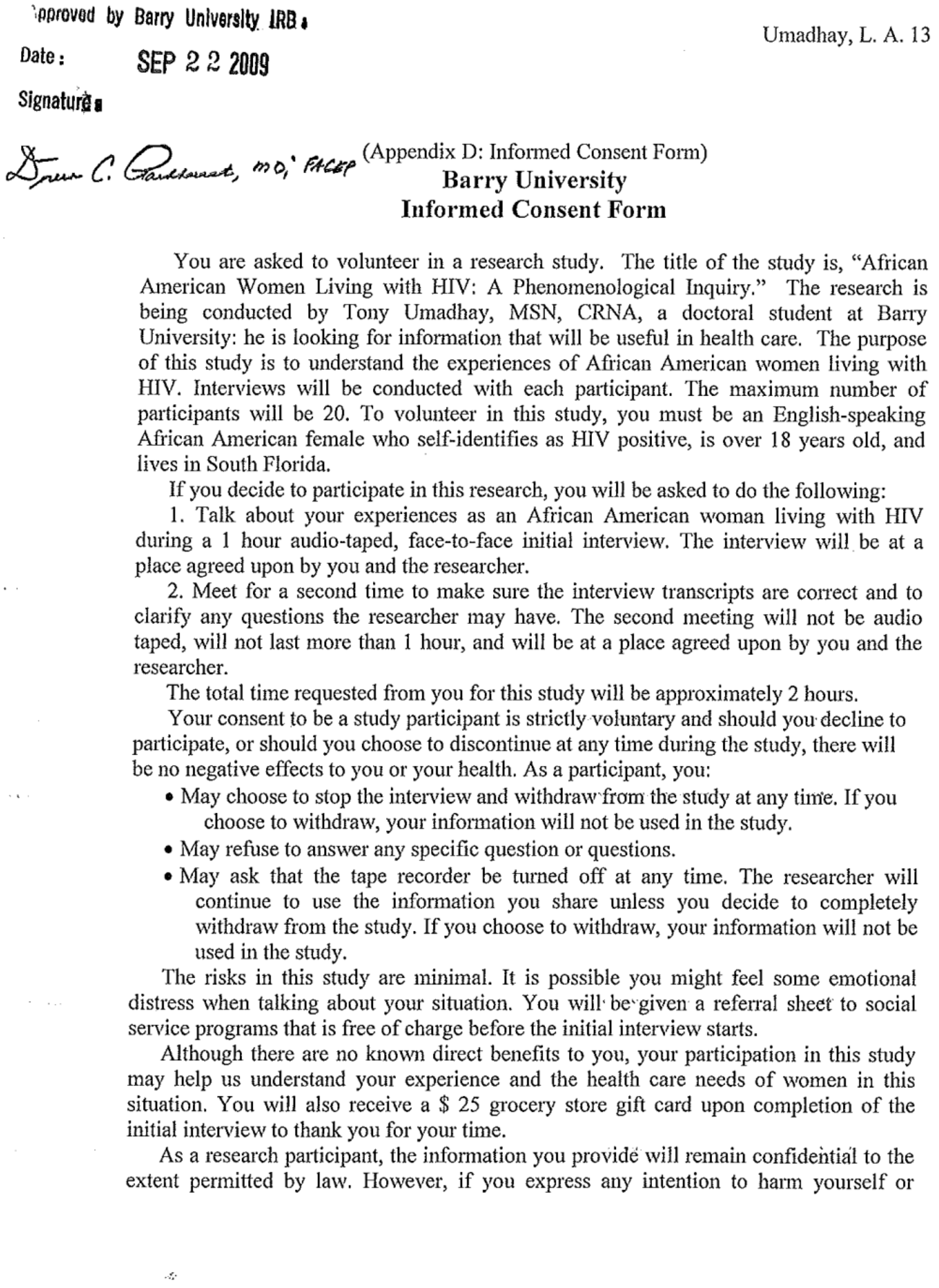
APPENDIX A

INFORMED CONSENT FORM



pproved by Barry University IRB:
Date: SEP 2 2 2009
Signature:

Drew C. [illegible], MD, FACEP

Umadhay, L. A. 13

(Appendix D: Informed Consent Form)

Barry University
Informed Consent Form

You are asked to volunteer in a research study. The title of the study is, "African American Women Living with HIV: A Phenomenological Inquiry." The research is being conducted by Tony Umadhay, MSN, CRNA, a doctoral student at Barry University: he is looking for information that will be useful in health care. The purpose of this study is to understand the experiences of African American women living with HIV. Interviews will be conducted with each participant. The maximum number of participants will be 20. To volunteer in this study, you must be an English-speaking African American female who self-identifies as HIV positive, is over 18 years old, and lives in South Florida.

If you decide to participate in this research, you will be asked to do the following:

1. Talk about your experiences as an African American woman living with HIV during a 1 hour audio-taped, face-to-face initial interview. The interview will be at a place agreed upon by you and the researcher.
2. Meet for a second time to make sure the interview transcripts are correct and to clarify any questions the researcher may have. The second meeting will not be audio taped, will not last more than 1 hour, and will be at a place agreed upon by you and the researcher.

The total time requested from you for this study will be approximately 2 hours.

Your consent to be a study participant is strictly voluntary and should you decline to participate, or should you choose to discontinue at any time during the study, there will be no negative effects to you or your health. As a participant, you:

- May choose to stop the interview and withdraw from the study at any time. If you choose to withdraw, your information will not be used in the study.
- May refuse to answer any specific question or questions.
- May ask that the tape recorder be turned off at any time. The researcher will continue to use the information you share unless you decide to completely withdraw from the study. If you choose to withdraw, your information will not be used in the study.

The risks in this study are minimal. It is possible you might feel some emotional distress when talking about your situation. You will be given a referral sheet to social service programs that is free of charge before the initial interview starts.

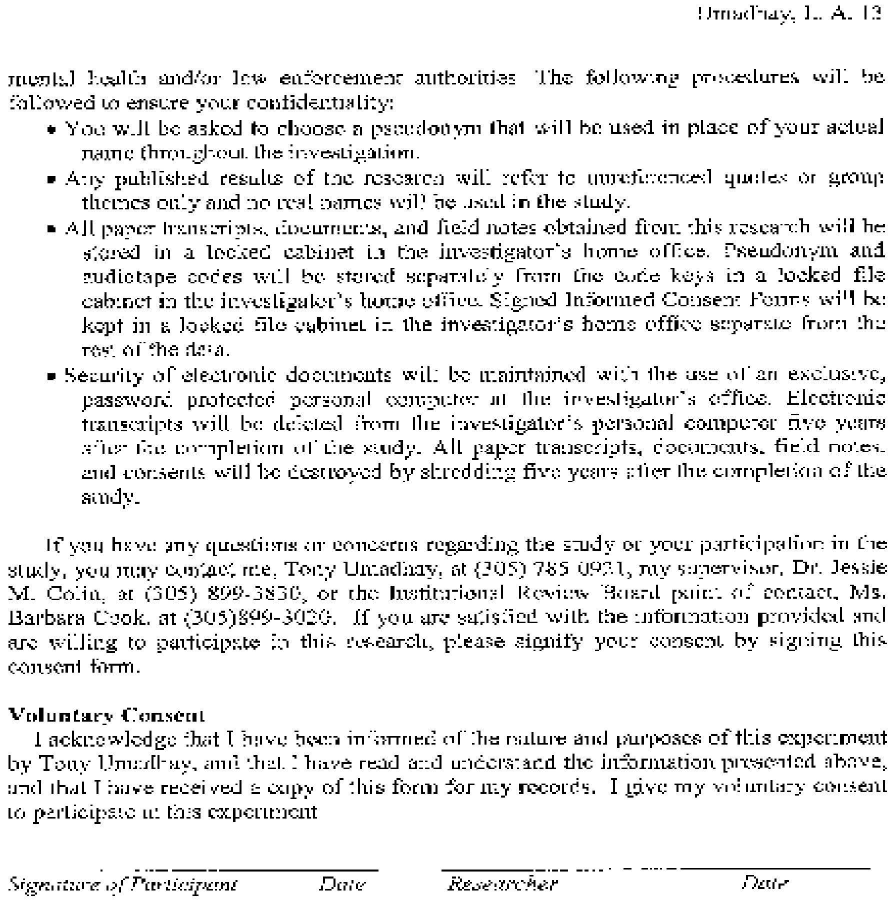
Although there are no known direct benefits to you, your participation in this study may help us understand your experience and the health care needs of women in this situation. You will also receive a $ 25 grocery store gift card upon completion of the initial interview to thank you for your time.

As a research participant, the information you provide will remain confidential to the extent permitted by law. However, if you express any intention to harm yourself or

APPENDIX A (cont.)

INFORMED CONSENT FORM

PAGE 2



Umadhay, L. A. 13

mental health and/or law enforcement authorities. The following procedures will be followed to ensure your confidentiality:

- You will be asked to choose a pseudonym that will be used in place of your actual name throughout the investigation.
- Any published results of the research will refer to unreferenced quotes or group themes only and no real names will be used in the study.
- All paper transcripts, documents, and field notes obtained from this research will be stored in a locked cabinet in the investigator's home office. Pseudonym and audiotape codes will be stored separately from the code keys in a locked file cabinet in the investigator's home office. Signed Informed Consent Forms will be kept in a locked file cabinet in the investigator's home office separate from the rest of the data.
- Security of electronic documents will be maintained with the use of an exclusive, password protected personal computer at the investigator's office. Electronic transcripts will be deleted from the investigator's personal computer five years after the completion of the study. All paper transcripts, documents, field notes, and consents will be destroyed by shredding five years after the completion of the study.

If you have any questions or concerns regarding the study or your participation in the study, you may contact me, Tony Umadhay, at (305) 785 0921, my supervisor, Dr. Jessie M. Colin, at (305) 899-3830, or the Institutional Review Board point of contact, Ms. Barbara Cook, at (305)899-3020. If you are satisfied with the information provided and are willing to participate in this research, please signify your consent by signing this consent form.

Voluntary Consent

I acknowledge that I have been informed of the nature and purposes of this experiment by Tony Umadhay, and that I have read and understand the information presented above, and that I have received a copy of this form for my records. I give my voluntary consent to participate in this experiment

Signature of Participant	*Date*	*Researcher*	*Date*

APPENDIX B

COMMUNITY SOCIAL SERVICES PROGRAMS

Florida HIV/AIDS Hotline: 1-800-FLA-AIDS (1-800-352-2437)

Switchboard of Miami: 305-358-HELP (305-358-4357)

Broward House: 954-522-4749

Comprehensive AIDS Program of Palm Beach County: 561-472-2466

APPENDIX C

NEWSPAPER AND INTERNET AD

Wanted: Volunteers for a research study

"*Are you an English-speaking African American female, over 18 years old, living in South Florida, and have been told by your health care provider that you have HIV?"*

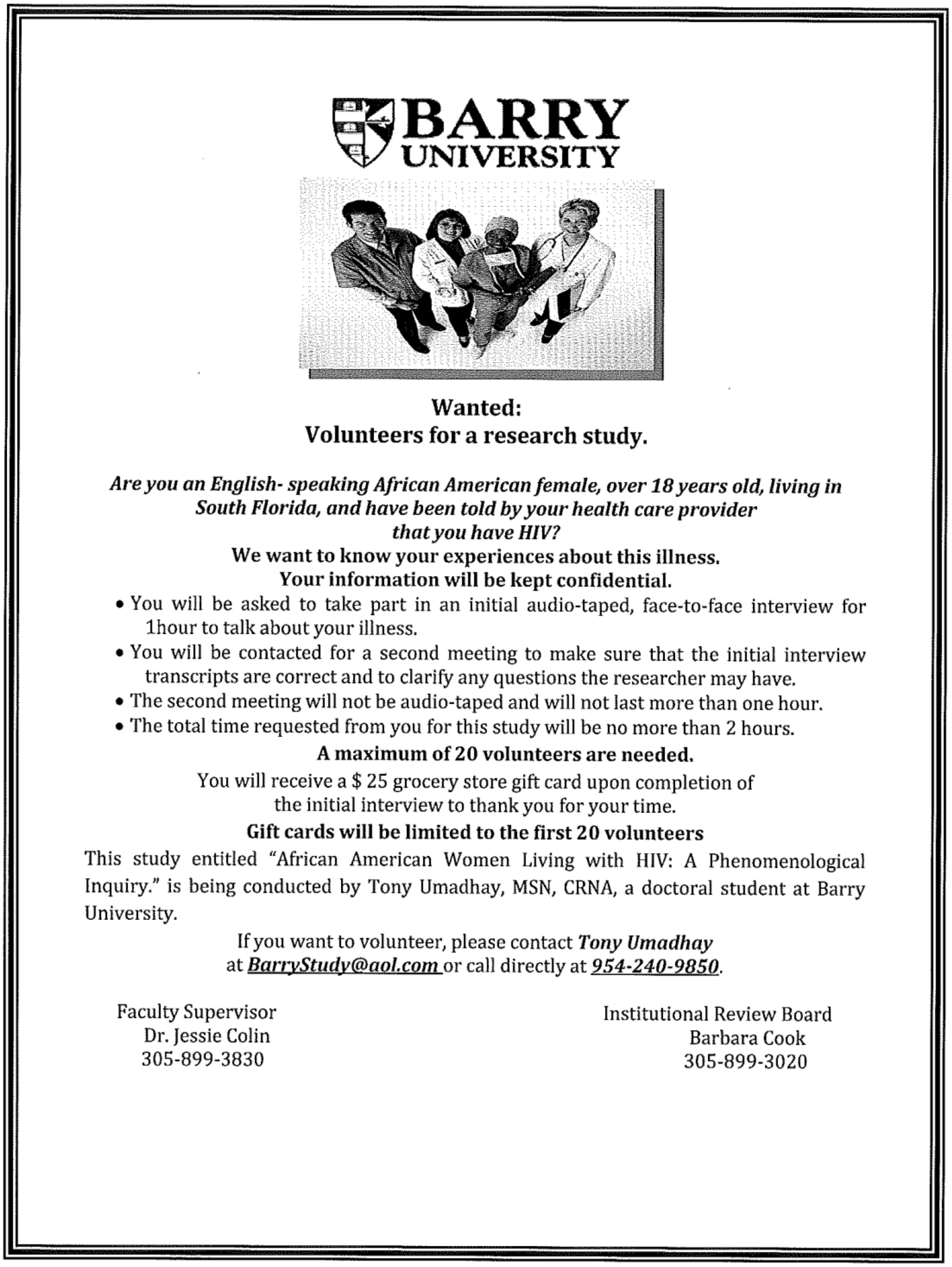
We want to know your experiences about this illness.

Your information will be kept confidential.

Please contact *Tony Umadhay* at *BarryStudy@aol.com* or call directly at *954-240-9850* to know more about this study.

APPENDIX D

RECRUITMENT FLYER



BARRY UNIVERSITY

Wanted:
Volunteers for a research study.

Are you an English- speaking African American female, over 18 years old, living in South Florida, and have been told by your health care provider that you have HIV?

We want to know your experiences about this illness.
Your information will be kept confidential.

- You will be asked to take part in an initial audio-taped, face-to-face interview for 1hour to talk about your illness.
- You will be contacted for a second meeting to make sure that the initial interview transcripts are correct and to clarify any questions the researcher may have.
- The second meeting will not be audio-taped and will not last more than one hour.
- The total time requested from you for this study will be no more than 2 hours.

A maximum of 20 volunteers are needed.

You will receive a $ 25 grocery store gift card upon completion of the initial interview to thank you for your time.

Gift cards will be limited to the first 20 volunteers

This study entitled "African American Women Living with HIV: A Phenomenological Inquiry." is being conducted by Tony Umadhay, MSN, CRNA, a doctoral student at Barry University.

If you want to volunteer, please contact ***Tony Umadhay***
at ***BarryStudy@aol.com*** or call directly at ***954-240-9850***.

Faculty Supervisor
Dr. Jessie Colin
305-899-3830

Institutional Review Board
Barbara Cook
305-899-3020

APPENDIX E

INTERVIEW QUESTIONS AND PROMPTS

1. Primary Question:

"Tell me what it is like for you to be an African American woman living with HIV".

2. Prompts:

- *What is it like for you to be a wife, mother, grandmother, sister, or daughter with HIV?*
- *How would you compare your life now from before you knew you were HIV positive?*
- *What made you go and get tested for HIV? Did you talk about this with your family or friends before being tested?*
- *What was life like for you immediately after you found out that you were infected with HIV?*
- *Did you tell anybody about your test results? Why or why not?*
- *How would you say life is for you now that you are HIV positive?*
- *What help or support have you sought and found to be helpful to you after you tested positive for HIV? Is there any other resource you wish you had but do not?*
- *Where do you see yourself five years from now?*
- *Is there anything else you want to talk about?*

APPENDIX F

DEMOGRAPHIC QUESTIONNAIRE

Date / Time: ______________________________________

Pseudo Name: _____________________________________

1. What is your current age?

2. Where did you grow up?

3. What grade level of education did you finish?

4. What type of work do you do?

5. What is your current marital status?

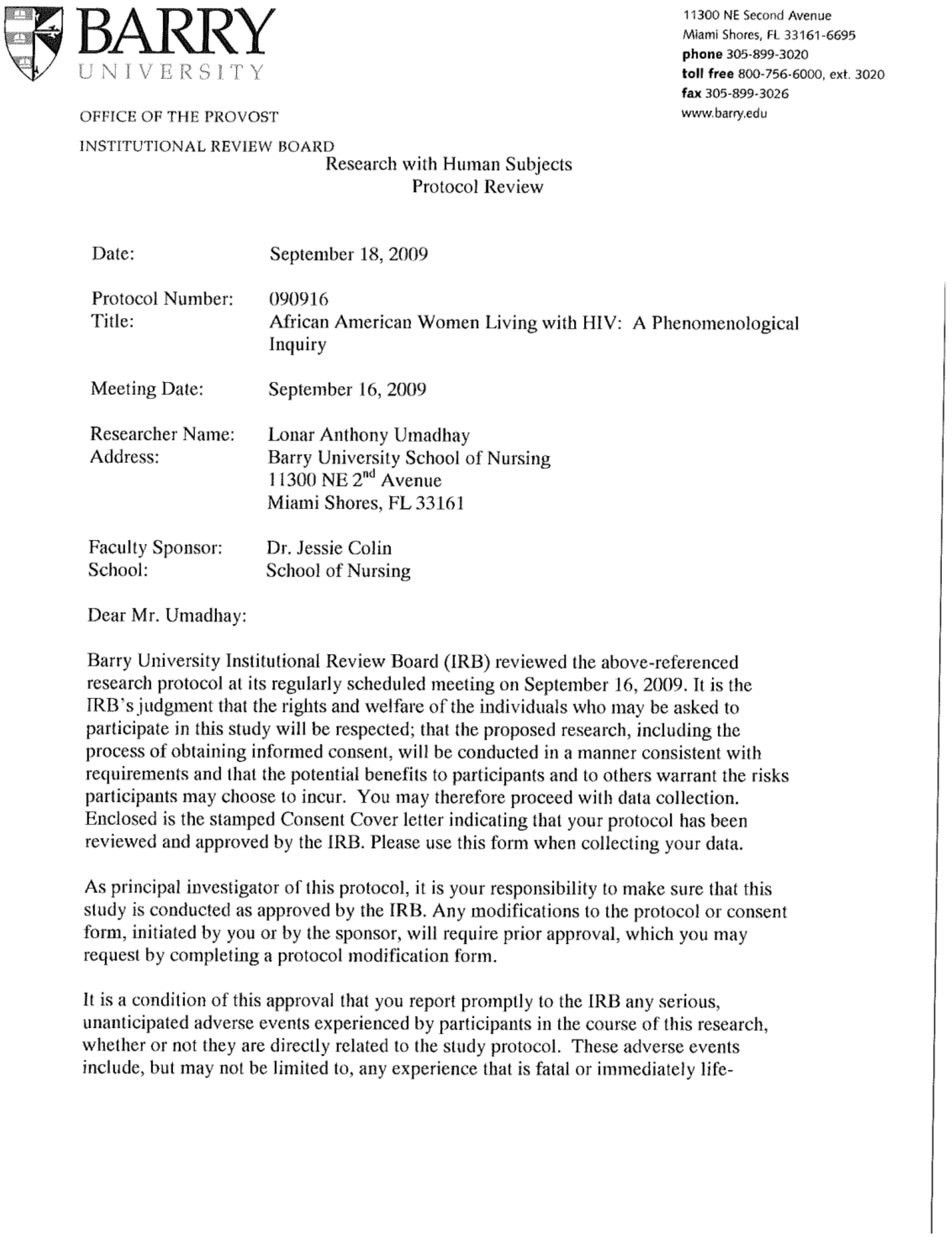
6. Do you have children? If yes, what sex and age?

7. What is your current living arrangement?

8. How old were you when you were diagnosed with HIV?

APPENDIX G

IRB APPROVAL



BARRY
UNIVERSITY

OFFICE OF THE PROVOST
INSTITUTIONAL REVIEW BOARD

11300 NE Second Avenue
Miami Shores, FL 33161-6695
phone 305-899-3020
toll free 800-756-6000, ext. 3020
fax 305-899-3026
www.barry.edu

Research with Human Subjects
Protocol Review

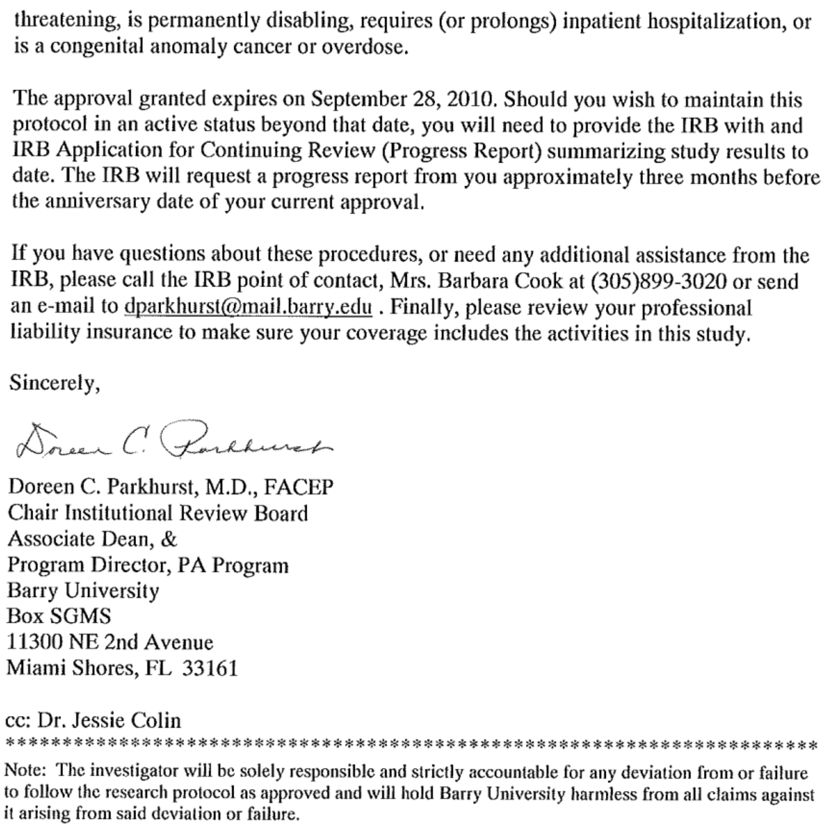
Date:	September 18, 2009
Protocol Number:	090916
Title:	African American Women Living with HIV: A Phenomenological Inquiry
Meeting Date:	September 16, 2009
Researcher Name:	Lonar Anthony Umadhay
Address:	Barry University School of Nursing 11300 NE 2nd Avenue Miami Shores, FL 33161
Faculty Sponsor:	Dr. Jessie Colin
School:	School of Nursing

Dear Mr. Umadhay:

Barry University Institutional Review Board (IRB) reviewed the above-referenced research protocol at its regularly scheduled meeting on September 16, 2009. It is the IRB's judgment that the rights and welfare of the individuals who may be asked to participate in this study will be respected; that the proposed research, including the process of obtaining informed consent, will be conducted in a manner consistent with requirements and that the potential benefits to participants and to others warrant the risks participants may choose to incur. You may therefore proceed with data collection. Enclosed is the stamped Consent Cover letter indicating that your protocol has been reviewed and approved by the IRB. Please use this form when collecting your data.

As principal investigator of this protocol, it is your responsibility to make sure that this study is conducted as approved by the IRB. Any modifications to the protocol or consent form, initiated by you or by the sponsor, will require prior approval, which you may request by completing a protocol modification form.

It is a condition of this approval that you report promptly to the IRB any serious, unanticipated adverse events experienced by participants in the course of this research, whether or not they are directly related to the study protocol. These adverse events include, but may not be limited to, any experience that is fatal or immediately life-



threatening, is permanently disabling, requires (or prolongs) inpatient hospitalization, or is a congenital anomaly cancer or overdose.

The approval granted expires on September 28, 2010. Should you wish to maintain this protocol in an active status beyond that date, you will need to provide the IRB with and IRB Application for Continuing Review (Progress Report) summarizing study results to date. The IRB will request a progress report from you approximately three months before the anniversary date of your current approval.

If you have questions about these procedures, or need any additional assistance from the IRB, please call the IRB point of contact, Mrs. Barbara Cook at (305)899-3020 or send an e-mail to dparkhurst@mail.barry.edu . Finally, please review your professional liability insurance to make sure your coverage includes the activities in this study.

Sincerely,

Doreen C. Parkhurst

Doreen C. Parkhurst, M.D., FACEP
Chair Institutional Review Board
Associate Dean, &
Program Director, PA Program
Barry University
Box SGMS
11300 NE 2nd Avenue
Miami Shores, FL 33161

cc: Dr. Jessie Colin

****

Note: The investigator will be solely responsible and strictly accountable for any deviation from or failure to follow the research protocol as approved and will hold Barry University harmless from all claims against it arising from said deviation or failure.

APPENDIX H

INTERVIEW PROTOCOL

Date / Time:

Researcher: Tony Umadhay, MSN, CRNA

Pseudo Name: ________________________________

1. Describe research project.
    - Purpose of the study
    - Risks and benefits of the study
    - Time commitment
2. Obtain consent.
3. Assure confidentiality and obtain pseudonym.
4. Provide a list of local community social services programs.
5. Ice breaker.
6. Obtain demographic information using demographic questionnaire.
7. Assure participant that she:
    - May choose to stop the interview and withdraw from the study at any time.
    - May refuse to answer any specific question or questions.
    - May ask that the tape recorder be turned off at any time.
    - May request to take a break at any time.
8. Request permission to begin interview and audio-tape recording. Conduct interview.
9. Ask if there is anything else participant might want to discuss.

10. Closing.

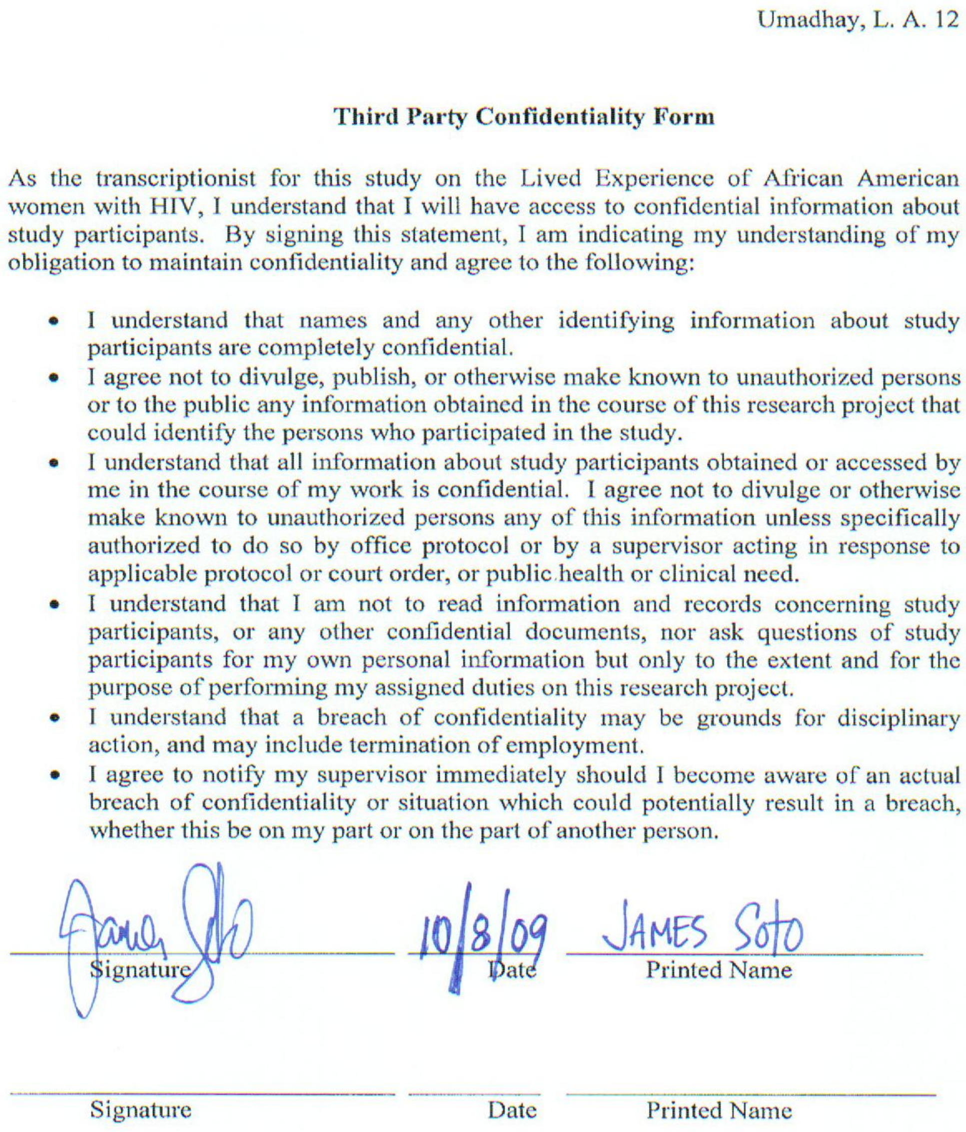
- Thank interviewee and give $ 25 grocery store gift card.
- Repeat assurances of confidentiality.
- Request for a follow-up meeting and confirm a method of contact for scheduling.
- Offer availability by phone or email if questions arise.
- Ensure that communication with the researcher will be through a secure, confidential, and password-protected e-mail account and phone number to be used exclusively for this study.

11. Post Interview:

- Label audio-tape with participant pseudonym.
- Complete researcher notes and reflection.
- Begin transcription of taped interviews as soon as possible.

APPENDIX I

THIRD PARTY CONFIDENTIALITY FORM



Third Party Confidentiality Form

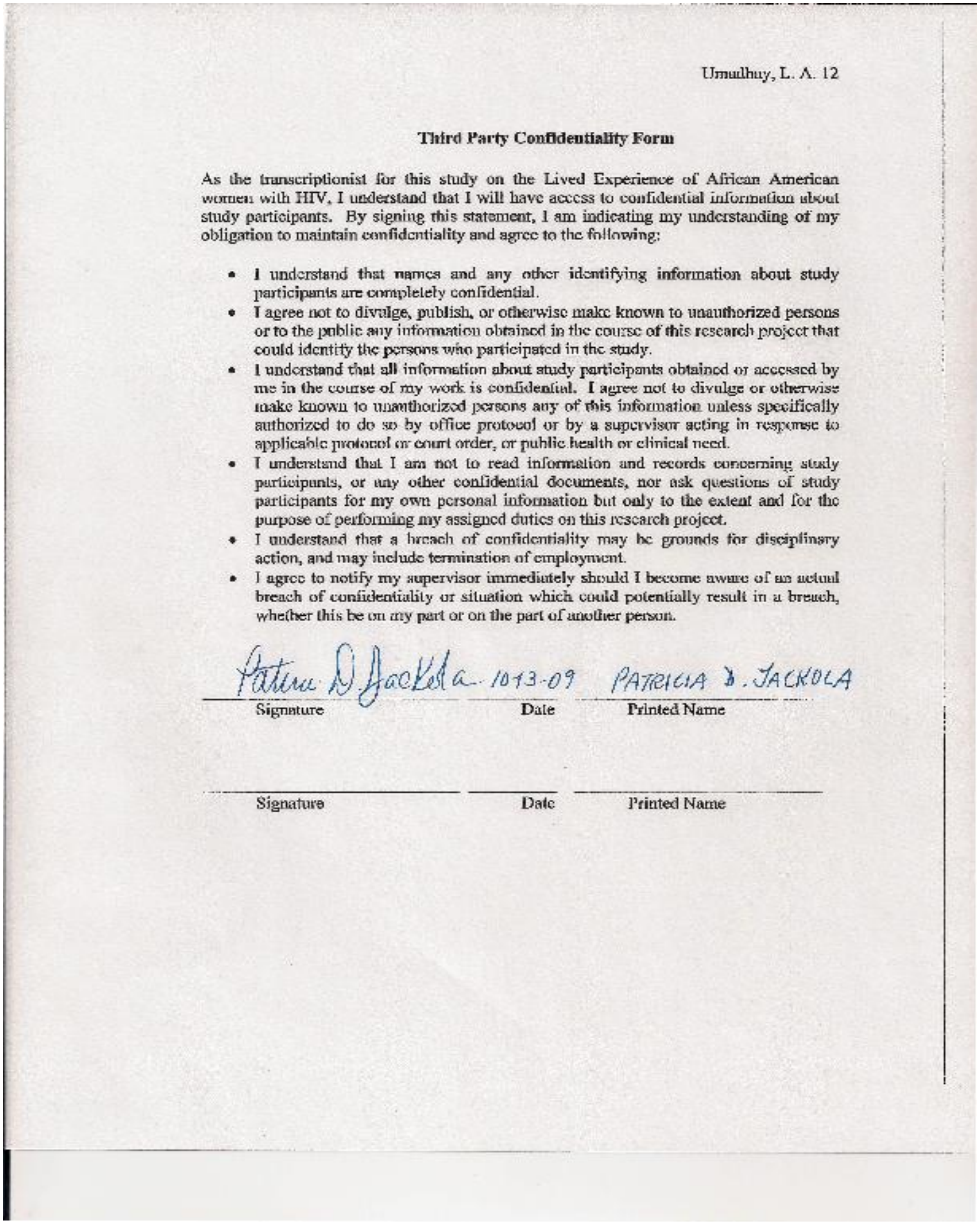
As the transcriptionist for this study on the Lived Experience of African American women with HIV, I understand that I will have access to confidential information about study participants. By signing this statement, I am indicating my understanding of my obligation to maintain confidentiality and agree to the following:

- I understand that names and any other identifying information about study participants are completely confidential.
- I agree not to divulge, publish, or otherwise make known to unauthorized persons or to the public any information obtained in the course of this research project that could identify the persons who participated in the study.
- I understand that all information about study participants obtained or accessed by me in the course of my work is confidential. I agree not to divulge or otherwise make known to unauthorized persons any of this information unless specifically authorized to do so by office protocol or by a supervisor acting in response to applicable protocol or court order, or public health or clinical need.
- I understand that I am not to read information and records concerning study participants, or any other confidential documents, nor ask questions of study participants for my own personal information but only to the extent and for the purpose of performing my assigned duties on this research project.
- I understand that a breach of confidentiality may be grounds for disciplinary action, and may include termination of employment.
- I agree to notify my supervisor immediately should I become aware of an actual breach of confidentiality or situation which could potentially result in a breach, whether this be on my part or on the part of another person.

	10/8/09	JAMES SOTO
Signature	Date	Printed Name
Signature	Date	Printed Name

APPENDIX I (cont.)

THIRD PARTY CONFIDENTIALITY FORM



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- I agree to notify my supervisor immediately should I become aware of an actual breach of confidentiality or situation which could potentially result in a breach, whether this be on my part or on the part of another person.

Patricia D Jackola	1013-09	PATRICIA D. JACKOLA
Signature	Date	Printed Name
Signature	Date	Printed Name

APPENDIX J

VITA

Lonar Anthony M. Umadhay, MSN, CRNA

July 30, 1970	Born – Iloilo City, Philippines
1991	BSN, University of Santo Tomas, Manila, Philippines
1992 – 1994	Staff Nurse, Philippine General Hospital, Manila, Philippines
1995 – 2000	Staff Nurse, Parkway Regional Medical Center, North Miami Beach, FL
1995 – 2000	Staff Nurse, Miami Heart Institute, Miami Beach, FL
1999 – 2001	Clinical Manager, Memorial Hospital West, Pembroke Pines, FL
2003	MSN, Florida International University, Miami, FL
2004 – Present	Staff Certified Registered Nurse Anesthetist, Jackson Memorial Hospital, Miami, FL
2006 – 2007	Assistant Professor, MS Program in Anesthesiology, Barry University, Miami Shores, FL
2007 – Present	Director and Assistant Professor, MS Program in Anesthesiology Barry University, Miami Shores, FL