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Shrouded in Stigma: A Heuristic Study of Living with HIV

by

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A DISSERTATION

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in

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Advisory Committee

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## ABSTRACT

HIV-related stigma is a serious hindrance to addressing the recruitment, maintenance, and follow-up nursing care of HIV-infected persons. This study was anchored within the heuristic research model, which engaged both the researcher and participants in a dialogical and aesthetic manner to unveil the stigma of HIV. The close proximity of the researcher and study participants revealed the most visceral, emotional, and self-reflective nature of gathering data, while maintaining the integrity and rigor of a qualitative study.

The purpose of this heuristic study was to examine the lived experiences of HIV-infected individuals relating to internalized stigma within an existential context. This framework required that the researcher had personally lived the phenomenon of interest and had a profound desire to pursue its meaning and essence. Twelve participants enrolled in this study. Data were collected through a series of two face-to-face interviews per study participant. Transcripts were analyzed using the heuristic method of thematic coding.

The central theme, *Shadows Lurking in the Gaze*, was identified and was further explored in a case comparative manner, resulting in 2 subthemes: *Raging Battle of the Gaze* and the *Transformational Process of Living with the Gaze* emerged. The central theme is defined as a discernible threat that presents an ominous oppressiveness which is perceived by the observed person cast from the other. The study participants expressed varying levels of the *gaze* cast upon them by others. Most notably, the casting of the shifting societal gaze has created a space for lurking shadows within each co-researcher along the life trajectory of living with HIV.

The first subtheme, *Raging Battle of the Gaze*, was centered on HIV-concealment factors. Regardless if the confirmation of one's HIV status is disclosed or if it remains concealed, the suspicion of who knows and who does not know is a relentless distraction among HIV-infected persons. This distraction among an HIV-infected person often manifests into the self-analysis of how the other is looking at him; the self-questioning of the intentions of the gaze cast by the other. The second subtheme, *Transformational Process of Living with the Gaze*, was exhibited by the healing processes within the study participants that allowed them to push forward with life and release themselves from the distractions of the ever-present and unwanted gaze that continues to hover around them.

These findings indicate that the heuristic research design provided rich and meaningful data in a therapeutic nature which may enrich the understanding of the healthcare professionals caring for HIV-infected individuals. Additionally, these findings may lead to intervention studies, steeped in art-based research, to decrease heightened levels of internalized HIV-related stigma.

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## CHAPTER I

### Background of the Phenomenon

The year 2011 will mark the thirtieth anniversary of the Acquired Immune Deficiency Syndrome (AIDS) pandemic. At present, it is estimated that 33 million individuals throughout the world are living with the human immunodeficiency virus (HIV) (Durham & Lashley, 2010). Historically, the labeling of HIV has undergone rapid changes in the clinical realm by health care providers; however, the societal remnants of these labels are ever-lasting in many communities in both resource-rich and resource-poor settings. For example, in 1981, the first cases of AIDS were identified in the United States among men who have sex with men (MSM).

Hence, at the dawn of this epidemic in New York City, Los Angeles, and other urban cities in the United States, the term “Gay-Related Immune Deficiency (GRID)” was coined. In July 1981, Lawrence Altman (New York Times) reported an outbreak of a rare cancer among gay men. Simply labeled as “gay cancer,” this medical phenomenon would later be properly identified as Kaposi’s sarcoma (KS). Alcamo (2002) reported that initial researchers appeared puzzled by the incidence rate among homosexual men. Alcamo described that “scientists searched for causes in behavior common to gay men, including risk factors...anal sex and use of the drug amyl nitrate...the months passed, female sex partners of bisexual men and injection drug users began showing signs of the disease” (pp. 2-3).

The early terminology (GRID) shifted to a more accurate identification which was steeped in the scientific world and became identified as AIDS and the causative agent

was identified as HIV, a retrovirus originating from simian species in Africa. Nonetheless, the original stigmatizing labels of GRID and gay cancer were firmly attached to this ominous medical condition and thus firmly planted within society. Soon, the previously sewn seeds of GRID and gay cancer sprouted the beginning of HIV-related stigma which remains pervasive in both resource-rich and resource-limited settings, among the educated and the uneducated, among the rich and the poor, and finally among persons of all races. The eradication of HIV-related stigma does not appear poised to dissipate as we enter the third decade of living with HIV/AIDS illness. Unfortunately, HIV-related stigma remains prevalent and continues to serve as a barrier to identifying and managing the complex health care needs of individuals.

In 2001, among men and women between the ages of 25 to 44, AIDS was the fifth leading cause of death in the United States (Kaiser Family Foundation, 2005); by the end of 2005, approximately 550,000 deaths had been reported by the Centers for Disease Control [CDC], 2008). At the end of 2006, in the United States, it is estimated that 1.1 million persons are living with HIV (CDC, 2008). In 2007, Blacks/African Americans accounted for over half (51%) of the estimated number of HIV diagnoses, followed by Whites/Caucasians (21%) and Hispanic/Latinos (18%) (CDC, 2009). Additionally, persons aged 40 to 49 years of age accounted for the largest proportion of newly diagnosed HIV cases (27%); individuals aged 30 to 39 years of age comprised the second largest proportion (26%); persons aged 20 to 29 years of age followed closely as the third largest proportion (25%) (CDC, 2009). Regardless of gender, age, or race, HIV remains a community threat that warrants further investigation through funding mechanism

inclusive of research designs representing both quantitative and qualitative methodologies.

### **HIV-Related Stigma**

HIV infection remains one of the most highly stigmatized medical diagnoses in the United States, drastically affecting the daily lives of those living with this illness. HIV-related stigma has declined since the early days of the pandemic; however, such stigma persists among the public as well as among healthcare providers (Parker & Aggleton, 2003). Among US healthcare providers, the refusal to care for HIV-infected patients has virtually been eliminated; however, negative perceptions and approaches, which arise from fear and lack of understanding, and prejudicial attitudes can manifest into barriers to delivering respectful, equitable, and compassionate care to HIV-infected patients (Earl & Penney, 2003; Li, Scott, & Li, 2003; Tyer-Viola, 2007; Watkins & Gray, 2006).

The pervasiveness of HIV-related stigma has led researchers to address the complexities of HIV illness. Recognizing the impact of HIV-related stigma, researchers have attempted to better understand the phenomenon. Sayles et al. described (as cited in Link & Phelan, 2001) the conceptualization of HIV-related stigma in which five components intersect to create stigma: (1) identification and labeling of human differences, (2) dominant cultural beliefs that link the labeled individual to undesirable characteristics, generating negative stereotypes, (3) categorization of labeled persons to separate “us” versus “them,” (4) labeled individuals experiencing status loss and discrimination, resulting in unequal outcomes, and (5) access to social, economic, and

political power by the dominant group allowing for the complete execution of disapproval, rejection, exclusion, and discrimination against the labeled group.

### **Significance of the Study**

HIV-related stigma has been researched extensively in both the quantitative and qualitative paradigms. Unlike traditional biomarkers such as CD4+ counts and HIV viral loads, stigma does not lend itself to such quantification. Rather, it qualitatively informs research on HIV-related stigma. Qualitative research on HIV-related stigma has demonstrated the importance of exploring and disseminating the vast array of voices among HIV-infected persons through the interpretation of researchers who have attained a proximity to the phenomenon without the actual lived-experience of HIV-related stigma. Thus, a certain distance and silence remains in these existing qualitative works in the contemporary body of research literature. Minimal research has been conducted from a holistic perspective in which the researcher and the co-researchers [study participants] engage in both a dialogical and an aesthetic nature in an attempt to unveil the phenomenon of HIV-related stigma in the United States. Most notably, no studies utilizing a heuristic phenomenological method to scientific inquiry were found in this literature review. This presents the opportunity for such a study in which the researcher and co-researchers engage in the research process together; both parties fully immersed within the phenomenon of interest without bracketing the most vital piece of a heuristic study – the clear and self-disclosed forestructure of the researcher combined with the holistic nature of engaging with study participants in dialogues with one another.

It is hoped that the proximity of researcher and co-researcher will reveal the most visceral, emotional, and self-reflective nature of gathering data while maintaining the integrity and rigor of a qualitative study. Exploration of the day-to-day experiences of living with HIV-related stigma will provide a greater understanding of the multifaceted components of this manageable chronic illness. Dialogical and aesthetic descriptions of the phenomenon of HIV-related stigma directly from the perspective of the co-researchers, as well as the process of retrospective reflection, may fortify the foundation for the further exploration and development of appropriate psychosocial and educational interventional strategies. These findings have the potential to enhance, not only quality of life, but also self-care behaviors leading to healthier lives for those affected by HIV-related stigma. Finally, this research may offer healthcare providers a more personal and descriptive account leading to a more profound understanding of what HIV-related stigma is as depicted by HIV-infected persons. A heuristic phenomenological approach is warranted to explore the multifaceted meanings of living with HIV in both a descriptive and interpretive manner.

### **Statement of Purpose**

The purpose of this heuristic inquiry was to examine the lived experiences and core meanings of HIV-infected individuals relating to internalized stigma within an existential context in which individual and collective experiences enhance awareness and significance of this phenomenon. This study explored the meaning of living with HIV-related stigma through a heuristic phenomenological approach (Moustakas, 1990). This framework required that the researcher had personally experienced the phenomenon of

interest and had a profound desire to pursue the meaning and the essence of this experience with the accompaniment of co-researchers. HIV-related stigma was explored through dialogue with the co-researchers as well as aesthetic interpretation of their representations to facilitate comprehension of what living with HIV-related stigma means to each individual as he/she strives for a sense of normalcy within their daily lives. The central question guiding this research was “How do HIV-infected persons in the US perceive *living* [emphasis added] amid a stigmatizing HIV-negative society of the 21<sup>st</sup> century?”

### **Contextual Definitions**

#### **AIDS – Acquired Immune Deficiency Syndrome**

Any of a list of illnesses that, when occurring in an HIV-infected person, leads to a diagnosis of AIDS, the most serious stage of HIV infection. AIDS is also diagnosed if an HIV-infected person has a CD4 count less than 200 cells/mm<sup>3</sup>, whether or not that person has an AIDS-defining condition. The Centers for Disease Control and Prevention (CDC) published a list of AIDS-defining conditions in 1993. The 26 conditions include candidiasis, cytomegalovirus disease, Kaposi’s sarcoma, *Mycobacterium avium* complex, *Pneumocystis jiroveci* pneumonia, recurrent pneumonia, progressive multifocal leukoencephalopathy, pulmonary tuberculosis, invasive cervical cancer, and wasting syndrome (U.S. Department of Health and Human Services [USDHHS], National Institutes of Health [NIH], 2008, p. 7). In 2010, with proper patient care management, the



HIV-infected person may live for decades with a decreased risk of developing AIDS.

### **Human Immunodeficiency Virus (HIV)**

HIV is the virus that causes Acquired Immunodeficiency Syndrome (AIDS). HIV is in the retrovirus family, and two types have been identified: HIV-1 and HIV-2. HIV-1 is responsible for most HIV infections throughout the world, whereas HIV-2 is found primarily in West Africa (USDHHS, NIH, 2008, p. 62). At present, there is no cure for HIV infection. However, combination antiretroviral therapy can halt the progression to AIDS.

### **CD4+ Cell**

Also known as helper T cell or CD4+ lymphocyte, this cell is a type of infection fighting white blood cell that carries the CD4+ receptor on its surface. CD4+ cells coordinate the immune response, which signals other cells in the immune system to perform their specific functions. Both the quantity and the percentage CD4+ cells in a sample of blood are indicators of the health of the immune system. HIV infects and depletes CD4+ cells, which leads to a weakened immune system (USDHHS, NIH, 2008, p. 21). Patient adherence and health care management of medication, behavior modification, and self-transcendence may all play a vital role in maintaining or elevating a CD4+ cell count.

### **Viral Load – VL**

The amount of HIV genetic material in a blood sample, reported as number of HIV RNA copies per milliliter of blood plasma is referred to as the viral load. The VL provides information about the number of cells infected with HIV and is an

important indicator of HIV progression and of how well treatment is working.

The VL can be measured by different techniques, including branched-chain DNA (bDNA) and reverse transcriptase-polymerase chain reaction (RT-PCR) assays.

VL tests are usually done when an individual is diagnosed with HIV infection and at regular intervals after diagnosis (USDHHS, NIH, 2008, p. 139).

### **Medication Adherence**

Important to HIV treatment is closely following (adhering to) a prescribed treatment regimen. This requires a patient to take the correct dose of a drug at the correct time, as prescribed. Failure to adhere to an anti-HIV treatment regimen can lead to virologic failure and drug resistance (USDHHS, NIH, 2008, p. 5).

Thus, an important component to HIV treatment is for the patient to closely follow a prescribed medication regimen which has been determined appropriate by the health care team. It is imperative that HIV-infected patients establish and maintain healthy and trusting relationships with their health care teams in an effort to keep the HIV-infected persons engaged in the health care system to properly manage the VL.

### **Highly Active Antiretroviral Therapy (HAART)**

HAART is the name given to treatment regimens that aggressively suppress HIV replication and progression of HIV disease. The usual HAART regimen combines three or more anti-HIV drugs from at least two different classes (USDHHS, NIH, 2008, p. 58). The importance of HAART is unquestionable in the extension of life to many HIV-infected persons.

**Lipoatrophy**

The loss of body fat from particular areas of the body, especially the arms, legs, face, and buttocks. Lipoatrophy is a potential side effect of some HIV medications and HIV itself (USDHHS, NIH, 2008, p. 79). Lipoatrophy may manifest into a form of HIV-related stigma as evidenced by body image changes among HIV-infected persons.

**Lipohypertrophy**

This is also known as hyper adiposity. Lipohypertrophy is distinguished by an abnormal buildup of fat, particularly in the breasts, on the back of the neck and upper shoulders (buffalo hump), deep within the abdomen (protease paunch), or in fatty growths known as lipomas. Lipohypertrophy may occur with the use of some HIV medications (USDHHS, NIH, 2008, p. 79). Lipohypertrophy is another form of body habitus changes which the HIV-infected person may experience. When experienced, lipohypertrophy may lead to increased levels of HIV-related stigma.

**Candidiasis**

An infection caused by a species of the yeast-like fungus *Candida*, usually *C. albicans*. Candidiasis can affect the skin; nails; and mucous membranes throughout the body, including the mouth (thrush), esophagus, vagina, intestines, and lungs. The infection appears as white patches when in the mouth or any other mucous membrane. Candidiasis of the esophagus is considered an AIDS-defining condition in people with HIV (USDHHS, NIH, 2008, p. 20). In addition to an often painful infection experienced by HIV-infected persons, thrush may also

manifest into a source HIV-related stigma as the visible appearances of an oral disorder are commonly seen by others.

## **CHAPTER II**

### **Review of the Literature**

Physical, psychological and behavioral sequelae have been associated with HIV-related stigma. Numerous studies have compiled data on HIV, stigma, and the assessment of this phenomenon. The reoccurring theme among many of these studies focuses on both quantitative and qualitative methodologies to assess degrees of HIV-related stigma from an epidemiological, economic, and provider-patient relationship perspective. Few studies have explored the lived-experience of HIV-related stigma within the context of dialogical engagements and aesthetic expressions in an attempt to better understand this phenomenon.

#### **Methodology of the Literature Review**

A systematic literature review was performed using various disciplines from 2008-2010. Nursing, psychology, philosophy, anthropology, and medicine were used as points of reference. To conduct as broad a search as possible, the search terms 'HIV' and 'Stigma' were utilized. The most useful databases found include: EBSCOhost (Medline and PsychInfo), CINAHL, and AnthropologyPlus. Medline produced 865 references; PsychInfo produced 956 references CINAHL produced 894 references; and AnthropologyPlus produced 62 references. With the exception of AnthropologyPlus, the remaining three databases were re-examined. The keyword 'ASSESSMENT' was added to the existing keyword couplet 'HIV AND STIGMA'. The following search results yielded: Medline produced 59 references; CINAHL produced 61 references; and PsychInfo produced 57 references. After accounting for duplicate references within the

four databases, 42 references for further examination were obtained. Lastly, the Dissertations and Theses database was searched in which 268 references were identified using the keywords 'HIV AND STIGMA'. Upon adding the final keyword 'ASSESSMENT', 15 references were found for further review, from which three dissertations were requested for review. The date range utilized for all search strategies included references from 1981 to 2010. Through an exhaustive review of the references from the identified articles in this literature search, additional articles were retrieved for in-depth review.

### **Stigma**

Stigma is associated with various societal and personal attributes and attitudes. A repetitive element in the definition of stigma is that of a mark, or a well defined stain on or associated with an individual (Goffman, 1963). This definition proposes a *stain* on the individual's character which may transcend to the interpersonal and societal levels. However, the common usages of the definition exclude a redundant usage of the term in the context of behavior, culture, and physical attributes that are also associated with stigma. Historically, the Greeks utilized the term stigma in the context of a physical blemish designated to identify something morally curious about a member of society. In the Greek culture, the identifiable mark was cut or burned into the physical body (Goffman). This form of representation clearly identified a marked individual within a particular societal context. The dominant or unmarked members of society could easily differentiate themselves by being free from the mark or stain which suggested a violation of a code or a representation of societal status such as a slave or a criminal. Goffman has

explained stigma in terms of a tainted or discounted individual. The negative connotations of these attributes equate to the differences between what society presumes in terms of common or acceptable characteristics of a person. The problematic nature of this definition arises as the attribute itself is not discrediting, rather it is the variance between the individual and the societal influence.

For clarification purposes throughout Goffman's (1963) work, he explained that

An individual who might have been received easily in ordinary social intercourse possesses a trait that can obtrude itself upon attention and turn those of us whom he meets away from him, breaking the claim that his other attributes have on us.

He possesses a stigma, an undesired differentness from what we had anticipated.

We and those who do not depart negatively from the particular expression at issue

I shall call the *normals*. The attitudes we normals have toward a person with a

stigma, and the actions we take in regard to him, are well known, since these

responses are what benevolent social action is designed to soften and ameliorate.

By definition, of course, we believe the person with a stigma is not quite human.

On this assumption we exercise varieties of discrimination, through which we

effectively, if often unthinkingly, reduce his life chances (p. 5).

According to Goffman (1963), three abundantly different types of stigma exist.

The first, Goffman referred as abominations of the body that account for physical defects

identified to an individual. Next, Goffman described the blemishes of individual

character. These traits are possessed by weak individuals as well as individuals with

unnatural desires. Lastly, Goffman proposed tribal stigma. This category of individuals share unique characteristics acquired via lineage such as race, ethnicity, and religion.

### **Abominations**

Goffman (1963) suggested that “the stigmatized individual – at least the *visibly* stigmatized one – will have special reasons for feeling that mixed social situations make for anxious unanchored interaction” (p. 18). Goffman clearly delineated a sociological interplay between normals and the stigmatized which creates a territory of *us versus them*. Further, Goffman explained “when normals and stigmatized do in fact enter one another’s immediate presence, especially when they attempt to sustain a joint conversational encounter, there occurs...the causes and effects of stigma must be directly confronted by both sides” (p. 13). The stigmatized individual may harbor emotions of how the normals will perceive and thus receive him within this social context. Goffman concluded that “this uncertainty arises not merely from the stigmatized individual’s not knowing which of several categories he will be placed in...but also from his knowing that in their hearts the others may be defining him in terms of his stigma” (p. 14).

### **Character blemishes**

Goffman (1963) expanded upon the notion of character blemishes which leads to stigma theory. Goffman detailed that such blemishes arise from individuals with “a weak will, domineering or unnatural passions, treacherous and rigid beliefs, and dishonesty, these being inferred from a known record of, for example, mental disorder,



imprisonment, addiction, alcoholism, homosexuality, unemployment, suicidal attempts, and radical political behavior” (p. 4). Goffman continued along this vein of character blemishes and societal outcomes,

The stigmatized individual tends to hold the same beliefs about identity that we do; this is a pivotal fact. His deepest feelings about what he is may be his sense of being a “normal person,” a human being like anyone else, a person therefore, who deserves a fair chance and a fair break....yet he may perceive, usually quite correctly, that whatever others profess, they do not really “accept” him and are not ready make contact with him on “equal grounds.” Further, the standards he has incorporated from the wider society equip him to be intimately alive to what others see as his failing, inevitably causing him, if only for moments, to agree that he does indeed fall short of what he really ought to be. Shame becomes a central possibility, arising from the individual’s perception of one of his own attributes as being a defiling thing to possess (p. 7).

### **Tribal Stigma**

Goffman (1963) referred to tribal stigma as “stigma that can be transmitted through lineages and equally contaminate all members of a family” (p. 4). In 2010, this form of stigma anchors within vulnerable societies lashing out against fear. African American and Hispanic communities finding reprieve within the boundaries of their respective communities face varying degrees of such stigmatizing behaviors from Goffman’s *us versus them* theory of societal stigmatization. Goffman noted, “this discrepancy, when known about or apparent, spoils his social identity; it has the effect of

cutting him off from society and from himself so that he stands a discredited person facing an unaccepting world” (p. 19). This double-layering effect of stigma further complicates the exploration of HIV-related stigma.

Finally, Goffman (1963) explained,

In social situations with an individual known or perceived to have a stigma, we are likely, then, to employ categorizations that do not fit, and we and he are likely to experience uneasiness. Of course, there is often significant movement from this starting point. And since the stigmatized person is likely to be more often faced with these situations than are we, he is likely to become more adept at managing them (p. 19).

The barriers of changing the defining attitudes of stigma pose unique challenges. Many attitudes attached to contemporary stigma are deeply embedded within the societal norms, the familial values, and the cultural mores of an individual. Goffman’s seminal work on stigma frames the context of HIV-related stigma.

### **HIV-Related Stigma**

Alonzo and Reynolds (1995) compiled and infused the previous stigma work from Goffman (1963) as previously discussed; Katz (1981) incorporated stigma dimensions such as threat, responsibility, visibility and sympathy; and Jones et al. (1984) distinguished their work with components of concealability, course, disruptiveness, aesthetic qualities, origin, and peril. The newly delineated stigma trajectory specific to

HIV/AIDS presented by Alonzo and Reynolds (p. 305) concluded that HIV-infected individuals are stigmatized because their illness is

1) associated with deviant behavior, both as a product and as a producer of deviant behavior (Conrad, 1986); 2) viewed as the responsibility of the individual (Sontag, 1988); 3) tainted by a religious belief as to its immorality and/or thought to be contracted via a morally sanctionable behavior and therefore thought to represent a character blemish (Kayal, 1992; Sontag; & Strommen (1989); 4) perceived as contagious and threatening to the community; 5) associated with an undesirable and an unaesthetic form of death; 6) not well understood by the lay community and viewed negatively by health care providers (Kelly, St. Lawrence, Smith, Hood, & Cook, 1987; Yedidia, Barr, & Berry, 1993).

The contemporary usage of this phenomenon relies heavily on the original meaning; however, today the individual's stigmatizing identifier may indeed be invisible to the rest of society, such as with contemporary manifestations of HIV.

For example, during the early years of GRID and gay cancer, the physically defining marks of wasting syndrome and the purple lesions of Kaposi's sarcoma were clearly linked to stigmata associated with AIDS (abominations of the body). Next, it is not uncommon for gay men, intravenous drug users, and sex workers to remain classified as deserving of this illness (blemishes of individual character) whereas children acquiring the virus from the mother, hemophiliacs, and heterosexual women exposed and infected by their male partners all remain classified as the innocent victims of this disease. HIV-related stigma is intensified in many cases because it is layered upon the existing stigmas

attached to homosexuality, illicit drug use, and sexual promiscuity (Crawford, 1996; Lee, R., Kochman, & Sikkema, 2002; Novick, 1997). Lastly, stigma (tribal) may be seen in Africa, Asia, and other resource-limited communities being ravaged by HIV across the globe today. Nonetheless, stigma is present throughout all societies. The nature and harm of stigma are uniform; however, the degree and circumstances of stigma vary among societies and cultural groups. Regardless of the context, stigma produces destructive effects. Blame, shame, fear, personal injury, violence, and death account for potential effects of stigma. The potential for both physical and emotional damage to the individual underscores the importance of this phenomenon.

When labeling, stereotyping, distancing, status devaluing, and discrimination simultaneously occur in one's life then it is believed that stigma exists (Link & Phelan, 2001; Vance & Denham, 2008). The stigma endured by those living with HIV has been viewed as "an enduring condition, status, or attribute that is negatively valued by a society and whose possession consequently discredits and disadvantages an individual" (Herek, 2002, p.595). Lastly, HIV-related stigma results in acts of prejudice, discounting, discrediting, discrimination, and a state that frequently leads to stereotyping and labeling (Herek, 1999). As demonstrated above, HIV-related stigma exists within all communities in varying degrees. The outcomes of HIV-related stigma have evolved into several specific types of stigma: internalized (an individual's internal sense of blame or shame), enacted (overt acts of labeling and devaluing an HIV-infected person), and associated stigma (effects of HIV on family members, friends, co-workers, health care workers for example). Of particular interest in this study is internalized HIV-related stigma.

## **Internalized Stigma**

Stigma experienced by HIV-infected persons has been well documented by numerous previous studies (Herek, Capitanio, & Widaman, 2002; Mahajan et al., 2008; Sayles, Ryan, Silver, Sarkisian, & Cunningham, 2007; Valdiserri, 2002). Research revealing the experiences of persons living with HIV has repeatedly documented the pervasiveness and deeply distressing features of HIV-related stigma (Chenard, 2007; Lee, R. et al., 2002; Schonnesson, 2002). Internalized stigma has often been defined as experiencing the fear of being stigmatized from the perspective of the HIV-infected person as well as actually feeling stigmatized relating to one's HIV status. The overwhelming need to know how an individual acquired HIV leads to a sense of shame and blame for an HIV-infected person as there is a constant assumption that he/she engaged in something bad or wrong to have become infected, and thus deserve the recourse experienced (Devine, Plant, & Harrison, 1999). Those who are HIV-infected are often portrayed as dangerous, untrustworthy, promiscuous, and personally responsible for their infection which contributes to a collective characterized by increasing fear, isolation, and alienation of others (Gray, D., 2004). The diagnosis of HIV transforms how a person sees himself/herself. This transformation involves both a personal challenge to redefine the self as well as a community transformation of how one perceives himself or herself as a member of this new community of HIV-infected persons. Internalized stigma forces a manipulation of one's self-verification through negative feedback, and, thus results in a careful management of one's stigma (Lee, J., & Craft, 2002).

Self-hatred and shame may develop from internalizing negative attributes to one's life. This promotes the experience of an HIV-infected individual to treat himself/herself as a devalued member of society. To the extent that one sees oneself as a member of a devalued group, one's sense of wholeness may become distorted and one's ability or willingness to join with others has the potential to lead to severe social impairment. The net effect of such imbalances is repression and denial rather than integration and inclusion (Gray, D., 2004).

In an effort to protect oneself from shame, blame, embarrassment, and social rejection precipitated by stigma, often an HIV-infected person steadily struggles with the decision to disclose or conceal his/her HIV-status (Goffman, 1963). Concealing an HIV-infected status, including incorporating ways to hide any visible manifestations of the HIV-diagnosis is commonly reported by HIV-infected individuals (Alonzo & Reynolds, 1995; Bogart et al. 2008; Chenard, 2007; Galvan, Davis, Banks, & Bing, 2008; Sayles et al., 2007).

Additionally, internalized HIV-related stigma commonly sensitizes an individual to heightened feelings of actual and anticipated rejection and stigmatization by others, which negatively affects patterns of HIV disclosure (Chesney & Smith, 1999). Secrecy of HIV leads HIV-infected persons to attempt hiding their stigma or their secret; however, like hiding any secret, the individual may become preoccupied with thoughts of stigma, which may negatively impact the individual's well-being and social functioning (Pachankis, 2007). Illnesses that are incurable and ongoing, that are poorly understood by the public, and for which the individual with the disease or condition can viewed as

morally responsible for acquiring the illness lead to difficult psychological consequences (Goffman, 1963; Herek, 1999; Jones et al., 1984; Pachankis, 2007). Cognitive preoccupations of secrecy or attempting to conceal one's stigma can be enormous and hence have been noted as a *private hell* (Smart & Wegner, 2000). While the phenomenon of interest for this study focuses on internalized HIV-related stigma, many co-researchers often depicted personal experiences of enacted and associated stigma related to living with HIV. Thus, the following review of enacted and associated stigma related to HIV merits further explanation to generate a better contextualization of the study.

### **Enacted Stigma**

The linkage between intentional acts of prejudicial attitudes, disruptions of ordinary social interactions, and discrimination from the stigmatizer to the HIV-infected person is commonly referred to as enacted HIV-related stigma (Block, 2009; Bogart et al., 2008; Chenard, 2007; Sayles et al., 2007; Vance & Denham, 2008). This form of stigma ranges from subtle remarks to overtly stigmatizing behaviors which influences the HIV-infected individual's strategy of illness disclosure or concealment. Acts of ostracism, breaches of confidentiality, and interpersonal avoidance manifest into severe compromises leading to debilitating declines in interpersonal relationships between the HIV-infected individual and the previous persons with whom the HIV-infected individual once had an established relationship. Block described "experiences of people refusing physical contact with them (HIV-infected persons) or items they used or touched, as well as refusal by friends, family members to have a relationship with them because they are HIV positive" (p. 9). Sayles et al. explained that verbal insults and hurtful remarks lead

HIV-infected individuals to search for “safe environments, which are supportive and accepting of their HIV status. In contrast, ‘unsafe’ environments involve judgmental and unsupportive people and often lead to withdrawal and social isolation” (p. 821).

According to the study conducted by Bogart et al., “rejection seemed to stem from a fear of HIV infection....A common response to such fears was to dispose of utensils used by the infected individual, or to refuse to eat food prepared by a person with HIV (p. 249).”

Bogart et al., (2008) reported that “enacted stigma can also be exhibited in the form of structural discrimination from institutions such as health care and housing” (p. 245). Sayles et al., (2007) reported “stigmatizing behaviors that ultimately led them (HIV-infected persons) to file for disability or resign (from the workplace). Those who chose not to disclose lived in constant fear of their colleagues finding out about their HIV” (p. 820). Block’s (2009) study described “reports of discrimination included being fired, harassed by police, and cut off financially for having HIV” (p. 9).

### **Associated Stigma**

HIV-related stigma affects not only HIV-infected individuals. The negative effects of stigma touches those associated with HIV-infected persons such as families, friends, colleagues, service workers, healthcare workers, entire communities, and society as a whole (Block, 2009; Bogart et al., 2008; Vance and Denham, 2008). Prejudicial and discriminatory acts against persons who are associated with HIV-infected individuals manifest into associated stigma (Bogart et al.). Caregivers, formal and informal, most frequently experience the manifestations of associated stigma. Grant, Keltner, and Raper (2010) explained that it is often difficult to secure support from direct and extended



family members as well as from social networks. Grant et al. further shared that “some informal caregivers even avoid employing the professional services of home health care, infusion therapy, and hospice providers in their attempts to avoid HIV/AIDS disclosure within their communities” (pp. 349-350). Bogart et al. reported that “a few children reported losing friends due to their parent’s HIV status, usually because friends’ parents prohibited the friendship” (p. 250). The effects of courtesy stigma often resemble the outcomes experienced by HIV-infected persons. For example, Bogart et al. described accounts of associated stigma which included “social isolation, rejection, and avoidance by friends, as well as employment and housing discrimination” (p. 245).

### **Implications of HIV-Related Stigma in Health Care**

Vance and Denham (2008) reported that nurses are frequently at the front line of daily care with HIV-infected patients. This nurse-patient proximity, according to Vance and Denham, potentially explained why nurses exhibited fear and anxiety when providing care for HIV-infected patients. Additionally, Vance and Denham suggested that “nurses are similar to others in society, and have personal values, beliefs, and attitudes that could negatively affect the ways they provide care. Nurses need...to sincerely examine personal values and reflect on personal bias that might conflict with professional responsibilities” (p. 60). Sayles et al. (2007) described that “in all seven focus groups, HIV-positive women and men reported experiencing stigma in the healthcare setting. The implication is that participants must negotiate *blame and stereotypes, fear of contagion, disclosure, and social contracts* in the medical community...” (p. 822).

The personal trajectory of living with HIV is highly variable among infected individuals. Researchers have focused attention on quantitatively describing the patient's experience via drug adherence and the impact of medication side effects, laboratory values, long-term outcomes, psychological manifestations, symptom management, and quality of life (Sterken, 2010; Gray, J., 2006; Kirton, 2008; Sension, 2007; Valente, 2003; Chou, Holzemer, Portillo, & Slaughter, 2004; Uphold, Holmes, Reid, Findley, & Parada, 2007). This set of measurements enhances the strategies for improved patient-care management of HIV; however, there exists a void when attempting to describe the daily lives and phenomena as experienced by the HIV-infected individual with such a prescribed set of criteria.

Unfortunately, the health care system in the US does not foster an intimate experience with practitioners (Bird, Bogart, & Delahanty, 2004). Thus, far too often, the patient is seen as a subset of numbers [RNA viral loads] and counts [CD4+] rather than as a living human being. This scenario translates into feelings of detachment. HIV-infected persons often suffer in silence as they are shuffled through the system. Studies of HIV-infected individuals in the U.S. have corroborated a relationship between stigma and multiple health-related outcomes, including health-related quality of life, poor antiretroviral therapy compliance, and increased HIV symptoms and depression (Sayles et al., 2007). Understanding how HIV-infected individuals look after themselves with HIV illness is vital to the development of effective interventions that may decrease HIV-related morbidities (Ashton et al., 2005).

As HIV transitions from a fatal diagnosis to a chronic medical condition, the uncertainty of living with HIV remains one of the most distressing factors associated with this disease (Northrup, 2002). A part of this fear is the fact that a cure for HIV does not exist and that the uncertainty of a premature death remains imminent to many HIV-infected persons. Even when threats surrounding the uncertainty of physical illness related to HIV dissipate for some HIV-infected individuals, there remains a new uncertainty related to the highly potent medications, their side effects, long-term benefits, and drug resistance (Schonnesson, 2002). Sterken (2010) described the scenario to that of Damocles, “a foreboding circumstance in which the potential for tragedy hangs by a delicate thread” (p. 206). Clearly, HIV forces the physical body to function on a cellular state-of-alert; the emotional stress of living with HIV, and the stresses of the unknown or uncertainty of one’s own destiny combine to create multiple outcomes related to self and behavior.

HIV-related depression has received major attention over the years (Badkoobehi, Chana, & Overall, 2006; Eller, 2006; Roeloffs et al., 2003; Schonnesson, 2002). According to Eller, the development of depressive symptoms in response to HIV and HIV-related stressors is all too common, ranging from 21% to 97% among individuals. The comparison of specific rates is further complicated by the varied conceptualizations of depression as a major depressive disorder or depressive symptoms, and by the use of multiple methods of measurement (Eller). The widely held assumption that people with incurable medical conditions are apt to become clinically depressed stems from the vast cancer literature. Atkinson and Grant (as cited in Schonnesson) reported that the majority of HIV-infected individuals appear to be psychologically resilient and there are

indications that those suffering from depression have experienced depressive episodes that antedate HIV-infection. Nonetheless, Schonnesson and Ross (1999) described that individuals with HIV often fear being alone in terms of abandonment and isolation, creating a sense of being invisible or a sense of being “no one” which may lead to or potentiate depression.

The mechanisms that underlie associations between depression and behavior are not clear. Although associations do not imply causality, several studies supported positive relationships between depression and risky behaviors. These behaviors include risky sexual behaviors (Eller, 2006; Nyamathi, Flaskerud, & Leake, 1997; Parsons, Halkitis, Wolitski, Gomez, & SUMS 2003; Rogers, G., Curry, Oddy, Pratt, Beilby, & Wilkinson, 2003; Semple, Patterson, & Grant, 2000). One study in South Africa reported that HIV-infected persons who experienced stigma or discrimination were less willing to disclose their HIV status to sexual partners, and this non-disclosure was associated with HIV-transmission risk behavior (Simbayi et al., 2007). Additionally, in France, a study of over 2000 sexually active persons living with HIV who had experienced stigma revealed an increased incidence of unsafe sexual behaviors (Peretti-Watel, Spire, Obadia, Moatti, & VESPA Group, 2007). The relationship between HIV-related stigma and risky sexual behaviors warrants further descriptive exploration among diverse communities of HIV-infected individuals.

### **Conclusion**

Health care providers may present an abundant and often confusing array of laboratory values loaded with optimal ranges for specific biomedical markers measured

through highly specific diagnostic testing procedures to HIV-infected persons in 2010. The question, however, arises if HIV-infected persons perceive that they are truly being heard by the health care provider. Additionally, HIV-infected persons may challenge their inner voice that cries out to be heard but fearfully assumes a submissive and muted role in the management and care of HIV disease. HIV-infected persons are positioned to receive optimal care when engaged in a trusting and respected relationship with health care providers. Unfortunately, many HIV-infected persons express disdain with their current care and may refuse follow-up care in an effort to remain within a zone of self-protection. Quantitative studies have addressed the various components of HIV-related stigma through survey responses or questionnaires. Qualitative studies have attempted to give voice to HIV-infected persons through in-depth interviews and focus groups translated via the voice of an HIV-negative investigator. These studies hold valuable merit in advancing the existing body of knowledge surrounding HIV-related stigma. In an effort to increase the volume and resonance of the voice among HIV-infected persons, the entrée of the HIV-positive researcher into the circle with the HIV-infected research volunteers provides the opportunity to enhance the understanding of stigma in a protective, caring, and sincere manner. This proximity enhances the collective sharing experiences of HIV-related stigma which have been encountered along each individual's personal trajectory of living with HIV.

## **CHAPTER III**

### **Methodology and Data Collection**

#### **Design and Methods of a Heuristic Exploration**

Compared with more established and older research paradigms, it is useful to explicate not only the qualitative, heuristic research model but also the model's roots in the philosophy of science and humanism. The heuristic research model is a qualitative scientific format anchored in the field of humanistic psychology. This explication will be organized in four sections. First, the qualitative scientific paradigm and its foundation in the philosophy of science will be examined; additionally, the forestructure of the researcher to this study within the context of the qualitative paradigm will be presented. Second, the relevance of art-based research methods which are central to this humanistic approach will be explored. Third, a section of humanistic research and its groundings in phenomenological philosophy will be addressed. Fourth, the heuristic research model, describing its philosophical bases, phases and basic methods of research will be examined. The rationale for selecting the heuristic research model as the best scientific foundation in the study of human experience such as HIV-related stigma will also be presented.

#### **The Qualitative Scientific Paradigm**

The process of research design in qualitative research starts with philosophical alignment that a researcher makes when undertaking a qualitative study. Additionally, a researcher brings his/her personal worldview or set of beliefs to a study, and these assumptions inform the process and writing of the qualitative study (Creswell, 2007). The

scientific paradigm, upon which this research is based, is anchored in existential philosophy. Existentialism views humans as being-in-the-world; Heidegger (as cited in Churchill & Wertz, 2001) explained that persons unfold collectively and individually by finding and sharing experiences, and thus creating an identified space in the world. Existentialism places value upon both objectivity (things which exist separate from human experiencing them) and subjectivity (the process by which all humans experience the world). This view supports a resolution of the subject-object split, which has defined logical positivism, through the attunement of an interactive relationship between the world and human being. According to this assumption, total objectivity in human beings cannot be achieved since human beings are constantly influenced by their own presence and by the world in which they live. The world is continuously changing as a result of human beings. The notion of the world and human experiences replicating exact principles which can be neatly organized in an authoritarian manner should be reexamined to include the notion that scientific research can be fluid and creative like an art in which discoveries are made (McNiff, 2009). Viewing science as an aesthetic process is a radical departure from the traditional positivist paradigm. A complete re-evaluation of the research method within the scientific world is required to glean the wealth of more naturalistic scientific approaches.

Leonard (1994) described:

Much of the current thinking in philosophy that attempts to get beyond the objective/relativism debate stems from the work of Martin Heidegger. It was Heidegger's shift from considering problems of epistemology to

considering the problem of ontology, that is, of what it is to be a human being that radically altered modern debates on the nature of science and of knowing. Nursing could well profit from considering the question of what it is to be a person, of ontology, prior to considering questions of epistemology. Once fundamental notions of what it is to be a person are clarified, the at times acrimonious debate concerning methodology will resolve (pp. 43-44).

A vital aspect of the qualitative paradigm hinges upon the personal qualities of the researcher. Moustakas (1990) stressed the idea that “the researcher be alert to signs or expressions of the phenomenon, willing to enter a moment of the experience timelessly and live the moment fully” (p. 44). Following this aspect of the qualitative paradigm, the researcher is passionately devoted to the search for an answer(s) to the scientific problem or phenomenon of interest. Additionally, the researcher is open to confronting the challenge from which the problem originates. This approach to science produces a dynamic atmosphere from which the researcher may launch his/her inquiry. The notion of the *self-in-relation* is reflected in the works of philosopher Martin Buber (as cited in Witherell & Noddings, 1991):

True science is loving science. The man who pursues such science is confronted by the secret life of things which has confronted none other before him, the life places itself in his hands and he experiences it, and is filled with its happening to the rim of his existence. He then interprets what he has experienced in simple and fruitful concepts, and celebrates the



unique and incomparable that happened to him with reverent honesty (p. 57).

Beneloiel (as cited in Munhall, 2007) emphasized five points to better situate the qualitative paradigm:

(1) social life is the shared creativity of individuals and *their perceptions*; (2) the character of the social world is *dynamic* and *changing*; (3) there are *multiple realities* and frameworks for viewing the world: the world is *not* independent of humankind and *objectively identifiable*; (4) human beings are active agents who *construct their own realities*; (5) No *response sets* are highly predictable (p. 10).

Finally, Moustakas (1981) wrote about the mere nature of scientific inquiry:

What is required is disciplined personal commitment, an approach that regards science as a process rather than a result, a thrust toward knowledge based on awareness and understanding rather than proof, a search for meaning rather than efforts to measure, and a satisfaction with approximation or plausibility rather than certainty (p. 2).

The qualitative paradigm facilitates the research which I have undertaken on the experience of HIV-related stigma. Further, this paradigm encourages the process of researching the subjective human experience, which by its very nature is enormously complex, immeasurable, and quite inexact from individual-to-individual. The study of subjective human experience, however, covets the promise of attaining vast new horizons in the manner by which researchers approach the understanding of human thinking,

behavior, and feeling. Secondly, the qualitative paradigm encourages the researcher's subjective human experience. This proximity permits the researcher to explore a phenomenon that has a deep personal significance, one necessary to create a passionate commitment and attachment by the researcher to his/her study. Lastly, biases are acknowledged as an unavoidable and a natural component of being human which ties into the notion of approximation in qualitative studies rather than certainties. This study seeks to answer the question "What is the experience of HIV-related stigma?" by using admittedly approximate methods for participant selection, data gathering and analysis, and finally expressing the findings. The goal is not to find a single or ultimate response to the research question but rather to explore and disseminate a new awareness and understanding of this human phenomenon which will contribute knowledge to the field of nursing and human science.

Watson (1994) described the researcher-proximity issue as follows:

Specifically at issue is ontological authenticity in relation to the human-to-human transpersonal and contextual field in which nursing research (as praxis) finds itself with respect to the conditions and experiences of being human. For example, although nursing research may attempt to capture the descriptive meaning of the subjective lived experiences of patients as part of a qualitative research paradigm (e.g., phenomenology, ethnoscience, hermeneutics), the empirical context of traditional science still looms large, keeping the focus external (even though subjective) and directed toward the 'other' out there....there is another way to think about this situation. First,

we can admit that it is never possible to *know* another person's experience; even though we may intuit it and vicariously identify with it, it remains uniquely *other*. Second, we can find it possible to *grasp* the other's experience by becoming better acquainted with how we encounter it as researcher, as clinician, and so on. By inverting the paradigm and understanding human experiences from the inside out, we come full circle – from modern, detached, sterile language to postmodern connections, interpretations, and aesthetics. We see the beginning of a new dynamic of understanding human experience (p. 13).

The qualitative paradigm promotes the practice of science in a manner which is consistent with my particular abilities and values. This paradigm permits me to utilize the skills in interpersonal communication that I have developed as a nurse to gather data through the execution of in-depth, personal, unstructured, and open-ended interviews. I am allowed to openly explore the meaning of HIV-related stigma rather than experience the limitations of searching for what can be measured or hypothesized. The qualitative paradigm allows me to immerse myself into scientific research in an intense manner while exploring a phenomenon of personal importance to me, with potential applications leading to interventions in various settings and disciplines.

It is important to note that the selected paradigm permits the researcher the opportunity to explore the chosen phenomenon from multiple approaches and hence report the data in a variety of narrative and aesthetic modes consistent with a holistic research approach while maintaining essential components of rigor and trustworthiness.

Remaining true to all scientific research models, the research question or phenomenon of exploration drives the selection of the research design. The heuristic design within the qualitative paradigm selected me. With this acknowledgement comes the journey of full-disclosure. Etherington (2004) noted that even though it may be perfectly acceptable to use the self in the researcher's primary discipline, in the broader world of academia, this subjectivity and reflexivity would almost certainly be viewed as self-indulgent or narcissistic, and a contamination of *objectivity* [emphasis added] which remains the legitimate benchmark for *good* [emphasis added] research. The burden of balancing the many voices of my co-researchers with my own voice becomes the central responsibility of the researcher in creating a solid study. Finally, the nature of nursing knowledge is such that nurse researchers frequently locate departures from the traditional qualitative approaches necessary and appropriate to address the phenomenon of interest (Dreher, 1994; Thorne, Kirkham, & MacDonald-Emes, 1997). This is precisely the mode of action which has been incorporated within this study by approaching the traditional phenomenological method from a heuristic inquiry model. As in all heuristic studies, the disclosure of the researcher requires a complete account to the readers. Additionally, in the pursuit of rigor in heuristic research, Lowes and Prowse (2001) concluded that the intentional exclusion of the investigator's preconceptions and positioning within the study is unfeasible and not a requisite in order to attain researcher objectivity if the investigator thoroughly explains the preconceptions and the contributions of the unique background which he brings to the study processes. Thus, at this point, I offer my disclosure, my proximity, and its appropriateness to this study.

### **An Intimate Journey: Reflections of the Researcher**

The forestructure of a qualitative study is the background, experiences, and prior knowledge that the researcher brings to the study. McNiff (2009) encourages the inclusion of the researcher's forestructure "with a narrative account of how they selected their methods and themes for research....that they provide a sense of context – the how, what, why, and where that informs and enables the reader to enter the world-view of the researcher" (p. 156).

Thus, growing out of many years of uncertainty about my own life and living with HIV, the question, "What is the experience of living with HIV?" resonates loudly within me. For over 19 years, I have sensed an extraordinary difference within my life from that of the HIV-negative community. This keen perception of my difference has shrouded many of my most visceral feelings about myself and my personal journey of living with HIV. Additionally, it has birthed intense emotional pain as well as heightened feelings of liberation and happiness. The diagnosis of living with HIV has partitioned me from many people, yet, it has fostered an intense closeness with many others throughout my life. Ultimately, my personal identity of living with HIV has shaped the creation and existence of my social identity. For most of my adult life, I have processed my most inner feelings and outer behaviors relating to my HIV status as a detached and uncommon experience. Society's reaction to the epidemic during the early 1990's fueled my intense feeling of "otherness" and being "tainted." Until recently, these feelings shaped my goals, dreams, desires, and ultimately my life as a whole. I had never woven

the numerous perceptions and actions to my reality of being different as components of a collective social experience.

In 1990, wounded, rejected, and exhausted, I became increasingly detached from the world outside the safety of my front door. Each time that I would brave the external world, I would retreat back home with both emotional and mental hesitations confirmed about my place in the world. During this period of the HIV epidemic, we were repeatedly told, ‘there is not much we can do for you; you should make plans for when you become too ill to care for yourself; you know this is coming, right?’ These words echoed through my mind on a daily basis for many years. I can still vividly recall the media images associated with an HIV diagnosis. I had few options but to wait, and wait, and wait until these images and verbal messages arrived and thus manifested into reality as I would gaze into the mirror. As a 23-year old living far from the securities and safety of my childhood home, I further retreated within myself and waited for my sentencing. I listened attentively to friends, family and co-workers discuss the HIV situation as it continued to unfold and touch our lives. Quite often, I would hear the guttural disgust, loathing and fear directed at the HIV-infected community. Unknowingly to them, one of their most feared creatures within society was shyly poised within their circle. I would ask myself, “What would they do? How would they react? What would become of these relationships which had been nurtured over the years?” Ultimately, I would not know at this time. I chose silence; a silence so strong that even I was muted from myself. I evidently did a formidable job since I was never singled out or ostracized by these individuals. Simultaneously, their silence nurtured my secret life bounding within me. Nonetheless, I was truly scared much of the time. This isolated fear would slowly

transform over the next 19 years into the most personal piece of my self-identity -- one which craved an equal place within our society. This quest for normalcy consumed my entire life.

As I continued to physically thrive, the images and verbal messages of living with HIV became blurred. Society had clearly defined the expected outcome of HIV: sickness, death, marginalization, and rejection. These prescribed outcomes of HIV offered limited space for the hopeful outcomes of health, living, acceptance and inclusion. Yet, I felt an awakening of hope as I rejected society's labels and I began to listen to myself and create my own quest for survival. The cloistered, internal life in which I had continuously retreated against society's assertions slowly unraveled during my late twenties. The tight grip of these societal messages slowly began to loosen. I interpreted this as a time to live again, a time to flourish, to re-ignite dreams and hopes that I had allowed to previously slip away. My deep secret remained invisible to the external world as I slowly positioned myself to shed hesitancy and fear. I asked myself, "How do I accomplish this?" I knew that if I did not formulate a plan to shatter the images attached to me then ultimately I would indeed succumb to these prescribed outcomes and ideals about who I am and how my life shall progress.

Reflecting upon these early years of living with HIV, I now see the change which occurred during my late twenties as a major shift in my life and my existence as an HIV-infected person. I realized that I had allowed the societal beliefs which I feared to dwell within me, otherwise, this internal struggle against them would not exist. I chose to live, to re-kindle my endeavors and to resume my quest for a proper place within society. I

rejected the restrictive assumptions labeled to me as a member of the HIV community. By doing this, I learned that it was okay to be different and to fully abandon efforts to pretend to be someone I am not. I attended support groups for the first time; I volunteered in an AIDS-ward at the local hospital. These initial steps of reaching out and confronting my life entangled with the lives of other HIV-infected persons were difficult. I experienced first-hand the immense pain, grief and loss of others within my community. In doing so, I tackled my own pain, grief and loss from years of social isolation, personal alienation, and the reality of my strangeness to others. I learned that I had been my own worst enemy all these years leading up to this moment. I had sacrificed my veritable self in order to assimilate into a worldview of others. Through this connectedness to other HIV-infected persons, I challenged my intense confusion about how we each define, interpret and share our experiences. I actively pursued this nurturing (to myself and others) path of working within the HIV community through the late 1990's. Particularly of interest, the attendance and often moderating of discussion groups and support sessions for men and women living with HIV offered me a snapshot of the current phenomenon of living with HIV.

These newfound interests to work closely with the HIV-infected community lead me to embark upon my educational studies in nursing. As I progressed through these studies, the topic of HIV remained highly salient for me. Later as a graduate student in nursing, the exposure to works by Moustakas (1990), Jourard (1971), Goffman (1963), Watson (1994), and Rosemarie Parse (2001) echoed loudly to my personal experiences of living with HIV as well as the experiences of others within this community. Moustakas' writings about self awareness and emotional experiencing fortified me to appreciate my



personal uniqueness as well as the search for collective aspects of living with HIV.

Jourard's work about self-disclosure reinforced my need to break the deafening silence of not only my own voice but also the voices of my HIV-infected co-researchers.

Goffman's work on stigma contextualized the reality of societal and cultural links of being different and how to navigate my way through this uncharted territory of living fully as an HIV-infected person. Watson's work on caring positioned my previous work with HIV-infected persons directly in the present via a model of caring for the self while caring for the other. Parse's writings on living in the moment and celebrating the truth of one's own experiences fueled my desire to further explore the lived experience of myself and my co-researchers as members of the HIV-infected community.

As a nurse, I honored what I had experienced as a patient and incorporated this into my own nursing practice. Most notably, I cherished the opportunities of being totally immersed with my HIV-infected patients, being wholly present during vulnerable moments, being respectful and unconditionally accepting of our diversities and life experiences. Attentive listening, an approach of being fully present, as well as abandoning my own fears to sincerely care allowed me to successfully use myself as an instrument to facilitate the healing process. This unspoken intimacy which developed between me and my patients guides me to continue to ask myself, "Who are these people? What is their experience of living with HIV in a world predominantly shaped by an HIV-negative society?" My goal is that this research will lend to answering these questions for me and others who desire to understand more about the HIV lived experience as accounted by HIV-infected persons rather than documented by persons unattached to truly living with this virus in a quotidian manner. Most importantly, I

chose to explore the HIV lived experience because it is explicitly my own experience. It is of crucial importance in the type of qualitative research I have undertaken that the researcher has lived the phenomenon being explored. Thus, I have selected a question which has significant relevance in my own life, and for which I have a deep commitment to find an answer. As I have described in this forestructure, the lived experience of HIV has had a profound effect on my life. I anticipate that I will glean new information about myself and my co-researchers, studying this experience with other men and women who strive for normalcy while living with HIV. I embark on this quest for new knowledge of others and myself with a profound excitement to share the HIV lived experience.

### **Art-Based Research Methods**

Art-based research incorporates the use of the arts as a mode of inquiry as well as a vehicle to facilitate the explication of the phenomenon under investigation (McNiff, 2009). Chinn (1994) described “the art of nursing is the art/act of the experience-in-the-moment....Art arises from the immediate embodied grasp of the situation, the tools or instruments with which the artist works, and the intuitive knowing of what is to be created” (p. 24). Additionally, Chinn commented that “art in its finest forms requires and builds on all other patterns of knowing, possibly extending beyond what has been described and named as knowing” (p. 24).

McNiff described that

We need both scientific and aesthetic knowledge, and the two have always complemented one another through human history as they continue to explore the unknown. It is time, however, to acknowledge that human experience cannot be

completely understood through the scientific method and to apply the discipline, rigor and intelligence that we commonly associate with science, to the process of aesthetic inquiry. We must also realize that creative arts...need to encourage research from this perspective (p. 15).

Art-based research will ultimately create results that merely happen as a result of the distinct conditions of the uniqueness related to the process of investigation (McNiff). This examination of one's feelings lends well to the phenomenological approach since the explanation of phenomena incorporates both introspective and tangible images (Betensky, 1996).

The act of fusing together the positivistic and naturalistic paradigms into one study will reveal a richer data set that resonates loudly. McNiff (2009) noted "the increased polarization between empirical and introspective approaches to research. McNiff added that "introspection is spontaneously re-emerging as a respected mode of inquiry....by heuristic research which shares many concerns with art-based inquiry....heurism connotes a method of learning through which knowledge is discovered through an inquiry based upon the examination of personal experience" (pp. 52-53). McNiff noted that "while art-based research makes good use of heuristic 'self-dialogue', it also includes the study of external phenomena and dialogue with the object" (p. 55). The phenomenological circle becomes vastly proliferated by the aesthetic processes and the artifacts it produces.

The approach to the method for discovery of new knowledge during a research project assumes a different vantage point in the art-based heuristic inquiries. McNiff

(2009) described that “the deductive methods of behavioral science encourage researchers to know the parameters of their research before they begin whereas creative inquiry typically discourages being at the end when you are beginning” (p. 145). Additionally, McNiff explained that “if we discover the right method, the one which is in synchrony with our interests and experiences, it will constantly unfold new meanings and possibilities, provide order, and ensure consistency, while encouraging depth and complexity” (p. 151). As nursing expands outside of the holds of positivistic scientific approaches, Malkiewicz and Stember (1994) explained that

Art is increasingly considered by nurse theorists as an important element of nursing. Art was described by Watson (1985) as a human-to-human means of establishing relationships between nurses and the recipients of care, thus allowing the genuine transmission of feelings. Paterson and Zderad (1976) noted that forms of art are valued as resources for enriching our knowledge of man and the human situation (p. 264).

A heuristic approach to research, according to McNiff, “benefits from being tempered with an orientation to other people, the medium of expression, and the objective properties of the process of creation....which holds and concentrates personal explorations and makes useful connections to the experiences of others” (p. 152). It is precisely this connection between the researcher and his co-researchers, achieved through the medium of the creative, aesthetic component during the research process, which shall contribute to the existing literature in a novel manner to give voice to the unspoken experiences of living with HIV-related stigma.

## Humanistic Research

A significant development for the behavioral sciences during the 20<sup>th</sup> century firmly situated the growing shift in recognition regarding the limits of the positivistic conception of science (Wertz, 2001). Further, Kuhn (1962), an intellect immersed in the study of changes and revolutions in natural science, asserted that evolution in science requires reevaluations in paradigms such as the researcher's basic worldview; methods, values, and the uniqueness of social processes in an effort assert that science is not a one-way, linear process. Giorgi (2001) supported the necessary shift in scientific thinking in order to facilitate a more complimentary approach to studying human phenomena while reflecting upon his personal scientific training in academia. Giorgi described

How to become a scientist was enforced more vigorously than was the sensitivity to psychological manifestations. This fact, in and of itself, could have been a great benefit if the balance between scientific emphasis and psychological sensitivity was proportional or if the sense of science being pursued was more in tune with the nature of psychological reality. However, neither desideratum actually was experienced by me. To be excellently scientific was the alpha and omega of all my psychological education (pp. 53-54).

Finally, Wertz (2001) offered that "humans, by virtue of *what they are*, make certain demands on how we know them, demands that are not encountered by the natural sciences" (p. 232).

The principle ideas of existentialism and phenomenology which apply to humanistic research include the attunement of personal experience in learning and personal growth, the holistic nature of the self, the individual's natural drive toward fulfilling one's potential and finding meaning in one's life, and the concept of being-in-the-world (Moss, 2001). As such, humanistic research pushes the qualitative paradigm further by attending to not only human experiences of the researcher but also the relationships between the researcher and the chosen co-researchers (Moss, 2001). A researcher attuned to the humanistic perspective approaches each study participant as a unique and special manifestation of humanity. Respect for and appreciation of these unique features and special needs of each person is the premise for humanistic, person-centered research. Carl Rogers (as cited in Moss, 2001) defined the core of the person-centered approach as two individuals who are in emotional contact; one being the co-researcher who is troubled by a phenomenon and the other being the investigator who projects genuineness in this relationship; the investigator emulates an unconditional presence with the co-researcher and an empathic understanding which in turn is perceived by the co-researcher and thus is permitted to self-actualize in his own self-defined manner.

This same perspective grounds qualitative research as each individual has a unique story to tell and each person assumes a special case to be explored with personal insights (Patton, 2002). The Humanistic Nursing Theory (Paterson & Zderad, 1988) posited that knowledge occurs on three levels: (1) objective (examined at a distance); (2) subjective (awareness of experience from the inside-out perspective); (3) intersubjective (exchanges with other human beings). Wagner (2000) suggested that the intersubjective

level maximizes the humanistic relationship within a lived experience. According to Wertz (2001):

The core of humanism in classical civilization, the Renaissance, and continuing in modern times is the conviction that humans are different from physical objects and from other animals. Humanists believe that knowledge of humans must reflect those distinctive characteristics. From this, it follows that humans, by virtue of *what they are*, make certain demands on how we know them, demands that are not encountered by the natural sciences (p. 232).

Further, Polanyi (1958) described that humanistic research indeed provides a framework for science dealing with living persons as logically different from a science dealing with inanimate things. Three primary types of humanistic research rooted in the qualitative paradigm are used in nursing research: heuristics, phenomenology, and participant-observation. Heuristic research, primarily stemming from existentialism, is the model of choice for this research study and will be addressed in more detail in the next section of this chapter.

Humanistic nursing advocates much more than the subject-object, one-way relationship initiated by the nurse; rather it requires that nursing continuously searches out those transactional relationships whose meanings demand a conceptualization founded on the nurse's existential awareness of self and the other (Paterson & Zderad, 1988). The awareness of both self and the other is coined the 'between.' These relationships with human beings create the actual lived

experiences and these experiences create the histories referred to as the 'between.' This 'between' allows the researcher to broaden his/her knowledge base of the phenomenon of interest while in constant presence with the other (Paterson & Zderad). Humanistic research calls forth in the researcher the struggle of sensing the complexities of human beings and the human condition as searching, experiencing, and an unfolding becoming (Paterson & Zderad).

Caring is central to a humanistic perspective. Bruderle and Valiga (1994) explained that "it [caring] also encompasses a broader awareness and understanding of people's concerns and feelings, the contexts in which they live, their cultures, and the ways they live in the world" (p. 118). Nurses experience, with other human beings, pinnacle life events such as birth, surviving, winning, losing, separation, and death. Through in-touchness with self, the authentic awareness of other, and reflection upon such lived events that the researcher comes to know (Paterson & Zderad, 1988). Precisely through this in-touchness with other individuals who have experienced HIV-related stigma, the exploration of this phenomenon can be further examined. Finally, the necessary reflection, by both the researcher and the co-researchers, allows each individual to self-present from a space attached to a proper clearing to better understand the phenomenon.

In the humanistic framework, the researcher is also viewed as a human person, as a being in a body instead of simply a doer of tasks or activities. This framework posits further the vast possibilities of exploring the development of human potential and understanding, both researcher and co-researcher, as it occurs



in the unique domain of nursing's intersubjective transactions. In this process of shared situations/phenomena between the researcher and the co-researchers, the focus is directed toward the significance of lived time and space, that is, time and space as experienced by the researcher and the co-researchers, and as shared as intersubjectively (Paterson & Zderad, 1988). Paterson and Zderad (1988) summarized,

We contend that humanistic nursing practice necessarily involves the conceptualization of that practice and an examination of its inherent values and that humanistic nursing theory must be derived from nurses' lived experiences. The interwoven theory and practice are reciprocally enlightening (p. 18).

Explorations of this nature may provide valuable insights into understanding HIV-related stigma from a unique and communal experience.

### **The Heuristic Research Model**

The ontology of the heuristic research model emerges from humanistic psychology. Heuristic, from the Greek *heuristein*, means to discover. Parse (2001) described the uniqueness to this research method by which the researcher's perspective assumes an essential element of the study. Heuristics is a form of phenomenological inquiry that brings to the forefront the personal experience of the researcher. Moustakas (1990) explained that "in heuristics, an unshakable connection exists between what is out there, in its appearance and reality, and what

is within me in reflective thought, feeling, and awareness” (p. 12). Patton (1990) described that heuristic inquiry poses the question: “What is *my* experience of this phenomenon and the essential experience of others who also experience this phenomenon intensely?” (p. 71). Heuristic research is a way of engaging in scientific inquiry via methods and processes aimed at discovery through self-inquiry and dialogue with others focused on finding the underlying meanings of important human experiences (Moustakas, 1994). At the onset and throughout an investigation, heuristic research requires self-search, self-dialogue, and self-discovery. Moustakas (1994) explained that “the self of the researcher is present throughout the process and, while understanding the phenomenon with increasing depth, the researcher also experiences growing self-awareness and self-knowledge” (p. 17).

The phenomenon of interest must abound from an inner awareness, meaning, and inspiration. Thus, the heuristic inquiry begins with the researcher’s own self-awareness and then explication of the problem until an essential insight is achieved which ultimately shifts to a critical human experience (Moustakas, 2001). Ultimately, a deeper understanding of the phenomenon will emerge as the researcher confronts challenges and doubts regarding the human concern at hand as a result of the personal involvement and attention directed at that underlying phenomenon. Heuristic research is structured to permit in-depth study of human experience as a holistic phenomenon. This process involves personal discovery through a committed involvement in the research inquiry and openness to the researcher’s own creativity as a scientist.

A primary emphasis is placed upon the researcher as he/she assumes the role as the instrument for describing and portraying human experience. Thus, the action of the researcher is to assume the role of the data collection instrument, assembling individual narratives from the deliberately selected sample (Norwood, 2000). The researcher arrives at a phenomenon of interest during the personal reflection of human experiences. The phenomenon flows directly from the researcher's personal awareness of meanings regarding human issues of great concern (Parse, 2001). An important tenet of heuristic research recognizes that the scientist brings biases into the research, and that this is unavoidable in any qualitative research. The advantages to gain, however, in passion, creativity, insight, and commitment by exploring a question of such personal relevance to the researcher outweigh the disadvantages of biases introduced into such a study.

Further, the sincere commitment, self-disclosure, and presence of the heuristic researcher during the interview process is seen as a way-of-being which often maximizes the likelihood of the co-researchers responding in a sincere way which will reveal more personal information about the phenomenon of interest (Jourard, 1971). This emphasis on a shared-quest for meaning between the researcher and co-researcher ultimately relies on the forthcoming nature and sincerity of the heuristic researcher while engaged in dialogue with fellow co-researchers.

The pioneering work by Polanyi (1968) in defining heuristic scientific research places as its framework the concept that scientific inquiry is one continued

act of tacit integration. Polanyi (as cited by McNiff, 2009) described tacit knowing as “explicit knowledge in science and relatively closed methods of inquiry limit the generation of new knowledge by blocking access to what we know tacitly” (p. 132). According to Polanyi (1968), tacit knowing is more profound than intuition or inference. Rather, it is holistic in nature and thus refuses to be dismembered into ordered segments for further analysis. It is in that instance when “we can know more than we can tell” (Polanyi, 1966, p. 4). For example, a nurse can administer a certain intervention, or respond in a caring manner, but, when asked to describe the actual process involved in each of these two holistic acts, is not able to do so. Further, the act of trying to analyze the task usually results in confusion and thus renders the individual incapable of completing the task as previously performed. Thus, the heuristic scientist is obligated to become sensitive and attuned, as an instrument, for collecting and analyzing the data in an effort to derive meaning.

Indwelling is a principle component of tacit knowing. This process of indwelling requires the integration of bodily clues to unmask meaning. Polanyi (1968) noted that indwelling stems from the complex manner in which human’s accumulate and store perceptions, thoughts, emotions, and feelings within one’s own body; in other words, we interiorize these sensations and in doing so, the researcher dwells in it. Ultimately, the body becomes the instrument by which the scientist knows the world. According to Moustakas (1985), when one curtails tacit knowing in the research process, the possibilities for knowing are limited, the potential for new awareness and understanding is restricted and the range and depth

of meanings which are inherent to human experience and understanding are severely restricted. Parse (2001) described that the heuristic research method is to

Discover the meaning of human experiences surfacing from the personal concerns of the researcher. The researcher seeks to understand the wholeness and unique patterns of experiences in a scientific, organized, and disciplined way. The assumptions of the method follow: (1) understanding of phenomena is deepened with persistent, disciplined devotion of intense study and (2) the researcher's frame of reference, self-discipline, intuition, and indwelling are reliable sources for discovering the meaning of human experiences (p. 47).

The basic research design of a heuristic study includes six phases: (1) initial engagement; (2) immersion into the topic; (3) incubation; (4) illumination; (5) explication; (6) creative synthesis. I will briefly discuss each phase as well as offer a detailed application to my own work on HIV-related stigma. Each phase of the heuristic research components follows and is accompanied by examples of how the researcher personally approached and fulfilled these necessary methodological requisites to remain consistent in this qualitative inquiry.

### **Initial Engagement**

Within each researcher inhabits a topic, theme, problem, or question that represents a critical interest and area of research. This deep and passionate interest within a researcher signifies the task of initial engagement. The researcher seeks to

unveil a compelling concern from within that has social meanings and personal implications. This initial engagement phase encourages self-dialogue, an inner search to discover the topic and address the problem. Throughout this process, the heuristic researcher encounters the self, one's autobiography, and meaningful relationships within a social context (Moustakas, 1990). This process which begins with a problem which the researcher seeks to illuminate is one that has been a personal challenge in the quest to understand one's self. The heuristic process is autobiographic in nature; however, with each question that has meaning to the researcher, there is also a social significance which extends into a collective nature (Moustakas, 1994). An example of the initial engagement phase of the heuristic research method is exemplified in the following self-depiction of the researcher.

I have a deep commitment to exploring the meaning of HIV-related stigma. This exploration required that I step back and reflect upon my own personal experiences of HIV-related stigma. The stigma surrounding an HIV-positive diagnosis is such that one truly cannot live in this moment unless you share the status of being HIV-infected. The overwhelming majority of the previous research and writings on HIV-related stigma is authored by the HIV-negative community of scholars, researchers, and educators. These individuals may arrive at proximity of awareness that resembles that of the HIV-infected community, however, it does not penetrate the visceral and day-to-day human experiences of living with HIV. For this, the lingering curiosity and passion to discover the meaning of HIV-related stigma among myself and my co-researchers, who have intensely experienced this phenomenon, became a priority in my personal and scholarly research trajectory.

The research question, “What is the meaning of HIV-related stigma?” warranted further pursuit.

### **Immersion**

Once the question is formed, the researcher lives with the question in a quotidian manner. This immersion process allows the researcher to arrive on intimate terms with the question; to live it and grow in knowledge and understanding of it (Moustakas, 1990). No attempt is made during the immersion phase by the researcher to purposively organize, collect or explicate the processed information. Rather, the researcher is wide-open taking in all the information possible relating to the phenomenon of interest without sorting, evaluating, or analyzing. This process of indwelling and tacit knowing permits the researcher to remain focused on what is being experienced but not all the constituents necessary to move the research forward are present. Douglass and Moustakas (1985) described that through this continuous self-search and reflection, the researcher shifts into a position of exploring how and where the phenomenon is relevant and how it may be approached to most effectively reveal its components. In the process, a more keen awareness is formed. In summary, Douglass & Moustakas explained that “immersion of this kind is more impulsive than deliberate, more a wandering than a goal, more a way of being than a method of doing” (p. 48).

Remaining consistent with the immersion phase of the heuristic method, I challenged myself to attentively listen to family, friends, co-workers, and peers as they broached the topic of HIV. Perhaps more interestingly, I watched and

attentively listened to these individuals in their interactions with me – realizing that some knew my HIV-status, others perhaps suspected, and others were completely unknowing. Nonetheless, I meshed these experiences together. I did not gather and analyze these details from conversations and body language. Instead, the compilation of details from these more intimate settings merged with my observations and perceptions from the media, such as the television, the radio, and journals. Again, no attempt was made to compartmentalize these occurrences; rather, I allowed myself to let these details remain one large collective piece of information waiting to be examined in greater detail.

### **Incubation**

An intentional retreat from the research question by the researcher in order to transition to another level of knowledge expansion is mandated during the incubation phase. This phase opens the inner tacit dimension of the researcher. The separation from involvement with the research question facilitates the creation of the necessary “inner workings of the tacit dimension and intuition to continue to clarify and extend understanding on levels outside the immediate awareness” (Moustakas, 1990, p. 29). Polanyi (as cited in Moustakas, 1990) suggested that discovery does not ordinarily occur through deliberate mental operations:

The way you reach the peak of a mountain by putting in your last ounce of strength – but more often comes in a flash after a period of rest or distraction. Our labors are spent as it were in an unsuccessful scramble among the rocks and in the gullies on the flanks of the hill and then when



we would give up for a moment and settle down to tea we suddenly find ourselves transported to the top...by a process of spontaneous mental reorganization uncontrolled by conscious effort (p. 29).

During the incubation phase of this study, the researcher achieved a distinct and purposeful retreat from the research question which allowed him to step away from the data on several occasions.

After the first round of data analysis, I distanced myself from the reams of paper which surrounded me for several weeks. This same system of self-distancing from the data after the second round of interviews persisted for several months. Subsequent returns to the transcripts permitted me to expand my original understanding of the data which facilitated the revelation of additional perspectives of the topic as well as novel approaches to the cohesion of the phenomenon. The periods of incubation during the data analysis and writing stages of this dissertation created a space from which the seamless transition into the next phase occurred.

### **Illumination**

During the fourth phase in the heuristic inquiry process, illumination opens the researcher's mind to the vast possibilities of new meanings, revised understanding of unclear qualities surrounding the research question, and a compilation of similar themes which until now had developed in an independent manner. The researcher's previous contemplation, over a period of time, now positions himself in a place to better grasp the essence of the meanings which the

co-researchers shared by becoming more attuned to the similarities and differences (Munhall & Boyd, 2001). Moustakas (1990) explained that this process develops naturally as the researcher positions himself into a state of openness to new knowledge and intuition. Additionally, a clustering of qualities discovered during the data collection phase transforms into a primary theme. Thus, new dimensions of knowledge are released from this experience or awakening from the data.

Further, Moustakas described:

In illumination, it is just such missed, misunderstood, or distorted realities that make their appearance and add something essential to the truth of an experience. The illumination process has been continually recognized in creative discoveries from the earliest thinkers on science and is a key theme in Capra's *The Turning Point* (1982) and in Kuhn's *The Structure of Scientific Revolutions* (1970), (p.30).

During the illumination phase, the researcher returned to the data with an openness to challenge previous findings.

I intentionally revisited notes in the margins of transcripts, reread comments and explications marked in my data documents with color coded highlights which guided me to further points of exploration. This approach allowed me to sit with the data and rework misconceptions, clarify vague and awkward statements within the original work, and finally to reorganize my thoughts and approach to understanding the data. Previously, during the incubation phase, I purposively remained detached from the data in an effort to allow the original findings and thoughts to sprout. The

silent nurturing of the incubation phase fortified me for the illumination phase, in which after episodic mental hibernation, I reemerged with the data and nourished the mental process of expanding and rebuilding. The illumination phase naturally propels the heuristic researcher into the fifth phase, the period of explication.

### **Explication**

After a period of illumination, the heuristic researcher is better positioned to extract, process, and finally explain the various qualities, themes, and nuances surrounding the research question. Moustakas (1990) described “the purpose of the explication phase is to fully examine what has awakened in consciousness, in order to understand its various layers of meaning” (p. 31). The awakening among the heuristic researcher permits the transformation of initial thoughts and identification of various meanings into an organized and processed form of interpretation for the reader. Moustakas further explained that

In the explication process, the heuristic researcher utilizes focusing, indwelling, self-searching, and self-disclosure, and recognizes that meanings are unique and distinctive to an experience and depend upon internal frames of reference. The entire process of explication requires that researchers attend to their own awarenesses, feelings, thoughts, beliefs, and judgments as a prelude to the understanding that is derived from conversations and dialogues with others (p. 31).

The explication phase arose after spending several months of passing through the engagement, immersion, incubation, and illumination phases of the heuristic

inquiry process. The researcher, by allowing and accepting these shifting periods of the research process, emerges with a refined appreciation and understanding of the relevant concepts of the study.

The deliberate attention, which I directed at developing an inward space by indwelling and focusing on newly developed and refined themes in the study, facilitated the creation and exhibition of meanings, textures, and constituents of the phenomenon. According to Moustakas (1990), a detailed depiction of the core themes are identified and the attuned researcher merges together the discoveries of meanings and assembles them into a comprehensive depiction of the experience under study. The next phase entails the creative phase in which the heuristic researcher organizes the various themes of the study in a whole experience.

### **Creative Synthesis**

A thorough familiarization with the data and a detailed explication of the meanings and details of the experience as a whole can now be created by heuristic researchers once they have mastered knowledge of the data which illuminates and explicates the research question (Moustakas, 1990). A creative synthesis, a compilation by the researcher of the vast experiences among the co-researchers, usually becomes represented via a narrative account; however, other modes of this expression may be demonstrated via a drawing, painting, poem, story or some other aesthetic form by the researcher as he creates the study synthesis. Moustakas described that the:

Knowledge of the data and a period of solitude and meditation focusing on the topic and question are the essential preparatory steps for the inspiration that eventually enables a creative synthesis...behavior is governed and experience is determined by the unique perceptions, feelings, intuitions, beliefs, and judgments housed in the internal frame of reference of a person. Meanings are inherent in a particular world view, an individual life, and the connections between self, other, and world (p. 32).

### **Trustworthiness in Heuristics**

By nature of the qualitative paradigm, the issue of trustworthiness or validity of heuristics assumes a unique position. Moustakas (1990) described:

The question of validity is one of meaning: Does the ultimate depiction of the experience derived from one's own rigorous, exhaustive, self-searching, and from the explications of others present comprehensively, vividly, and accurately the meanings and essences of the experience? This judgment is made by the primary researcher, who is the only person in the investigation who has undergone the heuristic inquiry from the beginning formulation of the question through phases of incubation, illumination, explication, and creative synthesis not only with himself or herself, but with each and every co-researcher. The primary investigator has collected and analyzed all of the material – reflecting, sifting, exploring, judging its relevance or meaning, and ultimately elucidating the themes and essences that comprehensively, distinctively, and accurately depict the experience (p.32).

Heuristic researchers position themselves in an approachable state in which they may directly collaborate with the co-researchers. Establishing and maintaining an open and direct rapport with the co-researchers and the significance of their contributions allow the heuristic investigator to move in-and-out of the data in an effort to highlight, share, and confirm study findings. Moustakas explained:

The heuristic researcher returns again and again to the data to check the depictions of the experiences to determine whether the qualities or constituents that have been derived from the data embrace the necessary and sufficient meanings. The heuristic researcher's "constant appraisal of significance" and "checking and judging" facilitate the process of achieving a valid depiction of the experience being investigated. They enable the researcher to achieve repeated verification that the explication of the phenomenon and the creative synthesis of essences and meanings actually portray the phenomenon investigated (p. 33).

As noted by Moustakas:

In heuristic investigations, verification is enhanced by returning to research participants, sharing with them the meanings and essences of the phenomenon as derived from reflection on and analysis of verbatim transcribed interviews and other material, and seeking their assessment for comprehensiveness and accuracy (p. 34).

Another technique to enhance the trustworthiness of such a study entails the involvement of interpretive sessions. This process is most commonly exercised within interpretive phenomenological studies to establish trustworthiness. The introduction of key segments of the research study transcripts with peers who are experienced with the phenomenological method is commonly employed during the data analysis phase. During this study, three interpretive sessions were completed to examine the analytic processes and evaluate the various studies' findings. Three peer reviewers, engaged in qualitative research studies and who had experience with phenomenology, were selected. One reviewer has a doctorate in nursing and has published extensively using the phenomenological method. The two other reviewers are doctoral candidates completing dissertations in the discipline of nursing using the phenomenological method. According to McNiff (2009),

Nothing has been more valuable to me...than the criticisms and suggestions of colleagues....The involvement of other people keeps us focused on how the outside world will respond to our inquiries, how useful our findings will be to others, and how we can frame our results to maximize their influence....The opinions of colleagues are typically the most important indicators of validity...they help us determine whether or not our findings ring true within the context of another person's experience (p. 157).

## Sample

### Selection of the Co-Researchers

Convenience sampling was used to recruit co-researchers from a parent quantitative study conducted at Washington University School of Medicine as part of the researcher's involvement in the Washington University School of Medicine's TL1 pre-doctoral program. The parent study investigated HIV-infection, the role of psychiatric disorders, high risk behaviors, and neighborhood conditions. Inclusion criteria in this larger parent study were HIV-infection documentation, 18 years of age or older, receiving HIV-related medical care at the Washington University HIV Clinic and were not currently experiencing a psychotic episode

This qualitative study used purposive sampling which entails an intentional selection of co-researchers by the investigator constructed upon the characteristics he determines supported by justification for selection to acquire the necessary data for the study (Burns & Grove, 2008). All 200 subjects from the parent study provided documentation that they agreed to be contacted for future studies. Co-researchers for the dissertation study were selected based upon the total score of the HIV-Related Stigma Screener Scale (Reece, 2003) (Appendix A), which was administered during the parent quantitative study. The nine-item Likert-based HIV-Related Stigma Screener Scale measures were pre-tested for validity and reliability and demonstrated a high level of internal consistency ( $\alpha = 0.88$ ) (Reece). Using purposive sampling, 36 participants met this criterion by scoring one standard deviation above the mean on the HIV-Related Stigma Screener Scale.



These 36 individuals, exhibiting the highest degree of HIV-related stigma, formed the sampling frame from which 13 individuals were successfully recruited and agreed to participate in the qualitative study. One co-researcher completed only one interview and was unable to return for interview two due to medical issues. The initial interview with this co-researcher was not included in the overall study data review since the incomplete data from the aesthetic synthesis would be void during the final creative synthesis phase of the study. The remaining 12 co-researchers completed the two requested interviews between September – December, 2009.

### **Sample Demographics**

The co-researchers were black females (n=5); black males (n=5); white female (n=1); and white male (n=1). The ages of the co-researchers ranged from 22-52 years of age; the median viral load of the sample was 61 copies per ml; the median CD4+ cell count was 415; and the median years of living with HIV per documentation in the medical chart was 8 years. Seventy-five percent of the co-researchers were on a HAART medication regimen. Additionally, within the heuristic research model, the researcher (white male) is considered as a study participant as data were collected via the forestructure and is represented in the final creative synthesis.

## **Procedures for Data Collection**

### **Recruitment**

Potential participants were contacted and recruited from the master list of 36 eligible individuals. To ensure a diverse sample, the researcher alternated between female and male names on the list for invitation to participate in the study by a phone call from the researcher. At this time, a brief overview of the study was explained. Upon the verbal expression of the potential participant to willingly learn more about the study, the researcher obtained demographic information regarding the potential participant, including an alternate phone number for contact purposes and a preferred mailing address. The researcher offered to answer any questions pertaining to the study, and received verbal permission to mail a packet to the address of choice verbalized by the potential participant. The study packet included a reminder card for the scheduled appointment and a formal letter to participate (Appendix B). An initial interview (date and time) was offered and agreed upon by both the potential participant and the researcher. Each potential participant was advised that he/she would be remunerated \$40. cash for each visit (Refer to remuneration log – Appendix C). Additionally, co-researchers were advised that travel vouchers (2 tickets per visit) for the Saint Louis Metro-link or bus would be available. Potential participants received a reminder phone call by the researcher 48-hours prior to the scheduled interview.

**Protection of Human Subjects**

This study was approved by Washington University School of Medicine's Institutional Review Board (IRB) on August 12, 2009 (Appendix E). Additionally, the IRB approval from the University of Missouri, Saint Louis was received on September 2, 2009 (Appendix F). Upon the approval of the Washington University School of Medicine and the University of Missouri, Saint Louis' IRB processes, the researcher commenced the study recruitment phase. The anonymity of the co-researchers was respected and protected. Additionally, initial participation, as well as the follow-up interview, was on a voluntary basis. Each co-researcher was at liberty to refuse or terminate the initial and follow-up interview at any time. A pseudonym was matched to the co-researchers' responses in order to maintain their anonymous identities at all phases of the data collection, analysis, and dissemination phases of the study.

**Setting**

For purposes of consistency and the safety of the researcher, all interviews were conducted in the researcher's office located at a separate site away from the Washington University School of Medicine HIV Clinic. Privacy, comfort, and safety for the co-researchers and the researcher were maintained throughout the study.

## **Co-Researcher Procedures**

In accordance with the heuristic tradition, data were gathered from in-depth, unstructured interviews which were essential to understanding the essences of the lived experiences of the phenomenon of HIV-related stigma. The use of interviews as a data collection method is fundamental to health research to ameliorate the understanding of human response to illness (Hutchinson, Wilson, & Wilson, 1994). The richness of the unstructured interview process created a milieu for the co-researchers to not only enter the dialogical engagement process with the researcher, but also to reflect upon the on-going conversation (Hiller & DiLuzio, 2004). Data were also derived from the co-researchers' aesthetic representations of personal experiences of the lived phenomenon. Aesthetic representation refers to the artistic depiction of the phenomenon by the co-researcher. Analysis and interpretation of an aesthetic representation facilitated the researcher with an in-depth understanding of the phenomenon not otherwise gleaned through the traditional analysis of discourse.

All co-researchers were met in the lobby of the researcher's office building. The researcher's office is located on the 4<sup>th</sup> floor of an academic institution in the mid-town area of Saint Louis, Missouri. The interview process consisted of two, 60-90 minute interviews which spanned from September to December, 2009. A minimum period of 30 days lapsed between interview one and interview two. The initial interview commenced with a social dialogue to facilitate discourse. Following this informal exchange, an informed consent form (Appendix D) was

presented to the potential volunteer. Upon answering any questions related to the study, the consent form, and the remuneration protocol, a signature was obtained and the researcher co-signed the informed consent form as well. The co-researcher selected a pseudonym of his or her choice and the researcher explained that for the duration of the taped interviews and the presentation of findings that the pseudonym would be used for reference. Remaining true to the heuristic method, the researcher's task of self-disclosure ensued. In order to truly engage in the heuristic research process, both researcher and co-researchers must initiate a space of community and openness. The HIV-infected status disclosure of the researcher was shared with each co-researcher at the beginning of the dialogical engagement to convey an earnest sense of communal interest to further explore the phenomenon of interest, HIV-related stigma. Speziale and Carpenter (2003) reinforced the importance of trust between the researcher and the co-researchers to establish a zone of safety and comfort, which is amenable to securely revealing information between two individuals.

After selecting a pseudonym, the digital audio recorder, an Olympus WS 100, was started and tested for audibility. Next, the unstructured interview started. At the conclusion of interview one, the researcher further explained that for interview two, the co-researcher would need to create an aesthetic representation of living with HIV-related stigma. The researcher offered that this artistic creation could take the form of a drawing, a small picture, a photo (with no identifiable persons, basically an object or setting), lyrics to a song, a poem, excerpts from a journal or personal diary. After answering questions pertaining to interview two,

the researcher and co-researcher scheduled interview two. Finally, the researcher thanked the participant for sharing his or her story, provided the participant with the remuneration and travel vouchers and secured a signature on the remuneration log. Field notes were immediately written following each interview, and the audio recordings were transcribed into a secured computer database by a professionally hired transcriptionist. After each interview, the researcher conducted a journaling session alone in his office to express his feelings about the interview and the data collection process. These reflections and notations were maintained in a reflective journal for the duration of the study.

During interview two, the same system applicable to interview one applied with the exception of not obtaining additional consent as this was not necessary. The researcher used member checking to verify, clarify, and confirm details from interview one. Next, the researcher asked the co-researcher to share his or her aesthetic representation of the lived experience of HIV-related stigma which is discussed in detail in chapter four. At the conclusion of interview two, the co-researchers' aesthetic representations were obtained by the researcher and placed into an acid-free plastic sleeve for protection.

### **Data Storage and Retrieval**

Data were stored in two separate locations which were only accessed by the researcher. All transcribed interviews, consent forms, remuneration logs, aesthetic representations, researcher field notes, and researcher journaling were locked in a cabinet behind a locked office door. Transcribed data were stored as Word

documents and the participant master list was stored on an Excel spreadsheet on the researcher's password protected and locked private computer stored behind a locked office door. Only the researcher had knowledge and access to the computer as well as the password protections.

### **Data Analysis**

The data generated from the interviews were “to understand the worldview of the interviewee on the theme of the research” (Hiller & DiLuzio, 2004, p. 4.). The data were analyzed using Moustakas' heuristic analysis method. According to Moustakas' method, “transcriptions, notes, and personal documents are gathered together and organized by the researcher into a sequence that tells the story of each research participant” (1990, p. 49). Mandatory to the operation of heuristic analysis is thorough knowledge of all materials from each co-researcher and for the group of co-researchers collectively (Moustakas). This engagement requires timeless immersion within the data, with periods of retreat and return to the data until exhaustive knowledge is achieved (Moustakas).

The first step in the heuristic data analysis process, the researcher initially read each verbatim transcribed text in entirety to attain an overview of the interview. The next step in the data analysis phase, the heuristic researcher returned to the text with field notes and began the process of isolating striking themes and patterns which emerged from the first interview by flagging relevant sections of data and utilizing a color-coding system to cluster relational themes from the transcripts. According to Smith, Flowers and Larkin (2009), “themes are

usually expressed as phrases which speak to the psychological essence...and contain enough particularity to be grounded and enough abstraction to be conceptual....the themes reflect not only the participant's original words and thoughts but also the analyst's interpretation" (p. 92). The researcher engaged in the same process of working with the data following the second interview as outlined above with the first round of interviews. A crucial step in the heuristic data analysis process requires that the researcher positioned himself within the data, retreated, revisited the data with a newfound openness, and retreated again with the intent to create individual co-researcher narrative portraits. This series of back-and-forth within the data is a hallmark of heuristic inquiry.

During the next phase of the heuristic data analysis phase, the researcher created a narrative portrait of each co-researcher's record. The goal of establishing individual narrative portraits allowed the researcher to identify exemplar narrative portraits for further scrutiny and expansion. The exploration of the aesthetic representation presented by each co-researcher facilitated the immersion of the researcher into the data in a non dialogical manner which allowed the researcher to approach the data from multiple angles. Moustakas (1990) described that from the aggregate of "individual depictions a *composite depiction* of the experience is constructed....Through immersion and analysis of the individual data, two or three *exemplary portraits* are developed; profiles that are unique to the individuals yet characterize the group as a whole" (p.50). After careful review of each narrative portrait, the researcher identified two exemplary portraits which contained recurrent themes found within the group for further presentation in chapter four.



The final step in the heuristic data analysis process involved the development of a creative synthesis, “an original integration of the material that reflects the researcher’s intuition, imagination, and personal knowledge of meanings and essences of the experience...the experience as a whole is presented, and unlike most research studies, the individual persons remain intact” (pp.50-51). During the creative synthesis, the researcher reflected upon each individual narrative portrait, isolating a core essence of the individual that would be reflected in the collective portrait of the group as a whole. Approaching the data from an individual piece and building into a collective piece reclaimed the hallmark of heuristic research in which the fragmented individual retained his/her uniqueness that was further represented as an essential piece of the whole as the researcher developed the creative synthesis, the collective portrait of the entire study group. The creative synthesis is presented in detail in chapter five.

### **Strengths of the Study**

The strengths of using a heuristic research model, nested within the phenomenological approach for this study, was in its ability to explore a vast array of dimensions within the social world, including the fabric of everyday life woven into the deep understandings and experiences of the co-researchers. The heuristic research model allowed an opportunity to capture and celebrate the richness, detail, nuance, and complexity of the phenomenon that cannot be neatly “pigeon-holed and reduced to a simple and prescriptive set of principles” (Mason, 2006, p. 3). Additionally, this methodology allowed the passionate quest for illumination of the

unknown and the intensity of engagement through evolving levels of meaning through the unfolding of experiences (Moustakas, 1990). This study will give health care providers the possibility to gaze into the lives of HIV-infected persons through the lens of this population as well as hear the voice of an HIV-infected researcher.

A second strength of this study was the use of multiple interviews. Smith and Glassner (1997) explained “research cannot provide the mirror reflection of the social world that positivists strive for, but it may provide access to the meanings people attribute to their experiences and social worlds” (p. 100). The understanding of living with HIV-related stigma was reinforced by the interactive component of interviews. The use of multiple interviews further strengthened the exploration of a deep mutual understanding of the phenomenon. In order to construct the milieu for the cultivation of an authentic and shared experience, a relationship with the co-researchers was imperative. This setting was achieved by allowing the co-researcher to interface with the researcher on more than one occasion in an unstructured dialogical engagement manner. This approach of multiple interviews allowed the co-researchers to immerse themselves in “conversations with a purpose” (Burgess, 1984, p. 102) as opposed to the traditional rigidity of other interviewing techniques using interview guides during a single interview. Multiple interviews also enhanced the verification of data by returning to the co-researcher with essences of the phenomenon which was derived from the researcher’s reflection of the first interview as well as the verbatim

transcribed interviews. This assessment quest facilitated the comprehensiveness and accuracy of the data (Moustakas, 1990).

A third strength of this study was the incorporation of three individuals into the reviewing and verification phases of the data analysis. The interpretive sessions served as an attempt to verify themes anchored within the exemplary portraits. The utilization of other qualitative researchers during this phase of data analysis permitted the voices of the “outsiders” to validate existing themes within the text as well as to offer insight to the researcher of other possible emerging essences within the text. These shared interpretive sessions assisted in reducing potential interpretive biases which may occur when data are analyzed in a solo setting. According to Pohlman (2005), the rigor of data analysis can be enhanced by the use of interpretive sessions.

A fourth strength of this study was the voice, lived experience, and membership to the HIV-infected community by the researcher. The importance of how an interviewee responds to the researcher is based upon who we are. The outcomes of social or membership distancing may lead to interviewees not placing trust in the researcher, the inability to understand the questions posed at them, and they may purposively mislead the researcher in responses during the interview process (Smith and Glassner, 1997). Further, Smith and Glassner explained that “given a lack of membership in their primary groups, we may not know enough about the phenomenon under study to ask the right questions” (p. 101). Thus, the researcher’s voice, personal disclosure of HIV status, and full membership within

the lives of the co-researchers enhanced the setting to permit the co-researchers to share intimate pieces of their lives in a meaningful and enriched manner.

### **Limitations of the Study**

Several potential limitations were identified within this study. The small sample size for qualitative studies is not uncommon and actually necessary to gain depth and insights (Pohlman, 2005). Heuristic research produces explanations and comparisons which are generalizable and have some degree of a demonstrable wider resonance (Mason, 2006). This study used a specific purposive sampling plan which had direct implications for how generalizability is possible. This study represented a small sample of co-researchers, yet the co-researchers formed a diverse set of individuals including African American and Caucasian men and women from a range of ages, heterosexual, bisexual, and homosexuals. Though this representation does not infer that the study findings can be generalized out to the population of all HIV-infected persons, the sampling plan does lend to comparing and contrasting the multiple and diverse voices heard by all co-researchers in an effort to guide healthcare workers in approaching and managing HIV disease from a multi-faceted approach based upon these demographics.

A second limitation of this study was the nature of the interviews. Co-researchers were requested to provide details from the past. The retrospective nature of this study required some co-researchers to recall experiences from many years ago; other co-researchers had received an HIV diagnosis more recently and thus were able to recall a potentially more rich and accurate account of their

experience. Interestingly, this variance in years of living with HIV allowed the researcher to capture a broader view of living with HIV in terms of longevity and experiences of living with HIV and the subsequent perceptions and internalizations of HIV-related stigma.

**CHAPTER IV**  
**STUDY FINDINGS**  
**Exemplary Portraits**

**Overview**

This chapter describes the exemplary portraits and the primary themes derived from the data. The presentation of the findings of a heuristic research study requires the use of exemplary portraits. According to Moustakas (1990),

The researcher selects two or three participants who clearly exemplify the group as a whole. The researcher then develops individual portraits of these persons, utilizing the raw data, individual depictions, and autobiographical material that was gathered during preliminary contacts and meetings, contained in personal documents, or shared during the interview. The individual portraits should be presented in such a way that both the phenomenon investigated and the individual persons emerge in a vital and unified manner (p. 52).

Two exemplary portraits are depicted in chapter four. Each portrait represented in this chapter contains themes identified by the researcher during the data analysis phase in which the data (narrative and aesthetics representations) of the twelve co-researchers were individually and reflectively examined. In an effort to maintain an accurate account of all twelve co-researchers as individuals while identifying essential themes representative of the group as a whole, the researcher revisited each narrative and aesthetic portrait repeatedly until the core themes were captured. Each of the twelve co-researchers contributed rich data which were extracted and woven into one collective

portrait. Inclusion of each co-researcher into the final creative synthesis in chapter five ensured that all 12 co-researchers' voices were heard as they shared vital essences of experiencing internalized HIV-related stigma during the interviewing process. The researcher's narrative portrait is considered the forestructure of the study. To ensure that my self-portrait would not be influenced in any way by the selected co-researchers, I conducted my own interview with myself via the constructed forestructure of this study prior to initiating any interview with the selected co-researchers during this study. Additionally, as each co-researcher would not have access to any other co-researcher's interview, it was the researcher's belief that it would be inappropriate for me to have access to the co-researchers' interviews before completing my own portrait.

As I began the process of writing the drafts which culminated into the two exemplary portraits and the thematic analysis, which is a requisite of the heuristic research model, I followed MacIntyre's (2010) editing process in order for the text to read more like a story. MacIntyre advocated that the researcher may take "the liberty or rearranging and editing the participants' statements...into a story that will be more coherent to the reader. Listeners are more forgiving than readers because they can always interrupt to ask questions" (p. 260). I left the linguistic style of each co-researcher intact and did not correct grammatical errors or hide expletives; however, I did eliminate repetitive statements which may have otherwise slowed the rhythm of the text. Additionally, I added antecedents when pronouns were dangling within the text and refrained from an over usage of parenthetical additions which may have altered the pace of the reader. The following stories are based upon actual statements provided by the co-researchers and me during the dialogical engagements.

## Exemplary Portrait One: Tee

### Introduction

Gazing out my office window, a beautiful autumn morning sets the backdrop for the first interview with Tee. A radiating sun painted my face as I drove to the office on this Saturday morning. I recall a sense of impending closure within myself as I pondered the recent interviews with my fellow co-researchers. Tee arrived at my office and we completed the formalities of small talk and preparing for the first interview. I met Tee earlier in the summer when she completed a battery of computer inventories as part of a larger study at a large HIV Clinic in St. Louis, MO. Tee, a heavy-set Black woman, arrived in faded jeans and a sweatshirt splattered with bleach stains and rather oversized. She appeared to be swimming in a tattered top that clearly allowed her to move comfortably; she is a rather animated woman who chooses to speak not only with her voice but her body as well. Tee is a single-mom, 23 years old, and employed. She has three children (fathered by two different men). Tee has a pleasing voice to the ear, making her interview a true joy to engage in; her passion for life, her children, and “making it” stood out very early for me during the interview processes. She freely talked about her childhood in the rough neighborhoods in a city that splits between the north and south boundaries of St. Louis. Tee, though removed from her childhood neighborhood of gangs, drugs, and few rules, remains in the North side. She lives in a 2 bedroom apartment with her three children and her current boyfriend (the father of her two youngest children). Today, Tee has the sniffles and a bit of a cough; I offer her a box of Kleenex, which she places on the desk in front of us. She shares that she is recovering from a bout with pneumonia and that her ears are a bit plugged; she laughs and mentions



that I may have to speak loudly and she may seem to shout because she cannot gauge well the strength of her own voice. We both laugh and I probe about her overall health as a nice transition from her previous comments. We sit next to one another and begin the journey into Tee's world of living with HIV; both of us with a nice view of the blue sky serving as a constant reminder that we are survivors of this disease. I get a sense that when our eyes meet, they dance with joy with intermittent lulls of pain, silence, and exhaustion as we speak about HIV, our lives as two individuals living with this, and how the perceptions felt by the blows delivered in a world beyond the safety of this office serve as a constant reminder of the realities of this illness.

### **The Journey Begins**

I: Well, refresh my memory, when was the date that you were diagnosed [with HIV]?

Tee: I want to say when I found out I was pregnant with her [Tee's youngest child], because she was born in '07, late '06. I went to the doctor; I thought I had a bladder infection actually.... I need to go get that checked out and get some antibiotics. So I go to the hospital and do the urine test, you know, and I waited on my results or whatever, and the lady comes in and she brings in another lady.... and it was like we have some good news and some bad news, which one do you want first? I'm like I don't know, the bad news, and that's when they said [HIV-positive diagnosis], I'm like what? I freaked out....I freaked out, I freaked out, I was crying and screaming and then, I don't even know when they told me I was pregnant. I'm like oh my God, I thought it was the end of the world, I did.

- I: Now did they tell you that you were pregnant that day too?
- Tee: Uh huh, the same day.
- I: So you got all this news the same day?
- Tee: Yes and I was ready to just drop dead, you know, not drop dead for real but just pass out, like are you serious? You're telling me this and I'm pregnant, I don't want neither one of them. You know what I'm saying? That's how I felt.
- I: How did you pick yourself up from all of that, to get yourself home?
- Tee: I sat there for a while, just boo hooing. They left the room and said I'm gonna give you time to yourself...come back in, are you okay? 'No, I'm not okay, no'.
- I: You said one other thing that was interesting to me...that the physician that was there wasn't real nice. What was that reaction?
- Tee: I don't know if she knew the results, kind of like a mama figure [the physician], pretty much what she was because she was like bladder infection? Are you having sex, do you use protection? I'm like...you know, I just didn't like the way she came to me.
- I: Okay, because this is the first time you had met her and she's coming right at you like that?
- Tee: Mm hmm, and she pretty much pissed me off, you know.
- I: Right.

Tee: And that's how, do you use protection, why don't you use protection? I'm like ugh, get out of my business is what I wanted to say, you know, I didn't want to hear it. So that's why I'm like she's like a mama, because you know, you suppose to use protection...and that's what she was doing. That's why I said she was kind of mean, you know, just...the way she came to me, because she shouldn't have came to me like that, you know.

I: She leaves, you're in a room by yourself processing all this.

Tee: Pissed.

I: So what happens?

Tee: Just ready to pass out, and now it's time to go home.

I: Right.

Tee: I'm like it's time to go home, I don't know who at my house, I need him (her boyfriend) by his self, so we can talk openly about what I just found out. Oh my goodness. But, I don't think I did it [the discussion] until later on that day.

The radiating, surreal feelings of receiving an HIV-positive diagnosis are shattering. As Tee describes, her world is falling down around her; she feels like the world she knows has abruptly ended, coming to a screeching halt. Coupled with a feeling of isolation, aloneness in a time when warmth, security and comfort are most needed. Tee offers a common snapshot of receiving HIV-positive news from a healthcare worker who has not been sensitized to the psychosocial needs of an individual receiving this information. Tee

has been reduced to numbers and lab values on a piece of paper from the laboratory. The coldness and precision flows from paperwork to human offering a chilling account of Tee's story of learning about her HIV diagnosis. According to Bird et al. (2004), research indicates that HIV-infected patients' perceptions of care received by health care providers have serious implications for their health and follow-up care. Zukoski and Thorburn's (2009) study confirmed Tee's personal experience, "most commonly participants talked about intrusive questioning and rude treatment by providers" (p. 271).

### **Searching for Answers**

Disbelief rapidly succumbs to anger and anxiety immediately following the devastating news of an HIV-positive test. Alonzo and Reynolds (1995) reported "the individual must struggle with issues concerning the meaning and consequences of their HIV status in terms of managing its potential discovery and orchestrating its disclosure to family, friends and relevant others" (p. 308). Tee's newfound discovery of HIV bounding within her leads her to the juncture that all HIV-infected persons must face: When did this happen? How did this happen? For Tee, the quest for answers is short-lived. Immediately, Tee's mind is drawn to her current boyfriend; anger mounts and merges with feelings of betrayal. Only one path is highlighted for Tee during this period of post HIV status confirmation. She plays the scenarios of confrontation through her mind as she journeys from the hospital to her apartment. A myriad of feelings flood her mind but her decision to confront her boyfriend does not sway.

I: Did you know how this happened?

Tee: It had to be my partner.

I: Were you already putting the pieces together in your head?

Tee: It had to be with the one I was with, because I don't do drugs, because you know, they say it's through drugs or sex. I don't do drugs, needles, I don't do none of that, so it had to be from him.

I: So you had to get yourself home and talk to him.

Tee: Mm hmm.

I: Was he home...?

Tee: Yeah, but my older daughter was around, so I'm like I have to wait until me and him is alone, go out riding around town or something. I was crying...we had to go over his mom house, I remember that, and I'm in the car just boo-hooing, just boo-hooing. 'What's wrong' [asked her boyfriend]?....There was so much water everywhere, I was so hurting. He kept asking, and I'm like 'I'll tell you later'.

I: Okay, so you're just crying and those two [boyfriend and oldest daughter] are in the car?

Tee: And she's [Tee's oldest daughter] like mama, 'what's wrong?' 'Nothing, don't worry about it'. Boo-hooing, boo-hooing....Tee, 'tell me [Tee's boyfriend] what's wrong' and I was like oh my God, I'm about to kill somebody, I want to kill somebody, but I was talking about him, and he didn't know it. I kept looking at him while he was driving, he's like 'what'? I was just rolling my eyes, ooh, dirty

looks, you know. 'What's wrong, tell me, why you keep looking at me like that?'  
'You'll find out'.

I: So you finally get home and you're able to talk to him or how'd that play out?

Tee: I want to say we was at home in my room....I was like 'so, you know I went to the doctor right?' And he was like 'right, what did they say?' I was like so I don't know where to start. I was like I think I told him I was pregnant first.

I: And what was his reaction to [you] being pregnant?

Tee: Shocked, shock out of this world....He went to the doctor like a day or two before me, for what reason, what was wrong with him? A regular check up, you know how you go once a year or whatever. He went for a regular check up and I think that's when he found out [about his HIV status].

I: Two days before this was all happening to you?

Tee: A few days, maybe not two but a few days before me. Sometime in that week he had went but he didn't say anything....I noticed him acting a little strange but not too much, and I kept saying 'what did they say, what's wrong, why are you looking all down?' You know what, and I also found out that I had Chlamydia too. When the doctor told me about [the HIV], I found out I had Chlamydia as well. Yeah, I forgot about that part. So, he knew he had Chlamydia. I guess he was scared to say something. So I'm like 'so, what did the doctor say'? He was just quiet. I'm like 'what did they say?' By that time I knew I had HIV, I knew I had Chlamydia, that's a lot.

I: And you're pregnant. That's a lot, Tee.

Tee: So that's why I was about to bust [later that same night]....I was at work. He had a lot of guys over [to Tee's apartment], all I hear is music and talking so I'm like you need to leave them, talk to me and tell me what the doctor said, but I guess it was so deep to where he couldn't because he had company....I was like 'what did the doctor say?' He was just quiet, I was like 'leave them and go in a quiet room and tell me what's up', and I slipped up and was like 'yeah, I found out I got Chlamydia' and he was like 'yeah, that's what they told me too', and I was mad at myself because I think he was gonna tell me [about the HIV]....So later on we got together and we get home and I'm just like....So, 'what else the doctor say'...I'm ready to get it [HIV disclosure] over with, and he's like 'they told me what they told you.' 'No, what did they tell you?' He's like 'I got Chlamydia', okay, I'm like he knows more because of how he was acting. It was deeper, I could tell, he's scared, he don't know how to say it. I want him to say it. What do I do to get him to talk? So I'm whatever and say 'I won't be mad, just tell me and we can go from here.' That didn't work, I was like 'you need to tell me what they said because if it's something deep I need to know about it.' I'm just trying to let him know I know.

I: Right.

Tee: I'm like, 'if it's something bad, tell me.' He's just like 'they told me what they told you.' That ain't it, so I'm like 'I won't be mad, I promise you I won't be mad, just tell me, you know, I need to know.' It took hours, hours and hours, so I'm

like okay, let's have sex, you know, 'come on, let's do it. Come on let's do it and then after that we can talk about it', and that's what did it. He was like 'no, you ain't gonna do that with me no more.' I'm like what, what you mean? He was like 'that's the reason.' I'm like 'huh?' You know, I heard it, but he was mumbling. 'What'd you say?' He's like 'you ain't gonna want to'...I'm like 'come on', I'm laying on the bed, I'm like 'come on', you know, just trying, I knew it was coming so I'm like yeah, he's gonna talk.

I: You're making progress.

Tee: Mm hmm, I'm like yeah, 'come on', I wasn't even in the mood, I didn't want nothing. I'm trying to figure out how to get him to talk. 'No' [Tee's boyfriend states], 'you ain't gonna want to do nothing with me no more.' 'What, what are you saying? I already know I got Chlamydia, come on, what's worse than that?' 'It's a lot worse' [Tee's boyfriend states]. 'What? Tell me, what's wrong?' 'I don't know how to tell you, Tee.' 'Just tell me...it's something, I ain't gonna want to have sex with you no more, what?' And he just sat there quiet. 'You gonna hate me, you ain't gonna want to talk to me no more, you gonna make me leave and I can't come back.' 'Come on boy, tell me what's wrong with you'....He's scared out of this world, he don't know how to say it, so I'm sitting there.... I can tell he's knotting up, he's scared. I'm like come on, 'I'm telling you now, it won't be as bad as you think it is.' That's what I told him, cause I knew, we got to deal with this together.

I: Right, absolutely.



Tee: So I'm like okay, let me calm down. 'Tell me, I promise you it ain't gonna be as bad as you think it is, I just want you to tell me, come out with it.' 'Tee, I went to the doctor, they told me I had Chlamydia and they told me I had HIV.' I said 'what?! You got what?!' I'm just playing like I didn't know, I had to. I don't know what's wrong, I had to go there.

I: Right.

Tee: I'm just cussing him out and I bust out crying again because it's out.

I: Right.

Tee: So I'm crying....I guess we was home alone. And I'm just crying. So, I'm like okay, I got that over with. Now I want him to come back and talk to me, so let me calm down. I called him, I was like 'come here.' He's telling me he never been with a guy, and he don't do drugs, so it had to be his sex partner. Actually, I don't know if I believe that.

I: Why is that? What makes you feel that way?

Tee: He smoke weed a lot, he drink here and there, I'm just curious have he ever done [IV] drugs....I'm just like, so he told me he got it from a girl, that's what I was like, can girls give that to guys? I'm like can girls do that, I don't think so. So, that's why I was like girls can't give it to guys, guys give it to girls.....And I'm like 'you sure you've never been with a guy, you're sure you've never done drugs?' 'I promise you, I promise, I ain't never did either one of them.' 'How

you get this then?’ ‘It had to be from her’, and I drilled him, drilled him. Same questions over and over, I need the truth, he stuck with his answer.

I: And that’s all that you can go with.

Tee: I mean so we talked about it [HIV] and so now what? He’s like ‘I ain’t going nowhere, I’ll be with you and this and that.’ I’m like I’m screwed, I can’t be with nobody else, because you have to tell this person before you be intimate with them. Ain’t nobody want to hear that, it’s over [potential intimacy with anyone else].

Tee’s quest for knowledge and honesty about acquiring HIV marks a shift in her emotions. She picked herself up at one of the most vulnerable moments in her life and charges forward with an earnest need to know, to understand what is happening around her in a world that resembles little to yesterday. Adapting to the reality that she is an HIV-positive woman resonates loudly along this path of questions. She vacillates between spaces of dark loneliness to spaces of energy in search of enlightenment. Tee’s account reaches the goal of knowing as she learns about her boyfriend’s news; however, the powerful conclusion to this dialogue arrives at an even darker reality which she now confronts her perception that life is over. She is “damaged” and no one is going to want to hear this or want her. Her story arrives at a point of isolation and being stuck.

Pachankis (2007) reported that “much research attests to the importance of self-disclosure for the development and maintenance of close relationships” (p. 336). The disclosure of Tee’s boyfriend attested to the first step in keeping the relationship with Tee intact – a relationship which Tee believes is her only option now.

### **Coping/Adjusting with HIV in Everyday Life**

The possibility of intimacy with another person is shattered. She alludes to a feeling of being stuck; even if she wanted to leave her current boyfriend, she asked herself who is going to want her? The notion of being stuck firmly plants Tee into a zone of fear. The potential rejection upon disclosing her HIV status to a future sexual partner becomes highly charged with emotional anxiety. Tee sees no option but to remain in a relationship with her boyfriend since the fear of HIV-based rejection is now non-existent. Ortiz (as cited by Sterken, 2010) described that “where a partner has become infected as a result of a relationship outside of the established relationship, disclosure becomes laden with other emotionally charged issues and may significantly impact intimate relationships” (p. 212).

I: Do you feel like you stayed in this relationship out of comfort, out of security, because you don't want to deal with starting it up with someone else?

Tee: Sometimes, yeah, yeah. I'm gonna be honest.

I: And why do you feel that way? Is it just like what you said, because you've got to...

Tee: I got to tell them, they gonna run I believe. They don't want to deal with it. Plus, okay now I done told my business to this person, this person gone, who's he talking to? I don't want to deal with that, I really don't.

I: You mean so who else is he out there telling?

Tee: Mm hmm.

I: After you told him, he runs away, and now he's telling everybody?

Tee: Mm hmm.

I: So it's just easier, you've taken the stand not to tell anybody.

Tee: And deal with him.

I: Just stick with the original.

Tee: Pretty much, that's how I feel. I met a guy recently, I gave him my number and he want to get with me but I just quit calling, quit talking to him.

I: Do you think it's because it comes to a certain point, like you talk and you flirt and then it's to the point that you've got to do something and if you do something....

Tee: Yeah, because the talk was good. I'm like oh gosh, I don't want to cheat on people, I've never been there, but it was exciting that someone was trying to hit on me, and it felt good.

I: Yeah. Well tell me about that feeling...how did that make you feel?

Tee: I felt good. I felt like, I don't know I felt higher than where I am now. Like I'm here, just say I went to here [points up in the air]. You know what I'm saying, I felt good. I'm like oh, okay.

I: Like you still got it [attractive to men]?

Tee: Right. I'm like cool, it made me feel good. He's like can I get your number? I'm like yeah, it's just something to do. I ain't gonna go out and mess with nobody.... The guy been calling, calling, I'm like oh, he getting on my nerve.... He's talking about sex. It was a turn off kind of, you know. It was exciting, then it got to be a turn off.

I: Well how are things today with it [life with her boyfriend] though, like the last couple months, the last several months? Are things better?

Tee: Yeah, yeah because we're on a whole other level. We don't dwell on it...I mean my heart is where it is though. Even though he...get on my nerves all the time, I want him gone, but he's the father of two of my kids. It's hard.

I: And then also, you said before that part of it is also...

Tee: I don't want to start over.

I: If he's gone, you've got to start all over...

Tee: I don't want to.

I: So sometimes we just get into a comfort pattern and that's kind of what I hear?

Tee: Pretty much.

I: Is it [comfort pattern] related to the HIV?

Tee: Uh huh.

I: If you were HIV negative, do you think you would've stayed around Tee?

Tee: No...I ain't gonna say I need sex, I want sex. He, I can do whenever, whatever. Somebody else, I have to start from scratch, tell them what's the deal. I don't want to.

I: You don't want to go there?

Tee: No.

I: And the reason you don't want to go there is because, you said before...

Tee: They might run, and I don't know, they might talk. I mean the person, whoever I meet, I don't know them, but I don't know who he [potential new boyfriend] knows. My name gets out there and guess what?

I: Right, your whole life history is out there.

Tee: Yeah.

I: What else is on your mind about this?

Tee: So that's what I go through right now, yesterday, today. I think about it all the time.

I: About being infected?

Tee: Yeah.

I: Does it consume a lot of your time?

Tee: No...Every, on and off.

I: How do you feel from it?

Tee: Only I guess when I really want to move on, as far as relationship wise, that's when I really dwell on it.

I: If you could move on and meet someone else...

Tee: Yeah, that's when I really trip off it.

I: And the HIV is really what's holding you back?

Tee: Yeah, very much so because I don't want to start over, and I tell him all the time, we get into it oh, it's time for you to go....I'm tired, I'm tired. I'm comfortable. If I were negative, yeah, because that's what's stopping me, or slowing me down, is the HIV because I don't want to tell nobody about it, but if I was negative it would be a different story. I'd have somebody else or by myself, but still I have friends.

I: But is it a physical tired or is it just a mental fatigue?

Tee: It's mental. I'm tired of his bull crap. I'm tired of him, he don't have a job so I'm taking care of five people on my one income, I'm tired. I'm ready to move on. I want to but I'm not going to, because of the HIV, I'm not. I'm not going to start over.

The sense of striving to reclaim a sense of normalcy within Tee's life is an overarching quest which ranges from dating to maintaining a healthy relationship with another person.

Tee's resolution to remain in a relationship for reasons of comfort and avoiding

disclosure with the “other” is a reverberating topic among HIV-positive persons facing a daunting dating world. This attachment to what is known as safe in her world reinforces her yearning for stability and control in a life that is spinning out-of-control. The weight of concealment is crushing Tee. Alonzo and Reynolds (1995) reported that “by concealing one’s HIV status, the individual attempts to protect his or her self-esteem...but there may be other negative consequences in doing so....it is emotionally exhausting” (p. 309).

### **Keeping the Secret**

I: Do any of your friends know about your HIV?

Tee: Nope.

I: Like your girlfriends?

Tee: Nope. So my boyfriend and his mom. That’s it, and my doctors....Nope. I want to tell a couple of close friends but...(silence).

I: Well what’s keeping you from it?

Tee: Same thing as my mom, scared...friends, I’m scared they’re gonna tell somebody. My mom, I don’t think she’ll tell nobody.

I: She’ll keep it confidential?

Tee: I believe so. Friends?

I: You think the girlfriends would do that to you?



Tee: This one I don't believe would talk but you never know....There's one I really think I can tell, I don't think I have to worry about it, but she might be like I got a friend, she might not say my name, but...

I: So once again, it's still just keeping yourself protected?

Tee: Yeah, and that's why if I have the choice I will never tell, but his [boyfriend] mom's telling me you need to tell your mom, what if something happens, you need to tell. I'm like no, I don't want to. She's like you need to talk to somebody, so that's why I called my (case) manager to get a person to talk to....We're (Tee and her mother) just to yourselves mainly. I don't know.

I: Tell me more about how you feel about talking to your mom about this.

Tee: I want to say a couple of weeks ago. I don't know, just, I think I was having a bad day, everything was going wrong and I don't know.

I: Was it related to living with the HIV at all, were you feeling down about yourself on that?

S: No, just life, just....I think I needed somebody to talk to and I didn't have nobody to talk to. I don't know, I just felt down.

I: What about your girlfriends, why didn't you call one of them?

Tee: I just kept quiet and just sitting there angry and upset.

I: Have you ever thought about meeting someone else...who has HIV?

Tee: I don't know how to go about that. I've thought about that, I would like to....Oh, if I could meet somebody that's already in the situation I'm good.

I: There's support groups for men, support groups for women, do you ever go to any of those for the women?

Tee: No.

I: Have you thought about going?

Tee: Uh uh...I don't want nobody to know.

I: But everybody in that room is in the same situation.

Tee: I know but what if I see somebody there I know?

I: Then you would talk to them, no?

Tee: I'm scared, because they might go off, 'guess who's in this meeting.'

I: So you can't...

Tee: I'm scared, I'm scared. Like right now I want...I need to go to a meeting to meet people. I would like to but I'm scared.

The cost of hiding is enormous. The pain and uncertainty of not knowing how or with whom to share the HIV status weighs heavily upon Tee. The emotional and mental anguish that accompany this uncertainty and fear may lead to increased anxiety which will accelerate an already overtaxed immune system. Tee's feelings of being scared are common among HIV-positive individuals. The act of balancing two lives – the life that

Tee lives and the life she projects to others – eventually becomes overwhelming. As I referenced in my own personal forestructure, the constant self-protective mode of information balancing results in feelings of exhaustion and confusion among many HIV-positive individuals. Pachankis (2007) described “the negative psychological consequences of concealing a stigma may lead to poorer health. The stress of inhibiting emotional expression has been shown to lead to negative physical health consequences” (p. 341).

### **Tee’s Poem: A Self-Portrait of Words**

Tee chose to write a poem (Appendix G) for her second interview, the aesthetic component of the research study. She shared that this was a struggle for her to reach deep within herself and even write the words H I V. Self-reflexivity permitted Tee to visit places where many persons, who have processed or are still processing an HIV diagnosis, hope to not return. As mentioned in my forestructure, this is commonly a place of darkness and despair. Once the HIV-infected person has crossed the initial line of shock and bewilderment of such a diagnosis, the hope is to move forward and not look back. Reflexive writing, however, permits the author to return to this space, discover unhealed wounds, reflect, and move forward. As Tee shared her experience, tears of joy and a sense of accomplishment rewarded her bountifully as she concluded her writing experiment. This was a moment that Tee will savor as she moves forward as a woman determined to survive the struggles of living with stigma attached to her HIV illness.

I: Well Tee, last time I asked you to bring something [aesthetic] in, what did you bring today?

Tee: I wrote a little song...how I feel...I don't know if it's a poem.

I: I'm going to have you read it to me and then we're gonna walk through...how you put this together and why you put it together.

Tee: All right. It says, 'living with HIV hasn't been that much of a challenge for me. Well I try to put it in the back of my mind so I don't cry all of the time. I wish I could just flow like the wind, but I can't, I have to keep it all in. I wish I was regular again. What keep me going is my family and kids, the faces that I look at every day, but often I have to sit down and play to make the pain go away. Well I try to live my life the best way I can and often I'm on the go, but I always think of HIV as it's just a blood flow.'

I: I think that's beautiful.

Tee: I've never done anything like this before...EVER. I was so proud of myself, I read it, I'm like, oh, I started crying. It's like, just me, this is how I feel.

I: Tell me how you built up to doing this. How did you get to the point of where you put the pen down on the paper and started writing?

Tee: Because I'm like okay, I need to express, I was like okay...he [interviewer] said how do I feel about living with this [HIV], and I was just thinking about what you said and I was like where do I start? So I just left the room and went in my bedroom, I needed peace and quiet, you know, got the paper and pens. I was like okay....I was just getting nervous.... it's like the question was living with HIV, so I started off with living with HIV, okay how is it? I try and put it in the back of

my mind, which I do because I don't want to think about it too much. So that's why...I try to put it in the back of my mind so I don't cry all the time, because if I keep thinking about it, I'm gonna get upset...why me, why me? You know, and I will cry. I'm so easy to cry.

I: And that put you in a place [thinking about HIV] where maybe you don't want to be all the time?

Tee: Exactly, and I do from time to time, I do. And like I say, I put it in the back of my mind so I don't cry all the time. I...wish I could just flow like the wind, you know how the wind just goes, I wish I could be like that sometimes, but I can't. I keep it all in because I don't want to be out there like that.

I: But do you think that that sort of goes back to that first line about, it really hasn't been much of a challenge because you're keeping it all in?

Tee: Yeah, I believe so, but I'm just scared....and I wish I was regular again.

I: What's regular?

Tee: Just normal, just without it, just a regular person. I know I try to do my work and I try to do everything because I'm constantly just trying to be normal, just like everybody else.

I: So it's that you've wished that that normalcy could be there, regular?

Tee: Right. I know I can't but sometimes I wish I could.

I: Okay.

Tee: And like I say, what keeps me going is my family and kids, which is the faces I see every day and it puts a smile on my face, you know, the kids they keep me going....I often have to sit down and play to make the pain go away, which I do. I sit down and play with them and I don't even think about it. You know, if I'm having a bad day or whatever, the kids keep me laughing. They doing something different every day. So that's what makes the pain go away...because I'm playing with them.

I: You get to play with them and that takes you away?

Tee: Right. That makes the pain go away. And like I say, I try to live my life the best way I can, and....I'm on the go a lot....I think about HIV, it's just a blood flow. That's what I try to keep putting in my head when I think about the word, the letters [HIV].

I: It's just something that's going on inside of you?

Tee: Yeah, because you have to protect your blood from, you know, you get a little cut, you can't let no one get around you. So I just say, well it's the blood flow, that's what I say in my head.

I: So like if you cut yourself in the kitchen, you're always worried about getting the kids away from it?

Tee: Right. 'Move, don't come closer'...I have to protect my blood from getting to them. That's what they told me when I first found out about it....You know, if

you get blood wipe it up with bleach and make sure you get it up real good, the blood, the blood, the blood.

I: How did you feel when it was all finished, and like you said you put it all together and you read it, what went through your mind?

Tee: I started crying, but I felt good because this is me, it's how I feel. I was like, I told my boyfriend, I got to do this, I need your help, help me....I'm like I know he heard me, I said come help me. I want this to be right, but he never came, so I got mad. I'm like forget him then. So I'm just back in the room, so when he came in the room I was [in], the last part I put was to make the pain go away...I'm like I need a closing part, I need to close it up a little bit. He's like 'do you need some help?' 'I'm like forget you, I'm done, I don't need you.'

I: And look at what a beautiful piece you did, all by yourself.

Tee: I was like I got one more part I got to put on there because I want to put the part about the blood flow, he's like 'what part, tell me?' I was like 'nope, I'm not telling you nothing.' I want to get it, I need to come up with this last part about how it feels to close it off, you know. He's like 'read it to me.' I said, 'no, I'm not reading it until I'm all the way done.' I was like you gonna wait, just be quiet, you distracting me, leave. You know, I was like forget it, I don't need you now, I'm almost done....I live my life the best way I can, and then when I read it he was like 'oh, that's good' ....He's like 'well that's how you feel,' you know, and he's

like ‘honestly that’s why I didn’t want to help you because it needed to come from your heart.’

I: He was doing you a favor... he was really thinking about you?

Tee: Mm hmm.

I: And that’s got to feel good too.

Tee: It did, and then we hugged after. ‘I’m [boyfriend talking] like to be honest, I heard you, I knew you needed [me], but it had to come from you, your heart, how you feel.’ ‘I’m like okay, you off the hook.’ But I was mad at the moment, come on, I need help. I don’t know how to do a poem, and he was like it’s from your heart. I was so proud of myself.

I: And I’m so glad that I get to be the person you get to share that with [the poem].

Tee: Oh thank you because I’m like a poem, I don’t know how to...but I love it, I love it [crying so I hand her a Kleenex].

The imagery in her poem of “flowing” carries a tension of yearning to experience a freedom from HIV as she depicts this as a “flow like the wind.” Tee’s poem creates a vision of a flow that would permit her to limitless goals and abilities of self-expression – a woman living with HIV. Unfortunately, she discloses that at this point in her life, she cannot flow like the wind; rather, she must “keep it all in.” Later in the poem, she returns to the fluid imagery of flowing. She depicts the tension of HIV as “just a blood flow.” She describes HIV as a toxic contaminant that must be avoided by those within her



physical presence. She associates the movement of a blood flow with her need for constant movement to occupy her mind to distract her from the reality of the virus, multiplying and circulating incessantly within her body. Interestingly, Tee's usage of blood flow in terms of "you can't let anyone get around you" challenges the interpretation that perhaps she roots this imagery in a vast space of distancing herself because of the HIV; stopping the blood flow from reaching others in both a physical and metaphorical sense of aloneness.

I: What if you read that to your mom?

Tee: Oh, I never thought about that, oh that would be good after I tell her, I don't know...I think that would be good though. And that might help me to open up too, I believe, now that I'm thinking about it [HIV] because if I express it on paper I'm gonna want to read it to somebody maybe or, yeah, that might be something.

I: It's a good start. Is there anything else that you want to talk about, anything about your life or living with HIV?

Tee: This is every day right here [pointing to her poem], this is every day, it's what I put down, it's me. That's me.

I: That's you, and what else can you say, that's you.

## Summary

The journey shared in the narrative and poetry by Tee resonates with a *mélange* of emotions from heartfelt pieces of a life filled with anger, fear, and loneliness resulting from the realities of living with HIV. A life, thrust in the shadows of internalized stigma, which positions her into a societal pattern of survival. She yearns to pick-up the shattered pieces of a former life without HIV; a life that is “regular again” in her own words. Tee mourns a life of yesterday, lost forever as the labels and sentiments of living with HIV will forever remain deeply attached to her life of today and tomorrow. Her story captures the many tensions, often times in a naïve and innocent manner of self-expression.

Tee invites me into her world; she draws me into her circle which converges into our circle of living with HIV. Tee opens the door and offers me the honor of listening, watching, questioning, and participating in the purest sense of dialogical engagement with her. Tee’s story commences with imagery of a young Black mother of three, shielding herself from the challenges of living with HIV. As her story progresses, she lays her shield down and slowly unravels a powerful account of her daily life as a woman, mother, partner, and provider. At times, she vacillates between being a woman, poised to resign to societal assumptions about a young woman living with HIV and yet she rebounds and smiles with playful thoughts of living in the moment of motherhood. Such tensions of resignation and resilience offer a snapshot of a life not lost to HIV. Rather, she understands that living in two worlds -- one foot firmly embedded in the land of HIV and one foot firmly anchored in the daily routines of being a mother and

anticipating the joys of what mothering means - is merely her reality, her mode of survival for today.

## **Portrait Two: Tasha**

### **Introduction**

On a Monday morning, awaiting the arrival of Tasha, I had the opportunity to scribble some notes about my weekend. The weather had been unseasonably cool; the heavy and gray sky loomed closer than normal, casting billowing clouds of uncertainty. Perhaps the overcast and crisp weekend echoed my personal scribbles: “reclaiming the self; liberation, moving ahead, invisibility.” These words represented my drive to not only find my own voice but to reclaim and honor it; the liberation of allowing myself a lazy weekend in which I felt no guilt for remaining indoors and reflecting as opposed to engaging in the hurried pace of weekend activities; the anticipation of today’s interview and the reality of moving one step closer to the shared moments of another co-researcher in the dialogical circle; and the imagery of being present but not seen for who I am as well as who my co-researchers really are casts a spell of invisibility upon me.

Upon Tasha’s arrival, I retreated from my inner world and welcomed her into the space which I had created for the two of us in my office. Tasha, a petite, African American woman exhibited the outer toughness of a person who has lived a million lives. Her gait, posturing, and clothing reminded me of a warrior who had finally returned home after a lengthy period of war in a distant land. Tasha looked to be extremely thin, much thinner than I recall from our first encounter when she participated in the computer-

based surveys which I administered as part of the larger, parent study. Tasha, wearing jeans that fit like armor and a torn jean jacket, gave the impression of having been damaged in battle. Tasha is a 30 year old married woman who lives in an apartment with her mother and her older sister. Tasha has two additional older sisters who live locally. Tasha chooses to live away from her husband because she prefers to have her own space from him as well as to freely see her former boyfriend, with whom she remains in contact after more than eleven years. Tasha freely spoke about the challenges of living with her older mother as well as the hardships of living with a sister who seeks out opportunities to degrade and instill insecurities within her. Tasha's voice was laden with shakiness which often abruptly shifted to unexpected outbursts of emotion and strength within her voice. Upon completing the formalities of establishing the first interview, Tasha and I positioned ourselves next to each other and began the deep journey into her life; one filled with immense pain and discomfort intensified by her HIV-infected status.

### **The Arrival of the Ominous Postcard**

I: When did you find out about the HIV?

Tasha: 2005. They [the St. Louis Health Department] called me in...I was living on XX street then, they sent a card out too, to tell me to come in immediately.

I: Do you remember where you were when you found out?

Tasha: It was a rainy day and the St. Louis Health Department called me and told me to come in, and I knew it was something real important if the health department call

you and say come back in...I was just looking at the AIDS poster and stuff on the wall...I was really tripping off of it.

I: Do you remember how you were feeling when they were telling you all this?

Tasha: My momma kept popping up in my head, how I'm gonna tell my momma? They [family/friends] gonna feel different about me, just how people...think you gross. I don't like that, and I still get the looks right now. I got to learn to deal with it, you know (tearful).

I: Do you remember when you went home what you did?

Tasha: Just cried.

I: Did you talk to your mom that day?

Tasha: I didn't tell her until I was laying up at XX Hospital. I had started losing weight. I didn't go get treatment after I found out [HIV diagnosis], because...I was just like these people have lost they damn mind, you know what I'm saying?

I: Right. You didn't believe it yet?

Tasha: Right, and I'm still...I don't believe it but I know I have it, you know.

Tasha's fear of self-disclosure surrounding her HIV diagnosis allowed her to slip into a world of denial. This form of processing a grieving situation is common. Poindexter (2005) noted that "because humans define themselves and understand the world through interaction, the fear of being negatively labeled is a significant deterrent to exposing one's stigma and a salient reason for striving to 'pass' as normal" (p. 64). The

progression from denial to acceptance often manifests in allowing oneself the risk of disclosing. In a study by Sayles et al. (2007), they reported that “despite the possibility of encountering stigma....Some participants reported that this type of full disclosure can lead to a sense of empowerment” (p. 821). Thus, the advocacy to support Tasha in her journey to resolve her own denial will lead to positive outcomes of self-acceptance and resilience.

### **Processing HIV through the Lens of a New Life**

The disclosure of Tasha’s HIV status to her family came as an abrupt and defining moment during a vulnerable moment when Tasha was hospitalized. Until this moment, she had concealed her secret from the world. During Tasha’s hospitalization, her HIV status was disclosed to her older sister [sister B] during a brief visit. In Tasha’s case, the unintended disclosure of her HIV status to sister B was devastating. Tasha explained that the relationship between her and her older sister had always been strained but now her sister possessed the ammunition to effectively destroy Tasha. Once again, images of a battlefield emerged and the wounded warrior, Tasha, perceived this disclosure as a personal loss during an ongoing war.

I: How did she [mother] react, what did she say?

Tasha: She was just like ‘oh, well put it in God hand and stuff like that’....my sister was there with her and I hated that she found out.... I’m very pissed off and angry at her [mother] for even bringing this bitch [sister B] to the hospital with her.

I: How have they acted towards you since then?

Tasha: I be wanting to say this shit but you can't trust everybody with your information...I got some sisters so evil. They'll try to destroy you just for somebody to like them, I don't know (crying). But I just don't feel comfortable...talking to nobody. You can't trust nobody. [I offer Tasha additional tissues to dry her eyes].

I: You have to be careful is what you're saying?

Tasha: Yes, and that's sad, that's real sad....You know people say shit on the street. 'Tasha have AIDS' and I don't have AIDS, I got HIV, it's a difference. People don't know that, but if I just sit down and break the difference down to them, they be like 'bitch you still got AIDS.' I don't like that.

I: So, since the HIV, it hasn't really changed that much with B [sister]?

Tasha: She just look at me like 'bitch, you is gross', just like I'm a nothing.

I: Does she say that?

Tasha: Yeah, she said that once, then I damn near bust her in her mouth. She'll get smart to the point where I'm fixing to physically hurt her, [then] she just shut it down [stops].

I: What does she say to you?

Tasha: Evil stuff... as evil as it can get....And now it's all over St. Louis....I'm tired of this....One day I'm gonna say I do got it anyway.

I: Then it might be the sort of thing that once you stand up and...

Tasha: And you know, she's my blood, you know, me and her live in the same house so they gonna believe that. It's been going on ever since that day [when Tasha disclosed in the hospital]. Oh she the bitch [sister B] who's saying it. And that is depressing. Every time I go places people looking. And I didn't really want to believe it but they [sisters] are, they just tearing me down. I didn't really want to face reality but I need to just move on. It's just mentally what they doing. I just, 'what the fuck did I ever do to you,' is it because I got this shit or what the fuck is it, that they don't like me? (tearful).

I: So the damage is already done?

Tasha: And people gonna believe that shit cause they all in my family...so of course people are gonna be like damn, for real? I get so tired of hearing this...I really do.

I: They start trying to judge you...there's a lot of judging going on?

Tasha: Right. That's what breaks me down. I don't know how to handle that, because I care what people think about me, I really do....Like my sister [B] really hurted me....It was my sister, you don't tell nobody nothing like that [HIV]....It just breaks me.

I: Have you sat down, Tasha, with her and said just what you just said that to me?

Tasha: No.

I: Maybe that would be a good place to start and let her know how much she's hurt you.



Tasha: I brung it to mom, I was like ‘mom, do you know she is going around telling people I got that shit?’ That’s exactly what I told my mom. She’s like ‘oh girl, you can’t believe what everybody saying.’

Tasha expressed her biggest disappointment was the lack of support and empathy from her family. She yearns for acceptance and support in a family that has not processed her illness in the manner in which she had hoped. This example of a lost hope and deep regret that she disclosed to her family reinforces the fact that HIV-infected persons engage in the concealment/disclosure dance and risk the loss of family, friends, and most importantly the life of yesterday; the life before the HIV diagnosis. Sayles et al. reported that “when HIV-positive women and men are successful in reconnecting with family...it is immediately recognized as a very meaningful and powerful experience. The support of loved ones...is instead met with gratitude and appreciation” (p. 821).

### **The Stress of Concealment**

Managing one’s HIV status assumes various concealment strategies. For Tasha, the outward signs of an illness are present in her severe loss of weight and reoccurring bouts with oral candidiasis, a white coating on the tongue and at times causing a pasty white film on the lips. For Tasha, a pseudo diagnosis of diabetes is the easiest approach to rationalize to others her oral disorder. Rather than delve into the disclosure of HIV, Tasha shields herself behind a false diagnosis within her community.

Tasha: I’m that depressed and naïve so I tell people I’m a diabetic.

I: So that way...

Tasha: That way they wouldn't trip off this [HIV].

I: So you just tell them you're diabetic?

Tasha: I be wanting to just sit and talk but you can't just come out and tell nobody nothing like that. They just look at you like 'why you still living?' I just trip off, what kills me and hurt me, you know, I used to mess with guys a long time ago and stuff...I probably didn't give it to them. I be thinking people's [former sex partners] gonna come shoot me and stuff. I'm not fucking nobody so why would they want to kill me? Then I be thinking in my head like damn, what if somebody do get it and say I gave it to them, not knowing that they done had the shit already and just try to throw it on me.

I: They're going to blame you?

Tasha: Right. That's the only fear that I got. I just fear that then somebody will hurt me....I didn't know [her own HIV status] at the time.

I: They can't blame you for something you didn't know?

Tasha: In '06...'09, see then you could kill me...It's so fucking confusing to me, I don't know if I should just come out with it...because me keeping it balled in, it's just making me more stressful...(tearful).

I: Does it make you stay home more....What's your personal life like?

Tasha: I be asleep. Then when I do get up I have the strength, I'll probably go have a drink or something. Come home and sleep again.

I: Now when you go up to have your drink, is it at least a nice group of people that you feel comfortable with?

Tasha: One time I was just at this little lounge up here....I was talking to this guy, which I don't want to have sex with him. And the dude on the microphone [singing] 'she got it [HIV],' and I walked back and said 'she got what?'

I: What did he say when you approached him?

Tasha: He was like 'I don't mean nothing by that'. Now don't play with me like that cause I'll slap your damn teeth out your mouth (anger in Tasha's voice). You know, if it's in a lounge, you know what I'm saying, I can just imagine where else it's at [Tasha's HIV status disclosed]. I got to get away from people. In that case I have to fight the whole [bar] to worry what they think about me...so that's why I limited my shit [HIV].

I: Is that why sometimes you choose just to stay home?

Tasha: Yeah.

Tasha's account of increased stress related to concealing an HIV-infected status is supported in the literature. Eller (2006) described "depressive symptoms in subjects who have HIV disease are associated with increases in risky behavior, medication nonadherence, immune dysregulation, and poorer disease outcomes" (p. 448). Lee et al. (2002) reported that stigma "also deters many HIV-positive people from seeking medical care and from disclosing their serostatus to others because doing so can lead to rejection, discrimination, hostility, and physical violence" (p. 310). Tasha's direct fears of physical

harm from the community are thus supported in the literature and should not be dismissed as unrealistic notions created from a stance of paranoia.

### **Does it Really Matter How this Happened?**

Growing out of the societal creation of a dichotomy which neatly organizes the innocent and the guilty victims of HIV, the intrusive question to many persons outside the HIV-infected community is often raised: How did this happen? For many within our community, this question remains offensive but becomes less lethal when posed by a member from within the community of HIV-infected persons. Nonetheless, the question remains and often generates an abundance of dialogue. The HIV-infected person often vacillates between searching for a justified and socially accepted response (children, hemophiliacs, blood transfusion, rape, needle-stick injuries) and the realization of truth which frequently follows when disclosing as a member in the guilty group laden with blame (homosexuals, sexual promiscuity, needle sharing). The latter group commonly receives further acts of ostracism and distancing from the HIV-negative community in comparison to the innocent victims.

I: Do you think that you can put your finger on how this happened?

Tasha: Well I could say from a tattoo, because when I was 14 I had got this tattoo...just somebody off the street with no license did it....Or somebody's nasty ass dick and that is just fucked up. How you can fuck me and know you got that shit? That's fucked up.

I: So you're thinking that it could be one of those two?

Tasha: That's all I could see where it came from, a dick or a tattoo. I'm still trying to figure it out. Who that fucking evil? I just want to know where it came from. If I just found out the source maybe I feel better. If not, I'll probably die not even knowing. Some nasty ass nigger didn't give a fuck, just didn't care, and I wouldn't never hold nothing out like that from nobody. You just don't do that.

I: What would you say to that person?

Tasha: I be 'why wouldn't you tell me that?' We would've used a condom or whoever put the tattoo on me, you should've told me if the needle was clean. I would've took care of mine. So I just want to know why me, out of every woman in this world, why you want to come fuck me up? I don't know, I really don't know. It's so confusing to me...and there be people I want to talk to. I feel comfortable talking to you. You know what I'm saying, that's what I come for. The \$40 [remuneration] ain't shit, I just want you to know what I be going through. If I live or die tomorrow at least somebody knew how I felt.

I: I think that that's important, that you've got to be able to talk to somebody.

Tasha: And I don't have nobody to talk to but my momma and my husband, but me my husband get into it. 'Oh bitch you got this' [HIV]. Now why would you tell all my business and you my husband?

I: Did you say anything to him about talking to you like that?

Tasha: Yeah, and I cries to him....I'll be like 'well you fucking me, you've got it too.'

I: Has he ever been tested?

Tasha: Yeah.... he never went back, he just went that one time and never been back [to get his results].

I: You think he's afraid?

Tasha: He should and I telled him this.

I: Well, so you don't know if they [husband and boyfriend] have it?

Tasha: Right. But I'm just saying, so why is you [husband and boyfriend] stay, if you know you don't have it, why don't you move on? Is you just you with me because you figure that you will never love nobody else cause you trapped, like I'm trapped?

I: You're in the same situation [HIV-infected too] so it's just easy?

Tasha: I'm tired, I'm tired. So I want to leave my boyfriend and I want to leave my husband too. I wonder if he's [boyfriend] just still with me because he think he's gonna have it in a few months to a year or something like that.

I: So how does that make you feel moving forward with him [boyfriend]?

Tasha: It's making me feel like at least he's still there, you know what I'm saying, because he's not diagnosed with anything right now. He's taking risk after risk after risk with me...that's just showing me, we are soul mates to me, that's what I think.

I: Do you talk to him [boyfriend] about that?

Tasha: I really be on that shit with my husband, because he really don't know if he got it for real....I be saying 'boy,' because he [husband] starting to sweat, and I been through them symptoms...and I be 'boy, in a minute you gonna need you some medication'. 'Oh ain't nothing wrong with me' [states husband], 'ain't nothing wrong with me.'

Tasha's dueling account of scenarios of her HIV-infection was shared in an open and safe environment. As a member of her community of HIV-infected persons, Tasha processed the questions in an unobtrusive and honest manner. The stage was not set for blame or judgment; rather, the dialogical engagement allowed Tasha a platform to freely discuss this chain of events. The unnecessary and often unproductive dichotomy that is often generated by family, friends, health care workers and society when attempting to establish causation regarding HIV-infection is outlined by Sayles et al., "our participants described feeling blamed for their HIV-infection by others, which is often compounded by their own internal self judgment....It becomes important...to differentiate *how* someone is infected....Which categorizes people based on how they were infected" (p. 818).

### **Dreams of the Former Life**

The quest for a return to normalcy is well documented in the illness literature. Particularly of interest among the HIV-infected community is an overarching craving for

the past; an urge to emerge from a nightmare and find the familiar comforts and safeties of a former life; most notably a life without HIV.

I: Before 2005, when you found out about the HIV, what was a typical, nice day like?

Tasha: Like...the day before I got the card in the mail...I always been...a party girl...I kicks it...I know how to bring a crowd. So I just kicks it...me getting up probably half of the girls in my neighborhood at my house, getting their hair done so we can get ready to go out, some shit like that or sitting back smoking my blunts...whatever I want to do I do it...I let life go as it is, whatever happened that day happened that day.

I: And you feel like you can't live that way today?

Tasha: I don't, I haven't since I been having this shit, cause it ain't normal....it's just how people [talk]...the shit on the streets....[now] when I be going places, people just look at me and just ball they face up....I want everyone to still crowd around me. Now the crowd just separating, there's probably only like 2-3 people around.

I: You don't want to deal with it?

Tasha: I talks to God....I be 'what is it you want from me, here?' I'm living on earth with HIV, stomach all destroyed, I don't like my body looking like this. I ain't never looked like this...I was looking at some pictures...I had the prettiest skin, just so thick and so pretty...I ain't like I used to be.



I: So it's almost like you want that back?

Tasha: I want that life back.... I think about that [HIV] every day.....why I'm not happy....It just fucks with me every day...I ignore it and it just slip back to me (tearful)... It's just, I don't feel like Tasha anymore, I just don't feel like I'm me no more. I talk to momma, it's just, she don't understand cause she don't have it....seriously, so you can't really tell me how you feel, not unless you in my shoes.

I: Absolutely....So it [HIV] comes into your mind every day?

Tasha: It creeps back in. I try so hard to block it out. Just when I hear that word [HIV] I just get quiet. Or a commercial will come on TV about HIV...and it just gets to me. I could be the talk of the town, but when they say something about that I close up. I don't know if that's a sign of telling people I got it, I just don't say nothing. I be even just talking...'yeah you got to be careful who you fucking with cause you know, there's people out here who got AIDS'. I just be sitting on the sidelines just looking like damn, I wish it wasn't me.

I: What I...hear is that you would really like to just step out of your house and have a fresh start?

Tasha: Just start the fuck over. I'm ready to do Tasha again, come back to being Tasha....I just be praying and hoping that I could just wake up and everything back to my old, but it ain't never gonna happen.

I: So what's your plan to keep going?

Tasha: I'm not gonna give up.

I: What about a good day since you found out about the HIV?

Tasha: Me waking up every day, that's a good day for me.

Sayles et al. reported in their study that “the desire for connection and reintegration into relationships and the community is a powerful theme in the lives of persons living with HIV and may contribute to an individual’s resilience in confronting and overcoming the stigma of their illness” (p. 825).

### **Tasha’s Poem: The Way I Feel**

Tasha selected poetry to express her aesthetic piece of the study (Appendix H) during the second interview. Tasha, the armed warrior, commenced the discussion surrounding her poem in a nonchalant and rather detached manner. As she began to read and I attentively listened, the emotions of a broken soldier slowly flowed outwardly. The pitch and inflection of Tasha’s voice shifted to a gentle and innocent girl when she read pieces of her work about her family. Clearly, she mourned the loss and craved collecting the pieces of a shattered family portrait. She openly discussed her recent events of facing her own mortality in a vulnerable and earnest manner in which she questioned her place here on earth and why God had not yet called her home. Her interpretation that He has a reason and her business is not yet accomplished pushed her poem into a space of hope and determination to find this answer by living.

I: Tell me what [aesthetic piece] you brought today.

Tasha: Oh this is just the way I feel, something I just wrote down.

I: So...go ahead and read it.

Tasha: 'The way I feel. Days I will sit up in the zone, thinking to myself when the day God's gonna call me home. Sometimes I will ask myself why I'm still here and the only thing that comes to mind is God love me and needs something from me, because when the accident had happened I noticed how my family stood over me, like they were angels sent from Heaven, I wondered was that a sign to tell me I can help you through more than this if I survive that, I can help you through more. So I came to think is there life after pain? I see there were, but mainly what I need to know, can it be cured one day and will I be still living? Who knows.'

I: It takes me into a piece of where you feel without us just sitting here talking....You've got your family in here...and the way...

Tasha: I love them so much....And I just want them to just help me, just help me. (tearful)...They just look at me like I'm disgusting or something. It ain't my fucking fault. It's my fault probably, I don't know.

I: You refer to them [mother and sister at hospital] in this as angels. They're not hovering over you like some angels [now]?

Tasha: Same thing go through my head. Don't you know I thinks like that? I don't know, I don't know.

I: How did you come up with that first part?

Tasha: I do be in a little zone...just so much just hit me at one time...I need to write how I really feel, and that's how I feel.

I: Now when you talked about dying and being called home, how does that all factor into this?

Tasha: I was just on my death bed [after being stabbed at a party]. Why am I, I'm already dying is how I look at it....So what do he [God] want from me, something God want from me, and I wonder what is it?

I: So why are you here is what you're saying in here [poem]?

Tasha: And that's where I came up with the part, is there life after pain? And there is.

I: And when you say pain, you're talking about all kinds of pain – mental pain, emotional pain, physical pain?

Tasha: Everything I go through....See right here [pointing to section of poem] it say, I can help you through more so I came, is there life after pain....I just want them to give me a shot and it's gone.

I: You want the virus out of your body.

Tasha: Period....It will never happen.

I: How do you feel after putting those words on paper and reading them to yourself?

Tasha: I mean I accomplished something. It made me feel like a big girl....I wish somebody in my family could do what you do [talking]....And I be wanting to go

to little meetings and stuff, but I don't feel comfortable. You never know who's sitting there....I really came open, out to you and now it's just...

I: It's just like we're sitting talking, and that's the way it's supposed to be.

Tasha: Right. I'm comfortable.

I: When you do this type of research together, remember we're partners in this....Sharing some of the most intimate, personal pieces of our lives.

Tasha: I just want to be, I mean I ain't saying I ain't nobody, but people treat me like I ain't shit...I don't like that....It's just how people look at me, like I'm...I don't get it....It's just these three fucking letters just do something to me.

I: H-I-V, those three letters?

Tasha: They just do something to me....Break me down, just ugh. When I look at it and just hear it, it sounds dysfunctional. How in the fuck did I ever come to have it? It's just sick to me. There's just a lot of filthy ass people.

I: You didn't think it would happen to you. Who did you think it would happen to?

Tasha: People who just nasty, that's what I thought. You got to be nasty.

I: But do you look at yourself as a nasty person because you have this?

Tasha: I feel nasty, I do.

I: Do you think I'm a nasty person?

Tasha: No.

I: What's the difference between me and you?

Tasha: Nothing.

I: We've both got the same story in our lives.

Tasha: If people talk about it more, people feel comfortable....My words too graphic for folks I guess, I don't know.

I: When you tell your story, and that's exactly what it is, your story, and you pick the words that are telling your story...

Tasha: I just want to tell the little girls, 'y'all need to get it together, because I thought I was all this. It's not right, you need to get it together.'

I: And when this happens, it can be a complete wake up call.

Tasha: Oh my God. It will send you, you will run into a wall.

I: Is there anything else you want to tell me?

Tasha: I never experienced and talked out the way I talked since I talked to you, and you encourage me to want to go and just get the shit together. Like, life is baby, so short.

I: It's precious and we've got to live it every day.

Tasha: Man, just thank you.

I: Tasha, we're partners in this. I couldn't do it without you and I've completely enjoyed our time.

Tasha: Me too.

### **Summary**

Tasha allowed herself to fully embrace the dialogical circle with me as she permitted me to enter her world of living with HIV and the multifaceted components which shape her experiences. Initially, Tasha appeared as a very tough young woman; but after she comfortably yielded her shield to the side, a very sensitive and distraught woman emerged during the research process. She shifted from the comfort and safety of her tough neighborhood visage into donning a mask which depicted a scared, angry, bitter, and isolated person. Tasha embraced the process of peeling back layers of pain and aloneness over the course of her lived HIV experience through both her verbal narratives and her poem. She engaged with me in a manner, which at times, resembled two old friends catching-up on the past and sharing intimate pieces that trickled from a lifetime filled with emotional, mental, and physical shifts in life directly resulting from living with HIV. Emotions, freely unleashed, Tasha spoke from her heart and most notably wanted her voice to be heard. She shared with me that her fear was that she would die one day and no one would have ever really listened to her and her story would go unheard. Tasha's candid approach to language usage, body language, and uninhibited expression of emotions as she depicted her charged story captured the essence of exploring the phenomenon of HIV-related stigma in the contemporary era. At times, I sensed a vast therapeutic element unleashed by Tasha as she turned inward and shared her intimate details. She craved the presence of "being" with me as a partner and not as the "other" during the research journey. The body of the investigator truly became the

driving instrument to allow Tasha to fully disclose her life with me; a life loaded with meanings which represent a unique experience but also confirming the stories of my other eleven co-researchers.

## **Thematic Analysis**

### **Shadows Lurking in the Gaze**

The existing HIV-related stigma themes found in the literature were supported by the co-researchers in this study. Such themes as blame, shame, fear, isolation, loneliness, and concealment were contrasted with themes of resilience, hope, spirituality, and self-power. The theme of the how the co-researchers perceived the gaze cast upon them by family, friends, healthcare workers, and colleagues revealed a novel stance during the research process. The co-researchers expressed, in a personal manner, how they viewed the way in which the “other” looks at them while living with HIV. The comparative nature of exploring this theme among the co-researchers, who offered different sets of experiences and contrasting stories, forms the framework for the thematic analysis of the gaze. The co-researchers openly expressed varying levels of this gaze cast upon them by others. Most notably, the casting of the shifting societal gaze has created a space for lurking shadows within each co-researcher along the life trajectory of living with HIV. The theme of *shadows lurking in the gaze* will be presented in two subthemes later in this section: *the raging battle of the gaze* that penetrates deep within the co-researchers and *the transformational processes of living* which results in pushing HIV-related stigma to the periphery of quotidian life.



According to the McKean (2006), a shadow is “an ominous oppressiveness, or sadness and gloom” (p. 823); lurking is defined as “to be present in a latent or barely discernible state, although still presenting a threat” (p. 531); and gaze is defined as “a particular perspective taken to embody certain aspects of the relationship between observer and observed” (p. 372). Thus, defining the theme within the context of this study, *shadows lurking in the gaze*, “is a discernible threat that presents an ominous oppressiveness which is perceived by the observed person cast from the other.”

### **Sub-Theme: The Raging Battle of the Gaze**

The HIV-infected person endures a plethora of psychosocial adjustments after a diagnosis of HIV. The concealment/disclosure component of HIV disease expends a great deal of energy and imposes stress upon the HIV-infected person. The question of when, to whom, and how will one disclose often lingers closely to the HIV-infected person. The fear of abandonment, rejection, and ostracism are viable concerns that fuel the decision-making process. Unlike other medical conditions that carry visibly stigmatizing attributes, HIV often goes unnoticed by the individuals who comprise the social network of most HIV-infected persons. In many cases, this invisibility does not always exist or is quickly dissipated as the HIV status is intentionally or unintentionally revealed among this social network. Regardless if the confirmation of one’s HIV status is disclosed or if it remains concealed, the suspicion of who knows and who does not know is a relentless distraction among HIV-infected persons. This distraction among an HIV-infected person often manifests into the self-analysis of how the other is looking at him; the self-questioning of the intentions of the gaze cast by the other.

Tiffany (TF), a young African American woman, shared that she does not like the fact the people are always staring at her. Uneasiness mounts within herself when she notices the uninvited gaze in her direction. She immediately perceives that her secret is revealed; her life is exposed and a deep sense of vulnerability manifests during this internalization process of HIV-related stigma.

TF: Don't stare at me, I don't like nobody staring at me....I figure if you staring at me you know me or you know something about me, that's why you are staring at me like that.

I: Why are they looking at you?

TF: Because a person look at me I just figure a person know me, a person saw me at a clinic or a person heard about me....Anybody look at me, I just think that you looking at me because you know that I have this [HIV]. If you're not living with it, don't speak on it, don't talk [down] about it, because you don't know who you're hurting.

Tiffany shared pieces of her daily struggle concerning how she perceives the other looking at her. She, along with other co-researchers, cluster on the extreme of the spectrum when dealing with the unknown gaze cast upon them by society related to living with HIV.

Chris, a middle-aged white male, shared his story about internalizing negative feelings associated with the gaze of others which is subjected upon him. He admitted that this has been an on-going struggle for him. He has confided in his wife about his HIV

status. No one within Chris' social network is privy to his HIV infection. He experiences the double-layered effects of HIV-related stigma as he freely discussed that if his friends and family knew his HIV status then he would be subjected to suspicions of homosexuality or IV drug use, both of which he vehemently denies. Broaching the phenomenon of HIV-related stigma requires shedding various other layers of internalized feelings of stigma surrounding an HIV diagnosis.

Chris: The thoughts of HIV are daily still today...it's definitely affected my confidence.

Now, when I look at people, when they're looking at me, in my mind I'm thinking what are they thinking?

I: And these people do not know your [HIV] status?

Chris: No. But it is something that really bugs me that I do this. I'm always hiding, and I do, I feel like I am hiding all the time. The stigmatism that comes from HIV and AIDS, and the people I socialize with, the people that I work with... I am mentally tired [of hiding].

I: If they knew it would just further...

Chris: The hiding process is probably easier because I already have the anxiety. I'm already worried what they are thinking when they are looking at me. If I weigh the two out [disclosure versus non-disclosure], I'm better off where I am now than just increasing the problem even more internally. They're gonna stigmatize me but they have, my family could be collateral damage. They're gonna

automatically think my wife is positive and my son is positive. People are cruel, so do I want to do that....So, I see a lose/lose situation.

The interview process with Chris revealed that he cannot release himself from the thoughts that others are looking at him with a suspicious gaze. A form of concealment for Chris has manifested into self-body image distractions. He disclosed that he constantly seeks confirmation from his wife about his appearance which is a product of constantly living under the suspicious gaze of others within his social network. This has created great challenges for Chris within his work environment. Chris' fears are rooted in reality as he shared a story about a co-worker at a social function:

Chris: I recall going to a function and hearing somebody say 'he looks like he has AIDS and that just, what little confidence I had was gone. Then when I would see people and they'd go 'you've lost a lot of weight'. It was very difficult. I didn't feel well at all. HIV may not have physically harmed me yet, but mentally, it's destroyed me.

Nikki, an older African American woman, shared that she feels isolated and alone because she fears disclosing to anyone, including her family. Nikki shared the following story surrounding her fears of the negative gaze that will be cast upon her after disclosure.

Nikki: I'm still struggling because I'm HIV-positive, don't nobody know but me. I don't want to tell my family (tearful) because I feel they'll look down on me. It's just a

struggle with something [HIV] by myself, which other people don't understand.

I'm dealing with it by myself.

I: Why is it that you do not tell anyone?

Nikki: They'll look down on me. Like I used to look down on people that [have HIV], but now I see it's nothing to look down, it could happen to anybody. It's a stress because you can't share it with nobody, [they] don't understand. I just wish I didn't have it. I'm just tired [mentally]. It's making me sick.

Nikki shared an important element in this discourse when she admits that she also harbored the negative gaze that she cast upon the HIV-infected community prior to her own HIV diagnosis. For Nikki, her fears are firmly placed within her own experiences of how she gazed at the other. Now that she is no longer a member of the other, she continues to recall the inner voice which resonates loudly that HIV-infected persons will be shunned and targeted with the cold and condemning gaze of her community.

James, an African American male, expressed that others refer to HIV like the plague and that it is a disease for nasty people. These images have shaped the strategy of concealment for James that consists of silence. A condemning gaze by the other resonates loudly within the interviews with James. During the first interview, James shared that it would be nice to openly discuss his HIV status with his social network to gain support during this battle with HIV. As James explained later in the interview, disclosure was not an option.

James: People think that it's a nasty disease. They think that it's contagious if you just like touch people or drink out of the same glass.

I: So what else is holding you back from being able to do that [disclose]?

James: I think just rejection or looked down upon. I think that's the whole thing, the rejection part.

Tasha, who represents one of the exemplary portraits discussed earlier, shared that the constant suspicious gazes from family and friends follow her on a daily basis. This harmful internalization has produced a hyper-sensitivity within her that results in poor self-esteem and isolation. Tasha shared several accounts during the interviews that explicitly described the effects of the hurtful gaze that constantly lurks behind her.

I: And she [sister] knows about the HIV?

Tasha: Right, to you know, [she] just look at me like bitch, 'you is gross,' just like I'm nothing....When they [family] look at me, talk to me it [HIV] be in their head. That's what breaks me down. I don't know how to handle that, because I care what people think about me, I really do. I'm just, my head about to explode...so I asleep a lot. Then when I do get up...I'll probably go have a drink...come home and that's that, sleep again.

The lingering gaze that is experienced by HIV-infected persons serves as a constant reminder that this disease remains a highly stigmatizing illness. HIV destroys social networks, increases stressors on the whole person, and inhibits the healing process while living with HIV. The voices of the co-researchers on the extreme pole of

internalized HIV-related stigma resonate that the condemned societal gaze is destructive within their lives. Mental fatigue resulting from long-term HIV status concealment strategies is a significant concern that warrants further investigation among healthcare workers when assessing this population. For many of the highly stigmatized individuals in this study, the fear of the ever-present lurking gaze creates a milieu of insecurity and isolation. The realized fear of the unknown in terms of reaction to disclosure produces viable concerns that demand a humanistic approach to when managing the care of HIV-infected persons. The perceived gaze received by the HIV-infected person by the other frequently creates a space of anxiety and fear which deserves appropriate attention by healthcare workers and should not be dismissed as mere cases of paranoia among HIV-infected individuals. According to these co-researchers, the *shadows lurking in the gaze* never dissipate.

### **Sub-Theme: Transformational Processes of Living**

During the interview processes, however, some co-researchers described the subtheme, *transformational processes of living* while surrounded by the *shadows lurking in the gaze*. These individuals represented the extreme polar position of managing the gaze cast upon them by society. The following co-researchers' stories exhibit the healing processes within themselves that have allowed them to push forward with life and release themselves from the distractions of the ever-present and unwanted gaze that continues to hover around them. These cases represent clear contrasts to the previous co-researchers, who have not attained this level of self-liberation from the societal gaze which remains deeply attached to them. The exploration of this subtheme supports the belief that HIV-

infected persons may never internally escape the external gaze resulting from HIV; rather, the voices of these co-researchers carry the message to healthcare workers that it is possible to live among the shadows of the gaze in a manner which permits self-healing, resolution, engagement within society, and moving on with life as an HIV-infected person.

The societal gaze from the external world onto the subject and deflected back onto society from within the subject in a controlled manner is presented by Tazz's story. Tazz, a young African American female, shared that living with HIV has changed not only the way that she has transformed her life but also the reality that surviving this illness rests upon the changes that she has incorporated into her daily life. Most notably, the way in which she copes with the societal gaze cast upon her living with HIV became the shield upon which she wielded and deflected the gaze back upon the other.

Tazz: I never thought it would happen to me. I learned my lesson. I stopped running the streets, I stopped hanging out with so many guys, everything. I started back to school, I started doing it all. My best friend even stop messing [hanging out] with me.

I: So, he wouldn't even call and talk to you?

Tazz: Nothing. I was like it's all good because you ain't doing nothing but making me even more stronger. You all do what y'all do and I'm gonna do me.

I: Do you see any of these people anymore, do you run into them?



Tazz: Yeah. I just look at them. They don't say nothing. But it's all good, I got my friends in my corner, that's all that matters. It actually made me open my eyes a whole lot wider than what I was seeing. It let me see who was my true friends and who was not there for real, just there, taking up space, so that means a whole lot. All that matters is that I'm still here, I'm fixing to do better than them, that's it. I don't need nobody to tear up what I got planned. It [HIV] helped me get back on track because at first I wasn't on track. I still have my guards up because now days you can't trust everybody, only the ones you are close with. I don't trust everybody, I just be looking at people. I went through a lot of struggling trying to find myself. It [HIV] just made me ten times stronger than I was before. made me a whole lot wiser, a whole lot more responsible, cautious about little things. It's a tough road but I can make it. The virus don't make a person, the person make theyself. It all depends on if you gonna fight to stay alive or you just gonna let it eat you alive. So, I fought my way, and I still fight my way, and I'm not gonna let it stop me. I make it every day.

Tazz' s story of deflecting the societal gaze and focusing on her survival represents an element of this theme which provides an evocative stance of transformation while living with HIV amidst a society that does not fully understand her illness. Tazz's voice resonates loudly with the reality that HIV-related stigma exists; however, she has managed to adjust her life and social network into a position of liberation and power. She maintains the power to control the gaze and utilizes this power to continuously strive for pushing the boundaries of living with HIV in a deeply charged community of stigmatizing realities.

Consistent with the subtheme of *transformational processes of living*, Boone, a young African American male, shared poignant pieces of his story of living with HIV-related stigma. While Boone and Tazz share common essences of survival and moving forward with life after an HIV diagnosis, Boone's struggle departed from Tazz's stance as a warrior. Boone's transformation from fears of ostracism and rejection are not fully resolved; however, he revealed moments of reflection and change within himself that have allowed him to choose the path of self-healing and surviving. Boone (BN) expressed that shedding the gaze of the other has permitted him to feel alive again; a feeling that he yearns to nurture and manifest into becoming a successful young man, regardless of his HIV status.

BN: Being a person that has AIDS is somewhat subhuman which made me feel bottled up on the inside. People tend to treat me funny if it be known that I have HIV but it [disclosure] kind of liberated me, because I mean it felt good to get it off my chest. I feel like a human again. Some people that I've met and told are positive influences on my life, it's made me and my parents have a more positive relationship but I also let them know that I don't want other family members knowing about it because I don't want to ostracized by the rest of the family.

The tension between HIV-disclosure and non-disclosure places a heavy weight upon Boone. He has experienced the liberating feelings of sharing his HIV diagnosis and thus casting aside the uncertainty that exist within those shadows of secrecy. Boone, however, continues to struggle with the concealment aspect of managing his HIV illness because of the reality of the uncertainty foiled within the gaze of the other. Boone's

situation represents the evolving transformational process within himself that as he gains more inner strength to dispel the fear of ostracism, he will surface as a stronger individual who is better equipped to fight the internalization of HIV-related stigma. Boone has experienced the liberating aspects of sharing his story and not receiving the dreaded outcome of rejection, distancing, and the gaze cast upon a common freak. Boone expressed that self-liberation and reclaiming control of his own life are the ultimate goals which have shaped his current transformational process of living with HIV.

BN: It's like a curve ball was thrown my way and right now I have to find a way to fight it. The way I feel about HIV is that HIV doesn't have me, I have it. I want to do something I can look back and be proud of, and not me, my parents and my whole family can look back at and be like WOW. It [HIV] kind of motivates me so I just want to do something good with it. I don't let HIV bring me down. I've got control over this.

Boone has chosen the approach to gaze back at the world as opposed to being the subject of the gaze. He is a realist, fully aware of the lurking shadows ready to frown upon him, yet he rejects the frown and looks to the future. Boone envisions a future of success, pride, and making a difference. These key elements are necessary components of the transformational process of healing while living with HIV.

The core theme of this study, *shadows lurking in the gaze*, represents the transition between and the tension among the subthemes: the *raging battle of the gaze* and the *transformational processes of living* with HIV-related stigma. The journey along the trajectory of living with HIV is highly personable and variable among HIV-infected

persons. The perceived gaze received and sent by the HIV-infected person is laden with power. For some co-researchers, the destructive forces of a mere regard produce highly anxious and suspicious internalizations. These internalizations often manifest into deeply rooted feelings of otherness among society. The co-researchers continue to strive to reclaim their former identity and shed the unwelcoming gaze of the other. This theme remains highly salient among this group of HIV-infected persons. The voices of these co-researchers support the notion that sentiments of the distant, but fondly remembered societal and familial gaze of a life without HIV is perhaps displaced forever. The quest to adjust to the shifting gaze varies among co-researchers. Most notably, the coping strategies and processing of internalizations resulting from HIV-related stigma appear to vary to an even greater extent within the many lives of the participants in this study. This finding, through the thematic exploration, warrants further investigation from an individual and collective nature to identify appropriate nursing interventions.

## CHAPTER V

### Summary Reflections of the Researcher

The data analysis phase of this study comprised a long, complex process entailing numerous rhythms of immersion and incubation over a period of eight months, until verbatim transcribed interviews, field notes, and individual aesthetic representations began to merge into the developed individual exemplary portraits. The emergence of patterns and themes were shaped by the voices and artistry of my co-researchers; however, my voice and my eyes were equally involved in the process. On numerous occasions, the co-researchers would shift the dynamics of traditional interviews in which the researcher maintains complete control with a scripted interview guide and thus creates little space for flexibility and personal vulnerability. As a researcher, I was trained in both the rigidity of the positivistic traditions as well as the naturalist approaches. Nonetheless, since the heuristic research model is relatively new in the field of nursing research, I had few exemplars or mentors to guide me along this journey. At times, I found myself fighting the necessary approach to this phenomenon. An open-ended, unstructured manner of interviewing, which more closely mirrors dialogical engagements or deep conversations with a mutual mission to better understand a social phenomenon was imperative. As a qualitative scientist, I knew the balance and sharing of voices must be maintained between me and my co-researchers in order to remain true to the method of heuristics, a research method that chose me to explore HIV-related stigma.

At times, as the traditional dynamics of qualitative interviewing veered away from my vantage point of asking the questions, quite often, the co-researchers would ask me

questions. A tenet of heuristic research is that the researcher assumes the role of a study participant as well as the role of investigator. Hence, the coinage of co-researchers which has been used exclusively through this study to describe my study participants was truly appropriate. I was honored and humbled by the experience of watching and listening as the shift in dynamics occurred. To me, this reinforced the hallmark of heuristic studies as I was being fully drawn into the circle of the lived experience. This invitation by my co-researchers into their lives confirmed that we had created a safe place to freely discuss the everyday patterns of living with HIV and being subjected to the ugliness of the stigma attached to this disease. I was no longer viewed as the researcher or the outsider with all the questions and answers; I was merely another human being, actively engaged in conversation and attentively listening to the range of voices. The variations in voices of my co-researchers spanned from the broken voice filled with fear and anger to voices laden with encouragement and resilience. In this process, I too found my own voice as a member of this community. My voice and the merging of the multiple voices of my co-researchers were marked with vulnerability of disclosure in such an intimate setting. These are the voices that I represent in the creative synthesis, the final phase of the heuristic circle.

### **The Creative Synthesis**

The lives of the 12 HIV-infected individuals were explored during this heuristic study. Individually crafted aesthetic representations of the co-researchers were additionally examined. The task of weaving together the narrative and aesthetic components of a heuristic research study culminate into the final presentation of these 12

persons. Each co-researcher possessed a unique voice, story, and aesthetic representation that echoed through my mind as I developed the final creative synthesis, a collection of the unique, contrasting, and similar experiences that were shared with me during the research process. In order to explicate the varied lives as accurately and forcefully as possible, I have created a narrative which corresponds to the aesthetic creative synthesis which is presented in Figure 1. The narrative and aesthetic creative syntheses illustrate the richness of the individual HIV-related stigma experiences which are finally depicted as a collective representation without losing the necessary tenet of heuristic work which leaves the individual intact within the collective description. This rejection of a Cartesian model of presenting fractured pieces of a phenomenon is a hallmark of the heuristic research model.

### **The Researcher's Narrative/Aesthetic Synthesis**

The work *Figures by the Sea*, by Edward E Boccia (1964) is an original work of art signed and dated. This painting represents the narrative synthesis below of the 12 co-researchers and me. Boccia, a modernist artist known for his expressionistic figures of oil pastel on paper captured the essences of the many stories and lived experiences shared among the co-researchers and me.

A man, a woman, does it matter? The power of three simple letters H I V shatters the life of yesterday. Fractured pieces of me, does anyone else see? A demon or an angel, are these pieces of me? Falling upon nails, I submit to my knees. I see a world spinning, a world with faces that do not recognize me. Weakened by the blow; fire within my limbs, I am not able to stand. I want to turn and run away as I see the shadow grasp my

way. Or is it an angel that flutters my way? A mirror, I see. The object, this is me. The shadow's red clutch catches my neck. The gaze of my eye broadens and spans. Am I the only one who sees this shadow and his clan? I extend my arm but my hand is hidden within. If only you could find my hand and pull me from the shadow, will you help me begin? I know you see me because I am in the mirror, there is no need to fear. I'm falling forward into the darkness. We, you and me, can save us from this harshness. Where is your hand? My dear friend, with your hand, we can begin for this is a battle I know we can win.



Figure 1: *Figures by the Sea*



### Implications for Nursing Practice

This study attempted to explore the lived experience of HIV-related stigma. The dissemination of these findings may provide nurses and other healthcare workers with newfound meanings of living with HIV disease. The daily demands of contemporary nurses include a myriad of responsibilities. Managing the care of multiple patients within a structured framework of temporal restrictions, encountering multiple patients who present with an array of medical complications, and functioning under the rigorous demands of a highly positivistic medical approach are to list only a few.

This study may allow nurses to reflect upon and thus return to the art of nursing. This transitional return to the art of our profession may create a space to present ourselves to others as well as allow our patients to present themselves to us in an authentic nature (Kleiman, 2009). Most notably, nurses may become better positioned to fully understand the psychosocial complexities of HIV-related stigma while delivering nursing care. The *shadows lurking in the gaze* serve as a constant reminder to nurses that these patients present to us for equitable care during perhaps the most vulnerable time in their lives. Because of the proximity from which nurses manage the challenging care of HIV-infected persons, it is clear that nurses arrive at this space of delivering nursing care with their own personal and historical perceptions of HIV illness. Nurses are not immune to casting the negative gaze upon this population.

This research hopes to facilitate the process for nurses to become more cognizant of the gaze that they project upon the other. The co-researchers in this study often compared their interactions with healthcare teams as sterile and uninviting. Patients

yearn to be heard in an authentic manner. Kleiman described authenticity as “each nurse using the scientific knowledge and technical skills he or she has acquired to express caring for a unique person at a particular time and place” (p. 12). Nurses and other healthcare workers need to simultaneously hear the voices of HIV-infected persons while reviewing a set of laboratory values or assessing the psychosocial status of this population. These two acts cannot be separated; nor can one exist without the other to successfully manage the complicated care of HIV-infected persons in 2010. The knowledge and tools to accomplish the identification and subsequent management of the whole patient (the physiological and psychosocial needs) living with HIV must be delivered to nurses in order for this transformational change in nursing care to manifest. Through this newfound awareness of HIV-related stigma and the hyper-sensitive nature of the gaze among many HIV-infected persons, nurses become instrumental in orchestrating the process of positioning the HIV-infected person in the direction of releasing oneself from the *raging battle of the gaze* to the *transformational process of living* amid the cast gaze. For many HIV-infected persons, this is the first crucial step toward embarking upon a life filled with fewer stressors associated with HIV-related stigma. The initiation of this process falls within the scope of nursing practice and thus does not require a medical order driven from the physician. Most notably, this nursing practice is paramount to changing archaic and historically driven fears among nurses. This change may be initiated by nurses who are armed with the knowledge of the destructive nature of this phenomenon. The dissemination of these findings through manuscript submissions and professional presentations may initiate this call for change among nurse clinicians, educators and researchers.

### **Directions for Further Research**

Previous qualitative studies of HIV-related stigma in the US have focused on exploring this phenomenon from various perspectives ranging from samples of homosexual men (Chenard, 2007); perceptions of family (Bogart et al., 2007) and different qualitative methodological approaches (Block, 2009). To my knowledge, no other nursing research exploring HIV-related stigma using a heuristic research model has been completed. Several co-researchers in this study explicitly shared the therapeutic nature of the research process. Mac, a young African American male, noted “I think this has been very therapeutic for me and I appreciate you having me. It really has given me a chance to just kind of start evaluating things so this has been a real helpful process for me.” Another co-researcher, Tee, said “I have not shared what I shared with you with nobody, not even my case manager. I haven’t even talked to her like I’ve talked to you.” The testimonials that surfaced during the research process indicate that HIV-infected persons respond well to the safety, concern, and up-front disclosure of the researcher. For many co-researchers, the shared and common voice between us permitted a therapeutic milieu. These findings indicate that the research design that affords HIV-infected study participants the opportunity to interact with HIV-infected researchers has the opportunity to provide rich and meaningful data in a therapeutic nature, which may lead to intervention studies to decrease heightened levels of internalized HIV-related stigma.

One such study could include the utilization of peer-centered focus groups led by other HIV-infected persons as members of the research team when exploring specific

phenomena within the context of HIV-related stigma. Nested within these focus groups, the aesthetic component of the heuristic research model warrants closer scrutiny as a potential source of data collection among HIV-infected persons. Such art-based, therapeutic research designs have the potential to permit the study participant to engage in the reflexive process, which in itself is therapeutic in nature, to peel away layers of stigma in a non-narrative manner to disclose deeply personal feelings of living with HIV-related stigma.

### **Conclusion**

The data presented by the co-researchers in this study were extraordinarily rich and meaningful. Since self-disclosure and vulnerability are ordinary characteristics of HIV-infected persons, the 12 co-researchers shared the essences of their lives with me in a very candid manner. Several of the co-researchers were visibly moved by the experiences of contributing pieces of their keenly personal lives to the research study, as was I. I honor this research experience not only for the novel findings it provided me but also for the intense personal connections I made with very noble and brave individuals living with HIV.

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APPENDICES

Appendix A.....HIV-Related Stigma Screener Scale  
Appendix B.....Letter of Invitation to Partciapte  
Appendix C.....Remuneration Log  
Appendix D.....Informed Consent Form  
Appendix E.....IRB Approval - Washington University IRB  
Appendix F.....IRB Approval – University of Missouri, St. Louis

Appendix A: HIV-Related Stigma Screener Scale

HIV-Related Stigma Screener

***In the past thirty days, how often have the following statements applied to you:***

1 = Never	2 = Rarely	3 = Sometimes	4 = Often	5 =
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<p>Sti1. Felt that having HIV was a punishment for things I had done in the past.</p> <p style="text-align: right;">Never 1</p> <p style="text-align: right;">Rarely 2</p> <p style="text-align: right;">Sometimes 3</p> <p style="text-align: right;">Often 4</p> <p style="text-align: right;">Always 5</p>	
<p>Sti2. Felt that people were avoiding me because of my HIV status.</p> <p style="text-align: right;">Never 1</p> <p style="text-align: right;">Rarely 2</p> <p style="text-align: right;">Sometimes 3</p> <p style="text-align: right;">Often 4</p> <p style="text-align: right;">Always 5</p>	
<p>Sti3. Feared that I would lose my friends if they learned about my having HIV.</p> <p style="text-align: right;">Never 1</p> <p style="text-align: right;">Rarely 2</p> <p style="text-align: right;">Sometimes 3</p> <p style="text-align: right;">Often 4</p> <p style="text-align: right;">Always 5</p>	
<p>Sti4. Felt like people that I know were treating me differently because of my</p>	

<p>HIV status.</p>	<p>Never 1 Rarely 2 Sometimes 3 Often 4 Always 5</p>
<p>Sti5. Felt like people looked down on me because I have HIV.</p>	<p>Never 1 Rarely 2 Sometimes 3 Often 4 Always 5</p>
<p>Sti6. Avoided dating because most people don't want a relationship with someone with HIV.</p>	<p>Never 1 Rarely 2 Sometimes 3 Often 4 Always 5</p>
<p>Sti7. Avoided a situation because I was worried about people knowing I have HIV.</p>	<p>Never 1 Rarely 2 Sometimes 3 Often 4</p>

	Always	5
Sti8. Was embarrassed about having HIV.	Never	1
	Rarely	2
	Sometimes	3
	Often	4
	Always	5
	Sti9. Felt that keeping my HIV status a secret was important.	Never
Rarely		2
Sometimes		3
Often		4
Always		5

Score \_\_\_/45

Appendix B: Letter of Invitation to Participate



# Washington University in St. Louis

## SCHOOL OF MEDICINE

Date: \_\_\_\_\_

Dear \_\_\_\_\_:

Thank you for agreeing to join me for the research study interviews. The interviews will be conducted by Neal Rosenburg at the Goldfarb School of Nursing in Suite 440B at 4483 Duncan Avenue in Saint Louis, Missouri OR at your home (whichever will provide you with the greatest comfort and privacy).

Should you decide to meet me in my office, please come to the lobby at the Goldfarb School of Nursing and request that the receptionist call me upon your arrival at 2-4831. You do not need to check in. I will come out and call your first name at your appointment time.

Your assigned interview is at \_\_\_\_\_ on \_\_\_\_\_. Please make sure that you arrive at \_\_\_\_\_ so that we can begin on time.

You will be able to ask questions about this study and sign the Informed Consent form prior to the beginning of your first interview.

You will be given \$40 for your time and participating in each interview (there will be two interviews in order to complete the study). If you need metro pass tickets, these (2 per visit) will be provided to you during the interviews. Visitor parking is located on the north end of the building.

If you have any questions or concerns, please contact Neal Rosenburg at (314) 362-4831. I look forward to meeting with you.

Thank you for your time,

Neal Rosenburg, RN, PhD(c)

Appendix C: Remuneration Log

Last Name	Pseudonym	Date of Interview	Metro Voucher	Remuneration Amount	Signature



Appendix D: Informed Consent**CONSENT FOR PARTICIPATION IN RESEARCH ACTIVITIES**

Title of Project: HIV-related stigma among patients attending an urban clinic HRPO Approval Number: 09-0851

Please ask for an explanation of any words you do not understand.

You may want to talk about the study with your family or friends before you decide to be in it. Washington University will keep a copy of this consent form. A copy of this consent form will be placed in your research file only.

**Research Description**

You are invited to participate in a research study conducted by Neal Rosenburg, RN, PhD(c) and Dr. Turner Overton. The overall purpose of this research is to understand stigma reported by patients in the HIV clinic. This study will consist of two individual face-to-face qualitative interviews. This study is focused on learning how to develop appropriate interventions that improve the health outcomes on the infectious disease clinic population. If you decide to participate in this study, you will be asked to participate in two individual qualitative interviews. Neal Rosenburg will ask questions that you as the participant will be able to discuss with him. You will select a pseudonym (a fake name of your choice) and your interview responses will be attached to only that pseudonym during and after the interviews. The audio recordings will be stored on Neal Rosenburg's password-protected computer in his locked office. The recordings will be transcribed and after that is completed the tapes will be destroyed. No identifying information will be included in the transcription of the tapes.

You will also be asked to bring one personal item like a photo of an object or scene (with no personal identifiers or persons in the photo), a drawing, or a poem to interview two. This item should represent how you personally feel as a man or woman living with HIV. This item should also reflect how you personally feel about the way you are treated by others who know you and your health status as a man or woman living with HIV. This item (with your permission) will become part of Neal Rosenburg's research findings and may be used in reporting the findings of this study. This item will become the research property of Neal Rosenburg and will not be returned to you. Your name and identity will not be shared with this item as it will be coded with your selected pseudonym from interview one. If you agree to this plan of the personal item, please initial below:

\_\_\_\_\_ YES \_\_\_\_\_ NO

The amount of time required for your participation will be in two 2-hour sessions spread over one month and you will receive \$40 at the end of each 2-hour session (for a total of \$80) for your time. Additionally, metro link travel vouchers (2 per interview) will be provided should you have a need if you come to Neal Rosenburg's office. Free parking is also located at his office should you drive. There are no costs to you from participating in this study.

**Risks and Benefits**

There are no significant risks to your health from participating in this study. Some of the questions asked in the interview may make you feel uncomfortable. You do not have to answer any questions that make you feel uncomfortable. Your agreement to be part of this study won't have any direct medical benefit to you. However, the information we learn will be helpful in developing interventions to improve HIV-related health outcomes.

**Voluntary Participation**

Your participation is entirely voluntary and you may choose not to participate in this study or withdraw your consent at any time. You will not be penalized in any way should you choose not to participate or withdraw. You may skip any question that makes you uncomfortable or any question you do not wish to answer. You will be compensated for each session you attend, even if you do not complete the study.

**Privacy and Confidentiality**

Protected Health Information (PHI) is health information that identifies you. PHI is protected by federal law under HIPAA (the Health Insurance Portability and Accountability Act). To take part in this research, you must give the research team permission to use and disclose (share) your PHI for the study explained in this consent form.

In addition to health information that may be created by the study, the research team may access the following sources of your health information to conduct the study: Data from the larger quantitative study (HRPO 08-1215) will include current and history of CD4 cell counts, HIV RNA, HAART.

**The research team will follow state and federal laws and may share your information with:**

- Government representatives, (including the Office for Human Research Protections or the Food and Drug Administration) to complete federal or state responsibilities
- Hospital or University representatives, to complete Hospital or University responsibilities
- Your primary care physician if a medical condition that needs urgent attention is discovered
- Public health agencies to complete public health reporting requirements
- Appropriate authorities to the extent necessary to prevent serious harm to yourself or others

Once your health information is shared with someone outside of the research team, it may no longer be protected by HIPAA.

The research team will only use and share your information as talked about in this form. When possible, the research team will make sure information cannot be linked to you (de-identified). Once information is de-identified, it may be used and shared for other purposes not discussed in this consent form. If you have questions or concerns about your privacy and the use of your PHI, please contact the University's Privacy Officer at 866-747-4975.

**If you decide not to sign this form, it will not affect**

- your treatment or the care given by your health provider.
- your insurance payment or enrollment in any health plans.
- any benefits to which you are entitled.

However, it will not be possible for you to take part in the study.

**If you sign this form:**

- You authorize the use of your PHI for this research
- Your signature and this form will not expire as long as you wish to participate.
- You may later change your mind and not let the research team use or share your information (you may revoke your authorization).
  - To revoke your authorization, complete the withdrawal letter, found in the Participant section of the Human Research Protection Office website at <http://hrpo.wustl.edu> (or use the direct link: <http://hrpohome.wustl.edu/participants/WithdrawalTemplate.rtf>) or you may request that the Investigator send you a copy of the letter.
    - **If you revoke your authorization:**

- The research team may only use and share information already collected for the study.
- Your information may still be used and shared if necessary for safety reasons.
- You will not be allowed to continue to participate in the study.

Please specify any contact restrictions you want to request for this study only. Additionally, the PI will not communicate with you via e-mail during the course of this study.

(Example – no calls at home, no messages left for you, no –emails, etc.)

**Contact Information**

If you have any questions or concerns regarding this study or feel that you have been harmed in any way by your participation in this research, please contact Neal Rosenberg at 314-362-4831 and/or Dr. Turner Overton at 314-454-8225.

If you wish to talk with someone else or if you have questions about your rights as a research participant, please call Dr. Philip Ludbrook, Executive Chair of Washington University's Human Research Protection Office, at 314-633-7400 or 1-800-438-0445.

I have read this consent form and have been given a chance to ask questions. I agree to participate in the research study described above titled, **HIV-related stigma among patients attending an urban clinic**. I will receive a signed copy of this form for my records.

\_\_\_\_\_  
Signature of Research Participant

\_\_\_\_\_  
Date

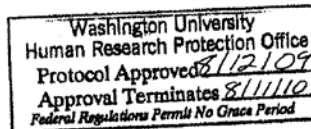
\_\_\_\_\_  
Printed Name of Research Participant

\_\_\_\_\_  
Signature of person obtaining consent

\_\_\_\_\_  
Date

\_\_\_\_\_  
Printed Name of person obtaining consent

**This form is valid only with the Human Research Protection Office's current stamp of approval.**



Appendix E: IRB WUSM



Human Research Protection Office

Barnes-Jewish Hospital  
St. Louis Children's Hospital  
Washington University  
August 12, 2009

Neal Rosenburg, RN, PhD  
Goldfarb School of Nursing at Barnes-Jewish College  
Box 90-36-697

HRPO Number: 09-0851  
Title: HIV-Related Stigma among Patients Attending an Urban Clinic  
Funding Source: NIH; Goldfarb School of Nursing  
Grant# TL1RR024995/UL1 RR024992/KL2RR024994

This project was reviewed and approved by the Washington University Human Research Protection Office (HRPO) according to the terms and conditions described below:

IRB Approval Date:	8/12/2009	Reviewing Committee:	Behavioral Committee
Expiration Date:	8/11/2010	Type of Review:	New (Behavioral Expedited 5, 6, 7)
Research Risk Level:	Minimal	HIPAA Compliance:	Compliant with Authorization

Released for accrual.

HRPO complies with Federal regulations 45 CFR 46, 45 CFR 164, 21 CFR 50, and 21 CFR 56, which allow the use of an expedited review procedure for research which presents no more than minimal risk to human participants and meets the criteria for one or more of the categories of research published in the Federal Register. All actions and recommendations approved under expedited review are reported to a Full Committee.

You are expected to comply with the requirements outlined in the WU HRPO Assurance of Commitment and Policies & Procedures (<https://hrpo.wustl.edu>). This includes reporting any unanticipated problems involving risk to research participants or others.

Changes in the conduct of the study, including the consent process or materials, require submission of an amendment application which must be approved by HRPO prior to implementation of the changes.

According to Federal regulations, this project requires IRB continuing review. As such, prior to the project expiration date above, you must submit either a Renewal or the Final Report. If you have questions or require additional information, please contact us at (314) 633-7400 or [eIRB@msnotes.wustl.edu](mailto:eIRB@msnotes.wustl.edu).

Sincerely,

Philip A. Ludbrook, M.D.  
Executive Chair and Associate Dean

Mitch Sommers, Ph.D.  
Chair, Behavioral Minimal Risk



Appendix F: IRB UMSL



**OFFICE OF RESEARCH ADMINISTRATION**

**Interdepartmental Correspondence**

Name: Neal Rosenburg

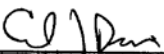
Title: HIV-Related Stigma among Patients Attending an Urban Clinic

The chairperson of the Human Subjects Committee for UM-St. Louis has reviewed the above mentioned protocol for research involving human subjects and determined that the project qualifies for expedited review under Title 45 Code of Federal Regulations Part 46.110b. The time period for this approval expires one year from the date listed below. You must notify the Human Subjects Committee in advance of any proposed major changes in your approved protocol, e.g., addition of research sites or research instruments.


You must file an annual report with the committee. This report must indicate the starting date of the project and the number of subjects to date from start of project, or since last annual report, whichever is more recent.

Any consent or assent forms must be signed in duplicate and a copy provided to the subject. The principal investigator must retain the other copy of the signed consent form for at least three years following the completion of the research activity and they must be available for inspection if there is an official review of the UM-St. Louis human subjects research proceedings by the U.S. Department of Health and Human Services Office for Protection from Research Risks.

This action is officially recorded in the minutes of the committee.

Protocol Number <b>090828R</b>	Date 9/2/09	Signature - Chair 
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## Appendix G: Tee's Poem

  
Living with HIV  
haven't been that much of a challenge for me.  
Well I try to put it in the back of my mind  
So I don't cry all of the time  
I wish I could just flow like the wind  
But I can't I have to keep it all in  
I wish I was regular again  
What keep me going is my family and kids  
The faces I look at everyday  
But often I have to sit down and pray  
to make the pain go away  
Well I try to live my life the best way  
I can and often I'm on the go  
But I ~~I~~ always think HIV is just  
a blood flow.

## Appendix H: Tasha's Poem

## The way I feel

Days I will sit up in a zone thinking  
to my self when the day God going  
to call me home. Sometime I will  
ask my self why are I am still here  
and the only thing come to mind is  
God love me and need something  
from me, because when the accident  
had happing I notice how my family  
stood over me like they were Angels  
Sent from Heaven, I wonder was  
that a sign to tell me I can help you  
throw more then this if I survive  
that I can help you throw more,  
so I came to think is there life after  
pain I see there were, but mainly  
what I need to know can it be cured  
one day, And I will be still living  
who know !!!