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The Interface of Attachment Relationships and the Implicit and Explicit Expression of
Spirituality among Older Men Living with HIV/AIDS as a Chronic Illness

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By

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The Interface of Attachment Relationships and the Implicit and Explicit Expressions of Spirituality among Older Men Living with HIV/AIDS as a Chronic Illness

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From the early 1980s when the first cases of HIV/AIDS were diagnosed, until the 1990s when the antiretroviral therapies became available, a person who contracted HIV/AIDS faced the prospect of an almost certain and painful debilitating death. With the development of the antiretroviral therapies, many persons once destined to die from AIDS had the possibility of surviving AIDS. These persons find themselves adjusting to the prospect of living with a life-limiting chronic illness. In 2007, the Center for Disease Control estimated that adults over 50 comprised 24% of persons diagnosed with HIV in the United States, and of these adults, 72% were men. This narrative qualitative study investigated the interface of attachment relationships and the implicit and explicit expressions of spirituality among seven older men, residing primarily in the District of Columbia Metropolitan area and living with HIV/AIDS as a chronic illness. Using semi-structured, in-depth, multiple interviews of each participant, a narrative was constructed highlighting the early awareness and diagnosis of HIV/AIDS, the adjustment to living with HIV/AIDS, and the meaning attributed to this experience. The data was chronologically organized into significant events and then analyzed by using Murray's four levels of analyzing health narratives: the positional (social standing of investigator and participant); the personal (perceptions of the participant); the ideological (cultural

beliefs in which the story takes place); and the interpersonal level (dynamic interchange between investigator and participant). Attachment relationships and the relationship with spirituality were emphasized to determine the role of spirituality in their lives. This research produced two major findings. First, attention to the implicit expressions of spirituality was critical to understanding the role of spirituality in these men's lives. Second, the medical doctor served as a significant attachment figure for these men. As transition from life with a terminal illness to a chronic illness becomes more prevalent due to medical discoveries and breakthroughs in treatments, information from this study may increase the competence and inform the interventions of social workers providing services to people coping with the illness of HIV/AIDS.

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CHAPTER I

INTRODUCTION TO THE STUDY

The seven men in this study provide over 131 years of living with HIV/AIDS. Some of them were among the first to be diagnosed with HIV/AIDS. Others learned of their infection after treatments were available. Together, they are part of a growing population of men over 50 years of age, who are living with HIV/AIDS as a chronic illness in the United States.

They have a story to tell – a story of living with HIV and its uncertainties. It has never been simple. No role models existed. On the contrary, the stigma often left these men silent with their own feelings about what was happening to them. They chose confidants carefully and infrequently; they did not share the knowledge of their diagnosis with their parents, work colleagues, or social communities. Often their partners were also infected and several died, leaving behind more secrets in the shadowed silence.

Yet, these seven men not only lived, they squeezed the last droplet of living out of every moment of life. They managed by confronting the virus and openly engaging in their own survival. They used complementary and alternative therapies, they created their own subcultures of persons with HIV who supported one another, they gave support when they were well enough and took it when it was needed. They attended too many funerals and visited too many hospitals.

The seven men interviewed in this research speak to how the virus came to be more than real to them. They speak of becoming aware of HIV/AIDS, contracting it,

learning of their diagnosis, and the adjustment to sharing life with HIV/AIDS. Most significantly, they speak to the meaning it has had in their life. To frame this journey, attachment theory is used to illuminate a particular pathway – the pathway of relationships that supported them in this particular journey. Specifically, the attachment to the spiritual is addressed to better understand its role in shaping the meaning of the journey. By glimpsing what these men held dear, the undertaking of such a difficult path, ending in such joy as these men possess, not only becomes possible, but becomes inevitable.

This qualitative research study is an exploratory investigation into the lives of older men living with HIV/AIDS. Now that these men are surviving, it is time to consider quality of life and issues of well being. Using a semi-structured interview guide, multiple, in-depth interviews were conducted with seven men primarily living in the metropolitan area of the District of Columbia. A narrative was constructed from their interviews to capture a chronological view of their life with HIV/AIDS. This view provides an historical marker for any future illnesses as well as a futuristic perspective of the increasing complexity of issues resulting from long-term survival.

Statement of the Problem

Many of the participants in this study live in the District of Columbia (DC), the capital of the United States, where the rate of HIV/AIDS infection is over 3% of the city's population (Epidemiology Annual Report [EAR], 2008, 2009). Another one third to one half of the residents of DC may be unaware of their infection – most certainly

resulting in prevalence greater than 3% (EAR, 2008). As of December 31, 2007, it is estimated that there are 15,120 persons diagnosed with HIV/AIDS. Nearly one third were between the ages of 50 and 59. Approximately 70% of these older adults were men. Of all of the residents ages 50-59 living in DC at the end of 2007, 5.2% were known to be infected with the virus. Furthermore, over 14% of persons living with HIV/AIDS in DC were diagnosed after the age of 50 (EAR, 2009).

Nationally, late middle age and older men comprise one of the largest emerging cohorts in the HIV epidemic (Center for Disease Control [CDC], 2008). According to Vance, Struzick, and Childs (2009), the cohort of older adults living with HIV/AIDS is expected to grow rapidly for three reasons. First, current medications are effectively extending the lifespan of an infected adult. Second, there are an increasing number of newly diagnosed cases among older adults, and third, this increase reflects the overall increase of adults in the general population. The Center for Disease Control (2007) estimates that adults over 50 comprise 24% of persons diagnosed with HIV in the United States, and of these adults, 72% are men.

From the early 1980s when the first cases of HIV/AIDS appeared, until the 1990s when the antiretroviral therapies became available, a person who contracted HIV/AIDS faced the prospect of an almost certain and painful debilitating death. Yet with the development of the antiretroviral therapies, many persons once destined to die from AIDS had the possibility of surviving (Rathbun, Lockhart, & Stephens, 2006). Though millions of adults and children throughout the world continue to fall victim to the AIDS

pandemic and the global threat of AIDS is far from eliminated (UNAIDS, 2004), some persons find themselves adjusting to the prospect of living with HIV/AIDS as a life-limiting chronic illness. Challenges of living with HIV/AIDS often mirror the more familiar challenges of aging, including psychosocial stressors (loss of close friends and relatives, decline in productivity, decline in financial resources, and changes in physical appearance); health and bio-chemical stressors (increase in co-morbidity); and cognitive stressors (Vance et al., 2009). These challenges create a new set of dynamics for those who care for and provide care to this growing population.

Given the chronic nature of HIV/AIDS and other issues related to aging, these persons are destined to need increasing services from the social work profession. Hospitals, nursing homes, treatment facilities, and clinics will be providing care to an increasing number of aging HIV clients. Fifteen years ago, before the antiretroviral medications, HIV would likely have been the issue initiating social work involvement. Yet HIV infection is now often not the issue of crisis among persons requiring social work services. Many older adults have health problems and/or psychosocial problems unrelated to their HIV/AIDS status. However, today there is no age cohort that is exempt from the effects of HIV, whether on a personal level or at a community level. This research provides social workers and other health care providers with preliminary insight into the issues confronting the population of older men with HIV/AIDS.

Knowledge from this study will contribute to the social work profession's understanding about providing services to this growing population and its unique needs.

In addition, this knowledge will add to the understanding of those not infected by the virus but increasingly finding they are living among those who are infected with HIV.

HIV/AIDS: What Is It? What Is Its Story?

Definition of HIV/AIDS

To facilitate an understanding of the lives of those living with the virus, it is necessary to examine the nature of HIV/AIDS and briefly review its short history. Human Immunodeficiency Virus (HIV) and the later stage of the HIV infection, Acquired Immune Deficiency Syndrome (AIDS), began to emerge as a public health threat in the early 1980s. Since that time, it has claimed over 571,378 lives in the United States and, worldwide, over 25 million. In addition, it is currently estimated that there are over 1.1 million persons living with HIV/AIDS in the United States (World Health Organization [WHO], 2009). It is now known that the virus is transmitted through blood, semen, vaginal secretions, and breast milk (Rathbun et al., 2006).

The virus attacks the immune system of the infected person creating weakness in the individual's ability to fight infections, viruses, and other diseases. A person who has tested positive for the virus is known as HIV positive (HIV+). In an HIV+ person, opportunistic infections (such pneumocystis pneumonia, extrapulmonary tuberculosis, or cytomegalovirus) eventually overwhelm their compromised immune system and the virus progresses to the later stage of AIDS, which occurs after at least one opportunistic infection or when the CD4 count falls below 200. The CD4 count refers to the number of cells per unit that are available to fight the infection. The virus kills the CD4 cells. It also

copies itself using cellular RNA, thus becoming more numerous. The number of viral cells per unit is known as the viral load. Usually following numerous infections and the increased replication of the virus, a person with AIDS succumbs to one of these opportunistic infections. For those persons who have been successfully treated with the antiretroviral medication therapies, the deterioration of the immune system is sometimes slowed, or even reversed, making the person less vulnerable to opportunistic infections.

It is thus possible for a person who has AIDS to revert back to an HIV+ status. To complicate an understanding of the diagnosis further, a positive HIV test initially diagnosed a person with AIDS regardless of blood levels. In the history of the disease, the distinction between AIDS and HIV came later, after the patterns of the illness were understood. It is thus possible for a person to have had AIDS, then HIV, and then either HIV or AIDS. In this study, unless the status is absolutely known or is referring to a particular status, HIV/AIDS was used. However, within the narratives of the men who are living with HIV/AIDS, in the majority of cases, these terms were used interchangeably by the participants.

A Brief History

The virus which claimed its first known victims in 1980 was initially named the “gay man’s cancer,” because it originally appeared to target gay men in urban centers (Shilts, 1987). By the time the virus was identified and a test to discover the presence of the virus developed, HIV/AIDS was recognized as a full blown epidemic with no cure, no vaccine, and no effective treatment options on the horizon. It took several years to link

the babies dying shortly after birth, the post blood transfusion deaths, and what appeared to be a sexually transmitted cancer to its common source — a virus attacking the immune system (HIV). Ignorance and apathy contributed to what Shilts (1987), the author of *And the Band Played On*, described as resulting in “a profoundly threatening medical crisis,” with “few who were willing to confront it” (p. xxiii).

The next ten years of the HIV/AIDS epidemic were mostly punctuated by an ever-increasing number of funerals. It soon progressed from a gay man’s disease to a disease affecting any man, woman, or child, without discrimination. Today over one half of persons with HIV in the United States are women and over half are minorities, with black women being 23 times more likely than white women, and four times more likely than Hispanic women, to become infected (CDC, 2008). Over 80% of new cases of HIV among women were transmitted heterosexually via a “committed” partner. Despite the common perception that men have sex with men and then transmit it to women, the 2009 behavior study of heterosexuals in Washington, DC, reported that 96% of the men studied reported only heterosexual contact (Heterosexual Relationships and HIV in Washington, DC, 2009).

In 1996, fifteen years after the first known AIDS related death, the first successful antiretroviral medications came onto the scene, extending the lives of persons with HIV/AIDS. Though these medications are frequently accompanied by difficult side effects and significant medication adherence issues (Rintamaki, Davis, Skripkauskas, Bennett, & Wolf, 2006), they have nonetheless facilitated a decline in AIDS related

deaths since 1996. The pandemic, now into its third decade, boasts a growing population of aging adults whose concerns extend beyond survival to enhancing quality of life with HIV. In addition, clinical attention has transitioned from helping individuals die with AIDS to helping individuals live with the chronic, life-long illness.

Spirituality, Attachment, and Living with HIV

A growing area of investigation has focused on spirituality as a factor influencing the quality of life of persons living with HIV/AIDS. For the purposes of this study, the definition of spirituality will be the one proposed by Pargament (1995), as the “search for the Sacred” or the “process through which people seek to discover, hold on to, and when necessary, transform whatever they hold Sacred in their lives” (p. 7). This definition has been selected to offer a broad enough definition to encompass the wide spectrum of terms that are used throughout the existing research. Therefore, the terms “spirituality,” “religiousness,” “God,” and “the Sacred” will occur interchangeably throughout this study with all referring to spirituality. This definition was also selected to incorporate the manifestations of spirituality that are used in the research and theory on attachment, a theory that examines the beginnings, maintenance, and termination of interpersonal relationships (Bowlby, 1969/1982, 1973, 1980). In attachment theory, spirituality is often understood as being expressed through the pathway of the Internal Working Model that underlies relationships (Bowlby, 1969/1982). In the current study, as well as other attachment research (Hall, 2007b; Ledoux, 1996), spirituality is viewed as an explicit

process (occurring consciously through observable behaviors), as well as an implicit process (evident through storytelling and its tendency to uncover the unconscious).

Several researchers have found that the use of spirituality as a coping mechanism has enhanced the quality of life for many HIV/AIDS infected persons (Fryback & Reinert, 1999; Ironson, Stuetzle, & Fletcher, 2006). A study by Siegel and Schrimshaw (2002) supported the notion that the practice of spirituality can slow the progression of HIV/AIDS in some individuals. A higher level of spirituality has been linked with treatment and medication adherence (Parsons, Cruise, Davenport, & Jones, 2006).

In addition, there is some research that has suggested that spirituality is potentially significant to attachment relationships in a person's life (Hall, Halcrow, Hill, & Deleney, 2005; Kirkpatrick, 2004). Attachment theory is based upon the premise that humans are biologically predisposed to seek out an attachment figure to provide a "safe haven" under times of distress, in order for the individual to gain a sense of safety and security (Bowlby, 1969/1982). An individual's attachment behavioral system is activated when a threat prompts the person to seek the close proximity of the attachment figure for protection. According to Ainsworth (1985), an attachment figure is someone who provides care, comfort, and a sense of security, and who is so central to the well-being of the individual that anxiety and grief may occur when the individual is separated from the attachment figure. When the distressed person feels a sense of security after achieving proximity and an accompanying sense of comfort, the attachment system alarm is deactivated (Bowlby, 1969/1982; Mikulincer & Shaver, 2007). When adults are

threatened, God reportedly serves as an integral attachment relationship for many individuals (Granqvist, 2006; Granqvist & Kirkpatrick, 2004; Hall, 2007a; Hall et al., 2005; Kirkpatrick, 2004) and fits Ainsworth's (1985) definition of an attachment figure. In this study, it was presumed that the diagnosis of HIV/AIDS would have served as a health threat sufficiently severe to activate the attachment system of the diagnosed individual. The role of spirituality in the study participants' lives was examined to determine if or how the participants used God or spirituality as a safe haven to manage the distress of living with HIV/AIDS.

The study of attachment theory as it relates to the pandemic of HIV infection is currently quite limited. Two studies, both utilizing the same sample, have addressed attachment styles and adjustment to the diagnosis (Turner-Cobb et al., 2002) and attachment styles and perceived social stress (Koopman et al., 2000). Turner-Cobb et al. found that those who were more satisfied with their relationships, securely engaged with others, and more directly engaged in their illness, experienced greater adjustment to living with HIV/AIDS. Koopman et al. found results that indicated that persons diagnosed with HIV/AIDS experiencing the greatest stress were those with lower income, those who disengage behaviorally and emotionally in coping with their illness, and those who tend to be more anxious in dealing with their interpersonal relationships. Both of these studies suggest the importance of the development of relationships in coping with the diagnosis of HIV/AIDS.

There is presently no research specifically investigating the influence of spirituality on older men living with HIV/AIDS (Brennan, 2008). In addition, no known research has examined the relationship between attachment and spirituality and its influence on older men with HIV/AIDS coping with their chronic illness. As a result, there is a need for expanding the body of literature addressing life with HIV/AIDS as a long-term chronic illness among older men.

Purpose of the Study

This study examines the interface between attachment and spirituality among late middle-aged and older men who have been diagnosed with the chronic and life-limiting illness of HIV/AIDS. This research is intended to provide preliminary information regarding the lives of older men and their management of their illness in order to inform future research in this area.

Research Question

For men, age 50 and older, living with HIV/AIDS as a chronic illness, what is the interface of their attachment system, their implicit and explicit expressions of spirituality, and their experience of coping with this life-limiting illness?

Methodology

This dissertation research is a qualitative narrative study of men, aged 50 and over, who are living with HIV/AIDS. Based on a constructivist epistemology (Denzin, 2008), the study explores how seven older men constructed stories about their lives with this chronic illness and how these men believed that spirituality and relationships affected

their quality of living. Narrative stories reflect the internal working models of the storyteller, providing a “gut level, implicit model of how to relate to emotionally significant others” (Hall, 2007a, p. 33). A narrative is defined using Polkinghorne’s (1995) definition, which is a discussion of causal relationships, organized around a plot, with a beginning, middle, and an end. In this study, themes from the individual narratives were analyzed from the four-level approach proposed by Murray (2000) for examining health narratives. More details about the methodology will be presented in Chapter III.

Significance to Social Work

This study provides preliminary understanding of the relationship between attachment and spirituality in the lives of older men living with the diagnosis of HIV/AIDS in the beginning of the twenty-first century. To date, there has been no research examining the relationship between attachment and spirituality among persons living with HIV/AIDS. Because men, 50 and over, comprise one of the fastest growing segments of the population with HIV/AIDS (Brennan, 2008), it is important to understand issues that may be unique to this group. Given the chronic nature of the illness, these persons are destined to need increasing services from the social work profession. Knowledge from this study will contribute to the social work profession’s understanding of the provision of services to the population of older men with HIV/AIDS.

Investigator's Interest in the Problem

As a person who seems to have a story for everything, I am struck by the difficulty of constructing a meaningful narrative to explain and validate my interest in this social problem. My story is like the lazily winding river passing through a life of silently disappearing people. That long river has doubled back countless times for me to catch the driftwood of the medical crisis that first appeared the same year as I was graduating high school. I followed the social tidewaters of my culture believing that this illness would be controlled and forgotten, as many of the deadly diseases of my parents' generation.

I was the generation raised on post World War II science. I watched the pests disappear from the cornfields and the weeds disappear from the garden. I enjoyed the benefits of miraculous antibiotics and witnessed the marvel of anti-depressants. I was taught that it was all good and there was nothing that could not be controlled. Despite the mysterious, and whispered about, deaths of classmates and acquaintances, I remained in the lethargic flow of the social denial that a silent killer walked among us tapping shoulders for premature deaths.

By the time I finally understood it, dozens of personal deaths and illnesses later, I had turned my professional career to child welfare and was trying to improve the lives of children in Washington, DC. But the narcotic of denial could not withstand the countless confrontations with HIV/AIDS among the families served by the child welfare system. I became acutely aware that as the public attention faded from this issue, I was encountering an increasingly alarming number of infected persons.

From these persons, the stories of the search for meaning to explain this disease began to strike at my conscience. It was the stories of individual encounters with this illness and the understanding of its presence in their life that tugged at my passion. As a witness to their struggle, I became acutely aware of the individualized importance of the role of the meaning of the illness in the life of the person with HIV/AIDS, to the intimate friends and families, to the professional caregivers and to me as the third party witness whose task it was to ensure the well being of the children within the family.

It became my turn, not to lift the banner of the HIV/AIDS pandemic into the air, but rather to wade into the rivers of those who have lived with the illness. I hoped to feel the currents of their relationships with others and their relationships with the Sacred. Through this witnessing, I became part of the meaning of this experience in their lives. And inevitably, they became part of the meaning of mine.

Summary

The HIV/AIDS crisis of the 1980s has mutated from a gay man's cancer to a global pandemic that does not discriminate among its victims. It has likewise become a chronic illness for many and not the terminal sentence of death that first characterized the virus. While a cure remains elusive, there are a variety of treatment options, which have resulted in a growing population of older adults entering their later years with the added challenge of managing their illness.

How older individuals currently live with HIV/AIDS is not well-known. However, it is known that adults who feel distressed or threatened—such as those diagnosed with a life-threatening illness—turn to an attachment figure for comfort. It is

further known that some adults turn to God or spirituality as a means of coping with severe chronic illness. In this study, it was anticipated that persons with HIV/AIDS may have found support in this manner. For these reasons, this qualitative study explored the relationship between spirituality and attachment with the goal of deepening understanding of how these variables facilitate coping for older men who have lived with HIV/AIDS as a chronic illness. In order to understand the presence or absence of a spiritual practice or beliefs in their life, the participants were asked open-ended questions about their early attachment histories, the development of their relationships, and the role of spirituality in their lives. Both explicit and implicit expressions were explored within the interviews to discern the connection of attachment relationships and the relationship (or lack of relationship) to spirituality. Finally, the participants in the research were asked to describe the influence of their spiritual development in living with HIV/AIDS and the influence of living with HIV/AIDS upon their spiritual life.

The following chapter presents a historical overview of the development of HIV/AIDS into its current status as a chronic illness. In addition, the theories underlying this research study are delineated in more detail. Basic concepts of attachment theory are discussed as they relate to the management of stress in adulthood. An overview of existing research as it relates to spirituality and attachment is provided to illustrate how God can be viewed as an attachment figure. The limited research studies on attachment and HIV are reviewed and serve to highlight the need for more specific research on older men living with HIV/AIDS.

CHAPTER II

REVIEW OF THE LITERATURE

The growing population of men over 50 diagnosed with HIV/AIDS presents unique challenges to the social work profession. Life as an aging man living with HIV is an unexplored phenomena in the early twenty-first century. This population must be integrated into the overall aging population with services designed for their particular needs resulting from aging. In order to provide a preliminary exploratory glimpse into their specific needs, their individual stories were collected regarding their attachment relationships, their spirituality, and their experience of their illness.

Before delving further into this existing research, it is critical to establish a historical framework of the progression of HIV from a nearly always fatal illness to a mostly manageable, chronic illness. This sets the stage for introducing the literature on HIV and spirituality. With this foundation, the connection between attachment theory, spirituality, and HIV in older men can best be glimpsed despite the absence of direct research in this area.

HIV Progression to a Chronic Illness

The syndrome was first identified in 1981. The first official name was GRID, an acronym for Gay Related Immune Disorder. The unofficial name was “gay man’s cancer” describing the syndrome as mostly occurring in the gay community and often presenting as a cancer (Shilts, 1987). In 1983, the virus was identified and a subsequent blood test was developed. If the blood test was positive, the person was diagnosed with

AIDS. Until 1989, there was no medical treatment for AIDS. Prior to 1989, a drug named AZT was frequently prescribed on an experimental basis, although AZT was later understood to have been toxic for many persons at the recommended dosage levels. The only other treatments were antibiotics for the infections (Vermund, 2006).

Walensky et al. (2007) estimated survival rates in accordance with the development of new treatments. These rates are compared to a person diagnosed with AIDS and not receiving treatment. In 1989, two treatments became available for two of the more common opportunistic diseases. This was considered the pre-ART era when PCP and *Mycobacterium avium* complex prophylaxis were available. This treatment extended the life of an AIDS patient by 1.7 years. In 1996, the first antiretroviral (ART) therapies were administered. With the receipt of first generation ART in 1996, the median survival was boosted to 7.4 years. By 2003, the fourth generation of ART had raised the median survival to 14.1 years. The anticipated median survival rate continues to rise as these men age and newer treatments are developed.

HIV and Spirituality

With the introduction of ART as a treatment option in 1996, the diagnosis of HIV began its migration away from a terminal illness to a chronic illness (Brennan, 2008). With this shift came a broadening of the research of those diagnosed with HIV/AIDS, attending to quality of life and maintaining well being. To facilitate quality of life, complementary and alternative medicine (CAM) use was frequently reported by persons with HIV. A form of religion/spirituality appeared on these lists of CAM establishing it as in some way contributing to coping and well-being. Accordingly, the

role of spirituality in achieving these goals of well being has been studied, revealing several connections between spirituality/religiousness and living with HIV (Barroso & Powell-Cope, 2000). However, the “why” of the effectiveness and popularity of religion/spirituality as a CAM remains a mystery.

In a qualitative study of older men and spirituality, Siegel and Schrimshaw (2002) identified several perceived benefits associated with spirituality, defined by them as “the Sacred”. Nine themes emerged from the 63 interviews of older men with HIV. The findings suggested that spirituality provided a sense of comfort, a sense of strength, control and empowerment over the illness, offered relief from the burden of illness, offered social support along with a sense of belonging, offered a personal relationship with God, helped create a sense of meaning in the illness, preserved health, provided comfort in facing death, and facilitated self acceptance and reduced self blame. These benefits were considered to enhance the adjustment to living with the illness.

Moreover, some studies seem to indicate a positive connection between the practice of spirituality and enhanced immunity. Coyle’s (2000) study found that spiritual practice and beliefs decrease levels of stress and provide a greater sense of well being. Ironson et al.’s (2006) longitudinal study of 100 diagnosed men, conducted over a series of four years, also found a significant difference in disease progression among those who reported that spirituality/religiousness was important in life and those who did not. Their research further suggested an increase in the level of

spiritual/religiousness beliefs and practice following the diagnosis of HIV/AIDS. When measuring spirituality/religiousness before and after the diagnosis, 45% of the participants showed an increase, 42% remained the same, and 13% showed a decrease following diagnosis. In another unpublished study of HIV-diagnosed men, over age 50 and living in New York City, church attendance was used as a measure of religiousness. In that study, 67% stated that their participation had not changed, while the remaining 33% were split between those who attended less often and those who attended more often (Cited in Brennan, 2008).

Spirituality among persons living with HIV/AIDS also has been studied to determine if there was any relation to medication adherence for those taking antiretroviral treatments. Kremer, Ironson, and Porr (2008) conducted a qualitative study of 79 HIV+ participants who had been offered antiretroviral medications by their doctors. Over 50% of those interviewed called upon spirituality and spiritual beliefs in their decision about whether to take the medications. In addition, those who reported a belief that spirituality helped them cope with medication side effects also reported experiencing fewer side effects. Overall, spiritual beliefs were a motivator in medication adherence. In contrast, some participants reported spiritual beliefs as the reason for not taking medications, as they tended to believe that God would take care of them.

It is noteworthy that to date, there is no research directly addressing older men with HIV and the influence of spirituality in their lives. Those over 50 are facing

different issues than their younger cohorts. Attachment processes and their relationships, the medical impact of HIV on the aging man, and a changing developmental perspective on spirituality which occurs in later life all present a unique set of variables acting upon this population. Increasingly, this emerging cohort, by virtue of its medical and aging needs, also will populate the clientele served by the social work profession.

Overview of Attachment Theory

Attachment theory is founded upon the observation that an infant is biologically predisposed to establish an attachment with a caregiver, usually identified as the mother (Bowlby, 1969/1982). This attachment is not tied to meeting the basic physiological needs of food and bodily care, but is rather based on the evolutionary premise that close proximity to the caregiver serves to protect the infant from predators. Bowlby described attachment as a behavioral system that is activated when the child is stressed or in danger or deactivated when safety is re-established through seeking proximity. Depending upon the degree of the threat, the deactivation may be as simple as a soothing tone or as intense as prolonged physical contact. According to Bowlby (1969/1982), the availability of the caregiver to consistently resolve this activation will initially determine the infant/child's development of a sense of security, and later, the development of a general internal working model (IWM) of attachment, which serves to inform the child's relationships across the lifespan.

There are four basic types of attachment styles that have been identified in the research and are thought to shape the attachment behavioral system from early

childhood (Main, 1991). A child who has a secure attachment feels secure or confident in the availability of a caregiver to provide care. Children with avoidant attachment styles tend to minimize the need for care from the attachment figure and are more likely to avoid intimate relationships. Ambivalently attached children tend to display distress when reunited with their caregiver and are very difficult to soothe. The fourth attachment style – disorganized – is considered a disordered pattern of attachment, because the child's behavior becomes confused and disorganized when the attachment system is activated. These children behave unpredictably, tend to be unsure of the caregiver's anticipated response, and have difficulty modulating affect (Main, 1991).

Bowlby (1969/1982) believed that these attachment patterns become integrated relational behaviors that characterize the child's style of relating throughout life, though these patterns are dynamic and subject to change, based on later relationships and emotional experiences. When the child fails to develop a secure attachment with a primary caregiver, the avoidant, ambivalent, and disorganized patterns tend to manifest themselves in future relationship difficulties (Basham & Miehl, 2004). These patterns are often reflected in adulthood in a dismissing (or avoidant), preoccupied (or anxious), or disorganized (or unresolved) style of relating (Mikulincer & Shaver, 2007). The underlying schemas of infancy and childhood are layered and reworked with new relationships and experiences. In other words, the child's IWM continues to evolve during the development of the child and throughout the lifespan of the adult.

Mikulincer and Shaver (2007) theorize that in adulthood, when a situation is appraised as threatening, the attachment system continues to be activated. For adults who have a generally secure history of attachment, this activation evokes positive feelings and memories of being cared for and protected. For those adults with a relatively insecure attachment system, the threats provoke negative images, thoughts, and feelings, and a sense of not being protected or cared for. Consequently, while being activated to seek proximity with a caregiver, these adults also experience simultaneous feelings of anxiety, ambivalence, and apprehension. In order to achieve the goal of proximity, insecure adults will employ an alternative strategy of either deactivating or hyper-activating the attachment system. Those who are more avoidant will deactivate the system in times of stress and become self reliant, while those who are anxious will hyper-activate the system in the hopes of achieving proximity through exaggerated distress (Shaver & Mikulincer, 2002).

The diagnosis of HIV or AIDS presents an immediate and mortal threat to the survival of an individual. In accordance with attachment theory, this threat likely would activate the attachment system, represented by the seeking of close proximity to an attachment figure. To successfully deactivate this alarm system, a sense of security would need to be re-established. For an adult diagnosed with HIV/AIDS, this seeking of security may appear in various forms.

There is limited current research utilizing attachment theory to better understand the lives of those living with HIV as a chronic illness. Two studies that are taken from

data secured from the same sample group provide a narrow glimpse into this area of research. Turner-Cobb et al. (2002) used a sample of 137 HIV+ adults to examine the psychosocial correlates of adjustment to living with HIV. Their findings suggested that those persons who had more secure attachment styles, who experienced more satisfaction with their social support, and who utilized less behavioral disengagement techniques, had more positive adjustment to living with HIV. Koopman et al. (2000) conducted a study that included 147 HIV+ participants who reported on coping strategies, attachment styles, and perceived social supports associated with perceived stress. Those persons who reported more anxious or less secure attachment styles perceived more stress in their lives. In addition, those who reported greater use of disengaging behaviors as coping strategies for dealing with their HIV also reported greater perceived stress in their lives. This perceived stress was enhanced for those who reported lower incomes. Both of these studies utilized solely quantitative measurements. Neither study investigated the origins of the attachment styles, the development of the styles over time, or any association of the styles in relation to the diagnosis. Nevertheless, these studies demonstrate the potential usefulness of attachment relationships in the lives of these adults, although the research does not provide the specifics about the composition of these relationships.

Attachment Theory and Spirituality

This dissertation research addresses the role of attachment and spirituality or religiousness. For the purpose of this study, “spirituality” and “religiousness” are used

interchangeably because much of the existing literature fails to make a distinction between the two terms. Spirituality is defined in this study as “the “search for the Sacred” or the “process through which people seek to discover, hold on to, and when necessary, transform whatever they hold Sacred in their lives” (Pargament, 1995, p. 7). As an attachment figure/caregiver, God may offer a sense of well being as an attachment and as a bridge to other attachments and support (Kirkpatrick, 2004).

To begin this discussion, it is necessary to first establish that God meets the fundamental criteria as an attachment figure. In his research on attachment and spirituality, Kirkpatrick (2004) references the characteristics of an attachment figure established by Ainsworth (1985). As an attachment figure, God must represent more than a close or significant relationship. Ainsworth identified five major characteristics of an attachment figure. First, the attached person seeks close proximity to the attachment figure in times of threat or alarm. Second, the caregiver (e.g., God) provides care and protection – often referred to as the haven of safety function. Third, the caregiver provides a sense of security – the secure base function of the attachment figure. In addition, the threat of separation results in anxiety for the attached person. Finally, loss of the attachment figure would cause grief for the attached person. In the following discussion and review of the research on attachment theory and spirituality, the assumption is made that God meets the criteria of an attachment figure for many individuals (Kirkpatrick, 2004).

Spirituality and Development of Attachment System

As an infant matures into early childhood, the attachment system becomes more goal-corrected (Bowlby, 1969/1982). This development allows for the beginning of symbolic representations, which permit longer separations from the primary attachment figure. With this emergence of symbolic representation, the child can experience the caregiver without the physical presence of the caregiver. This symbolic representation can then be generalized to a religious symbol, such as God, who is not concretely experienced by the child (Granqvist & Kirkpatrick, 2008). In addition, at this time in development, the child begins to form what is called “the theory of mind” – an understanding that other persons have individual thoughts driven by their own motivation that are different from that of the child (Wellman, 2002). If a child is exposed to the concept of God during this developmental process, God can easily be integrated into the child’s cognition (Granqvist & Kirkpatrick, 2008).

Given this exposure to the concept of God, Granqvist and Kirkpatrick (2008) summarize the developmental process through middle childhood and older adulthood as varying in intensity, depending upon the developmental tasks. As the child moves through middle childhood, he or she begins to view God as a safe haven, which sets the stage for adolescence, when peers usually replace the primary attachment figures from early childhood. It is during the adolescent phase that religious conversions are most common (Granqvist & Kirkpatrick, 2004). Middle adulthood is usually associated with the maintenance and transmission of spirituality and usually represents religious

stability unless an activating crisis occurs, such as divorce or a life threatening illness.

Relationship with God regains importance during older adulthood when separations, loss, and one's own mortality take on a greater significance. Although the study of religion/spirituality stretches back thousands of years and attachment theory spans several decades, the application of attachment theory to spirituality did not begin in earnest until the 1990s. Consequently, the current research is evolving and tends to include gaps and overlapping conceptualizations that are challenging to navigate. Nonetheless, there are two distinct areas of research combining attachment theory with spirituality. The first cluster of research studies link parental attachment histories with adult attachment relationships with God. The second cluster of research focuses upon the internal working model, neuroscientific study of the brain, and the way persons "know" God via implicit and explicit expressions of spirituality.

God as an Attachment Figure

Research on the main effects of attachment style upon later attitudes toward God as an attachment figure has repeatedly concluded two results. First, people with secure characteristics tend to view God as more loving and caring than those with insecure characteristics, who tend to have an image of God as controlling and distant (Granqvist & Hagekull, 2001; Kirkpatrick, 2004; Kirkpatrick & Shaver, 1992). Second, persons with insecure characteristics have a religiosity that seems to be less stable over time, often resulting in sudden religious conversions (Granqvist & Kirkpatrick, 2004). Other main effects of attachment are found to be consistently weak or non-existent (Granqvist,

2006; Hall, 2007; Kirkpatrick, 2004). The Correspondence Model, the Social Correspondence Model, and the Compensation Model were developed in order to interpret these consistent findings.

The correspondence and social correspondence models. Kirkpatrick (2004) hypothesized that if God is assumed to be an attachment figure, this relationship should parallel the child's early experience with parental attachment figures. Thus, securely attached adults would view God as possessing the positive characteristics of an attentive caregiver, while those with insecure attachment histories would view God as possessing a more distant, less intimate caregiving style. Granqvist (2002) applied an alternative interpretation to the data. In what he termed as "socialized correspondence," he referred to correspondence as the parallel between a person's religious beliefs and the religious beliefs of the person's parents. In this interpretation, secure attachment lends itself to the adoption of the parents' religion; whereas, insecure attachment does not facilitate the adoption of the parents' religious beliefs. These explanations, though somewhat contradictory, have become integrated into a two-level hypothesis, which, according to Kirkpatrick (2007), acknowledges the variance in socialization experienced on an individual level.

The compensation model. Another hypothesis has emerged to explain the presence of sudden religious conversions among insecurely attached persons. This interpretation asserts that when the attachment system is activated and there is no adequate caregiver available, a person may turn to God to compensate or substitute for

the absent attachment figure. In Kirkpatrick and Shaver's (1990) original exploration into the occurrence of sudden religious conversions among adults and adolescents, they discovered that those who reported insecure parental relationships were more likely to have experienced sudden religious conversions. Among those participants reporting their childhood relationships with their mother as being avoidant, 44% reported having had a sudden religious conversion. For those who reported this relationship as being secure or anxious, the rates of sudden religious conversion were 8% to 9% respectively. In an attempt to replicate these findings, Kirkpatrick (2004) reported finding similar results. However, in this study, it was the parental relationship with the father that was significant. Thirty percent of participants with avoidant paternal relationships experienced sudden religious conversion, compared to 5% to 6% in the other groups. Two studies conducted in Sweden (Granqvist, 1998; Granqvist & Hagekull, 2000) reported similar findings, with both maternal and parental avoidant childhood relationships serving as significant predictors of sudden religious conversions later in life. Finally, Granqvist and Kirkpatrick (2004) conducted a meta-analysis on combined data from these studies ($N = 1,465$), revealing similar results. The rate of sudden religious conversions was significantly higher for those reporting insecure (anxious and avoidant) childhood relationships with mothers (9.3%), compared to secure relationships (5.7%). No significant effects were observed for gender or the interaction between attachment and gender (Granqvist, 2003).

Neuroscience and Internal Working Models

While Kirkpatrick, Granqvist, Shaver, and Hagekull were forming and reforming hypotheses about parental attachment styles and religious attachments, a body of knowledge was emerging that linked neuroscience and brain development with the aspect of attachment theory referred to by Bowlby as the internal working model (IWM), discussed above. According to Fonagy and Target (1997), the original formulation of IWM lacked specificity. However, current literature from those actively researching this aspect of attachment theory appears to have blossomed into a myriad of terms that explain what Bowlby referred to as the IWM.

The search for understanding an application of the IWM seems to be a critical aspect of current research in attachment theory. Many of these ideas have not yet been specifically linked to research on attachment and spirituality; however, they are nonetheless an important contribution to understanding of attachment. These terms refer to neurological activities that are closely linked, sometimes overlap, and originate in the same area of the brain.

Fonagy (2003) begins his summary of the theory in this area by introducing a new term – the Interpersonal Interpretive Mechanism (IIM). He defines the IIM as the mechanism for processing new information. He admits that this IIM overlaps with the concept term, Theory of Mind, which is “the ability to attribute independent mental states to self and others to explain and predict behavior” (Fonagy, 2003, p. 226). Attempts to link this Theory of Mind to specific areas of the brain seem to indicate that

humans are hard-wired to achieve this maturational function (Schoore, 2000). In addition, others have referred to the capacity as mentalization, implying a process whereby mental representations of mental states are created (Fonagy & Target, 1997). The introduction of the Interpersonal Interpretive Mechanism appears to be intended to establish an umbrella term for what Fonagy (2003) called “the neurocognitive mechanisms that are naturally selected to evolve under the influence of early social interactions (predominantly) with the attachment figure and that serve to mediate the impact of the quality of early relationships into adult personality functioning” (p. 226). These mechanisms include affect regulation and implicit and explicit functioning. In addition, according to Fonagy, these mechanisms may include many other components that ultimately bring early attachment relations into play in the adult personality. Each of these terms is associated with neurological activity that originates in the right hemisphere of the brain (Shore, 2000).

Implicit and Explicit Religious Functioning

Bowlby (1969/1982) originally proposed that the IWM was primarily comprised of two models. These models, referred to as the Environmental Model and the Organismic Model, are sometimes referred to as the explicit knowledge and the implicit knowledge of mind, effectively facilitating the body-mind connection (Schoore, 2000). Neurologically, Ledoux (1996) describes explicit knowledge as conscious knowledge. It is linear and exists in images and words often referred to as the “high road” of brain circuits based in the pre-frontal cortex (primarily on the left side of the brain). It is

responsible for analytic and abstract reasoning. In contrast, implicit knowledge is unconscious or “gut-level” knowledge. It is carried in our bodies, emotions, and in our stories (Hall, 2007a). Ledoux describes the implicit knowledge as “low road” brain circuits, located primarily on the right side of the brain involving activity in the amygdala.

Hall et al. (2005) approach the existing attachment research on spirituality from an interpretation based upon the concepts of neurological functioning. These researchers chose to conceptualize spiritual attachment through the lens of implicit and explicit functioning. Implicit spiritual functioning focuses “on automatic, pre-symbolic, emotional informational processing”, whereas explicit spiritual functioning focuses on “symbolized beliefs and behaviors” (Hall et al., 2005, p. 21). In two studies performed by Hall et al., they found differences in the implicit functioning, but no differences in the explicit functioning of different attachment groups. This research illustrates that the relationship between attachment histories and adult expressions of spirituality may best be captured through narrative analysis and its expressions of implicit spiritual functioning. The social correspondence model and the compensation model of spiritual functioning may no longer contradict one another if the models were based upon implicit indicators of spiritual functioning as opposed to the former use of explicit measurements.

Summary

This chapter presented an overview of existing literature and research on attachment theory and spirituality, which together served as an underpinning to the research question. Simultaneously, this review emphasized the paucity of research in this area of study. Attachment theory establishes the framework for the examination of various relationships and how an individual may react when faced with the stress of an HIV/AIDS diagnosis. Spirituality serves as a source of support for many people and often leads to a personal relationship with God. The literature suggests that it is the individual's attachment history that influences a connection to spirituality and, in turn, gives meaning to the event of living with chronic illness.

The following chapter discusses the methods used in this study to capture the meaning the study participants revealed in their narratives about living with HIV/AIDS. It is hoped that the findings of the analysis, which follows the methodology chapter, will fill some of the gaps in the existing literature and, perhaps, throw a dim light into new possibilities for exploration.

CHAPTER III

METHODOLOGY

The previous two chapters focused on an introduction of the question under study and a review of the theory that underlies the research question. In this chapter, the methodology that was utilized in this study is described. The methodological approach was deliberate – intending to create a coherent, honest depiction of relational attachments, including the spiritual, in the lives of older men living with HIV/AIDS. As previously mentioned, the research question that was the focus of this study was as follows:

For men, age 50 and older, living with HIV/AIDS as a chronic illness, what is the interface of their attachment system, their implicit and explicit expressions of spirituality, and their experience of coping with this life-limiting illness?

Research Design

Epistemology

A constructionist epistemological perspective was used in this study to frame the research design and address the research question. From this perspective, realities are multiple and exist in each individual's mind. Therefore, each interaction with an investigator results in the construction of a unique reality (Denzin, 2008). The transactional action of the interview produced its own reality peculiar to the elements in the interview and the interpretation of the interviewer and the reader. Polkinghorne (1998) likens this process to emergent theory where two distinct elements, such as

hydrogen and oxygen, combine to create a complex compound, such as water, which is distinct from the elements but dependent upon them. The construction of the following story, as told by the participants, emerged from the interaction occurring within the interview processes, which provided direction to the interviews. This interaction was subsequently funneled through the socio-historical context of the participants and the investigator, which created an interpretation unique only to this writing.

Smith and Osborn (2003) surmised that there is a two-level hermeneutic analysis occurring in a qualitative study with this design. The participant is trying to make sense of his world, while the investigator is trying to make sense of the participant making sense of his world. There are numerous types of narrative analysis available to the researcher. The choice of analysis, described below, influenced the construction of the reported reality, thus closely linking the constructivist epistemology and the narrative analysis into an effective methodology for this research.

Narrative Analysis

The writings of Donald Polkinghorne (1995) guided the analysis utilized in the current study. Specifically, Polkinghorne (1995) stressed the importance of “narrative configuration,” defined as “...the process by which happenings are drawn together and integrated into a temporally organized whole” (p. 12). Thus, the development of the plot of the story was critical in determining the meaning of the story. This form of analysis seemed particularly relevant to the narrative analyzed in this research. Since the meaning of the story depended upon the plot, the constructionist perspective was revealed by the

opportunity for the investigator to identify the plot. The plot was ultimately defined by the investigator, based upon the knowledge and experience brought to the interviews, the questions asked to guide the interviews, the answers provided by the participants, and the interpretation of these elements into the whole.

Given that the “plot” was dependent upon a particular historical point in time, under particular social and economic conditions, and with a particular presentation of the illness, the plot would have been quite different if the study were conducted in the past or if the study were to be conducted in the future, when circumstances inevitably change. In other words, the meaning of a narrative is dependent upon the time-sensitive plot. In a narrative relating to having HIV/AIDS, for example, the development of a new treatment, the failure of an existing treatment, the loss of health insurance, or the natural process of aging shifts the meaning of the experience and, hence, the plot development.

In addition, narrative stories reflect the storytellers’ internal working models of attachment, providing a “gut level, implicit model of how to relate to emotionally significant others” (Hall, 2007a, p. 33). Stories reveal both unconscious and conscious understandings and experiences enriching the details and highlighting the significance of events. Thus, narrative analysis is particularly well suited for the research question of this study and the underlying concepts of implicit and explicit expressions of attachment theory.

Sample

In this study, a non-random, purposeful sample consisted of men who were at least 50 years old and had been diagnosed with HIV/AIDS. Neither the sexual orientation of the participants nor the duration of their illness was considered in the parameters of the sample. Following approval by The Catholic University of America Internal Review Board (IRB) for the protection of human subjects, seven participants were recruited through acquaintances and snowball sampling methods, meaning that they were selected based upon availability (Padgett, 1998). Each participant was asked to refer anyone he knew who fit the criteria of the study and might be willing to participate. A pilot interview was conducted prior to the recruitment process, and though the pilot interview was not included in the findings, this individual was critical in the recruitment process. As a member of a spiritually based support group for HIV+ persons, he was able to post an announcement on the group list serve (Appendix A). The pilot participant's non-denominational support group served as an excellent resource of persons who gave personal consideration to the role of spirituality in their lives following diagnosis. Another resource that proved invaluable was the posting of the announcement to social work professionals working in the DC area.

Interview Guide

Prior to the scheduled interviews, a semi-structured interview guide was created and tested through an interview with the pilot participant. After revisions, the finalized interview guide consisted of general questions designed to direct the discussions

regarding the participant's perceptions of coping with a life-limiting illness, his attachment system, and his implicit and explicit spirituality (Appendix B). Probe questions were used to gain clarification. The initial guiding questions were based upon the literature review regarding attachment and/or spirituality as they pertain to HIV/AIDS. Questions used in follow up interviews focused on clarification, as well as themes that emerged from other participant interviews. The semi-structured approach provided an opportunity to establish rapport, generated an opportunity to probe areas, and allowed the investigator to be flexible with the ordering of questions, providing freedom to examine areas of further interest (Smith & Osborn, 2003).

Data Collection

Data consisted of transcriptions of audio-recorded, in-person interviews with the seven participants interviewed by the investigator on two to four occasions to achieve an in-depth narrative of their experiences. A total of 16 interviews were conducted and occurred at locations designated by the individual participants (their home, a coffee shop, the investigator's home, and over the telephone). Duration of each interview considered the health status of the participant and lasted one to two and one half hours. Recorded interviews were transcribed into Word documents using DragonSpeak 10.0 software, which enabled the spoken word to be directly transcribed into the computer. These Word documents were then edited for accuracy by the investigator. Additional data included the investigator's detailed field notes and personal journal about the interview process.

Data Analysis

Interviews from each participant were gathered to form an individual set of transcribed data for each participant. A participant's narrative was highlighted in a single color in order to identify the author. After several readings of the narrative, a chronological sequence of themes became apparent to the investigator. Eight themes were originally created and the narratives were then broken up and placed into these thematic categories. The original themes included: 1) awareness of the danger; 2) contracting HIV; 3) being diagnosed with HIV; 4) adjusting to the HIV, 5) attachment relationships; 6) religion/spirituality; 7) meaning of illness; and 8) aging issues. These categories were then collapsed into five themes which became parts of the final narrative.

Polkinghorne's (1995) definition of a narrative as a discussion of causal relationships, organized around a plot, with a beginning, middle, and an end was utilized to construct the final narrative. The themes were the awareness of HIV, contracting of HIV, and diagnosis of HIV which became the *prelude* to the final narrative. Adjustment to the HIV became the plot of the narrative, renamed the *journey*. Finally, the *resolution* incorporated the meaning attributed to the illness and the spirituality/religion themes. Attachment issues appeared throughout the narrative and did not appear in a separate category.

The final narrative was analyzed further using the four-level approach proposed by Murray (2000) for examining health narratives. This approach specifically analyzes the narrative from the *personal* level (expression of the lived experience of the narrator);

interpersonal (the co-created narrative of the narrator and the interviewer); the *positional* (considering the differences in the social positions of the narrator and the listener); and the *ideological* (concerned with the socially shared stories of a community). Based on Murray's four-level analysis of health narratives, all four levels were explored to create a more holistic understanding of the primary narrative. The positional level preceded the final narrative to assist in establishing the characters of the narrative and their relation to the investigator. The personal and ideological levels were combined to illustrate the poignant cultural influence in this narrative. The interpersonal level followed the narrative providing the perspective of the influence upon the data created by the interaction of the participants and the investigator.

Rigor and Trustworthiness

Rigor was established following Drisco's (1999) suggestion to have "coherence of question, philosophical base, purpose, method and conclusion" (p. 4). Research bias was managed through the maintenance of detailed field notes about the interview process and a personal journal maintained by the investigator (Padgett, 1998). The credibility and trustworthiness of the study was enhanced by prolonged engagement in the field, consultation with and auditing by the dissertation chair regarding methodology, and triangulation of the interview data, field notes, and the investigator's journal (Padgett, 1998). In addition, the opportunity for member checks was offered to the participants to ensure that the transcripts accurately reflected the intention of the participants (Padgett, 1998; Reisman, 1994), but none of the participants chose to review the transcripts.

Ethical Considerations

Human Subject Concerns

After participants volunteered to be in the study, they were mailed or emailed an IRB-approved consent form (Appendix C) outlining the study, describing terms of confidentiality, and informing them of risks and benefits of the research. The name of the study and language in the form were simplified to enhance comprehension. Each participant signed the informed consent at the beginning of the in-person interview. Both audio and Word documents were maintained in a password protected secure computerized database. Data was backed up on a password protected removable disk stored in a locked safe. Digital recordings were initially electronically transcribed by voice recognition computer software and professionally edited by the investigator to ensure accuracy. Identifying information was removed at the point of transcription. All data will be destroyed after five years, a standard IRB requirement.

Reflexivity

An essential element of ethical qualitative research, reflexivity is the investigator's ability to examine oneself, including biases and assumptions, within the context of the research (Padgett, 1998). If the use of reflexivity is executed honestly and exhaustively, the researcher adds dimension to the study and to the words of the research participants. While sometimes intensely powerful and cathartic and sometimes overwhelmingly grueling, reflexivity is as integral to qualitative research as statistics are to quantitative research. It is its own narrative within the narrative.

My memories of our family visit to underground caverns are analogous to an understanding of reflexivity in the current qualitative study. The cautionary advice all investigators strive to follow is similar to the clear instructions at the entrance of the cave – “Do Not Touch Anything!” As visitors to this hidden world, we were to stick together and not stray from the group. And though there would be objects protruding into our pathway, we were not to touch or disturb even the droplets of water adhering to the surface. We were to minimize our noise as sounds echoed in eerie distortion of the natural silence. The way was already lit and the shadows were already cast; even the temperature would remain constant. We were the intruders, the visitors, spectators who must know our place, lest we interfere with the underground marvels of the illumined caverns. We were entering Sacred space that was meant to remain pristine and uncompromised by our visit.

This well orchestrated descent into the silent caverns was designed to share the magnificence of the sculpted stone and imprint its splendor into our collective minds. It was to be all input with no interaction; it was a purposeful, post-positivist excursion, one-way observation with the cavern remaining indifferent to our presence. If we followed the rules, we would have a brochure experience without disturbing the natural world.

But I realized I was part of the natural world; and I was disturbed. It was probably enough that I simply did not see well in dimly lit places – probably enough, but not all of it. I also depended upon my hearing, and an echoing cavern full of footsteps and murmuring, whispering strangers added to my concerns. As for the objects

protruding into the pathway that we were not to touch, the rule should have gone both ways, and they should not have had license to accost me. In addition, I have an aversion to close spaces and things that may potentially succumb to gravity and fall upon my head. Clearly, some of my trepidations were quite realistic and some were probably deep within my psyche, but they were all with me in my underground travel.

The conclusion, or resolution, was that I did tour the underground caverns. It was a spectacular experience. And it was as far from a brochure inspired visit as it could get. From the moment my foot slipped on the moist, man-made, metal step, until the moment I again surfaced into breathable air, it was a 100% interactive experience. And when my visit to the caverns is recounted, it is constructed from that interactive place – despite the instructions at the entrance that said “Do Not Touch Anything!”

What does that trip have in common with this dissertation research? It simply serves as a reminder that my interviews, my data, and my results are as much a part of who enters the cavern as what is encountered beneath the surface. This research is constructed from my experiences, and I am using a narrative to bring it into the light. I have installed the lighting fixtures to highlight areas that pique my interest, reflect the elements of my research question, and gently pull from the crevices of the existing research. Although I tried to be mindful of the “Do Not Touch!” my fingerprints are visible to those who know where to look for them. I am the explorer who cannot bear the thought of being left behind on a journey of discovery. Like the research participants in this study, I share the challenge of living with a chronic illness that requires daily

maintenance. As did the research participants, I found myself struggling to integrate this reality of compromised health and well-being into my life. I wanted to know how they did it – how they faced each day with its dosage of medications, medication side effects, disease symptoms, and dependency upon the medical establishment. I am curious on a personal level. And I am curious as a caregiving social worker.

Summary

This chapter discussed the methodology used in this research. A constructivist epistemology provided the template for this narrative research. Utilizing Polkinghorne's (1998) map for developing a narrative using causal relationships organized around a plot, the following chapter contains a narrative taken from seven older men who were diagnosed with HIV/AIDS. The narrative took shape around the journey to find a place to co-exist with the virus. The journey is introduced by the prelude which sets the stage for the eventual conflict between life and death. As the participants emerge from the journey, they strived to understand the meaning of the HIV in their lives – the resolution.

The narrative was organized according to Murray's levels of analysis for understanding health narratives. The first level considered the positional standing of the investigator and the participant within the research. The next level combined the personal (the perception of the participant) and the ideological (the beliefs of the social culture). The final level paused to consider the interactive experience that occurred between the investigator and the participant. These differing levels provided the opportunity to consider the narrative from a more holistic perspective.

CHAPTER IV

FINDINGS

This chapter provides the story of HIV in the lives of seven men who were over the age of 50. Semi-structured interviews were conducted to examine the interface of their attachment system, their implicit and explicit expressions of spirituality, and their experience of coping with this life-limiting illness. A narrative was compiled from the data collected in the interviews. Using Polkinghorne's (1995) definition of a narrative as a discussion of causal relationships organized around a plot with a beginning, middle, and an end, the following narrative is comprised of the *prelude* of the story of HIV/AIDS in the life of these men, their long-term *journey* with this illness, and their *resolution* or adjustment to the chronic nature of living with HIV/AIDS.

The findings were analyzed and will be presented according to Murray's (2000) four levels of analysis of health narratives. These levels include: 1) the *positional* level of analysis, which refers to the differences in social standing between the investigator and the participant; 2) the *personal* level of analysis, which refers to the story that reflects the experience and perception of the person who lived the story; 3) the *ideological* level of analysis, which refers to the socially shared stories of a community; and 4) the *interpersonal* level of analysis, which refers to the influence of the dynamic interaction between the investigator and the participant. These levels do not represent different realities, but rather, this form of analysis provides different ways of looking at the same reality.

The data presented in the following pages first includes a demographic and positional snapshot. The demographic description reveals who the participants are in relation to one another. The positional level examines who the research participants are in relation to the investigator. The narrative will follow, presenting the personal and ideological levels of analysis. Comprised of the prelude, the journey, and the resolution, the narrative addresses the main areas of the research question. The chapter then concludes with an examination of the interpersonal level of analysis as experienced by the investigator.

The Positional Analysis: Who Were these Participants?

Seven men were interviewed for a total of 16 interviews. Five of these men were in their 50s and two were in their 60s, averaging 56 years of age. Each of the men had completed a minimum of a college education. One man was retired; two were on Disability Income; and the remaining four maintained full-time employment and earned over \$75,000 annually at the time of the interviews. In terms of race, five self-identified as White-Caucasian, one self-identified as African-American, and one self-identified as Jewish-American. All of the men were self-identified as gay, although this sexual orientation was not a prerequisite for participation in the study.

In regards to current living situations: three were living alone at the time of the interviews, two were living with partners, one was living with extended family, and one was living with a roommate. Six of the men were living in the metropolitan area of Washington, DC, but one participant was living outside Miami, Florida. Two of the men

were parents and one was a grandparent. At the time of the interview, five of the men had lived with HIV/AIDS over 20 years. The newest diagnosis came three years ago. All of the men reported that they were taking medication for the HIV. The names of the participants in this research have been changed, and identifying information has been removed.

Murray's (2000) positional level of analysis refers to the identified differences in social positions of the participant and the researcher. This form of analysis recognizes that relationships illustrate existing power dynamics that are known or implied to those who are involved in the research process. Taking a positional perspective on this study, four issues seemed to predominate. First, all of the research participants were men and the investigator is a woman. Second, each participant was at least fifty years old. The investigator, though in her late forties, is younger than everyone who was interviewed. Third, it was presumed by the participants, though never verified as correct, that the investigator does not have HIV/AIDS. In addition, there was an educational level difference that each research participant was aware of and the research investigator became aware of during the interview. Each participant had a college degree and one had additional credits toward a Master's degree. Given that all the participants credit the knowledge of his medical doctor and the researchers with their current survival, the researcher likely held a respected position for these men. The investigator and all participants have participated in other research studies.

The Personal and Ideological Analysis: What was their Narrative?

This is the story of HIV, AIDS, and HIV/AIDS. Even the proper name can be as elusive and cunning as the virus itself. It is the story of the life of the virus told through the lives of seven hosts. It is the story of how HIV slithered into consciousness, took its victims, made itself known to the hosts, fought for dominance, and in at least these seven situations, finally became relegated to the back row of a life determined to move forward in spite of its unwelcome guest. Several renditions of this tale exist in the world today. In this particular story, there is a prelude, a journey, and a resolution. The prelude refers to the appearance of this virus in the culture, and then in the individual. The journey is the struggle for dominance: Will HIV overwhelm its victim, or will there be some mechanisms of hope and coping that string the conflict along until medical reinforcements push the HIV backwards into a chronic nuisance? What can the travelers tell us about what they brought to the journey? How did they strategize to remain on their path as their colleagues fell around them? And when their road was clearing, what meaning or resolution did they bring to their quest?

The prelude, the journey, and the resolution – these are in line with Polkinghorne's (1995) description of a narrative. This is only a single strand of an ever-evolving story. It does not reflect the unknown future which could twist the narrative into another sequence of events with other aspects of the HIV story taking center stage. I am the researcher and investigator. I am the storyteller. The following narrative is a summary of the tales I heard in my interviews with these older men who were diagnosed

with HIV/AIDS. It is not the only story, but it is the story of consideration at this moment.

At these levels of analysis, Murray's personal level takes on the perspective of the lived experience of the interviewees. It represents their story or narrative as they have lived it and interpreted it. At the ideological level of analysis, the focus is upon the socially shared stories of the interviewees. This level takes into consideration the societal beliefs and ideology of the culture in which the stories occurred. The personal and the ideological are presented together in the following narrative of the prelude, the journey, and the resolution in order to preserve the entwined nature of the cultural upon the personal.

The Prelude: How Did This Happen to Me?

In this particular beginning, a mysterious something was surfacing in the gay men's community. This something presented itself in various forms such as cancer and pneumonia, shingles and blindness, dementia and blood disorders. In fact, there seemed to be only one common factor in the end – if it struck you, you would probably be dead within a few months. In the beginning, it was a deadly mystery that seemed to prefer homosexual men.

For the men in this study, they began to learn about this mysterious something in various ways. For some it came into their life before it came into their consciousness. For others, there was the knowledge of some type of danger without knowing what the enemy was or how it traveled. How does one become aware of such a danger? These

seven men tell seven stories about how it materialized for them. They speak of what they knew, and what they did not know. They tell of how it came to live in them. And finally, they speak to how they became aware that they had become the danger and the endangered. This is the beginning. For many men, it became the end as well. The men in this study have a longer story to tell beyond the initial prelude. Nonetheless, the prelude sets the stage and introduces the characters of the contemporary struggle with HIV/AIDS.

Aware of danger of HIV. It is difficult now, almost thirty years after the beginning of the epidemic, to understand why these men did not take precautions to prevent HIV infection. However, history reminds us that there were several years when there was no real certainty about the origins of the illness. One of the men interviewed, Henry, participated in the first study in DC, which studied men who fit the profile of the men who were getting sick and dying (Graham, 1999). Henry was finally diagnosed HIV+ through a blood test a few years after he entered the study. He believed he had the virus for several years prior to the test results. He is likely correct because it was not until 2001 that he needed his first medications. Will, who has known he was positive since 1985, reported that he was not even aware he was at risk for getting the virus at the time he likely contracted it.

There was also a lot of misinformation and confusion about the origins of the virus even among those who were aware that there were dangers lurking in the gay community. Oliver states:

Well, back then they had just started barely figuring out that it was a virus that was causing this thing. I remember reading articles in the paper and they thought it was just people using drugs so much that it just destroyed their immune system. I knew I didn't do drugs, and I didn't really drink that much.

As an African-American, Marty added a different cultural interpretation to the emerging epidemic. He said that when he first heard about it and read about it in the paper, “it was being called a gay cancer, a gay virus, a disease,” and most of the people talking about it “were Caucasian men.” He recalls, “I didn't see any African-American men talking about it or admitting to it.” Even though, at some level, Marty knew his thinking was not quite rational, he allowed himself to deny his personal danger by embracing this belief. “I guess I sort of started thinking it was more prevalent in the white community than in the black gay community. Honestly, in my ignorance, I thought that. I felt that.” Although he says he was intimate with men who were not African-American, he started laughing and admitted, “If they were white Americans, I would practice safe sex with them.”

And then there was Rick who attributed his HIV to a single lapse in judgment, something he swore happened only once. “I had a friend who had been reading the papers, like the *Blade* [a gay newspaper]. He said, ‘Be very careful. There is something going around.’ So I had been wearing condoms. I missed it once.”

Even for those who suspected that there might have been an exposure, the best attempts to figure out what was happening could lead to the wrong conclusions. Such

was the case for George. “This was the beginning of safer sex, and how do you figure out how to do that? I had an experience on my way to L.A. when I thought maybe I caught something. Maybe I was exposed. My hunches went up like that.” When he finally got health insurance, he investigated his hunch. “I went to a friend’s mom who was a doctor, and I said I want to be tested for HIV. She looked me up and down and said ‘Oh no, you don’t have it.’ I said ‘how do you know?’ She said, ‘I can tell.’” George relentlessly pursued his request until the doctor finally acquiesced and took a blood sample. “It would change the way that I live my life. I want to know. I came back for my results, and she said ‘you don’t have it...I want to show you all these abnormalities in your blood and find out what you are and are not eating.’” George adds philosophically, “There was nothing you could do in those days anyhow. We were at the AZT time where we were figuring out those 12 pills a day were killing everyone anyway.”

Even for David who got the virus only a couple of years ago, his cautionary lifestyle that led him to request a copy of the HIV/AIDS test results prior to becoming intimate in a relationship, was not enough. “Yes, I made a stupid mistake, but I did find out that with AIDS tests, you can have a false negative and you can have a false positive.” So he had had a false negative test which led him and his partner both to believe he did not have HIV.

All of these men became infected with the virus. Their knowledge and experiences with HIV were based on cultural and media reports of the disease. They each had a different story reflecting the entrance of HIV into their personal lives.

Unquestionably, their pathways were different and lined with various assumptions, yet in the end, they were each conquered by the insidious virus that came to reside in their bodies. From an absence of knowledge of the existence of the virus to a cautionary, preventative strategy to fend off the foe, each man begins his unique journey.

Contracting HIV. While being aware or not of the potential dangers of becoming infected with HIV varied from one participant to another, each research participant experienced a similarly unique encounter with HIV, which ultimately led to his own HIV infection. On one end of the spectrum, Henry clearly articulated his ignorance of how he acquired HIV. “Does anybody ever really know? Does anyone know the answer to that question? I wasn't a great one for exchanging bodily fluids, so I'm not exactly sure. No I have no idea.” He was even incredulous that anyone could ever know. “I don't think anybody can; you can't point to a specific time on such and such day.” He was adamant that he did not get it through drug use. He seemed particularly annoyed and uncomfortable with the idea that he could be suspected of drug use and said he “certainly didn't get it” that way. He explained, “I was not a drug user, I was not a needle user...and that is something that bothers me, because I think as soon as you tell someone you're HIV, then you are an intravenous drug user. There is just a stigma connected to it.” Marty shared his sentiment about how he contracted the infection. “And even when I was diagnosed and was looking through a number of my friends who were diagnosed HIV – some of them are so sure they know from whom they contracted it – I never went through that.”

On the opposite end of the spectrum, Rick was absolutely positive he knew the time, place, and identity of all the details of his experience of contracting HIV. It represented the only time he did not use protection. He was conscious of the danger and got caught up in the moment. He stated simply, “I got nailed.” George admitted that his exposure was a mistake from the beginning. He had partied too much, which was unusual for him. He was horrified when he awoke in the morning. “I think I contracted it back in 1985 in Houston at my brother’s cottage, in one drunken night. Laying there with someone when I woke up I said, ‘Oh no, my god, you got to be kidding.’” David had a similar response. Having seen the negative test results of his partner, he still chides himself for not being more cautious. “I kind of let my heart go ahead of my head. I am a very cautious person. And for one time in my life, I wasn’t. And this is what happens.”

As for the remaining two research participants, their exposure dated back to the time before anyone was really thinking about HIV. However, they can still identify the person who shared the virus with them and at least narrow the time frames. Will was finally able to determine the origin of his infection. He said:

Process of elimination...At the time, no, they did not know they gave it to me. They did not know they had it. That person has subsequently passed away. After we stopped seeing each other – actually that was a year before I found out I had HIV. You don’t know at that point who gave it to you. The only way you find out is through the subsequent years.

Similarly, Oliver discovered that he might be HIV positive when he learned that a man he had had sexual relations with the previous year was seriously ill in the hospital. When he tried to contact the man the next day, he was dead. “So basically from then on I assumed I was positive. And then I got tested in early 86 and that confirmed it.”

Diagnosis of HIV. For some of the research participants, the actual event of the diagnosis barely seems memorable. For others, the diagnosis was the equivalent of a death sentence. The depth of the response appeared to be most related to the degree of the threat – in this case, the progression of the illness at the time of diagnosis. When Marty was diagnosed with AIDS in 1995 (he had never been previously tested for HIV), his death seemed only hours away. “I found myself deathly ill. And it wasn't until I went into the doctor and he said I think you need to have an HIV test. That is when my world just went dark. And just the mention of the word at that time...my life just fast forwarded immediately.” He was diagnosed with full blown AIDS.

I had pneumocystis pneumonia. My T cells were...less than 10 at that point. My doctor was very frank and very open with me at that time. He said I was in a critical state and he would do everything he possibly could, but I had waited a very long time – out of fear.

Marty admitted, “I had been ignoring the night sweats, the loss of weight, and the lingering colds. I knew something was wrong and I just didn't want to confront it. It was during that time, you know, HIV AIDS was just the death sentence. It truly was for me.” He was fortunate enough to respond to the medications.

At that point, Marty took leave from his work, moved back into the family home where he was nursed to health, regained his strength, and once again resumed his independent lifestyle. He had participated in all of the necessary treatments except for finding an acceptance of his disease. Despite his near-death encounter, once he felt better, he abandoned the medications. Thus began his five year ride on a terrifying roller coaster with off and on periods of being medication compliant.

Although it did not take a face-to-face with death to convince him, George put up a fight of his own against his diagnosis. George and his partner had an agreement that if either engaged in unsafe sexual activity outside the relationship, he must divulge this information. George was very angry when his partner revealed that, indeed, he had engaged in such behavior and, indeed, the third party was known to be HIV positive. George and his partner went to the testing center together. He was relieved when his partner, “comes running down the stairs with his hands in the air, ‘yeah, yippee, we are free and clear.’” His relief was short-lived, however, when it was his turn to go in for the results. “They told me I was positive. I said, ‘oh no, that is impossible. Not me.’ They said the test is ninety some percent accurate. But we will test you again. We don’t have very many false positives.” But George was adamant that he was not positive. Even after the second test returned positive, he still protested, and a third test was run. When those results came in, George submitted. “I started crying bad when they told me because why would I think they would lie to me? The only help they could offer at the

time – ‘Do you smoke?’ I said, yes, and she said ‘well, you might want to consider quitting.’ That was 1990.”

Will took a more hedonistic and practical approach to the news that he had AIDS. “I don't think I was depressed... when you are told to ‘get your affairs in order, you are going to be dead in six months’, you kind of go ‘okay well I'm not paying credit card bills, I'm not worried about the future, I'm just going to have fun.’” Of course, in addition to his own life threatening diagnosis, his partner had been diagnosed a few days earlier. “Clinical depression? Treatment? I never went through any of that.”

Both Rick and Oliver were aware that there was a possibility that they might have the virus, though neither had experienced any symptoms. Rick stated, “People were dying right and left within three to six months after first getting sick. So I got checked right after the test came out. It came back positive and I was put on the [AZT] pill.” Having an inkling that he might have the virus, despite the lack of symptoms, did not diminish the fear aroused by the diagnosis for Oliver. “I remember it like it was a physical blow kind of thing. I went to Whitman Walker [Clinic]. Nobody wants to hear that – especially back then.”

David is the only participant to report having an “episode” prior to his diagnosis which, according to his doctor, was the indication that he had become infected:

We went on a little mini vacation over the weekend, and when I was in the shower, all of my hair fell out. Not all of it, but a lot of it. And you know I have

a lot of hair. It just covered the bathtub. The bathtub was almost black, so I knew something was wrong but I didn't know what it was.

He was probably aware of the connection between this “episode” and the actual time of infection, at least partly due to the brief time between exposure and diagnosis. He said:

We had spent some time together, he started getting very ill. And I said to myself “oh my God,” because in the back of my mind I had been so careful all of my life. It was in the back of your mind, but you never want to think that it's going to happen to you.

As soon as his friend was confirmed having AIDS, David was tested, and not unexpectedly, he was positive for HIV.

As for Henry, he had been involved in the early research long before there was a test to confirm his diagnosis. Perhaps that had prepared him to accept the news more complacently:

I wasn't very excited. Nobody wants to hear that, but I was accepting of it. And I believed I had been positive for a long time. And I didn't go around broadcasting it... but I was not having promiscuous activities either. My reaction to it was I have to live with this life-threatening disease. And people were dying right and left at that point in time. And I mean it was an epidemic. I feel that I was very, very lucky. I don't know why I was able, I am able, to still be here in 2010.

The Journey: Where Do We Go From Here?

In the journey section of this narrative, participants describe how the HIV exerted its stronghold in their lives. HIV's normal, uninterrupted course would be to overwhelm the immune system and shut it down. Initially, there are no outward initial signs, but a blood test reveals that the number of T-cells is dropping and the viral load is increasing. This would set the stage for any infection, great or small, to enter the body from any common source and replicate unchecked until the host is incapacitated and killed.

Though this is the "normal" track of HIV, there were some individuals who did not participate in the "normal" process of falling victim to the virus. The seven participants in this study are among those who have alternatively needed to learn to live with it. During their interviews, the participants were asked what they believed had prevented their submission to AIDS. For the record, there is no known scientific reason why these individuals reacted differently to the invasion of the virus. There are many theories and many beliefs, but no absolute answer. For these research participants, they created their own stories for surviving this stage of the infection. For some, this stage was quite lengthy. There was either no medication available or there was a significant period of time determining the effective medication. Except for David, the participant most recently diagnosed, the first medications ingested by these men were either part of a drug protocol study or a medication with no long term effect history. In contrast to their infected peers, these men were surviving for reasons other than an effective medication. The following discussion outlines their perceptions of possible reasons for their long-

term survival. Some of these factors emerged freely in conversation, while others were responses to specific questions pertaining to the study's focus.

Mindset and attitude. Anger ranked as one of the initial reactions of six of the participants. Whether the anger was directed at God, the virus, the person who gave him the HIV, or himself, it was palpable and motivating. None of them stayed with this emotion for very long. Instead, they started activating coping emotions that had been useful in the past. George brought forth his tenacity and determination. Oliver stated he felt his “stubborn” self strengthen. Henry struggled between his denial and his acceptance of the diagnosis. David deepened his role as a caregiver and leaned upon his generally positive outlook on life:

I have a very positive attitude about life. I try to live each day to the fullest. I don't try to dwell on the negatives. I try to bring out the positive in people and my own situation. I really didn't have time to think about myself because I was trying to think about everybody else.

Participation in research. Due to the absence of treatment options as well as the timing of their infection, most of the men in this study participated in research studies about the illness and potential treatments. The participation in the research seemed to be a positive influence for some of the participants. Henry stated, “When you think of the nonchalance and the shunning and the prejudicial thinking about it, the idea that I might help somebody improve the medical science helps me. I feel good about that.” Henry had never been ill from the HIV despite being a long-term survivor. His research

participation dates back to the first study in the Washington, DC area which included men who fit the characteristics of the men who were dying. At that time, it was not even known that a virus was behind the deaths. As a consequence of being in that study (still ongoing), Henry has literally known hundreds of men who have died from AIDS.

Self care. Another interesting area identified by several of the participants is the attention to self care. Rick is the oldest man who was interviewed. Extremely physically active, retired but working part-time, involved in community activities, and a regular visitor of his 94 year old mother, Rick uses exercise, a low-fat diet, regular rest, and valued community involvement to keep his health rigorous. He has never had symptoms from HIV or medication side effects:

I smile a lot because, if you look, if I don't, I get the sunken face. That is one of the after effects – you get the sunken look. You tend to lose fat sometimes in your arms and legs and some guys are very skinny from it. If you smile a lot, people don't notice it.

Oliver shares Rick's dedication to self care. "It seems to be working; taking care of myself, trying to eat right, and getting sleep." In addition, Oliver swims and bikes regularly.

Complementary and alternative medicine. It is common for those engaged in such a vigorous fight for life and death to utilize every possible weapon in the limited arsenal. When this battle involves a health crisis, any technique or practice that is not the usual recommended medical treatment is known as "complementary and alternative

medicine” or CAM. Duggan, Peterson, Schutz, Khuder, and Charkraborty (2001) identified several therapies that are commonly used as CAM for HIV positive patients. These include: exercise, lifestyle changes, dietary supplements, counseling, herbs, mega-vitamins, and prayer therapy.

All of the participants in this study accessed at least one of these measures against the HIV. While the effectiveness of any of these techniques may or may not be known, George stated, “I would try extreme, crazy, extreme, measures. That helped people have hope.” Some of the practices are known to be medically effective and are only considered CAM because they are not the primary treatment for HIV/AIDS. Some CAM used by the men included taking vitamins specifically targeted to the HIV, using massage therapy, special diets, and participating in 12-step recovery programs. Spiritual and religious practices are also forms of CAM and will be addressed more fully later in this narrative.

Mental health treatment, also viewed as a complementary medicine, was utilized by four of the participants. Two were prescribed anti-depressants along with psychotherapy, and the other two engaged in some form of counseling. Interestingly, two of the remaining men were adamant that mental health treatment was not necessary and not worthwhile. However, they were the only two who reported that they had consulted a professional regarding religious/spiritual issues.

Use of community resources. Other resources that were implemented on this journey were provided to persons living with HIV/AIDS. For those men in the study who

needed to access these resources, their importance cannot be overstated. In many instances, the participants would find themselves simply too sick or too fatigued to manage daily tasks of living. For example, Whitman Walker Clinic, located in Washington, DC, was identified as an entity that provided not only essential, affordable medical care, but also legal services. For at least two of the men, issues with insurance companies threatened to interfere with health care. The legal services of Whitman Walker significantly reduced some stress and provided resolution to these matters without interruption in care.

Other resources in the community included Food & Friends, an organization which provided a healthy diet of food along with nutritional guidance for those who are HIV/AIDS infected. The Gay Men's Chorus also provided community services to those with HIV/AIDS. Though Rick did not use their service, he did participate as a volunteer providing assistance. "They helped guys who were sick. They would walk the dog. Lug in the groceries, clean, cook."

Work and community involvement. Employment and work related activities were also often used to help these men cope and keep going. Though Rick retired in 1994, he had remained busy ever since. He worked part-time jobs for the "exercise" and the "company." Even for the men who were unable to work because of disability, they lamented the loss of work and admitted that when they were employed, they usually worked a minimum of 12 hour days. Oliver is eligible for retirement next year, but though he is not fulfilled by his work, it would be terrifying to think of not working.

Clearly, there is an identity associated with working and employment that is important to these men. Though not entirely health related, not working would force an attention upon health issues that may be more easily ignored at this point. Henry remarked, “My work was my entire life. I lost my job. It was like I lost my purpose. I had to redefine a lot.”

Each of the research participants were members of a community that helped to mediate the impact of HIV/AIDS in his life. Three of the participants happened to be members of the Gay Men’s Chorus of Washington at some time. Each of them mentioned this participation as being integral to their emotional coping. Rick had been in the chorus for 20 years. During that time, he had known 37 of the members of the chorus who died from HIV/AIDS. For Rick, the chorus represented a hugely supportive community on many levels. “The Director was positive and the Executive director was positive. They would come out and sit on the stools and talk about it. At that time, it was very rare for someone to come out and say they were positive.”

Initially, for Will, one of the most helpful communities was the HIV community. There was a group of around 30 men who hung together mostly because they did not wish to integrate into the non-HIV community. “You never knew how you were going to be received.” These men supported one another when one got sick and shared medications when someone ran out or could no longer afford the medication. Will stated that there is really no longer such a need for this type of group since integration is no longer such an issue. In addition, Will had become the last remaining member of this

group. He attended the funerals for all of the other members. Will was the only research participant who reported being a member of such a group.

Henry reported that he was active in an organization that supported persons with his disability, which was unrelated to HIV/AIDS. Aside from those who reported participation in the chorus, George mentioned his 12-step programs as being supportive, and Will, Rick, Henry, Marty, and David each stated that participation in their church community was very important to them. Only one participant identified “loneliness” as a significant problem that he experienced during these years.

History of prior health issues. Another less obvious coping mechanism occurred in relation to two participants who had a history of dealing with difficult health conditions. Both Henry and David were disabled by conditions unrelated to the HIV. In addition, Henry was a cancer survivor. It is possible that these experiences reduced some of the threat conjured by HIV. David remarked upon learning he was HIV positive:

Okay, it is another speed bump in the road. I didn't have time to have any of the pity parties. I don't drink alcohol very much. I don't take drugs. I don't smoke. I didn't have time to do any of the things other people do. I have a strong faith in God. I just took it in and went forward.

Family and significant relationships. Since one major focus of this study was the influence of the attachment system for individuals with HIV/AIDS, the investigator intentionally asked these men a number of questions related to their interpersonal relationships with family, adult partners, and other significant adult relationships. In

conversations about family, disclosure seemed to be a central issue for these men. They had all wrestled with the secrecy associated with being gay. These interviews revealed there was a striking similarity for these men between the disclosure process of “coming out” as gay and the sharing of their health status with their family of origin. It appeared as though the same reasoning process was utilized within the family system as to how issues of this nature were to be handled. To illustrate this point, the following narratives about the “coming out” process accompany descriptions of the participants’ sharing of their diagnosis with their families of origin. Subsequent discussions of other significant relationships for these men include their relationships with partners and their medical doctors.

Family relationships. With the exception of the most recently diagnosed man, the participants’ families of origin were aware of their HIV status. However, in some cases, this took years and often appeared to occur only after the death of a parent who might not have been accepting of the participant’s sexuality. Interestingly, the process of “coming out” as gay, though usually occurring years prior to disclosing the HIV diagnosis, often mirrored the method used to disclose the HIV diagnosis. Even in those situations where the family is viewed as supportive, it may be a somewhat ambivalent support.

George never told his family that he was gay and never told them he had HIV. Over time, his family members learned these facts, but not from George. He stated, “I use my family a little bit. I can call them. I finally realized that they were not going to let me at least starve to death. They have never really offered to take care of me.” Oliver

reported that his family was, “very close, very supportive.” However, when asked if he would turn to them if he needed anything, he answered, “I don’t know that I would turn to them...I don’t like to worry them.” His mother and father approached Oliver while he was in college about his sexuality. They stated that they supported him and his gay lifestyle. Almost two decades later, his mother took him to lunch and asked if he had HIV. He had been HIV positive nearly ten years by then.

Will claimed the only time in his life when his relationship with his parents was stressed occurred after he was diagnosed with HIV. “When I found out I was HIV, I kept my distance. But that was my choice.” In fact, he stayed away from seeing his parents for almost five years. He felt his mother would know if she saw him that he had HIV. He felt he could never tell her and he never did. He shared his diagnosis status with his father 11 years after diagnosis and a few days after Will’s partner died from AIDS. Will did not mention his “coming out” during the interview. He did state that his parents had always been welcoming of his partners.

Rick discussed his HIV with his sister who is a nurse. His mother is aware of the HIV but they have never talked about it. Rick could never bring himself to tell her. He did not disclose his sexuality while his father was alive. “I thought he wouldn’t be terribly comfortable.” He came out to his aunt, “If she knew it, everybody knew it.” His mother is aware of his sexuality and they “just don’t talk about it.”

Henry likewise never disclosed his HIV with his parents. To his knowledge, they never knew. His parents did know about his sexuality because someone sent a letter to

them. Henry and his father talked about it. As for his mother, he said: “My mother never really completely talked about it or accepted it. But she knew it was just one of those things that parents accepted and probably wish were otherwise and have their tears over. And then went on.”

David came out later in life than the other research participants. Very few people know that he is gay and even fewer people know that he has HIV. He has not disclosed either his sexuality or his HIV status to his family. He stated, “My family is the kind of family that if you are gay, you are shunned. They just turn their back on you and say ‘Okay fine. Go your own way.’ Regarding the HIV, he said: “But as far as me being HIV positive, no one in my family knows and no one ever will.”

Marty’s family, on the other hand, knew that he was gay and they were not accepting of his gay lifestyle, because it was in opposition to the family’s religious practice. However, when he got sick and needed care, he said that he went to his grandmother’s house:

When... my mother explained to her [grandmother] what was happening to me, she waited on me every day. She made my breakfast. She made me eat my food. She made all kinds of country remedies. It was coming from a place, I think a mother’s love, and I think that exceeds all religious boundaries and messages and anything when it is your child.

Adult partners. Post-diagnosis, each man reported being involved in at least one long-term significant relationship with a partner. Four of the participants were involved

in a relationship with a partner and only one of the remaining three reported that he was not actively seeking a relationship at the time of the interview. The other two stated that they were actively involved in dating.

For several of these men, loving a partner also meant losing a partner to AIDS. This happened to Rick twice. He said: "I had two lovers die. I did not give them the HIV. They had it when we became partners. One died in '96 and the other in 2000...That was a rough period of time." Not only did he lose his partners, they both died "hideous" deaths. Will also had a long-term partner of over ten years die a difficult death from AIDS. Both Rick and Will stayed with their partners until their death. David, who was formerly married for 20 years, remains in a committed relationship with the man who gave him the virus. During the three years they have been together, David has twice been advised that his partner would not live through the night. David often finds himself in a caregiver role with his partner.

Marty was motivated by his dedication to fatherhood to avoid any committed relationships while he was raising his daughter. "I was committed to my daughter, and for me, anybody else who came into my life, they were going to fall behind my daughter...And I felt that if you are going to be in a committed relationship, that person you are with should be Number One." He added, "Trust me. I was very, very, very, lonely for many, many, many, years." Within the past year, Marty has met someone and feels free to treat him as Number One now that his daughter has reached adulthood.

Medical doctors. At the top of the list of significant relationships, as well as factors that helped these men survive, were their medical doctors. Admiration and respect for their medical doctors was strikingly universal among these men. Each man described a personal relationship with their doctor that surpasses the usual description of a doctor/patient relationship. For each of these men, his doctor is credited with saving his life.

Oliver changed insurance companies in order to get the doctor he wanted. He chose this doctor: “Well, him being gay and HIV positive, I tell him everything.” Will stated: “I do credit God, and I credit my doctor. It may be blasphemy, but I credit them both equally. I think the knowledge my doctor has was given to her by God. I think spirituality is a part of that and I think relationship is a part of that.” Using similar language that he used for both his mother and God, he added, “She has been watching over me since the early 1990s.”

The special nature of this relationship seems to go both ways. Marty’s doctor had promised him that he would do everything he could in spite of the late stage of illness Marty was in at the time he first came to the hospital. After a rough set of years of medication non-compliance, Marty finally accepted the treatment. His doctor reportedly told Marty, “It has been a rough road with you. I love you, we have very good conversations, but you have put me through hell.” Marty added, “I love the doctor. I love him very much.” The love and appreciation appeared to be powerful and mutual. Rick does not deny that he believes that luck has contributed to his survival, but the

medical relationship is also essential. “I am also one of the doctor’s better patients. Anything he tells me to do, I am going to do.” David commented, “My doctor said call him any time.” He then added that his no nonsense doctor who has treated him for 20 years was in tears when he told him that his test had come back positive.

Religion and spirituality. Another major focus of this research was the role of implicit and explicit spirituality in the lives of these men. Certainly in this group of seven research participants, religion/spirituality and its related expressions were used as a method of coping with the HIV. Despite the earlier presentation of religion/spirituality (Chapter I) as the “search for the Sacred or the Divine,” adopted from Pargament (1995), it became very evident throughout all of the interviews that each participant distinguished between religion and spirituality. This distinction tended to view religion as the formal, organized sects of religions and they viewed spirituality as the relationship with “God.” Based on this distinction, religion and spirituality will be discussed separately. Religion represents the more explicit expressions of the Sacred. Spirituality refers to the more implicit representations of the Sacred. The distinction between explicit and implicit expressions of the Sacred is in line with the research of Hall (1997b).

Religion. In response to questioning about religious affiliations in their families of origin, three of the participants identified themselves as growing up in the Catholic Church. They had similar experiences in the Catholic Church and each was confirmed within the Catholic Church. All three of these men had left the Catholic Church and were attending an affirming Christian Church that is accepting of their sexuality. During the

period of time between their 20s and 40s, there was a time when each felt disconnected from the church. The return to a church was neither dramatic nor immediate. Will, one of the former Catholics, described his return to the church. “It would be great to sit there and say that I had an epiphany and God just worked miracles. And that is not what happened.” His friend invited Will and his partner to a small non-denominational church in the country. “I was horrified. I sat on my hands the entire time. I wouldn’t get up and wouldn’t go to communion.” The next week the pastor met with them and they shared their story. “We started going and slowly over the course of months, I just started feeling more spiritually connected. There was something in me that had lain dormant for ...I don’t know how many years. All of the sudden I was feeling closer to God.” The three men all report that they attend church regularly, they use prayer and meditation, and they read the Bible and participate in religious rituals. These are all forms of explicit expressions of religion.

George grew up Jewish and considered himself to still be Jewish. “Judaism is what I was taught because that is what I was born into. Blood-wise, I am still 100% Jewish.” At the time of the interviews, he did not attend Temple or celebrate the Jewish holidays. He said he did attempt to meditate, which represented his only form of explicit expression of religion. Another of the research participants, Oliver, reported that he had no religious affiliation during his childhood and youth. Furthermore, he had not pursued any religious affiliation as an adult. This participant did not mention having any explicit forms of religious expression.

Of the two remaining research participants, both left the religion of their parents. One went from a Methodist Church to an Episcopal Church and the other went from a Pentecostal Church to a non-denominational church. Both men experienced a period of religious disconnection in adulthood and did not return to a church until after being diagnosed with HIV. Both attended church regularly. The Episcopalian practiced a much more ritualized, explicit form of worship. Both practiced prayer though the participant in the non-denominational church reported that he was more likely to practice meditation.

Spirituality. Regardless of the particular stance and observance of organized religion, each research participant was secure in the presence of spirituality in his life. Oliver, not provided a religious foundation by his parents, nonetheless devised his own story about the Sacred. “Having spirituality is your relationship with God or the Universe.” The “relationship” represented the implicit aspect of his spirituality. He described his personal belief system as follows:

It is kind of a golden rule of treating other people as you would like to be treated. I kind of made up this thing about God and dying. When you die, you live through everything you lived through before, but instead of being you, you are everyone else you interacted with. So if you treated people well, it would be nice. If you treated people awful, it would be awful. So hopefully after that you would have learned your lesson and you would go to heaven.

Oliver grinned and added: “I am going to heaven.”

Will described spirituality as “the feeling that you have that God is looking out for you and taking care of you; that there is something bigger out there. It is felt inside.”

Marty’s spirituality was “The Divine Energy that lives inside of me.” David stated, “If you are spiritual, I believe you really have a connection with God. It is really trying to get to know him.”

Asked about the things in his life that have spiritual significance to him, Rick did not hesitate. He spoke of his garden. “Oh how I look forward to it. I have a thousand bulbs every Spring-tulips, hyacinths, it is like God’s hands are bringing back old friends.” And without prompting he added, “And of course there is the [gay men’s] chorus, it is tremendously spiritual. The songs that they sing, sometimes I wonder, my God, this is so beautiful.” At this point in his life, Rick may have been unsure about his religious leanings, but of his spirituality, he was most reverent.

The Resolution: Moving Forward

Though initially, the resources and strategies listed above appear to be a meager match for coping with a disease as invasive and debilitating as HIV/AIDS, they proved to be enough for these seven men at the time of the interviews. Armed with coping strategies, supportive families and friends, stringent vitamin regimes, special diets, exercise, adequate sleep, assistance from caring strangers and compassionate doctors, and finally, a religious/spiritual belief system based on unconditional love and acceptance, it was somehow enough to push HIV from its frontline advantage. These seven men were the survivors. These seven men were outfitted with the supplies they needed. It is not to

say that the ones who did not survive were any less determined or courageous. Many of them undoubtedly received the placebo in the drug studies or did not have the benefit of the “best” and loving doctors. This survival, unlikely though it was, has translated into a special meaning for some of them. It is this meaning that forms the resolution to this story. It is by no means the end of the story. It is merely the resolution to this part of the story.

For David, he felt his diagnosis was too new to understand its meaning. “I haven't even thought about that. I am so busy trying to help everybody else get their life straightened out that I haven't really had any time for myself.” Yet, as a caregiver and a man of deep faith, his meaning may have already been established, and being HIV may fit into his previously constructed meaning. He said: “My philosophy is you give as much as you can give. And when God is inside you, you are there for people who need you – stranger, friends, anyone who needs you.”

Henry also depended upon faith. “I simply have to have faith that things are going to work out. They may not work out like I wanted them to work out, or had hoped, or as they might have, but life is going to go on one way or another.” He presented his philosophy of life:

You do come to a place where either you have to accept things and move on or you get in a rut and get all muddy, or you can get completely bogged down and never go anywhere. I don't choose to get bogged down, and I don't choose to get

muddy. I do muddle through it; but I don't get muddy. I am trying to keep my head out of the pit.

Rick and Oliver both deny any particular meaning in the experience. Rick said: “I appreciate it when people get cancer and are told they only have six months. I understand what they are up against. Every event is precious...every birthday...it is bizarre how they feel.” Oliver just shook his head. “Yeah, I mean, of course I wonder why I lived and others didn’t. But I have no idea. I don’t know if it is physical or mental or both, or luck, or what...I mean, doctors don’t seem to know.”

Though severely physically ravaged by the virus, George remained in awe of his own survival. He explained:

I understand what it is to have quality life and not quantity life. I know a lot of people could not have gone through what I went through. They would not have survived. Sometimes I feel like maybe I was tapped because somehow I would end up helping a lot of other people.

George believed his work is not yet complete in this life. “I do sometimes think I was chosen to go through this journey and I'm not sure exactly the reason. I have the feeling it is to carry the message on for others to be a voice for the people who can't speak.”

After coming very close to death, Marty’s meaning was found in the wonder of living and the richness of family. He said:

Live your best life. Live your life to the fullest. Put your focus and energy into the things that matter the most in life – your family, your friends, and as corny as

it all sounds, it is all very true. To even hear myself say it, it sounds corny. I have lived it and it is very true.

Will, representing the longest documented survivor of the seven men in this study, was resolute about the impact of HIV in his life:

People always ask if you could do it again, would you change anything. No, I wouldn't, even being HIV. Would I love to not be HIV? Yes. Would I be a totally different person? Yes. I like who I am. To change things, changes your dynamic. Changes who you are. We learn to deal with it and live to move on. Yes, people will still die from this disease. Not HIV, but AIDS and AIDS-related issues. People will die. I'm in the first generation of the people who were diagnosed. Nobody had a clue what to expect when we were first diagnosed. We're the ones who are teaching all the newly infected people how to do things how to adjust and live. It's an awesome responsibility. My God, I have my moments.

The Interpersonal Analysis:

How did their Narrative Affect the Investigator?

And I have had my moments as well. This brings me to the final level of analysis proposed by Murray (2000). The interpersonal level of analysis acknowledges that the story does not exist in a vacuum. It is the product of a joint interaction of at least two individuals – the research participant and the investigator, who is a novice researcher. In addition, it is the nature of a dissertation that it also involves the hidden committee of

scholars who influence the process. In order to capture the individual influence of the interviewer and the research participant, a description of the interview process that existed beyond the verbal interchange is provided.

Each participant chose the location of the interviews. All follow-up interviews occurred over the telephone. Distance dictated that one of the initial interviews occurred by telephone and, in one instance, the health of the participant necessitated the use of the telephone for conducting the interviews.

Undoubtedly the most physically challenging setting of all the interviews was a crowded coffee shop in Washington, DC, the site of Oliver's interview. This interview was the first interview with Oliver. The participant chose the location, stating that he did not mind having the interview in a public place, despite the investigator's concern for Oliver's privacy. In the interview process, we nearly had to scream at one another over the loud din of Sunday morning patrons crowding the coffee shop. The interview was interrupted by a shrieking blender, and it was chaotic and nerve wracking for me. Oliver gave short answers and did not elaborate on his own and did not elaborate much with prompting. He was surprised that the interview "touched some nerves" and his eyes teared a couple times and his voice cracked. He did not read the consent form but signed it dismissively. There was no interpersonal verbal exchange in the interview. It was not unpleasant, just distant and difficult, primarily due to the location and his short answers.

The tone of the second interview with Oliver was much different. This interview was conducted over the telephone. He took his time answering the questions and

elaborated without much prompting. He appeared much more at ease, and I am sure, I reflected his ease and interest, once I initially connected with him and understood that this interview would not be as trying as the first. There was very little interpersonal discussion, which remained consistent with the initial interview.

My third research participant proved to be one of the most personally difficult interviews for me. I had been told by the person who contacted Henry that Henry had a disability. I happen to share this disability with Henry. When I arrived at his home for the initial interview, Henry became aware that I am also visually impaired. He indicated to me that it would be easier for him since he would not have to explain aspects of his disability that might come up in the interview. I found this to be true for myself as well. If I had to make an accommodation, I did not feel the need to justify it with an explanation. At the conclusion of the interview, Henry commented:

I think my discussion with you has been helpful to me to make me realize that I need to get off my fanny and have more initiative to take charge of things. I have vented with you a lot. I have told you a lot of things that have been on my mind that I can't tell anyone else because I do not have that confidence and trust, confidentiality. And I miss that. So, for me personally, it has been helpful. You have helped me to think about a lot of things in a different way and a different perspective, too.

Rick's interview was conducted in his home. He was a gracious host and evidently proud of his beautiful flower garden. He had a vase of flowers from his garden

on the table, and he immediately showed them to me, providing a brief history of how he came to have them. When we discussed the spiritual aspects of his life, the flowers and garden once again became the center of focus. Interestingly, from his garden, he proceeded to discuss his other spiritual passion, his participation in the Gay Men's Chorus. He gave me a copy of a CD to share, much as he had shared the flowers on his table. Being at his home allowed me to experience the physical aspects of his passions and the two things he identified as " Sacred" in his life.

Getting a complete interview from George proved to be the most difficult research activity of this study. He provided an education in patience and a personal example of what living with HIV/AIDS on a daily basis can feel like. It took over one month to obtain the four interviews that constituted his interview. Because George is affected by his illness in almost everything he does or attempts to do, he never seemed to know when he would be up to an interview. If he knew he might have time on a given day, I was to begin contacting him after noon to determine his health status for the day. We would tentatively schedule a time and maybe it would work and maybe he would not be well enough to participate.

It took four sessions to get through the questions with George. The benefit of having the interviews stretched out like this was that I was able to think of better follow up questions. This, no doubt, added to the interview time. With so much contact, I did feel a more personal connection. This connection allowed for me to ask more personal questions. In addition, it gave him a sense of comfort to disclose very intimate details.

Due to his health status, I never met George in person. It is important for me to note that this did not seem to interfere with the process.

Marty was another research participant whom I did not meet in person. He does not live locally and was recruited as an African-American to add diversity to the sample. Again, though I did not meet him, the interview over the telephone was effective and quite personal. He told his story without a lot of affect, but when he was finished, he made sure that I understood the depth of the emotions that underlay his narrative:

I hope this didn't come off as though it's been a smooth ride. It hasn't been a smooth ride. It has been very difficult, [but] better than I could've ever imagined at this point in time. I never could've imagined 15 years ago that I would be here living my life the way I'm living now. It is very awesome, very awesome. It has been very cathartic speaking with you.

Will is the only research participant in this study that I knew prior to the interviews. He attends the same church as I do, and he is, in some ways, the impetus for my choice of the research topic. He is outspoken about being HIV positive, so he is the only person I directly asked to participate in the study. His interview was conducted in my home presumably because he knew it might be difficult for me to get to his home. It was his choice. I was comfortable because I knew him and uncomfortable because I was going to ask him very personal questions. His interview taught me that it is sometimes easier to ask a stranger personal questions, than it is to ask someone you know. I thought I knew his story because I had heard him speak in public. I was wrong about that. What

I learned early in the interview process was that I had no idea what his experience of living with HIV for 24 years had been. He was the first person I interviewed for this research. I realized if I did not know what it had been like for him, I would have no idea what it had been like for anybody. From him, I learned the value of listening, and listening, and listening.

Because I was fortunate to obtain research participants who were invested in the process and willing to talk about very difficult issues, it became easier for me to forget how much many of them were willing to stretch beyond their comfort zone. When I interviewed David, I was reminded of the somber nature of living with these secrets and the trust that was being given to me to handle their stories with care. David had the most recent diagnosis of all of the participants. This seemed to correlate with his comfort level when discussing his situation:

Very few people know. I don't believe it's anybody's business. It is my business. Now my friend who has it wants to shout from the rooftops. And I can see his point. Because it is a very dramatic story, and basically don't let this happen to you, whereas, I don't have that dramatic of a story.

His willingness to share his vulnerability and his humbleness regarding his journey provided one of the most sincere and emotionally vivid illustrations of life with HIV. His gift to me and the world, by being part of this study, was the reminder that the story is only one perception of the person, and beyond that, there is still the person.

Summary

This chapter provided a review of the content of the interviews conducted in this research study. The information was provided in narrative form and organized according to Murray's (2000) suggested four levels of organizing health narratives. The data was examined from the positional level of analysis, which presented the research participants and the investigator's social standing in relation to one another. This was followed by the personal and ideological levels of analysis, referring to the perceptions of the research participants within the social context of the story. This level contained the majority of the narrative.

The narrative reflected Polkinghorne's (1995) description of a narrative as illustrating the causal relationships organized around a plot. In this narrative, the prelude represented the introduction of HIV into consciousness and then into the personal lives of the participants. The journey represented the various techniques, strategies, and coping mechanisms adopted by the participants. In particular, the participants discussed the role of significant attachments and the influence of religion/spirituality in overcoming the power of HIV. The stabilizing force of effective medications diminished the turbulence of the journey, leaving the participants with the task of identifying a meaningful resolution. The resolution, the conclusion of this narrative, brings forth an emerging philosophy particular to each participant.

The chapter rightfully concluded with the interpersonal level of analysis, which examined the interaction between participant and researcher. As the participants were

charged with seeking out a meaning for their experience with HIV, the investigator is left with the similar task of finding resolution in her own understanding of meaning. The following final chapter provides a discussion and review of the data and findings.

CHAPTER V

DISCUSSION AND CONCLUSION

This research study examined the interface of the attachment system, the implicit and explicit expressions of spirituality, and the experience of coping among seven HIV+ men who were over fifty years of age. Sixteen semi-structured interviews were conducted with these research participants. Questions were specifically asked regarding their knowledge about HIV prior to their infection, their exposure to the virus, and how they coped with the subsequent diagnosis. In addition, questions were explored regarding the significant relationships in their life and their experiences of religion/spirituality, variables that were thought to play an important role in the lives of individuals with chronic illness.

These interviews were transcribed and coded into Murray's (2000) suggested levels for the exploration of health narratives. These levels included: 1) the positional (consideration of the social standing of investigator and participant); 2) the personal (consideration of the perception of the participant); 3) the ideological (consideration of the cultural beliefs in which the story takes place); and, 4) the interpersonal (consideration of the dynamic interchange between investigator and participant). From these coded interviews, a narrative of the experience of contracting, living with, and finding or constructing a meaning from this encounter with HIV was created. Using Polkinghorne's (1995) definition of a narrative as causal relations organized around a plot, a story was constructed illustrating these experiences of living with HIV/AIDS.

Presented in the previous chapter, the plot of this particular story focused on the prelude, journey, and resolution of the struggles of these men with their disease.

Three primary areas of inquiry shaped the narrative that took its form from the interviews and coding. The discussion that follows synthesizes the findings from this research and compares them with the research and theories on attachment and spirituality previously presented in Chapter II. The first area of consideration focuses upon the coping mechanisms and external structures these individual men identified as supportive in their life with HIV. The second area of exploration involves the role of spirituality/religion in the lives of these men as they dealt with HIV and its complications. The third and last area of examination concerns the influence of attachment relationships and the attachment systems of these men in completing the strategic barrier they erected against the chronic illness of HIV. A contemplative look at the interface of attachment and spirituality in the lives of the participants is included, followed by the strengths and limitations of this study and recommendations for policy, practice, and future research.

Coping Mechanisms: The External Structures of Defense

The men in this study were tireless and relentless in their struggle against HIV/AIDS. As with any effective strategy, they approached the illness from various angles. All the participants participated in numerous research studies of HIV. They utilized complementary and alternative medicine (CAM): massage therapy, mega-vitamins, exercise, 12-step programs, meditation, special diets, mental health treatment in

the forms of anti-depressants and therapy, spiritual counseling, and prayer. In addition, they were both recipients and donors of services to the HIV community. All of these strategies represented an active, engaged, participation in their illness process.

In addition to using CAM, another significant finding among the participants was their engagement with the HIV illness and the HIV community. Several participants utilized community resources in times of need and also assisted in providing these resources when they were physically, emotionally, and financially able to do so. In addition, every participant in this study had previously engaged in other HIV related research. The participants reported that both accessing and providing services to the HIV community assisted in coping with their own life with HIV. Staying active and engaged in the community was also universally expressed as being important to the participants. For those who were still employed, they worked excessive hours and had not entertained the notion of retiring. For those who were forced from employment due to disability, it was experienced as a significant loss.

A small number of participants reported that they had experienced, and were currently, experiencing other health issues that complicated coping with the HIV. Paradoxically, however, these men indicated that since they had experienced these other significant health issues in their lives, having HIV had become less emotionally draining. Having these other illnesses and/or disabilities gave them a perspective on living with HIV that was not present for the other participants.

The findings stated above are consistent with other coping research for men with HIV/AIDS. The use of CAM among HIV/AIDS patients is in line with Duggan et al. (2001), who identified several therapies that are commonly used as CAM for HIV positive patients. Similar to the participants in the current study, Duggan et al.'s participants used exercise, lifestyle changes, dietary supplements, counseling, herbs, mega-vitamins, and prayer therapy.

Findings from this study also are in line with those of Turner-Cobb et al. (2002), who examined psychosocial correlates to adjustment to living with HIV. Their findings suggested that those persons who had more secure attachment styles, who experienced more satisfaction with their social supports, and who utilized less behavioral disengagement techniques, had more positive adjustment to living with HIV. Although there was insufficient data in the current study to make assumptions about the attachment styles of the participants, there were strong indications that these men valued their social supports. For example, their willingness to participate in research suggests that behavioral disengagement was not an issue for them, and they all had participated in previous studies. Although they did not necessarily view family as being the most significant social support, they all expressed gratitude for their social supports. Clearly, the relationship with the medical doctors discussed later in this chapter denotes a secure relationship. Thus, considering that the men in this study successfully adjusted to HIV, this research supports the findings of Turner-Cobb et al. that social supports play an important role in successful adjustment.

Stress and anxiety were not quantitatively measured in this study; however, there does not appear to be much expression of anxiety among the participants. Their active participation in research and self care, along with the use of CAM, reflect the behaviors of men who were actively involved in managing their illness. This is analogous to Koopman et al.'s (2000) findings that those persons who reported more anxious or less secure attachment styles perceived more stress in their lives. In addition, Koopman et al. found that those who reported greater use of disengaging behaviors as coping strategies for dealing with their HIV also reported greater perceived stress in their lives. In contrast, the research participants in this study achieved a successful level of living with HIV. They did not express stress around issues of testing, a lack of external support, or thoughts about the future. Although the participants emphasized that it has been a difficult journey, only one man perceived his struggle as a daily stress. For that participant, much of his HIV life had centered on debilitating illness. He did not enjoy the stabilization effect of the medications until very recently. Interestingly, though it is not possible to categorize an attachment style from this study, the narrative of this particular man is less coherent, his relationships were reported as somewhat tumultuous, and he was not involved in a significant relationship with a partner. He has also denied any successful attachments within his family of origin. These characteristics suggest an insecure attachment, though such a conclusion is not definitive.

In summary, the coping strategies identified by the participants as contributing to their overall well-being and struggle against HIV are similar to those previously reported

in the coping research. It is not surprising that men who are so active in managing their illness are also aware of, and utilize, these strategies reported as successful for other men with HIV. Another area often associated with coping – religion and spirituality – is further discussed in the next section and was a central focus of this study.

Religion and Spirituality

It became quite evident early on in the interviews and throughout the interview process that the participants certainly did not view religion and spirituality as remotely the same in their lives. Participants were asked to provide their own definitions for these terms and to relate both back to their lives with HIV. In general, for these participants religion referred to the organized religions and the rituals associated with a formal church. Spirituality referred to the connection or relationship that the participant had with “God.” According to Miller and Thorensen (2003), this is a common distinction made by research participants when given the opportunity to create their own distinctions.

Another aspect of religion/spirituality presented in attachment theory also appeared in the findings. Interviews with the participants identified both explicit expressions of religious functioning and implicit expressions of religious functioning in the lives of the men. The explicit expressions of functioning appeared with discussions of religion. These expressions included church attendance, confirmation classes, reading the Bible, and tasks and rituals associated with a formal religious sect. In contrast, implicit expressions of functioning tended to appear in discussions of spirituality.

Spirituality was viewed as the relationship and connection with something greater than the self. Spirituality was expressed implicitly through meditation, nature, singing, and love. It was not a specific action but was identified as an internal feeling.

The participants reported that there had been a period of time in young adulthood where there was a religious disconnection in their lives, meaning they were not involved at that time in an organized, explicit expression of religion. However, each participant stated that there was never a time of spiritual disconnection. It is quite possible that the return to a church, though desirable, was not urgent because each participant reported that there was never a time of spiritual disconnect. Even the participant who had not grown up with any formal religion had developed his own personal spirituality. It was common among the participants to report a more intense engagement with their spiritual selves, rather than organized religion, in assisting them with coping with the diagnosis of HIV.

The research previously presented in Chapter II discussed two very different clusters of literature regarding religion/spirituality existing in attachment research. One of the clusters dealt with Kirkpatrick's (2002, 2004) theories and research about the Correspondence Model, the Socialized Correspondence Model, and the Compensation Model of religion and attachment. The other body of research (Hall, 2007b) addressed religion and spirituality from an explicit and implicit perspective, also related to attachment theory.

The only model that was supported by the findings in this study was the Correspondence Model, which hypothesized that if the early relationship with the parent

were secure, the later, adult relationship with God would be secure (Kirkpatrick, 2004). Based upon the narratives and the interpersonal interactions experienced by the investigator, the majority of the participants demonstrated what *appeared* to be secure attachment relationships with caregivers from a young age. These were the same participants who expressed a religious relationship with God. Similar to Kirkpatrick's (2002) findings, there *did* appear to be a positive correlation between a secure parental attachment and a secure adult attachment with God. However, none of these men adopted the form of organized religion of his parents, which may have been a decision related to the sexuality of the participants. In contrast to their childhood experiences of religion, all of these participants sought out an affirming church that accepted their sexuality.

Hall et al. (2005) conceptualized spirituality and attachment through the lens of the Internal Working Model (Bowlby, 1969/1982). Specifically, they investigated the explicit and implicit expressions of spirituality. As stated earlier, the explicit expressions are those things that are conscious (usually measureable) and the implicit are those expressions that are unconscious and more difficult to measure. Hall et al. introduced the idea that implicit expressions may be a more accurate measure of spirituality because it is in line with the Internal Working Model of attachment, a construct that speaks to the unconscious internalization of relational patterns. Hall (2007a) also proposed that storytelling, because of its tendency to uncover the unconscious, was the best form for discovering the implicit expressions of spirituality.

Given that religion represented the external motions of being religious and spirituality was the implicit nature of the relationship, it seems clear that Hall et al. was correct, at least for these men, that the implicit expressions were more closely tied to spirituality than the explicit expressions. Whether this is solely associated with this sample of the HIV population remains a question for other research projects. As the men discussed the meaning of the HIV in their lives, spirituality undoubtedly occupied a significant role. It would appear that the earlier exposure to organized religion resulted in a return to an organized church. Yet, even when this childhood connection was weak or non-existent, each man found a connection to the spiritual.

Attachment and Significant Relationships

A third major focus of this study was to understand the significance of relationships and attachments in the lives of men living with HIV/AIDS. For the men in this study, being gay also meant they knew many persons who had died from AIDS. Clearly each of the men at some period of time had been intimate with someone who had HIV. For several of the participants, this intimacy included losing a partner to AIDS. It is not clear from the interviews conducted in this research whether these relationships created security or an increased sense of threat. Both of the men who had lost partners to AIDS also reported that these deaths were “hideous” and very difficult because dying from AIDS is often a physically unpleasant experience to witness and presumably to experience.

Some of these men had already experienced the loss of one or both of their parents. None of these men reported an estranged relationship with a parent though there were reportedly a few stressed relationships (primarily occurring with the men's fathers). Since all of the participants were gay, they could speak to the "coming out" process as a gay man and as a man with HIV, and none of these disclosures occurred simultaneously. The parents were either deceased, or they were informed of their son's sexuality prior to learning of the HIV. At least for these men now over the age of 50, disclosure did not, and does not, come easily. There is no doubt that among this particular group of men, learning of the threat of HIV did not activate their attachment system toward finding comfort and safe haven from the family of origin.

Perhaps the most significant finding in this study relates to the relationship with the medical doctor. When the participants speak of their doctors, there is an obviously heartfelt admiration and gratitude for the care they have provided. This respect and gratitude was universal among all of the participants. These doctors are credited with saving the participant's life.

Among the traits commonly attributed to the medical doctors was accessibility. If they needed their doctor, several participants reported that they could reach him/her any time. In addition, when a doctor-patient relationship was threatened by a change in insurance, the participants reported that they fought to maintain the relationship. The participants also reported that they trusted the judgment of the doctor and were willing to follow doctors' orders. Some of the doctors shared the participant's gay identity and also

were HIV+, factors which reportedly made the doctor a safe confidant. In addition, the medical profession keeps confidentiality, which was critical for some of the participants, and these doctors had not abandoned them or given up on them at any point in the illness. In other words, for these men in this study, no other person or entity was spoken of as highly and obviously held so dear in their lives. The belief in the unconditional love of their doctor and the doctor's commitment to their well-being appeared as the most evident and utilized attachment presented in these interviews.

Returning to the original discussion of attachment figures presented in Chapter II, the medical doctors seem to meet the criteria of an attachment figure established by Ainsworth (1985). Ainsworth proposed that an attachment bond exists between a care recipient and a caregiver (i.e., attachment figure) when: 1) the care recipient seeks close proximity to the caregiver in times of threat or alarm; 2) the caregiver provides care and protection; 3) the caregiver provides a sense of security; and 4) the loss of the caregiver would cause anxiety and grief. It seems quite clear that the medical doctor was a professional caregiver who became the attachment figure during the crisis of being diagnosed with and living with HIV/AIDS.

This observation does not preclude the possibility that "God" served as an attachment figure at least on some level. Certainly the participants speak to a relationship with "God", and a sense of being watched over. It is quite possible that this relationship with "God" is in an earlier, less developed stage and will strengthen over time. Taking into account Murray's (2000) views about the importance of the positional level of

analysis, it is also undeniable that there is a positional consideration that should be acknowledged. That is, medical doctors are often expected to perform God-like functions in our society, and these particular doctors did seem to “miraculously” save the lives of men who had no known reason for being alive. Perhaps in this way, the medical doctors were substituting for “God” in the minds of these men. In some way, the medical doctors may have interrupted the more natural connection that is cultivated with “God” under this type of mortal threat.

It is impossible to fully understand the role of these doctors in the spiritual development of these men. With such influence in the participants’ lives, the doctors’ attitudes toward spirituality may be more significant than that of the family of origin. If the doctor was not enthusiastic about spirituality and expressed this to the patient, the doctor could easily become a barrier to the development of “God” as an attachment figure. Conversely, a positive view of spirituality may have facilitated the development of this attachment to “God.” The answer is left to future research, but acknowledging the strength of an attachment relationship, this finding is potentially quite powerful.

Strengths and Limitations of this Study

A significant strength of this research was the ability to achieve in-depth interviews with the participants through the use of qualitative research methods. This depth allowed for an exploration of the participants’ perceptions of their experience living with HIV/AIDS. The use of the semi-structured interview allowed for an exploration into areas that had not been anticipated by the investigator. The use of

multiple interviews with each participant also allowed for the development of a more personal relationship between participant and investigator, which enabled the discussion to enter into extremely personal, and often difficult, subjects. The use of multiple interviews was useful for those participants who were experiencing health issues that made the interview process more challenging. Finally, this method allowed for clarification and collaboration of data from previous interviews. It provided the opportunity to compare new emerging themes with the stories of participants previously interviewed and to re-interview participants regarding new data.

One of the study's strengths and limitations was the diversity of the sample. It was advantageous to have diversity in participants' religious origins and current practices. In addition, it was a benefit to interview men who had such varying experiences with HIV and to be able to include disabled men in the study. However, this research was limited by the difficulty of attaining much diversity in race and ethnicity. Snowball sampling resulted in the identification of men who were of the same economic strata, educational level, and with the exception of one man, the same Caucasian race. The research was therefore limited in these areas of diversity.

Another unanticipated limitation resulted from recruiting from a population that seems to maintain two areas (sexual orientation and HIV) where disclosure can be an issue. This limitation may have been complicated by the request for participation from a stranger who attends a university supported by a church that is generally known to be in conflict with their homosexual lifestyles.

Finally, a significant limitation was the challenge of capturing attachment histories and styles without the use of a standardized attachment instrument. The lack of such data made it extremely challenging for the investigator to compare results from this study with existing literature on attachment, spirituality, and coping among chronically ill men with HIV/AIDS.

Recommendations

Despite the limitations of this study, a number of important recommendations can be made based on the observations that emerged from the narratives of these men. The following discussion presents some recommendations for health care policy, social work practice, and future research.

Policy Recommendations

The doctor/patient relationship emerged as a point of great significance for the research participants. Each of these men had a different doctor but all believed they had the best doctor. This relationship was integral and appeared as a strong positive attachment for the participants. Policy should reflect the importance of the doctor/patient relationship in treating chronic illness. Care should be taken to foster this relationship and maintain it throughout the illness. In the current era of major health care policy changes, it is critical to note the significance of consistent, reliable, and committed medical care from one primary provider.

Another important consideration for health care policy might be finding a way to incorporate implicit spiritual beliefs into the religious/spiritual inventory of a patient. At

present, information is usually collected by healthcare professionals only regarding religious affiliation. This research suggests that other forms of spiritual expression might be more important than just religious affiliation.

Finally, there is a need to update the cultural perception of HIV/AIDS. There continues to be misinformation about the dangers and the treatments as well as the characteristics of those who have HIV. There is immense power in sharing stories about this illness and how it lives among us. This power is needed to continue the fight for those who are infected, to support those who are affected, and to prevent new infections. Policy should be aimed at reducing and eliminating the stigma related to having HIV. Among older men, this belief in the related stigma may not be the same as for younger cohorts and this should be considered in any policy decisions.

Practice Recommendations

In addition to collecting information about religious affiliation, it would be useful for practitioners to understand the nature of the patient's spirituality in order to incorporate that into treatment plans. For example, a connection with nature may be a source of spiritual comfort for some, and time spent outside in a garden would be fulfilling for such individuals. For those persons who have felt excluded from traditional religious traditions, links to their implicit spiritual supports could provide a powerful resource for them. Especially among discriminated minorities, it could be invaluable to recruit strong spiritual expressions in the fight against chronic illnesses.

Further, as the lifespan of HIV lengthens and the illness becomes increasingly a chronic illness, additional education will need to be incorporated into treatment plans. Specifically, attention will need to be focused upon the interaction of HIV with other more established chronic conditions associated with aging. It bears repeating that those infected with HIV continue to feel stigmatized and marginalized in our culture. Older individuals with HIV face the stigma of aging, as well as the stigma of the disease, in a society that values the young and the healthy. Social workers should be mindful of this perception and work toward eliminating the stigma and minimizing its negative impact upon the clients served.

This study also adds credence to the power of listening to the stories of those we encounter. While these narratives are all related to the same experience, the perceptions of that experience are absolutely individual. This research gives voice to those small voices that have such a resounding story to tell. These men help to educate the profession about many stages of a complicated illness that occurred in an amazingly short period of time. It is likely that the lifespan of future illnesses in our culture can be well informed by understanding the story of HIV/AIDS. With current medications and treatments, older men with HIV are becoming more numerous. As they age, their need for social work services may likely increase. Having an understanding of the illness and the survivors of the illness provides critical tools in providing compassionate and informed care.

Future Research Recommendations

This particular research has presented many interesting avenues for further research. First, it would be helpful to deepen the understanding of the role of the doctor as an attachment figure for men with HIV/AIDS. This research could investigate the doctor's presentations as "secure" and "insecure" medical providers and examine the impact upon persons with different attachment styles. In addition, data could be collected on these patients' progression of illness and determine if there is any significant relationship.

Future research should include both explicit and implicit expressions of religion/spirituality in its analysis. It also appears that it would be useful to distinguish between the terms religion and spirituality. Though the research remains uncommitted to a distinction, those being studied may have a clear distinction in their minds.

Another area of exploration should center upon the provision of religious/spiritual interventions with persons who have differing explicit and implicit expressions of "God." In addition, there appears to be an opportunity in understanding the impact of explicit and implicit expressions of religion/spirituality among oppressed persons who feel they are excluded from traditional religious experiences. This research should investigate the stigma of HIV and its impact upon those seeking religious/spiritual meaning and relationships.

Conclusion

This exploratory research has come to its natural conclusion. It has raised many interesting and intriguing questions for future research. It has provided the shell of the framework for understanding the interface of attachment and spirituality in older men with HIV/AIDS. It has justified itself as a legitimate concern for those who create policy, plan care, and treat the aging population of men living with HIV/AIDS as a chronic illness. It has created the opportunity to slightly shift the cultural knowledge of an illness that has killed millions.

This is an important area of study because, in the end, people are still dying. People are still becoming infected at alarming rates. Children continue to be orphaned. The cost is outrageous, no matter how it is measured. And where there is a need for well-being and quality of life, there is a profession of social workers prepared to engage in the struggle.

I return now to my personal goal of trying to understand how these men survived. Not even knowing of whom I would ask the questions at the onset, I now know seven men in an intimate way that only this type of research can foster. I have listened to seven stories – stories that seemed to just be awaiting the opportunity to be known to the world. At some point in time, many interviews ago, I stopped listening for the magic something that had kept the men alive in spite of the odds. I lost touch with my curiosity of learning what had saved them. I lost myself in the process of the survival, and now that the stories have been told to me, I realize that I have emerged at a different place.

I no longer need to know how they did it. It is enough to know that they had the courage to survive. It was a simple formula in the end. These men just moved forward, perhaps in part because of implicit spiritual supports and due to significant attachments to their doctors. I feel like an honored guest who shared a very small part of each man's journey. I think, perhaps, it is the mystery that keeps us all just moving forward. I know it is enough for me.

Appendix A

Invitation to Participate in Study

Men, at least 50 years of age and diagnosed with HIV or AIDS, are now being recruited for a research study investigating the influence of spirituality and personal relationships. The study will involve at least two interviews, one to two hours in length, at a time and location convenient to the participant. The researcher is interested in learning the stories of adjustment to the diagnosis as it affects daily life.

If you are interested in participating in this study or would like more information,

please contact: ***Linda Ripley, M.S.W., at (301) 661-1213.***

If you know anyone who might be interested in participating in this study,

please forward this information.

This dissertation research study is in partial fulfillment of requirements for a Ph.D. in social work at The Catholic University of America, Washington, DC

Appendix B

Interview Guide

The following introduction will begin each interview:

“As you know, I’m working on my dissertation and the purpose of my research is to find out what it is like for someone to live with HIV. More specifically, I would like to understand how a person’s spirituality and relationships, both current and past ones, have affected managing this difficult situation. I want to do this by listening to people’s stories, and I would appreciate your sharing your story with me.

If you have any questions about the consent form I sent you before this interview, I can address them now. If you would like to go forward with the interview, we can sign the form and begin.

My first question is very general because I would like you to tell me about yourself as an introduction, based on what you think is important for me to know about you. You do not need to think about what I might want to know: I will get to that. What would you include in a brief biography of yourself?”

The interview will then follow the guidelines listed below. The following demographic information will be gathered throughout the interview and will only be asked directly if it has not naturally emerged during the interview:

Self defined race /ethnicity
Age
Sexual orientation
Highest Level of education
Length of time since diagnosis of HIV
How HIV was transmitted to the participant
Treatment History
Current treatment
Living situation (alone, with partner, etc.)
Number of children and where does each reside
Employment History
Current income level and source of income
Self identified religious/spiritual affiliation

Open-ended questions:

I. Living with HIV

When were you first diagnosed with HIV, how did it affect you emotionally when you learned of the diagnosis?

What has been your history of adjusting both physically and emotionally to the diagnosis over time?

How, if at all, does having HIV impact activities in your typical day-to-day living?

Describe any activities in a typical day that you use to manage the daily experiences of living with HIV.

II. Attachment System

Who (or what) comprises the significant relationships in your present life? Describe these relationships and their roles in everyday life.

Describe the significant relationships that you have experienced throughout your life.

Describe any changes in these significant relationships.

What, if any, have been your experiences with loss or trauma in your early life?

Describe the relationships in your family of origin. Describe any significant relationships during childhood that occurred outside your family of origin.

If being diagnosed with HIV has altered any significant relationships, describe these experiences.

To whom do you turn when you are frightened or scared?

To whom did you turn for support when you were first diagnosed with HIV?

To whom do you turn now when you experience concern or anxiety about your illness?

III. Spirituality

What does spirituality mean to you (or how do you define it?)

Describe the role of spirituality in your present life.

How do you express this spirituality

Describe your religious/spiritual history and any significant alterations in your spirituality throughout your life.

What is the spiritual history of your family of origin and how do you think that has influenced your present spirituality?

When you think about your relationships with others, as well as your spirituality, how do you feel your relationships and your spirituality are related?

How do you feel your relationships and your spirituality have influenced your life with HIV since your diagnosis?

How or in what ways do you feel your diagnosis with HIV has altered your spirituality?
And how do you feel your spirituality has affected your adjustment to your illness?

IV. Closing Questions

What have you learned from your experience with HIV/AIDS?

What advice would you give to a man who is over fifty years of age and has just been diagnosed with HIV?

Looking ahead at your own future, how do you anticipate living the rest of your life?

Is there anything further we have not discussed that you would like to share with me about these topics?

Appendix C

CUA



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CONSENT FOR PARTICIPATION IN RESEARCH

Name of the Study: The Interface of Attachment Relationships and the Implicit and Explicit Expressions of Spirituality among Older Men Living with HIV/AIDS as a Chronic Illness

Investigator: Linda S. Ripley, M.S.W.

Research Supervisors: Susanne Bennett, Ph.D.; Barbara Early, Ph.D., Karlynn BrintzenhofeSzoc, Ph.D.

Purpose: I understand the purpose of this research is to learn about the interface between spirituality and attachment relationships among men who are over 50 years of age and diagnosed with HIV/AIDS. This study is being carried out in partial fulfillment for the requirements of a Ph.D. degree in social work at the Catholic University of America.

Procedure: I am aware that I am being asked to participate in this study because I am a man who is at least 50 years old, and I have a medical diagnosis of HIV/AIDS. I understand that I am being asked to participate in an interview that will be audio recorded. I am aware that participation in this interview is strictly voluntary. I understand that I will participate in at least two interviews from one to two hours in length. The audio recording and investigator's notes will be kept in a locked safe and remain in the sole possession of the investigator. After five years, the tapes and notes will be destroyed.

Risks, Inconveniences, and/or discomforts: I understand there are no known risks for participating in this study. I understand that I may experience some discomfort in discussing my experiences. If I feel any discomfort through the participation in the interview, and I would like to discuss this with a professional, the investigator, who is a licensed clinical social worker, will offer to provide a list of names, addresses, and phone numbers of appropriate professionals. I understand that my involvement in this research is completely my choice. I understand that I am free to discuss any aspect of this research with the investigator. I also understand that I may choose not to participate or may end the interview at any time without penalty. I further understand that the interviews will be scheduled when and where it is convenient for me.

Benefits: I understand that my participation in this research may not benefit me directly but that the information obtained may be helpful in furthering knowledge of men at least 50 years of age who are diagnosed with HIV/AIDS.

I am aware that I will receive no monetary compensation for my participation.

Confidentiality: I understand that all information collected for this study will be kept confidential. I understand that my name and any identifying information will be erased from the audio recordings. I understand that findings generated by the study will be published in the dissertation and professional literature and that my identity will not be revealed. I also understand that research records, like hospital records, may be subpoenaed by court order or may be inspected by federal authorities.

I have read the above and am satisfied with my understanding of this study and its possible risks and benefits. My questions about this study have been answered. I hereby voluntarily consent to participate in the research study as described. I have been given a copy of this consent form. I am a legal adult.

Printed Name of Participant

Signature of Participant

Date

Investigators Name

Date

Phone number to call Linda Ripley if questions arise: (301) 661-1213.

Any complaints or comments about your participation in this research project should be directed to the Secretary, Committee for the Protection of Human Subjects, Office of Sponsored Programs and Research Services, The Catholic University of America, Washington, DC 20064; Telephone (202) 319-5218.

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