
Theses, Dissertations, and Projects

2008

The living and spiritual experiences of gay men with AIDS : an exploratory study

Jerry Dale Beene
Smith College

Follow this and additional works at: <https://scholarworks.smith.edu/theses>



Part of the [Social and Behavioral Sciences Commons](#)

Recommended Citation

Beene, Jerry Dale, "The living and spiritual experiences of gay men with AIDS : an exploratory study" (2008). Masters Thesis, Smith College, Northampton, MA.
<https://scholarworks.smith.edu/theses/1306>

This Masters Thesis has been accepted for inclusion in Theses, Dissertations, and Projects by an authorized administrator of Smith ScholarWorks. For more information, please contact scholarworks@smith.edu.

Jerry Dale Beene
The Living and Spiritual
Experiences of Gay Men with
AIDS: An Exploratory Study

ABSTRACT

This research study will explore the experiences of ten gay men living with AIDS.

Gay men with AIDS are a unique group in part because they are doubly stigmatized. Due to their sexual orientation, they have commonly experienced condemnation and marginalization, often from early on in their lives. My question for this study is: How does this particular group of men enduring this unique disease and treatment find and define their individual spirituality and sense of meaning as they face end of life issues?

This qualitative research study used an exploratory, flexible methods design. I interviewed 10 gay men with AIDS to hear their story. I asked participants what they do in their daily lives that helps them cope with their illness. The data from this study translated to several major themes. This involved a conscious effort for the individual to maintain a strict medical regime of taking medications while also attempting to maintain a healthy lifestyle. Other themes that emerged were about previous losses, authenticity, fear, isolation and intimacy and finally spirituality and meaning.

The stigma of having AIDS was felt on a daily basis by all participants. Spirituality as a source of strength beyond the physical and social realities of their disease was an underlying but also dominant theme throughout the interviews.

THE LIVING AND SPIRITUAL EXPERIENCES
OF GAY MEN WITH AIDS:
AN EXPLORATORY STUDY

A project based upon an independent investigation,
Submitted in partial fulfillment of the requirements
for the degree of Master of Social Work.

Jerry Dale Beene

Smith College School for Social Work
Northampton, Massachusetts 01063

2008

ACKNOWLEDGMENTS

First, I want to give thanks to God for making this thesis project part of my journey. I am deeply grateful to the men who participated and shared their personal stories for this study, without them there would be no study.

I wish to thank Shella Dennery my research advisor, who kindly and patiently taught me the way to write a literature review. I wish to thank Barbara Lui whose skillful guidance, advice, editing skills and patience instilled the confidence which allowed me to complete this thesis project.

I also would like to thank Ann Friedrichsen, my field placement supervisor at Providence Hospice Seattle for her support during the 8 month process.

Lastly, I want to thank my mother and brother for their unwavering support and for always believing in me.

TABLE OF CONTENTS

ACKNOWLEDGMENTS	ii
TABLE OF CONTENTS	iii
CHAPTER	
I INTRODUCTION	1
II LITERATURE REVIEW.....	10
III METHODOLOGY.....	17
IV FINDINGS.....	22
V DISCUSSION.....	34
REFERENCES	42
APPENDICES	
Appendix A: Recruitment Flyer.....	45
Appendix B: Informed Consent Form.....	46
Appendix C: Referral Sources	48
Appendix D: Interview Guide	49
Appendix E: Human Subjects Review Approval Letter	50

CHAPTER I

INTRODUCTION

This research study explores the experiences of ten gay men living with Acquired Immune Deficiency Syndrome (AIDS). Gay men with AIDS are a unique group in part because they are doubly stigmatized. Because of their sexual orientation, they have commonly experienced condemnation and marginalization, often from early on in life. Persistent fears and erroneous beliefs about the disease of AIDS and its transmission further stigmatize and isolate them from the society's mainstream. As a result, support or faith communities are too often not available to meet the end of life needs of gay men with AIDS. My question for this study is: How does this particular group of men enduring this unique disease and treatment find and define their individual spirituality and sense of meaning as they face end of life issues? How can we as social workers enhance and support their efforts? The purpose of this study is to add to the knowledge we already have about the end of life needs of gay men living with AIDS, specifically around issues of spirituality and the search for meaning.

I will ask the participants what they do in their daily lives that helps them to cope with their illness and if and how they engage in spirituality as part of living with HIV/AIDS. My hope is that this study will add to the body of knowledge already written about spirituality and end of life issues. It will offer additional information specifically

about gay men with AIDS that will assist social workers working with clients in this demographic. In addition, it can perhaps help social workers gain a deeper understanding of those who are in on-going relationships with people living with HIV/AIDS.

History of AIDS

To come to a more complete understanding of the particular challenges the ten men in my study have undergone, it is helpful to put the study in an historical context. The following is an overview of the history of this pandemic and its treatments.

Over the last 30 years, AIDS has affected the lives of over 45 million people worldwide (Center of Disease Control, 2005). The Global Health Council (GHC), also in 2005, estimated that 4.9 million people became newly infected with HIV. From these statistics it would appear to indicate most of us will meet or know someone who has HIV/AIDS; yet, AIDS as the pandemic it continues to be no longer garners the mainstream media headlines. People in the U.S seem to have become inured to AIDS, a consequence of the perception that AIDS is no longer an immediate death sentence, but a highly treatable disease. The reality is that people still struggle with the complications of the disease as well as with its treatments - and, still die from AIDS.

According to 2005 statistics, more people in the United States are living with AIDS than ever before. For various reasons, including psychological denial – and also fear - that they will contract the disease, and ignorance about how common it truly is, many of these never get tested and so do not realize they are infected. It is estimated that in the U.S. 1,039,000 people are living with HIV/AIDS (Centers for Disease Control and Prevention, 2005) and of that estimate, 45% are gay men. The CDC also statistically purports the number of infected gay men has probably doubled.

AIDS: 1981 to the present

The first identified cases of HIV/AIDS appeared in the United States in 1981, acquiring the designation, GRID or Gay-Related Immune Deficiency. However, scientists later found evidence that the disease existed prior to 1981. Subsequent analysis of a blood sample of a Bantu man, who died of an unidentified illness in the Belgian Congo, in 1959, showed evidence of the existence of the AIDS antibody. Both of the AIDS viruses HIV-1 and HIV-2 originated in Africa. As is often the case with microbes, a jump from one species to another is probably to blame for the transmission of chimpanzees (HIV-1) and sooty mangabeys (for HIV-2) (Hobson-Wain CNN, 1998).

The virus had spread to every corner of the North American continent. When the first isolated gay men began falling ill from strange and exotic ailments in 1980, nearly 5 years passed before institutions of public health, federal and private scientific research establishments, the mass media and the gay community leadership—mobilized against this health threat. The AIDS problem had been festering throughout the decade between 1980 and 1990. The death tolls of the late 80's were not startling new developments but an unfolding of events predicted for many years (Shields, prologue xxi). The first two AIDS patients were admitted to the National Institute of Health (NIH) research hospital arriving six months apart in June 1981 and January 1982. After that an enormous number of cases were reported. The societal impact of HIV/AIDS shocked the U.S. public.

There were also reports and evidence of gay men developing a rare and fatal form of pneumonia or other opportunistic infections that would lead to death. Suddenly a number of healthy gay men began getting sick with a deadly and rare form of PCP (lung infection) called Kaposi's sarcoma, a rare form of skin cancer. A forty-four year-old

white, homosexual man was hospitalized in April 1981 for an evaluation of fever and abdominal cramps. In March, his symptoms reoccurred. On the third day of his hospitalization, a dry cough developed and on the eighth day, a transbronchial biopsy, stained with methenamine silver was found to be positive for pneumocystis carinii, a protozoan distributed widely in nature and found in both humans and lower animals. The true incidence of infection in humans has not been ascertained (Brodie, Hamel, Brady, Kates & Attman, 2004). It took years before scientists developed a test for the virus, to begin to understand how the virus is transmitted in the human body, and more importantly, the knowledge to determine how people could protect themselves. Indeed, on the day the world learned that Rock Hudson was infected, some 12 million Americans were already dead or dying of AIDS and hundreds of thousands more were infected.

In the early 1980's as many as 150,000 people became infected with HIV. The new "gay disease" hit the press in 1981 and by 1982 the condition began being referred to as AIDS. Content about the disease was controlled by the Centers for Disease Control and Prevention. This new information about HIV/AIDS and the new number of cases being reported to the CDC began to give the population a glimpse of the severity of the spread of HIV/AIDS. In 1983, Dr. Luc Montagnier of the Pasteur Institute in France announced the isolation of the LAV retrovirus, (lymphadenopathy-associated virus, which later became identified as AIDS. In 1983, an estimated 33 countries reported new cases of AIDS. In 1984 the research work of Dr. Robert Gallo, of the National Cancer Institute, isolated the HTLV-III (Human T-Cell Lympototropic Virus III). The Journal of the American Medical Association (JAMA) continued to use Gallo's findings as the primary etiologic agent of HIV, but in 1986 researchers discovered that HTLV-III and

LAV were exactly the same virus and as such were given the new name of Human Immunodeficiency Virus or now more commonly called HIV. Although HIV could now be detected, the medical community had little to offer in the way of treatment options.

It wasn't until superstar Rock Hudson was diagnosed with AIDS that Americans began to pay attention to the health crisis facing the country. His death in 1985 brought HIV/AIDS into the public's awareness. Other famous personalities also began dying from AIDS. The well-known pianist Liberace died in 1987 and actress Amanda Blake died in 1989. Additionally, Anthony Perkins died in 1992 from AIDS related pneumonia. There were also documented HIV cases of heterosexual men and children prior to the deaths of Hudson, Liberace, Perkins and Blake. However the infrequency of those cases was too rare to capture the attention of most Americans (Fee & Fox, 1998).

In 1986, President Ronald Reagan, upon hearing the news of Rock Hudson's death made his first public mention of the word AIDS at the Third International AIDS Conference in Washington, D.C. Unfortunately by this time there were 60,000 cases of AIDS and 30,000 reported deaths. Eventually, President Reagan asked Surgeon General C. Everett Koop to prepare a comprehensive report for the American people about AIDS. The report, released in 1986, was the largest public government mass mailing ever done, going to 107 million households in the United States.

In April, 1987, an important breakthrough occurred in how the public perceives the disease. Princess Diana surprised Britain by opening a specially built ward for people suffering from AIDS. At this time, many people, including some in the medical field, were afraid to touch or be touched by people with AIDS. The Princess, by her own example, showed the world that she could physically touch people with HIV/AIDS and

not “catch it”. Her compassion, coupled with her desire to help those infected with AIDS, created a new awareness and a better understand of the HIV/AIDS pandemic. Another breakthrough in public perception occurred in 1990, after the death of nineteen-year-old Ryan White, a heterosexual male from Indiana, who contracted AIDS from a transfusion of contaminated blood while he was being treated for hemophilia. While in school, he had come forward with his story and he was expelled for being a health “risk”. Soon after, White testified before the President’s Commission on AIDS. Just a few months after his death, the United States Congress passed the Ryan White Comprehensive AIDS Resources Emergency Act (CARE) to financially assist those with AIDS. As of 1998, more than 6.4 billion dollars have been appropriated and have served 500,000 individuals with AIDS (Findlaw, 2001).

By 1991, the public had a new awareness that HIV/AIDS seriously damages the immune system. Basketball star, Magic Johnson, who tested positive for HIV but had yet to develop full-blown AIDS, made his condition public his resiliency sent a ray of hope to others affected by the disease. Johnson’s openness about his medical regime to stay alive set an example for the need to adhere to the complex array of medications that kept a person healthy.

By 1993, we began hearing conspiracy stories about the origin of AIDS. Dr. Alan Cantwell, a known gay man, published a book entitled “Queer Blood”: The Secret AIDS Genocide Plot that detailed a conspiracy by an unnamed “them” against gays and blacks. Cantwell attempted to construct his idea of a chain of events that would evoke understanding and empathy for the gay community comparing this alleged crime to the Holocaust (Cantwell, 1997). A review of his work was given to the head of the reference

department at the University of Illinois in Chicago. He states, “There has long been a story of a secret genocide with the culprit being a genetically engineered virus” (Cantwell, 1997). Dr. Cantwell was a disbeliever in this idea for quite some time until he started noticing similarities between when and how the infection happened around the world. There is no concrete evidence available to suggest genocide is taking place; however, there are many questions that have not been answered satisfactorily.

Research and Treatment of AIDS

In 1987, AZT (known as Retrovir, zidovudine) manufactured by GlaxoSmithKline, became the first anti-HIV drug (a nucleoside reverse inhibitor) to be approved by the Food and Drug Administration (Avert.org, 2005). AZT was a major research discovery that prevented HIV by altering the genetic material of healthy T-cells; but the caveat was that the drug had to be used with at least two other HIV drugs. No new developments in the treatment of AIDS occurred until 1996 with the introduction of Highly Active Anti-Retroviral Therapy (HAART) which provides new medications for the treatment of infection by retroviruses, primarily HIV. Different classes of antiretroviral drugs act at different stages of the HIV life cycle. This new medical development slowed the progression of the disease and blocked it from overwhelming the body’s immune system. Sometimes referred to as “The Cocktail,” it offered a majority of patients a second chance at life and a new hope of living longer. However, many patients have found the treatment process to be confusing and exhausting. A person being treated for AIDS must adhere to an intensive, complex medication schedule taking from 15 on upwards to 30 pills a day. Medication levels must be monitored for toxicity and could include adverse reactions making the results of medical interventions unpredictable and

problematic. Additionally, there is a subset of individuals for whom the medications no longer work and other treatment options have been exhausted. For these people, their daily choices must focus on end-of-life issues such as choosing hospice care or planning out their last wishes.

In 1999, scientists at the University of Alabama at Birmingham discovered the origin of Human Immunodeficiency Virus Type 1 (HIV-1), the virus that causes AIDS. This solved a twenty-year-old puzzle about the beginnings of the AIDS epidemic. By this time, AIDS had affected approximately 30 million people worldwide. The researchers had identified a sub-species of chimpanzee, native to West-Central Africa, as the natural reservoir for HIV-1. While the origin of the AIDS epidemic has now been clarified, the exact explanation for why the epidemic arose in the mid-20th century, and not before, is still a matter of speculation. Chimpanzees are identical to humans in over 98% of their genome, yet they appear resistant to the damaging effects of AIDS to their immune system. This raises many unanswered questions.

In 2000-2004 according to the International AIDS Vaccine Initiative, “Only an AIDS vaccine can end the HIV/AIDS pandemic”. AIDS worldwide was now killing more people than any other combined diseases, with an estimated 40 million people living with the disease and expected to die within the next twenty years. Currently, AIDS medications can slow the progression of the illness, but they do not arrest it.

The spread of HIV/AIDS is showing no signs of slowing down. Five million people were newly infected in 2003 with 14,000 new infections occurring daily or 600 infections per hour- a death rate of roughly 600 to 1,000 people per day from AIDS related complications. Sub-Saharan Africa remains the worst affected area with an

estimated 21.6 to 27.4 million people currently living with HIV/AIDS (Wikipedia.org). At the time of this writing, there are approximately two dozen HIV vaccine experiments being conducted, but they have not yet proved to be successful. It is estimated it will be another 10 years before a vaccine is available (aidshistory.nih.gov). In a 2005 article entitled, “Anti-HIV Bacterium Isolated?” (Wired.com), it was suggested that an answer to HIV infection may be near. Lin Tao, a groundbreaking researcher at the University of Illinois, is on a quest to find the natural enemy of HIV. Perhaps if a vaccine is found we then may be able to control the spread naturally and cost effectively. Since Tao’s work has only been seen in the laboratory, the HIV research committee has refrained from proclaiming premature success. Tao noticed that probiotic foods, such as yogurt, contain beneficial bacteria that appear to have an effect on stemming the infection of HIV. Tao postulated that different bacteria have different sugar preferences. “To block HIV, we must find a new bacterium that prefers the unusual mannos and thus capture it”. Clinical trials are underway. The developmental cost for a vaccine is about “100 million to one billion dollars,” Tao said, “but a probiotic may only cost a few million” (Wired.com). The pandemic continues to evolve in 2008.

CHAPTER II

LITERATURE REVIEW

The importance of addressing spiritual needs for patients at the end of their lives is recognized in most of the literature on end-of-life care. The majority of these authors are oriented toward a whole person model of care which takes into consideration not only physical, psychological, and social needs, but spiritual needs as well. Most counselors and social workers work within a traditional medical model of care which tends to focus on the bio-psychosocial needs of patients who are dying and defers to chaplains or hospice workers for even broadly defined spiritual needs. Research and writing on the importance of spirituality at end of life is especially important to give support to caretakers of dying patients as they work within a medical model.

I have also researched spirituality and end-of-life needs specifically for gay men with AIDS. I have found in my literature search that there is a need for more qualitative research on end of life and spiritual needs for all patients - and there is a definite gap concerning AIDS patients and their end of life needs. Such research is needed to develop good assessment tools and to point us to what exactly are the spiritual needs of people at end of life, and specific to my study, the spiritual needs of gay men with AIDS.

The Importance of Attention to Spiritual Needs at End of Life

The medical field often focuses only on the physical and psychological needs of patients. Some medical doctors, however, have acknowledged the importance of the

spiritual needs of their patients and have contributed to the literature on spirituality and end of life. In his important book, *Medical Care of the Soul*, Bruce Bartlow, M.D. (2000) stresses that spiritual needs are considered central to care. Bartlow defines spirituality as “having mostly to do with the soul . . . as individual in three senses: the soul as legacy, the soul as eternal and the soul as one, something we all share.” Bartlow then defines medical care of the soul as “Acceptance, Resolutions, Aftershocks and Reorganization” (p.3). The first three topics have been covered extensively throughout the literature, especially in Elizabeth Kubler-Ross’ *Death and Dying*. The main concern for people who are in the process of dying is fear of the unknown. If one were to define spirituality for the medical model it would be that spirituality can be seen as a way to alleviate psychological distress.

If these issues are addressed it may be beneficial to patient, doctor, social worker and clergy as they work as a disciplinary team to assist the patient facing end of life. The concept of team care is a vital one. As Meador (2000) states “the best spiritual care for the dying patient is most likely to be delivered in the same way of other types of care are best provided; through partnerships within the team of persons caring for the patients” (p. 227).

Research shows that the patients themselves want their caretaking teams to address the issue of spirituality. A recent survey on what constituted a “good death” for Americans found that 89% of respondents felt that it was important to be at peace with God, 85% endorsed the importance of praying, and 61% of respondents felt that discussing existential distress and the meaning of death was a critical aspect to a good dying process (Steinhauser et al., 2001, p. 727). There are many palliative care treatments

available to control pain completely and reduce suffering. But patients also want concerns of the soul to be addressed. Sulmasy, (2006) tells us: “Despite increasing evidence that patients would like their physicians to do so, spiritual issues are rarely addressed by twenty-first century physicians. In a survey of inpatients 77% believed physicians should consider their spiritual needs and 48% wanted their physicians to pray with them but 68% said no physician had ever inquired about their spiritual or religious needs.” (p.1387)

Many patients who have life threatening illnesses experience death distresses that are often associated with the psychosocial-spiritual dimensions of the patient’s life (Chibnall, 1999, p. 331). Therefore, if a person is facing great distress in dying perhaps addressing spiritual issues may alleviate some or all of the physical distress and give the patient a sense of control.

A theme that has been explored in health care research on spirituality is the effects of spirituality on various health conditions. Attempting to speak in spiritual terms to people at end-of-life is a highly individualized undertaking but one that can make an enormous difference to them. As the great Tibetan Buddhist spiritual master, Rinpoche (2002) says:

Imagine how things would be if we could live our lives infusing them with a sacred meaning; if our end-of-life care were always lit by a sense of awe in the face of death; and if we looked on life and death themselves as an inseparable whole. (Rinpoche, p. xiv)

Spiritual pain often manifests itself in physical and psychological symptoms and generally there is little understanding about the link between such symptoms and underlying spiritual issues. Kuhl (2006), a medical doctor, writes with sensitivity about the patient’s search for spirituality at end of life: “A spiritual journey brings our whole

being into question as we become quiet to listen to the voice of our hearts we begin to hear who we really are” (p. 19). Dying persons want to know if there is any meaning in their suffering or in their dying. In the book, Living With Dying (Berzoff, 2004), Jacobs writes that it is not the social worker’s role to solve spiritual or religious problems, “but rather to create an environment that enables the client to explore their concerns and to find meanings that move them towards a healthy resolution or a comfort in their questioning” (p. 191).

Gaining a better understanding of an individual’s beliefs by having conversations that are explicitly about spiritual needs could provide opportunities for improved care. Patient’s issues often are mistreated as medical or emotional problems when they really have to do with something deeper. Patients at end-of-life often begin to pay attention to more authentic and less external and superficial needs. Taylor-Brown and Sormenti (2004) describe this process:

Spiritual issues left unaddressed both impede recovery of authenticity issues and effects overall suffering of the patient. Today’s superior medical knowledge has created a complicated web of treatment options and decisions that would be overwhelming to anyone. By gaining a better understanding of individual beliefs, by having conversations more explicitly spiritual could provide opportunities for improved care especially in regard to the patient’s finally having the freedom to being truly authentic. It is this authenticity that is the thread throughout the literature that brings the patient to a place of peace and a willingness of to let go of unfinished business with loved ones (p. 16).

According to their article, “End of Life Care” (2004), Taylor-Brown and Sormanti note that there is a need for future research examining the experiences of being at end-of-life because the final phase of a person’s life has enormous implications for the individual, his or her family, and the community. The authors go on to say that society has extensive bio-medical knowledge and treatment options “when a supportive, caring

approach is needed and too often denied” (p. 5). Authenticity becomes a major point in communication for the person who is dying. There is no longer a need for artificiality and this itself could translate to a spiritual moment. Addressing spiritual needs is strongly linked to the patient’s perceptions of experiencing a good quality of dying. Fryback and Reinhart (1999) found that many of the subjects “viewed spirituality as a bridge between hopelessness and meaningfulness in life. Those who found meaning in their disease thought they had a better quality of life than before the diagnosis” (p. 13).

It is the patient’s concepts of a good death that should be the guiding principle in having a spiritually satisfying death. Clark (2003) points to the importance of patients feeling empowered in end of life decisions: “What troubles patients is a lack of autonomy over the circumstances of their dying and in particular powerlessness in decisions over medical treatment including those that prolong life” (p. 1). Perhaps anticipatory guidance, education, support, and a companioning presence to hear another’s story can be called spiritual work.

There is a growing realization that spirituality and religion can affect every aspect at end-of-life. This effect may also extend to those patients with advanced disease, life threatening illnesses, struggles with fears, anger, physical discomfort, loss of independence and troubling spiritual issues as well as changing self-image roles and relationships. The medical model tends to exclusively focus on curative treatment and, failing this, to focus its energies on making the patient comfortable through medicinal intervention. Meador (2004) writes:

The inclusion of “spirituality” in medical practice research has become increasingly commonplace in recent years. Clarity as to exactly what is meant by this

term continues to gain a better understanding of its role in the care and development of related standards of practice (p. 266). Again, this points to the great importance of individual patients defining for themselves how they would like their spiritual needs met.

Despite the overwhelmingly positive assessment of spirituality and religion on health in general, the response to spiritual issues may vary for individuals including negative effects for some. In an effort to be more broadly inclusive, most discussion of spirituality in the medical literature has viewed spirituality simply as one's search for meaning. The quest for spirituality is a search for a place of peace, tranquility and safety. Many people begin searching for this place during the final chapters of their lives. Much of the research on end of life points to the need for quality assessments of dying patients' spiritual needs and the importance of the medical community to acknowledge this need.

AIDS Patients and End of Life Needs

There is a need for more research on the end of life needs of AIDS patients even though HIV/AIDS, according to Curtis, et al. (1999), is currently the "leading cause of death among Americans aged 15-44" (p. 1124). "Future studies should test interventions to improve quality of communication and determine whether the communication improves the quality of care at end of life" (p. 107). Kaldjian, et al. (1998) note that "little is known about the spiritual beliefs of persons infected with HIV/AIDS and their impact on end-of-life decisions." These authors also observed that "spiritual needs go unrecognized or unaddressed by health care teams even though a patient's spiritual beliefs can influence in important ways clinical decision making" (p. 104).

In my research, one author, (Beckett, 1998), found AIDS to be no different from any other life-threatening illness; as with any other patient with any other disease, AIDS

patients are concerned with the manner in which they will die and to live and die as well as possible (p. 179). The other two articles point out that AIDS patients have specific and unique needs because of the stigma of the disease, especially for gay men. Curtis, et al., (1999) points to evidence that physicians have a particularly difficult time communicating with AIDS patients and because of this patients are at risk of getting inappropriate care at end-of-life (p. 1123). Kaldjian, et al. (1998) also note that the spiritual needs of AIDS patients often go unaddressed and discuss the causes of this: “The morbidity, morality and negative social forces associated with HIV/AIDS challenge the deepest beliefs that HIV/AIDS patients hold, beliefs that deal with questions of hope, meaning, purpose, forgiveness, and relationship with the deity (God)” (p. 103). There is a need for more research on how to communicate effectively with this stigmatized and marginalized group, especially about their end-of-life spiritual needs and desires.

CHAPTER III

METHODOLOGY

The purpose of this study is to explore the lived experiences of ten gay men with HIV/AIDS and how they define their inner strengths on a changing daily basis using their spirituality as they face end-of-life issues.

This qualitative study used an exploratory, flexible method design. This method allowed me to focus on the primary question: What are the interpersonal, subjective and spiritual experiences of gay men living with AIDS? Due to the nature of the research question, I will use an inductive, flexible, qualitative, relational research design method. Given the gap in the current literature on the spiritual end-of-life experiences of those living with AIDS, I felt a need to examine this important subject. I chose this method because it provides a deeper, richer description under study in this context, often involving data that is narrative in form. This method allows for an open system whose boundaries include the observer as well as the person being interviewed. It was chosen because it offers a broad narrative focus which allows me to bring forth implications and nuances of the interview process which might otherwise be overlooked.

This research study is specifically designed to explore the lived, spiritual experiences of a relatively small sample: gay, HIV/AIDS positive men. It is intended to examine how they face life on a day-to-to- basis, and what are some of their most pressing concerns as they cope with a chronic illness. The sample was defined as gay

men who have HIV/AIDS and are living with this illness. This study was conducted in the Seattle Metropolitan area using three agencies that support the Gay, Lesbian Bi, and Transgender (GLBT) communities where the participants are most likely to be found.

Sample

This small, non-probability convenience sample is not expected to generate a representative picture of the population affected by this phenomenon, but rather to portray the lived experiences of ten gay men ages 40-68, living with HIV/AIDS. The sample consists of ten research participants living in the Seattle metropolitan area. Participants were recruited from flyers (See Appendix A) posted at three local downtown Seattle agencies that serve the GLBT community. Information on the flyer stated that the participants must fulfill the following criteria: (1) age 18 years or older; (2) English speaking; (3) self identified as gay; (4) diagnosed with HIV/AIDS; and (5) willing to participate in an audio-taped interview lasting approximately 60-90 minutes. The flyer described the purpose of the study and that participants would engage in a semi-structured interview designed to elicit narrative data from their perspectives. Because of the sensitivity around the subject, a more flexible, person to person interview style was chosen. By using the personal interview process, this will allow me to draw on observational data from the interaction with the client and then to better understand the responses offered. Additionally, Anastas (1999) writes that people are often more willing and able to reflect at length on complex feelings, understandings, and past experiences through the spoken word rather than the written one (p. 351).

By using the interview methods and specific questions, I hoped to glean some new information from this poorly understood phenomenon of gay men living with AIDS.

Informants that participate in the research study will be asked 15 semi-structured questions. These responses will give an account of their personal experiences of living with HIV/AIDS. Additionally, it will look at an overriding question: Has this disease caused these men to rely on their own inner strength or do they succumb to the fears of daily living with HIV/AIDS?

There is a lack of contemporary information on gay men living with AIDS. The data/insight gathered from these interviews will be used to view the similarities which may exist among gay men living with HIV/AIDS. I am also interested in investigating spiritual insights as a coping mechanism. By listening to their lived stories, beliefs, and experiences, we can have insight into what it is really like to live with HIV/AIDS.

The experience of gay men living with AIDS is a phenomenon that lacks sufficient empirical study and what little information does exist is poorly understood. By using a qualitative method, my hope is to give voice to a marginalized group. Over the last few years there appears to be a decline in the perception of HIV/AIDS as being the nation's most pressing health problem. According to the article, *Media Coverage of the HIV Epidemic (1982)*, the authors say that mainstream coverage of HIV/AIDS by the news media ultimately serves as an important gauge of the political agenda of HIV monies for cures.

There was no difficulty in finding participants, because within the first week, twenty-five people had called expressing interest in the study. Not only that, but it was necessary to turn away at least fifteen would-be participants.

Once interested, participants contacted me, their HIV/AIDS status was confirmed, and the informed consent procedure was described and explained to them. All interviews

were held at Seattle University libraries located in Seattle, Washington as this offered convenience and privacy.

Data Collection

Data was collected from ten participants in face-to-face interviews ranging from 60-90 minutes in duration. All interviews were tape recorded and labeled with a number. Anastas (1999) describes the narrative data as minimally structured, that is, recorded as a flow of events and conversation with written commentary, or as a verbatim record of a conversation with a given purpose, as in an interview (p. 351). Although data is collected with flexible methods it is often characterized as minimally structured or completely unstructured. The desire to conduct the interview myself was mainly my desire to provide a comfortable environment for the participants. Individuals that met all selection criteria and agreed to participate in the study were mailed Informed Consent (See Appendix B) letters that further described the nature of the study, risks and benefits of participation, and the federal regulations that will be met to protect their confidentiality. Once the consent forms were signed and returned to me, I called the participants to schedule the interview.

I used a semi-structured in-person interview that was to last approximately 60-90 minutes. The Interview Guide can be found in Appendix C. Conducting interviews with the flexible methods research allows for intensive interviewing because the research question springs from a desire to explore a phenomenon that has not been previously studied. According to Anastas (1999), by using flexible methods research, the content of the interview itself is always developed as an integral part of the research process (p.353).

Data Analysis

Data was gathered through interviews that were tape recorded. Since I was the only interviewer, consistency was maintained throughout the study. The tape-recorded interviews were transcribed by one other person who has signed a transcriber agreement that assures confidentiality of the narrative content and of the participants' privacy.

I used content analysis of the participants' narratives to find and discern descriptive data through repeated or developing themes. The coding was completed manually. According to the repeated themes, participants were categorized and direct quotes were used for further examples.

A potential bias is that all participants were male, English speaking, have HIV/AIDS and reside in the Seattle Metropolitan area.

CHAPTER IV

FINDINGS

The data from this study translated to several major themes. All participants reported that facing the daily struggle to simply stay alive dominated their lives. This involved management of their medication regimen and trying to maintain a healthy lifestyle. Related to this were their constant concerns about being unemployed and living on state aid and the resulting loss of self respect and self esteem. The loneliness and isolation that resulted from having HIV/AIDS was also a central theme. The stigma of having AIDS was felt on a daily basis by all of the participants. Spirituality as a source of strength beyond the physical and social realities of their disease was an underlying but also a dominant theme throughout the interviews. Along with this was the lack of support for their spiritual journey due to their being marginalized and stigmatized by their disease and sexual orientation.

Demographics of Participants

Participants were ten gay, HIV/AIDS positive men ranging in age from 40 to 68 years. Three identified as African-American, six as Caucasian, and one man as Native American—Navajo. Nine reported their relationship status as single; only one was coupled and had been for the past 28 years. All participants were raised in Christian families: four reported being raised “Christian”; two Baptist; one Pentecostal; two Episcopalian; and one born-again Christian. Seven identified currently as Christian.

Two identified in particular as Baptist and one as Episcopalian.

All of the participants were diagnosed recently except for two who were diagnosed 20 and 30 years ago respectively. Nine participants experienced periods of severe illness due to the diagnosis of AIDS. Because of their disease and the requirements of state aid, none of the men were gainfully employed at the time of the interview. Before diagnosis, some of the jobs they had held included: a prison guard; an engineer; a mailroom clerk; a performer; an HIV/AIDS caretaker who had a masters degree and quit work to take care of his sick friends; a concession stand clerk; a former counselor with an M.S.W. degree; and a merchant seaman. One man was a ninth grade dropout who did not report holding a job in the past; one other obtained his G.ED but never worked due to his health issues.

Emergent Themes

The obvious and overriding themes were about daily struggle – trying to stay healthy; managing the demanding medication regimen and its dangerous side effects; dealing with loss of income due to the inability to maintain employment; loneliness and isolation due to the stigma of the disease. The data also revealed one further theme: Spirituality issues were underlying all other themes concerning daily survival – in most of the responses on all other questions, undertones of spirituality revealed its importance for the individual's survival.

Daily Management of HIV/AIDS

All of the participants reported the need for proper rest and exercise in order to manage their daily living. But dealing with the medications that were prolonging their lives was the major concern about health management. In order to continue to have a

certain quality of life, AIDS patients must take a rigorous course of medication. Most of the participants of this study had mixed feelings about taking the pills, a reflection of the fact that the medications saved their lives at the same time the dangerous side effects seriously compromised their health. One participant wondered if during the times he had tried more natural treatments his health had been affected adversely. When he stopped taking the pills and tried acupuncture instead, he knew he had suffered from symptoms. He has been on the medication regime since 1992, or 18 years of an almost totally uninterrupted medication schedule, and he believed it had taken a great toll on his body, especially his liver and kidneys-- even as it allowed him to live. He found that after he resumed taking the medications his CD4s never did return to the previous, acceptable level of 800. Another participant said he did not take his medications for 30 days and got sick immediately during which time he lost 14 pounds. The medication regime is in no small part a matter of life and death.

One participant believed that people aren't dying from AIDS, but from the toxicity of the medications. Most participants mentioned that they wanted to "take a vacation" from the medications. So arduous is the regime that people sounded gleeful as they spoke about not having to abide by it anymore. But many of the men voiced the opinion that it becomes second nature and that they no longer think about taking the pills—they just do it. The men who voiced this opinion tended to be those who had been on the medications a long time - for 20 or more years.

One man reported he had been a participant in studies that required him to take his medications regularly. He remained on these programs for years. Then he discovered that many of his positive friends didn't take any medications so he decided to do the

same—telling himself it would be just for a short time. This evolved into a two year period with no meds and without warning he found himself very ill. He also admitted to using street drugs during this period. His health deteriorated and when he went to get his blood drawn he discovered his CD4s had diminished from 800+ to 150. No longer in denial, now he never misses a dose. This theme of not wanting to take the drugs because the participant didn't feel sick and/or had received acceptable lab results was one that ran throughout the interviews.

The cost of the medications is worth mentioning. On average, a full-blown AIDS patient's medication will cost around \$4,000 a month! How and where these medications are made available depends on the state. For example, in the state of Washington, MEDICAID pays for these. All of the interviewees in the study were on Social Security Disability Insurance (SSDI), which automatically made them eligible for MEDICAID.

An underlying and unstated theme among the participants was the idea that the medication regimen is so strict and complex, in terms of taking multiple medications properly and simultaneously, that this in and of itself induced yet another symptom: clinical anxiety. How to survive on a day-to-day basis was of utmost concern to each man. All the men reported that adhering to the schedule of the medications and enduring the daily side effects were overwhelming.

In addition to all the medications, there are other things to consider. One of the most important is that each individual must fully comprehend his serious medical condition. Contradictory thought processes were common among the participants. One participant felt that when he was first diagnosed, his denial made him omnipotent. He believed that the disease just wasn't going to be that bad. After he began to get the

inevitable symptoms of his disease, he deeply regretted his initial denial and avoidance of treatment; now, he thanks God for the new medications, and states that he has learned to live within its limitations - one day at a time.

Isolation and Intimacy

The desire for intimacy and the reality of isolation are intertwined in the lives of the interviewees. There are several reasons for the majority of participants reporting being or feeling isolated. This can be demonstrated by the fact that only one out of the ten men interviewed was actually engaged in a monogamous relationship, in his case of many years duration. The others hoped for and were sometimes actively looking for a relationship; however, most were so afraid to disclose their HIV status that they avoided seeking and engaging in intimate relationships that may involve sexual intimacy. This can be the most pivotal moment for gay men when they are trying to engage in relationship. Although it might seem that the gay community would have a better understanding of a person with AIDS, it seems that the stigma is still pervasive even within the community, complicating an already complex web of emotions involved with relationship. All except one participant completely avoided intimate sexual relationships; however, they maintained intimate, non-sexual relationships with others in unique ways. One man claimed he really didn't want a relationship that he liked to be by himself; then, in a seemingly contradictory statement he said that he had many close friends in Texas that he spoke on the phone with everyday. He then said he was isolated but yet again he wasn't. In the world of AIDS and the way people communicate and sustain community, this statement was perhaps not actually contradictory. Most of the participants reported that they felt supported in some degree by family members or other men with AIDS.

Eight men in the study lived in state AIDS funded housing. Two men lived in their own homes. When asked about the support groups available to them, the men living in AIDS housing talked about there being only one such group available to them. Most said they had attended only once, and of these, all said they had gotten nothing out of it. They reported that they often felt lonelier and more isolated after attending the meeting than before. The general consensus seemed to be that the illness defined each man to the point where he would choose isolation over going to a support group because of the emptiness they found there. These men seemed to be looking for community and connectedness through positive, life-affirming activities and did not perceive a therapy group where members talk about the hardships of their disease as filling this need.

According to my findings, participants in a long term, supportive relationship with a significant other was the exception not the rule. Only one man was currently in a monogamous relationship; he had been with his partner for 28 years. He said he was madly in love with his partner since the day they met. Having this kind of stability to rely on seemed to help this man cope with his disease much easier and in a much healthier manner than the other men interviewed.

A large majority of the men spoke of being celibate out of necessity; they wanted to have a relationship but were too afraid to disclose that they were positive. One man said he hoped to find someone he could just hold hands with; he said that sex was no longer what mattered most to him but just to share things - a movie, a walk - anything to foster companionship.

The interviews revealed that all of the men's attitudes had definitely changed toward intimacy and sexuality since their diagnosis. Usually, if a person is positive, in

order to keep intimacy a part of their lives they hopefully will find a positive partner. In most cases, this was not the outcome and therefore each person was left to deal with their lives alone and often isolated to a great extent.

Isolation was also a part of the AIDS housing construct. The men I interviewed in state funded AIDS housing reported feeling isolated from the broader community just by the fact that they are living in a house for AIDS patients in a kind of quarantine situation. Residents, including the men I interviewed, tend to isolate in their rooms and only come out to share meals where there is little conversation. Where one would expect community and camaraderie, there was the usual continuous thread of isolation and silence that weaves through the AIDS community.

Perceptions of the Future and Finding Meaning and Purpose

The final question for the participants was: Projecting into the future for the next 10 or 15 years, do you have any unfinished business or unresolved issues, or things you would like to do? Although they did answer the question, all of the participants felt it was an irrelevant one because they dealt with their lives solely on a day-to-day basis; the question did not seem a pragmatic one to them. In slightly different ways, they expressed a philosophy of living in the moment, or living for today, an attitude that came out of living with AIDS. As one participant exclaimed, he was happy and thankful just to have made it to age 45 and beyond this, he did not project into the future. He claimed to have accomplished everything he had set out to do, quickly adding this did not mean he had given up. Another participant answered that he lives everyday to the fullest and that his future was no longer about planning to acquire material things. Another participant was a bit angry about the question; he said he didn't even want to think about the future. He

lives only for today because there is no promise of tomorrow. One man had a different way of expressing living in the present. Other than wanting to be more creative, he simply said he didn't know what he wanted for the future, he just didn't.

A primary desire for the great majority of the men was to have a significant other in their lives - although most did not feel this particular wish would come true for them. Anxieties about finances were also commonly expressed. One participant expressed great anxiety about getting and keeping a job. He thought quite a bit about finding employment and was fearful he would fail because his previous attempts had not been successful. He was concerned that his partner may die and he would not be able to survive without him financially. He admitted to being a 'worry wart' even to the point of wondering if he would have enough food for the week ahead. One man's hope was to pay off his house and have a little money in the bank for stability. He was glad he didn't have to depend on anyone to do this. Some men's needs spoke only to the immediacy of the moment. One participant expressed that he only wanted to get some dentures. His teeth were quickly falling out due to his drug addiction and this is what he reported consumed his thoughts.

All of the men reported that they wanted to stay alive, even expected to stay alive; but most said they wanted to stay alive not just for themselves but for the others who were important in their lives. The participant, who at first said he only wanted dentures, later expressed a great desire to be closer to his family, lamenting that this could not happen for him because of his disease. Many expressed a desire to help their children have a better life. One participant echoed the longing of many of the men: He wanted to

live long enough to leave something for his loved ones. Another wanted to help his disabled sons and see them set up in decent, safe housing.

Beyond their families and a desire for a relationship, it is significant to note that as consuming as their disease was for them, all of the men expressed a desire to help other men with AIDS who were less fortunate than themselves – the homeless, the drug addicted, the very young. Most of the men had helped out in AIDS food banks when these were funded. Most of the men also expressed a desire to do something good for the world before they died. One participant, who was an artist, believed he could create something for the whole world and this is what kept him going - his hope that he could give the world something beautiful.

The discussion of the future often gave insight into the spiritual lives of these men: their desire for loving connectedness; their desire to act as guardians and guides for their families and caretakers of those less fortunate; their wishes to be creative contributors to the broader world. The ability of many of them to for the most part live in the moment and be grateful for small things may seem insignificant, but is at the core of all great spiritual practice.

Spirituality As a Source of Strength and Finding Meaning

It was clear from most of the interviews that organized religion was of secondary importance to an individualized sense of spirituality that each man had developed. Only one participant currently attended church and was part of a faith community; the remaining nine men reported they did not attend church because they feared condemnation. This was not something new for them. As gay men, many had felt ostracized generally from society and some from the Christian church from early on in

their childhoods. Stigmatization and isolation had made them resort to designing their own, deeply individualized spirituality. Most felt spirituality was important but couldn't be expressed through mainstream religion.

Although often not expressed overtly, spirituality manifested itself in various shapes and forms but clearly came through each interviewee's life, whether spoken or unspoken. One participant who was raised in the Baptist tradition felt as if they taught the wrong things. He also said he had changed completely since his diagnosis. He said he used to think of himself as a snob, especially about material possessions, and that he had been cruel to some people. After he was diagnosed, he was brought back to a level where material things didn't mean a lot to him anymore. He reported not wanting to go back to church but felt he was a much better person now, one with a lot more compassion. The only participant who claimed to have an on-going relationship within the church said that if wasn't for Jesus Christ and the fellowship the Church brought him, he simply could not make it. He especially values his church family and thought that his life now was meant to be a blessing to others.

Another participant focused on the concrete things that make up daily life. He expressed his mainstays in life since his AIDS diagnosis as "a bowl of cereal, a can of cola, a can of pop." At first glance it would appear that little thought had gone into that response but after a second look these were the things that made up his daily life and gave him pleasure in the moment. Additionally, he simply admitted he did not know if spirituality played an important part of his daily life and yet he focused on the mundane things that make up daily living, eating and drinking, as though he were grateful for just

that alone. This gratefulness for small things can be considered at the core of any spiritual practice.

One participant who had children with severe mental and physical problems was worried that he would not live long enough to get his children settled in proper environments. He said that a lot of his friends thought this project of getting his children taken care of was what kept him going. He thought they might have been right but he did not admit to it entirely.

Oftentimes participants were philosophical about their lives and their existence. One participant believed that everything happens for a reason and that this is part of God's grand design. He thought perhaps his testimony to me would help other people or maybe even prevent someone from making the same mistakes he had. This was something he hoped for, so that his experience would be more meaningful. The participant who identified as Navajo reported that his spirituality was expressed through nature – "It's a Native American thing" – reporting that even a small houseplant on his windowsill gave him great joy and meaning in his life.

One participant found his grace to live each day through music. He claimed that music brings him great joy and that the reason he was strong was due in part to participating in music. The love of his family also brought him comfort. He believes his strength to go on comes from being enveloped in the arms of his loving family. He claimed he has the grace of God and that he gives God all the credit for his survival. Threads of spirituality were expressed by all participants in highly individualized ways. Meaning at end-of-life was drawn from various aspects of their lives, unique to each man. The men were for the most part on their own to come up with a sense of spirituality and

meaning and few if any opportunities to share their experience. Churches would be a logical place for these men, all raised Christian, to find support and help with spiritual issues at the end of their lives; however, all but one felt ostracized and marginalized by organized religion. Medical staff also did not bring up these issues. This interview was the first chance for most of them to discuss this fundamental aspect of their journey.

CHAPTER V

DISCUSSION

This study examined the daily lived experiences of ten gay men and the role spirituality played in their lives. I placed flyers at three different agencies that support the GLBT community. Within the first week after posting the flyers, I received over 25 calls expressing an interest in the study. In addition, I had approximately 20 more calls I had to turn away. It immediately became evident there was a need in the HIV/AIDS community for people to tell their stories.

Losses

Prior to the time of their interviews, the men had suffered losses beginning with their former level of health and physical strength; and, most had lost their partners who had passed away or had left the relationship. Most participants reported a loss of intimacy in their lives after their diagnosis. One participant said, “I might never be able to have sex again.” Another man said, “We are even robbed of the simplest things such as holding hands or cuddling with a new partner.” Potential partners may suspect that mere cuddling might be a transmission route and are often not willing to take the risk. In addition all of the men reported being distressed by the sudden demise of many of their friends who had had AIDS. Changes in financial status were also of great concern. One man, who once was gainfully employed and self-supporting, had to transition to losing these fundamentals. For him, this was perceived as the ultimate loss. Many of the men

felt this same way about the loss of their earning power.

After diagnosis, all of the men experienced the reality of the stigma of learning to live with AIDS. A majority of the men spoke of losing their identity - their usual roles in the world as bread-winners, fathers, partners - resulting in an additional loss of self-esteem and self-confidence. They were now only able to identify themselves by the disease. One participant said, "I didn't know who I was anymore or how long I would live." This was another theme: the agony of losing self identity and self-image; it was literally taken away forever. There were no sign posts telling you go this way, or that, a prevailing feeling of being left alone in the desert with no water and no way out. Most of the men perceived this as a deep, infinite loss - perhaps not survivable without the element of spirituality.

Authenticity

No sooner is the diagnosis of AIDS pronounced and an individual's life is forever changed. In order for us to understand the human experiences of the men in this study, we need to be aware of the significance of authenticity in their lives. Authenticity is generally defined as being genuine, or reliable or trustworthy. One of the participants reported in a moment of absolute honesty he probably had never had to reach before: "At one point of each and every day, I think of my survival and having to take pills...my world has narrowed to a convoluted medicine regime, doctors and T-cell counts... my life is a composite of the medical model and brings with it an ungodly anxiety." Paradoxically, it is in this kind of truth – this point of reaching an ungodly anxiety - where one can begin to see the importance of spiritual practice. One's spiritual beliefs

have a profound impact on how each person copes with their illness and end of life issues.

Authenticity is an important element in the patient's daily life. According to Byock (2007), "spiritual issues left unaddressed both impede recovery of authenticity issues and effect overall suffering of the patient" (p.437). By gaining a better understanding of an individual's beliefs and by having conversations more explicitly spiritual, opportunities are increased for improved care especially in regard to the patient's finally having the freedom to be truly authentic.

Despite Elizabeth Kubler-Ross' seminal publications more than 25 years ago regarding patients at end of life, the psychosocial spiritual needs of the patient remain marginalized. Managing a life threatening illness includes a desire to be helped to "live well" until death. The participants of my study felt the only way of achieving this was to be authentic. Authenticity often means that the patient no longer has the time or the inclination to present a false self. This is the period in life to uncover all that lies beneath the patient's exterior but which he has yet to acknowledge in his life – a time to seek his own spiritual nature. Living with HIV/AIDS caused patients to reach a time in their lives where they felt compelled to be authentic to a degree they never had before. They had reached a point where they knew they would suffer greatly by not saying how they truly felt and as often as possible.

The Medications – Staying Alive

One of the daily realities of all of the participants was the complex and rigid medication regime. They often found the combination of the treatment therapies an arduous task to maintain on a daily basis. Medications must be taken at exactly the same

time and in the same sequence, keeping in mind that one does not have a choice to not to take these prescriptions; patients must adhere exactly to what the doctors have prescribed. Many participants complained of the toxicity of the drugs; some of the side-effects included severe fatigue, nausea, vomiting and Irritable Bowel Syndrome (IBS). As one man simply said, “I lost the routine of life.”

In addition to having to deal with this anxiety provoking medication schedule, the cost of the medications is so prohibitive that many patients wonder how long they will be able to access and afford the proper treatment. It is as simple and complex as this: without the medications you begin to decline and ultimately you will die - not directly from AIDS but from complications of the disease. Most of the participants had to take between 15 -30 pills a day at various times, some with food, some without. This requires a stamina that may be lacking in a person whose health is already compromised. One participant told me the disease was like “living and dying at the same time.”

Fear/Isolation/Intimacy

A predominant symptom for the AIDS patient, exacerbated by the medication regime, is fear. AIDS becomes the dark shadow. Most doctors tell their AIDS patients not to be fearful and to try to stay stress-free. While this advice is well-meaning, ironically, it can cause deeper fear and more frequent and more serious anxiety. Unanimously, all of the participants felt this. As one participant said, “How could I not be fearful?” Often isolated and with no one to express their fears to, patients tend to try to bury them; but they arise in new ways that can be more frightening and that carry with them complex repercussions.

All of the participants expressed an immense fear of dying alone. They also expressed anxieties about how they would die. Surprisingly, it was not the fear of death that was the worry, but the fear of not having control over how they would die. One participant related that he fears “getting down to a point where I am so weak I can’t take care of myself.” Another participant said he feared his emotions most. “When I don’t have a handle on my emotions they tend to run rampant and take me to areas in my mind and places I don’t need to be. I hope to be non-detectable and live life to the fullest and be the person God had intended me to be.” Fear is a highly individualized emotion, shaped and exacerbated for the participants by their unique perception of their illness.

The reports of the participants in my study were consistent with Maslow’s concept of a hierarchy of basic human needs: they were concerned first about making it financially, having food and a roof over their heads; then about intimacy, a sense of belonging and satisfaction with oneself; and, lastly, they expressed thoughts about their life meaning and purpose (spirituality). This last is considered most important by patients facing end-of-life and is the most neglected by medical staff. A majority of the participants felt that getting right with God was a significant priority for them, especially when living under the shadow of the anguish and anxiety that AIDS creates.

Intense feelings of anxiety and even anguish at end of life are often exacerbated if no spiritual questions are addressed. End-of-life research has shown that spiritual intervention brings better outcomes in quality of life. My hypothesis from hearing the stories of the men in my study is that a majority of the men expressed their spirituality in highly individualized ways but all with the same outcome: a sense of spirituality and meaning gave them the will to continue to live and to try to live as well as possible.

Spirituality and Meaning

I expected to find that the men I interviewed would consider spirituality to be the most important facet for them as they struggled to stay alive. In fact it wasn't. Their primary concerns were about daily survival: getting by day to day, getting proper rest, and taking the medications. Yet, underlying these daily concerns and the accompanying feelings of isolation, fear, anxiety, and loneliness, was a search for meaning and even for a spiritual identity.

In Western culture, spirituality is generally thought of as how we express our essential relationship with the transcendent questions that confront us as human beings and how we as humans relate to these types of questions. According to Sulmasy (2006), these are pressing questions for almost all patients facing end of life.

Spirituality is derived from the Latin word "spiritus" which refers to a non-material life force within the body. It is an awareness of something greater than we are, without form or substance materially. An individual's naming of spirituality and how they define it at a particular point in time, holds a tremendous power – especially for patients at end-of-life. In the framework of living in the unknown and wondering each day what will happen next, a sense of spirituality gives a person the opportunity to explore their unique meaning, purpose and value. Often a patient may use the two terms spirituality and religion interchangeably. Therefore, it is important for the social worker to interpret exactly what the patient is seeking in terms of comfort be it from their religion or a more universal and individualized spirituality.

According to Brenner (2001) in his article, "Spirituality in Hospice," some of the spiritual conflicts that arise in the disjuncture between personal experience and religious

beliefs may have to do with addressing guilt, the need for forgiveness, fear of retribution, the need for rituals and prayer – and, feelings of abandonment and isolation. These specific issues arise within the larger context of reviewing life, sensing closure and experiencing transcendence (page no). Fryback and Reinhart (1999) found that many of the subjects viewed spirituality as a bridge between hopelessness and meaningfulness in life. Remarkably, those who found meaning in their disease thought they had a better quality of life than even before the diagnosis (p. 13).

The quest for spirituality is a search for a place of peace, tranquility and safety. Many people begin searching for this place during the final chapters of their lives. One of the things the researcher learned was that all the men had their own individual way of expressing their spirituality and that this often appeared to give them the will to go on.

Community Support Groups/Activities

Group therapy was provided for the men in the AIDS housing project. The goal was to support the men emotionally in living daily with their disease. The participants in my study perceived the HIV/AIDS support groups as ineffective in several ways. One man voiced the feeling of all of the participants when he described the meeting as painful. He stated: “All the group did was discuss their problems.” He felt this was overwhelming. The men seemed to be looking for a different kind of support system, or a more varied support system. They expressed a need for positive ways for men to connect such as physical activities or community activities that were not based on the management of their disease. There seemed to be a lack of initiative on the part of the various AIDS services toward bringing together the many men who are disconnected from the main AIDS community – even those who live in AIDS housing. One way this

problem could be addressed is to support an array of activities, developed from the suggestions of the men themselves that would provide them with positive interaction with one another - organized athletic and fun activities, meditation and relaxation groups. Advertising would be targeted especially to reach those men who tend to isolate. Individual therapy with a partial focus on encouraging healthy connection with others could be provided for patients at little or no-cost with emphasis on accessibility.

References

- Anastas, J.W. (1999). *Research Design for Social Work and Human Services*. New York: Columbia University Press.
- Avert.org (2005). *United States HIV & AIDS statistics by year*. Retrieved July 30, 2007, from <http://www.avert.org/statsum.htm>.
- Bartlow, B. (2000). *Medical care of the soul: A practical and healing guide to end of life issues for families, patients and healthcare providers*. Boulder, CO: Johnson Books.
- Beckett, A. (1998). *End of life decisions in AIDS*. Boston: American Psychological Association.
- Berzoff, J., & Silverman, P.R. (Eds.). (2004). *Living with dying: A handbook for end-of-life practitioners*. New York: Columbia University Press.
- Brenner, P.R. (2001). *Spirituality and hospice*. Retrieved June 15, 2007, from www.Parkridgecenter.org/pages 515.html.
- Brodie, M., Hamel, E., Brady, L.A., Kates, J., & Altman, D.E. (2004). Media coverage of the HIV epidemic 1981-2002. *Columbia Journalism Review* 42, 1-10.
- Byock, I.R. (2007). To life! Reflections on spirituality, palliative practice and politics. *American Journal of Hospice and Palliative Medicine*, (23) 6, 436-438.
- Cantwell, A. (1997). *Queer Blood: The secret AIDS genocide plot* [Electronic version]. Retrieved July 20, 2007, from <http://www.fohn.net/history-of-aids/>.
- Centers for Disease Control and Prevention (2005). *HIV/AIDS Surveillance Report* [Electronic version], Department of Health and Human Services. Retrieved July 30, 2007, from <http://www.cdc.gov/hiv.htm>.
- Centers for Disease Control and Prevention (2001). *HIV and AIDS in the United States, 1981-2005*. Retrieved July 20, 2007, from <http://www.fohn.net/history-of-aids/>.
- Centers for Disease Control and Prevention (1982). *Kaposi's sarcoma (KS), Pneumocystis Carinii Pneumonia (PCP) and other opportunistic infections (OI). Cases were reported to CDC in 1982* [Electronic version]. Department of Health and Human Services, 1-2.
- Chibnall, J. T., Videen, S. D., Duckro, P. N., & Miller, D. K. (2002). Psychosocial- spiritual correlates of death distress in patients with life-threatening medical conditions. *Palliative Medicine*, 16, 331-338.

- Clark, J. (2003). Patient centered death: We need better, more innovative research on patient's views on dying. *British Medical Journal*, 327.7408, 174-176.
- Curtis, R. J., Patrick, D. L., Caldwell, E., Greenlee, H., & Collier, A.C. (1999). The quality of patient-doctor communication about end-of-life care: A study of patients with advanced AIDS and their primary care. *AIDS*, 13 (9), 1123-1131.
- Fee, E. & Fox, D. M. (1988). *AIDS: The Burdens of History*. Los Angeles: University of California Press.
- FindLaw (1998). *Ryan White CARE Act passed in 1990* [Electronic version] Retrieved July 27, 2005, from <http://www.findlaw.com>
- Follansbee, S. E., Busch, D. F., Wofsy, C. B., Coleman, D. L., Gullet, J. A., Gerard, P., Ross, T., Hadley, W. K., & Drew, W. L. (1982). An outbreak of pneumocystis caronii pneumonia in homosexual men. *Annals of Internal Medicine*, 96(6), 705-804.
- Fryback, P., & Reinert, B. (1999). Spirituality and people with potentially fatal diagnoses. *Nursing Forum*, 34, 13-21.
- Hobson-Wain, S. (1998). Where did the HIV (Human Immunodeficiency Virus) come from? *Nature*, 391, 532-533.
- Hodge, D.R. (2003). *Spiritual Assessment*. Botsford, CT: North American Association of Christians in Social Work.
- Hooper, R. (2005). *Anti-HIV Bacterium Isolated?* Retrieved July 30, 2007, from <http://www.wired.com/medtech/health/news/2005/04/67274>.
- Kaldjian, L. C., Jekel, J. F., & Friedland, G. (1998). End-of-life decisions in HIV/AIDS positive patients: The role of spiritual beliefs. *AIDS*, 12(1), 103-107.
- Kuhl, D. (2006). Spirituality at the end of life. *Journal of Cancer Education*, 21(1), 19-22.
- Meador, K. G. (2004). Spiritual care at the end of life: What is it and who does it? *North Carolina Medical Journal*, 65, 226-228.
- National Institutes of Health (NIH) (2001). *AIDS History* [Electronic version]. Retrieved January 12, 2008, from http://aidshistory.nih.gov/discovery_of_HIV/index.htm

- Rinpoche, S. (2002). *The Tibetan book of living and dying*. London: Ryder.
- Shilts, R. (1987). *And the band played on*. New York: St. Martins Press.
- Steinhauser, K. E. (2001). Preparing for the end of life: Preferences of patients, families, physicians, and other care providers. *Journal of Pain and Symptom Management, 22*, 727-737.
- Sulmasy, D. (2006). Spiritual issues in the care of dying patients. *Journal of the American Medical Association, 296*, 139-141.
- Taylor-Brown, S., & Sormanti, M. (2004). End of life care. *Health & Social Work, 29*, 3-5.

APPENDIX A

RECRUITMENT FLYER

EXPLORATORY STUDY

ABOUT MEN LIVING WITH HIV/AIDS
THEIR HUMAN EXPERIENCES AND
INNER STRENGTHS

INTERVIEWER:

JERRY DALE BEENE

MASTER'S CANDIDATE
SMITH COLLEGE SCHOOL FOR SOCIAL WORK
PLEASE CALL
TO SCHEDULE AN INTERVIEW

****Interviews Will Take Approximately 1 Hour****

206-XXX-XXXX

APPENDIX B
INFORMED CONSENT FORM

January 21, 2008

Dear Potential Research Participant,

My name is Jerry Dale Beene, and I am a social work student at Smith College School in Northampton, Massachusetts. I am conducting a research study about men living with AIDS. The study will examine the lived experiences of men having AIDS, their spirituality, and end-of-life issues. I'm conducting this study as part of my master's thesis for possible presentation and publication.

Participants in this study must be at least 18 years of age, male, and diagnosed with AIDS. Your voluntary participation is requested because I am a researcher who wants to pursue this topic. I will interview and tape record our sessions about your understanding of your illness since receiving the diagnosis and your thoughts and feelings about the experience. The interview will be conducted in person and will last approximately one hour.

The risk of participating in this study is the discussions concerning living with AIDS, could potentially cause you some emotional distress. Should you wish to speak with someone I will provide a referral list of clinicians in the area. It is important for you to know that as a participant you can decline to answer any question or end the interview at any time, that your participation is voluntary and you may at any point, withdraw from the study.

There will be no financial benefit for participating in this study. However, your willingness to participate can contribute to the knowledge base in the helping professions. Potential benefits are your unique life perspective of living with AIDS would contribute to this area of research. Your participation may possibly enlighten other males living with AIDS and struggling with end-of-life issues and their questions regarding spirituality.

Your participation in this study will be confidential. Only I will know your name and demographics. I will label audiotapes and interview notes with a number and remove any identifying information from the transcripts.

Should you choose to withdraw all materials pertaining to you will be immediately destroyed. You have until March 30, 2008 to withdraw from this study: after this date, I will begin writing the Results and Discussions section of my thesis.

YOUR SIGNATURE BELOW INDICATES YOU HAVE READ AND UNDERSTAND THE ABOVE INFORMATION; THAT YOU HAVE HAD THE OPPORTUNITY TO ASK QUESTIONS ABOUT THE STUDY, YOUR PARTICIPATION AND YOUR RIGHTS; AND THAT YOU AGREE TO PARTICIPATE IN THE STUDY.

Signature of Participant

Signature of Researcher

Date

Date

Please keep this form for your records.

If you have any questions, or wish to withdraw for the study, please contact:

Jerry Dale Beene

One Chapin Way

Northampton MA 01060

jbeene@email.smith.edu or

Chair of Human Subject Review at Smith College at 413-585-7974

APPENDIX C

REFFERAL SOURCES

Lifelong AIDS Alliance
1002 E. Seneca
Seattle, WA 98122
206-957-1660

GAY CITY
511 East Pike Street
Seattle, WA 98122
206-860-6969

Dunshee House
303 17th Ave East
Seattle, WA 98112
206-322-2437

HIV/STD Hotline: 206-205-7837 or 1-800-678-1595:
Provides referrals for clinics, support groups, needle exchange.

The Harborview Madison Clinic, 206-731-5155

APPENDIX D
INTERVIEWER GUIDE

1. What is your first name?
2. What is your present age?
3. What is your racial/ethnic identity?
4. What is your educational level?
5. What is your religious affiliation?
6. What is your current relationship status?
7. What is your current employment status?
8. Can you tell me what you knew about HIV/AIDS prior to your diagnosis?
9. How did you discover you were positive?
10. Initially, did you keep the information to yourself? If you did confide in someone, who was it and what was their reaction?
11. How have you been managing your life at this point, i.e., self care, emotionally, adherence to meds, personal hygiene?
12. Have you had any insights or discoveries about spirituality or values?
13. When you find yourself at the end of the day what do you tend to think about?
14. What are the most common and frequent emotions that come up for you?
15. How has your health issue changed your attitudes toward intimacy and sexuality?
16. Projecting into the next 10-15 years, what are the most important things for you to accomplish? Are there any unresolved issues you need to address?

APPENDIX E

HUMAN SUBJECTS REVIEW APPROVAL LETTER

January 9, 2008

Jerry D. Beene

Dear Jerry,

Your revised materials have been reviewed and all is in order. There are three small corrections we would like you to make in the Consent. First, in the fifth paragraph, you say that their participation will protect their privacy. Please correct that sentence.

At the end, when you give contact information, we strongly advise that you not give your home address. Please give a cell number or your agency number, if you can, plus your email.

Finally, add that they may also contact the Chair of Human Subject Review at Smith College at (413) 585-7974.

We do give final approval to your study, but ask that you send Laurie Wyman a copy of the Consent amended as above.

Please note the following requirements:

Consent Forms: All subjects should be given a copy of the consent form.

Maintaining Data: You must retain signed consent documents for at least three (3) years past completion of the research activity.

In addition, these requirements may also be applicable:

Amendments: If you wish to change any aspect of the study (such as design, procedures, consent forms or subject population), please submit these changes to the Committee.

Renewal: You are required to apply for renewal of approval every year for as long as the study is active.

Completion: You are required to notify the Chair of the Human Subjects Review Committee when your study is completed (data collection finished). This requirement is met by completion of the thesis project during the Third Summer.

Good luck with your project. I was glad to see that the agencies were so supportive of the study. It will help with recruitment.

Sincerely,

Ann Hartman, D.S.W.
Chair, Human Subjects Review Committee

CC: Barbara Lui, Research Advisor